



# **Call for Input Submissions**

As part of the Panel's evidence-gathering activity, a Call for Input was carried out by the Panel over a three-month period beginning in July 2017. In addition to inviting written input from 500 groups and organizations across Canada affected by, or involved in, MAID, the Call for Input was made available online to any interested organizations. Specifically, the Panel asked organizations to: (i) describe their main issues concerning requests for MAID in the three topic areas under study; and (ii) submit, or provide links to, any knowledge they would like the Panel to consider. The CCA received 59 submissions from a wide variety of organizations in the areas of advocacy, medicine, nursing, pharmacy, social work, law, and religion.

Call for Input submissions were shared with Panel members and reviewed to identify issues related to the three topic areas. Call for Input submissions also identified a range of evidence, including professional guidelines and codes of ethics, additional peer-reviewed articles, surveys of membership of professional bodies, and lived experience testimony, not previously available to, or identified by, the Panel. Where relevant, these sources were included in the body of evidence assessed by the Panel.

Of the 59 organizations that made a formal submission, 54 of them agreed to make either their full submission, or a portion of their submission, public. Because some organizations submitted jointly, there is a total of 49 submissions. To access a particular submission, simply click on the name of the organization. Please note that CCA did not make any additions, edits, or translations to these submissions; they are included below exactly as they were submitted.



## **Table of Contents**

- Addictions and Mental Health Ontario
- Alberta College of Social Workers
- Alzheimer Society of British Columbia
- Alzheimer Society of Nova Scotia
- Association for Reformed Political Action
- Association médicale du Québec
- Association of Registered Nurses of British Columbia
- Autism Canada
- British Columbia Humanist Association
- Canadian Association for Community Living
- Canadian Association for MAID Assessors and Providers
- Canadian Bar Association
- Canadian Coalition for the Rights of Children
- Canadian Federation of Catholic Physicians' Societies, Christian Medical and Dental Society of Canada, and Canadian Physicians for Life joint submission
- Canadian Medical Association
- Canadian Medical Protective Association
- Canadian Mental Health Association
- Canadian Psychiatric Association
- Canadian Society of Palliative Care Physicians
- CARP
- Catholic Civil Rights League
- Catholic Health Alliance of Canada
- Centre for Mental Health and Addiction
- Christian Legal Fellowship
- Collège des médecins du Québec
- College of Physicians and Surgeons of Ontario
- College of Registered Nurses of Manitoba and the College of Licensed Practical Nurses of Manitoba joint submission
- College of Registered Psychiatric Nurses of Manitoba
- Community Health Nurses of Canada
- Covenant Health

- Dying with Dignity
- Empowerment Council
- Evangelical Fellowship of Canada
- Federation of Medical Regulatory Authorities of Canada
- Institut de planification des soins
- Manitoba Provincial MAID Clinical Team
- Nurse Practitioner Association of Manitoba
- Ottawa Catholic Physicians' Guild
- Ontario Psychiatric Association
- Ontario Shores Centre for Mental Health Sciences
- Physicians' Alliance against Euthanasia
- REAL Women of Canada
- Right to Die Society of Canada
- Salvation Army
- The Hospital for Sick Kids
- Toronto Catholic Doctors Guild
- Toujours Vivant – Not Dead Yet
- University Health Network
- University of Toronto Joint Centre for Bioethics MAID Implementation Task Force



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## **Addictions and Mental Health Ontario's Response to the Canadian Council of Academies on the Issue of Medical Assistance in Dying**

### **Context**

On May 30, 2016 Bill C-14 passed into law. The bill amends sections of the Criminal Code to decriminalize medical assistance in dying (MAID). The bill includes a number of eligibility criteria, including that the person must have a "grievous and irremediable medical condition" defined as including the following criteria:

1. Have a serious and incurable illness, disease, or disability;
2. Be in an advanced state of irreversible decline in capability;
3. Endure physical and psychological suffering that is intolerable to them; and
4. Their natural death has become reasonably foreseeable.

The Council of Canadian Academies (CCA) was asked by the Government of Canada to undertake independent review on three particularly complex types of requests for MAID including: **requests by mature minors, advance requests, and requests where mental illness is the sole underlying condition**. In part of their review they reached out to organizations asking the following question:

What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying condition?

In response to this question, Addictions and Mental Health Ontario (AMHO) has consulted with its members and has put together recommendations for consideration by CCA on this issue.

### **WHO WE ARE**

AMHO provides a provincial voice for over 220 community-based mental health and addictions service providers throughout Ontario. AMHO represents the full continuum of mental health and addiction organizations and services, ranging from community-based service providers to peer and consumer survivor groups, to community health centres and hospitals. Our mission is to achieve optimal addictions and mental health outcomes for Ontarians by partnering to build a better service system, and being the collective voice of our members.

### **PROCESS**

To better understand the implications associated with the proposed legislation, AMHO consulted with our members that provide services directly to the population of Ontarians living with mental



illness. A number of providers responded that the key issue is the state of funding for the current mental health system. Treatment services that should be universally available to support all the needs of Ontarians who are faced with mental illness are currently unavailable in an equitable manner. If these services were available and accessible at levels that are required to meet the needs of those living with mental illness, then the issue of people's health deteriorating to a point that they need access to MAID would not arise. A number of members also stated that with the right supports in place, there would also be less suicide overall. Some of our members are faith based organizations and strongly felt that MAID must not be an option as a result of their philosophies. A large number of our members felt that client choice must be central to all decision making and that this choice must be based on evidence informed options. As well, the issue of consent and capacity arose in relation to mental illness. Some clients may not be considered capable of consenting based on their current state in respect to their mental illness.

From the diverse views presented by our members, we recognize that this issue is a complicated one and requires a significant amount of research and evidence to support it. To further support AMHO's recommendations on this issue, we looked at what other organizations are saying on the issue, and briefly consulted the literature.

## **EXTERNAL PERSPECTIVES**

CMHA National released a position paper on Medical Assistance in Dying (MAID). The paper provides an overview of Bill C-14 and completes a case review of the Netherlands and Belgium where euthanasia or assisted suicide (EAS) for non-terminally ill patients is legal. CMHA's position is that psychiatric-MAID should remain illegal and that any mental health condition is treatable, and that recovery is always possible.<sup>i</sup>

The Empowerment Council developed a website to facilitate discussion surrounding perspectives on MAID in Canada from and for clients/consumers/survivors and ex-clients of mental health services. The council does not endorse any one opinion about MAID but aims to place service users at the centre of the conversation.<sup>ii</sup>

Adam Maier-Clayton a well-known advocate for MAID for mental illness shared his own experiences with mental health issues as part of his campaign. Maier-Clayton argued that not allowing access to MAID confines individuals to a lifetime of pain. He also asserted that even without MAID, people who want to die will die. Adam Maier-Clayton died by suicide in April 2017.<sup>iii</sup>

The Journal of Ethics in Mental Health grouped all content related to MAID in their current Open Volume as a special issue including articles from a variety of viewpoints.<sup>iv</sup>

## **LITERATURE FINDINGS**

The Journal of Ethics in Mental Health released a special, open volume issue dedicated to providing multiple perspectives on MAID.<sup>v</sup> A major area of focus addressed in this literature is assessing capacity to consent when considering inclusion of requests for MAID where mental illness is the sole underlying condition. Charland et al. examined current tools available to



determine capacity, pointing out that they are limited to measuring cognitive ability and fail to take into account other key components of decision making including emotions, passions, mood and values. The authors call for the development of a more holistic set of capacity measures before allowing access to MAID for mental illness<sup>vi</sup>. This article elicited a number of responses published in the journal questioning whether it is possible to develop such a tool to measure how people should make decisions<sup>vii</sup>, whether it is the place of the medical profession to give “approval” to die as a response to societal failures<sup>viii</sup>, and arguing that capacity is already measured in life or death situations including the refusal of life saving treatment.<sup>ix</sup> Contentions in the literature echo what AMHO has heard from our members about the complexity of assessing capacity to consent and that MAID has served to highlight the need for mental health prevention and to ensure access to mental health services

## **AMHO’S RESPONSE**

AMHO appreciates the federal government of Canada’s review of the MAID legislation and its impact on people with mental health issues and thank the CCA for undertaking this specific review.

Based on the feedback received from our members and currently available information on this issue, AMHO understands that MAID for people with mental illness is a complex and contentious issue. As an organization, we strongly believe that with the right supports, people can and do recover from mental illness. We also recognize that many people with mental illness experience suffering and deserve humane treatment and response. AMHO firmly believe that client choice with respect to preferred treatment plan should always be a priority when considering treatment options. In considering MAID for mental illness and based on these factors, AMHO highlights the following points for consideration: the need to strengthen mental health care, balance self-determination with safe guards to protect people with psychiatric disabilities and the need for data monitoring and ongoing system review.

- *Strengthen mental health and substance use disorder care*

AMHO’s membership consists of mental health and addictions service providers who understand that people can and do recover from mental illness and part of their therapeutic work is instilling this positive message of hope with the clients they serve. With proper supports, access, and choice in methods of treatment, people can recover. Another important aspect of mental health care is to recognize the social determinants of mental health including social inclusion, access to economic resources, and freedom from discrimination and violence.<sup>x</sup> By strengthening mental health supports and making social determinants of mental health a priority, it is possible that the demand for MAID due to mental illness would be lessened. AMHO recommends that CCA works with health system funders to identify those bio-psycho-social supports that will support populations experiencing mental illness who are currently under supported. Health funders will need to ensure that those supports are made available at the levels that match the need of the population seeking access to those services. Investments into these areas could work to reduce the demand for MAID down the road.



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- *Balance self-determination with safe guards to protect people with psychiatric disabilities*

Self-determination is a key feature in mental health recovery and recognized as an essential element of mental health service delivery. The Health Care Consent Act in Ontario states that people with mental illnesses have the right to make decisions about their treatment if they are capable. “Capable” means that he or she understands the information relevant to the treatment and appreciates the consequences of consenting or refusing the treatment.<sup>xi</sup> Because of this, it is essential to ensure that the rights of individuals with mental health issues to choose the type of treatment they receive are upheld. It is also important to recognize that a number of individuals living with mental health are capable, and as such have the ability to make their own health care decisions. However, because a desire to die may at times be a symptom of an individual’s mental illness, it is essential that safeguards be in place. Specific safeguards may include developing standards that define key terms such as “grievous” and “irremediable” in the context of mental illness. Specifically these key terms must be defined in relation to mental health and not physical health. Some members surveyed feel deeply concerned that there may be no level of safeguards that will be sufficient to accurately assess capacity. We also heard concern from our members that some clients may experience stigma and discrimination that they may pursue MAiD out of shame or hopelessness and may be particularly vulnerable to opt for MAiD by external pressures. AMHO strongly recommends that the CCA works with others to clearly define consent in terms of mental illness, and to set standards that clearly identify capacity. Medical practitioners who will be making these assessments must be individuals who have been involved for a significant length of time in the clients care.

- *Data and system response are essential*

AMHO supports the fact that data collection is currently provincially and federally mandated with respect to MAiD. The use of data to monitor who is requesting MAiD, and whether these requests were approved or not, is increasingly important in the event this legislation is implemented to include MAiD requests for mental illness. The collected data should be reviewed regularly and used for mental health system planning and to help ensure that access to MAiD is equitable without certain vulnerable populations being over or underrepresented. One area of particular concern is the fulfillment of the condition that patients “be in an advanced state of irreversible decline in capability”. In relation to mental illness, fulfilling this condition may require detailed history of the breadth of treatment options utilized by the patient. With inequitable access to treatment options, those who have greater resources and access to treatment options may be more readily approved than someone without those same opportunities. In this case, it is essential to ensure system response is adequate so that we are not leaving disadvantaged populations without access to MAiD or treatment options to ease their suffering.

Overall, AMHO’s main message is that clients should have access to a range of options in relation to their care and that these options must be evidenced based in order to support informed client choice. Additionally, the CCA must meaningfully engage patients, families and



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caregivers throughout this process. AMHO and our members look forward to engaging with the CCA further on this issue and bringing the expertise of our membership to the table.

## Endnotes

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<sup>i</sup> <https://sk.cmha.ca/news/canadian-mental-health-associations-position-paper-medical-assistance-dying-MAID/>

<sup>ii</sup> <https://mentalhealthandassisteddeath.wordpress.com/>

<sup>iii</sup> <https://beta.theglobeandmail.com/life/health-and-fitness/health/as-a-person-with-mental-illness-heres-why-i-support-medically-assisted-death/article29912835/?ref=http://www.theglobeandmail.com&>

<sup>iv</sup> <http://www.jemh.ca/issues/v9/theme2.html>

<sup>v</sup> <http://www.jemh.ca/issues/v9/theme2.html>

<sup>vi</sup> [http://www.jemh.ca/issues/v9/documents/JEMH\\_Open-Volume Benchmark Decision Making to Consent to Medical Assistance in Dying-May2016-rev.pdf](http://www.jemh.ca/issues/v9/documents/JEMH_Open-Volume_Benchmark_Decision_Making_to_Consent_to_Medical_Assistance_in_Dying-May2016-rev.pdf)

<sup>vii</sup> [http://www.jemh.ca/issues/v9/documents/JEMH\\_Open-Volume Commentary 1 Science Cannot Resolve Problems of Capacity Assessment Nov18-2016.pdf](http://www.jemh.ca/issues/v9/documents/JEMH_Open-Volume_Commentary_1_Science_Cannot_Resolve_Problems_of_Capacity_Assessment_Nov18-2016.pdf)

<sup>viii</sup> [http://www.jemh.ca/issues/v9/documents/JEMH\\_Open-Volume-Editorial-Assisted%20Death%20in%20Canada-May2016.pdf](http://www.jemh.ca/issues/v9/documents/JEMH_Open-Volume-Editorial-Assisted%20Death%20in%20Canada-May2016.pdf)

<sup>ix</sup> [http://www.jemh.ca/issues/v9/documents/JEMH\\_Open-Volume Commentary 6 Decision Making Capacity to Consent To Medical Assistance in Dying-Meynen-Dec2-2016.pdf](http://www.jemh.ca/issues/v9/documents/JEMH_Open-Volume_Commentary_6_Decision_Making_Capacity_to_Consent_To_Medical_Assistance_in_Dying-Meynen-Dec2-2016.pdf)

<sup>x</sup> <https://ontario.cmha.ca/provincial-policy/social-determinants/>

<sup>xi</sup> [http://www.camh.ca/en/hospital/visiting\\_camh/rights\\_and\\_policies/Pages/Understanding-your-rights.aspx](http://www.camh.ca/en/hospital/visiting_camh/rights_and_policies/Pages/Understanding-your-rights.aspx)

## **Alberta College of Social Workers**

### **1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

In Alberta, we have done extensive work to establish guidelines to inform social workers in making the decision as to when a minor is a mature minor for the purpose of providing social work services. When working with minors a social worker will assess, on a case by case basis, the minor's ability to understand the nature and consequences of the service being provided. If the minor is deemed to be a mature minor, then he/she has all the rights around informed consent and confidentiality that an adult client would have. We have established factors to consider when making the determination as to whether a minor is a mature minor for the purposes of providing social work services.

Our Guidelines imply that for minors aged 14-15 years, a social worker should consider why the minor may be deemed a mature minor when accessing services, whereas for minors aged 16-17 years, a social worker should consider why the minor would not be deemed a mature minor when accessing services. In other words there is a rebuttable presumption for minors ages 16-17 that they are mature minors, while for minors 14-15 there is a rebuttable presumption that they are not.

The question arises if these guidelines apply equally in the context of MAID given the implications of this decision making authority in this context. From our perspective, these guidelines apply equally and that it is possible that a 14-15 year old could be deemed a mature minor for the purpose of Medical Assistance in Dying.

### **2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

See link:

Alberta College of Social Workers - Information Sheet  
Guidelines on the Management of Consent and Confidentiality When Working With Minors

[http://acsw.in1touch.org/uploaded/web/NEWS\\_GUIDELINES\\_ConsentwithMinors.pdf](http://acsw.in1touch.org/uploaded/web/NEWS_GUIDELINES_ConsentwithMinors.pdf)



# INFORMATION SHEET

## Guidelines on the Management of Consent and Confidentiality When Working With Minors

In the province of Alberta anyone under the age of 18 is considered a minor. However, it is recognized that as teens age they develop a greater ability to make independent decisions regarding their own bodies and well-being. When a teen is deemed capable of making such decisions he/she is deemed a mature minor for the purpose of independently engaging with a defined health service, for the duration of the consented to episode of care.

These guidelines are intended to help social workers manage consent and confidentiality when working with minors in the province of Alberta. They are not meant to be fixed protocols and do not supplant the need for on-going consultation in the provision of social work services to minors.

### 1. When a minor is a client

ACSWS Standards of Practice require that consent be obtained from a client before providing professional services to them (B.4 (e)). The ACSWS Standards of Practice define a client as “an adult or minor age 14 or over who has the requisite understanding to appreciate the nature and consequences of the professional services being provided” (A(a)(i)). A minor may also be a client when legislation provides for the provision of services directly to the minor (for instance in the case of the *Child and Youth Advocate Act* Chapter C-11.5).

Notwithstanding the definition of “client” in the Standards of Practice all persons receiving services from a social worker, irrespective of their age or their capacity to consent to services or to share information, must be treated with respect and dignity, and the principles of confidentiality and consent must be honoured.

### Mature Minor Doctrine

#### 2. Rebuttable presumption that minors 16 years and older have capacity to consent to services

The law recognizes that as minors age they should have increasing say over decisions that affect them and their bodies. A minor’s thought of what is in their best interest becomes increasingly determinative of what their best interests are as they mature (*A.C. v. Manitoba (Director of Child and Family Services)* 2009 SCC 30). Consequently, case law has established that minors aged 16 and over have *defacto* medical decision making authority, unless the minor does not understand implications of the decision or appreciate its consequences. Thus, there is a rebuttable presumption that minors 16 years and older have medical decision making authority.

#### 3. Minors under 16 years of age may establish decision making authority

In Canada, the Mature Minor Doctrine addresses the ability of a minor to consent to medical treatment. Mature Minor Doctrine can also be applied in the same manner to consent for social work services. The ACSWS Standards of Practice suggest that a minor age 14 or older can be a client. However, this age

should not be taken as an end point in determining whether a legal minor is deemed a mature minor. Rather, it is a starting point for assessing whether a minor has the requisite understanding to appreciate the nature and consequences of the service being provided.

Factors to consider in determining whether a minor has decisional making authority (adapted from the College of Alberta Psychologists Practice Alert for Mature Minors):

- What is the nature, purpose and utility of the recommended treatment/service? What are the risks and benefits? The greater the risk and the more intrusive the intervention, there is a correspondingly greater expectation of maturity with the youth.
- Does the minor demonstrate the intellectual capacity and sophistication to understand the information relevant to making the decision, and to appreciate the potential consequences?
- Is there reason to believe that the minor's views are stable and a true reflection of their core values and beliefs? Or, are there other factors unduly influencing their values and core beliefs?
- What is the potential impact of the minor's environment (lifestyle, family relationships and broader social affiliations) on their ability to exercise independent judgment?
- Does the minor have any emotional or psychiatric vulnerabilities?
- Does the minor's condition or illness have an impact on their decision-making capacity?

In determining whether a minor is a mature minor social workers must be responsible for their subjective views of what the best decision is for the minor.

For practice purposes the discussion above implies that for minors aged 14-15 years, a social worker should consider why the minor may be deemed a mature minor when accessing services, while for minors aged 16-17 years, a social worker should consider why the minor would *not* be deemed a mature minor when accessing services.

#### **4. Exception for Legislated Services**

When provided for by legislation, minors may have a right to receive services from service providers designated under the legislation, whether or not they are a mature minor. The legislation may also provide that minors have a right to confidentiality, whether they are a mature minor or not (Including and not limited to the *Child and Youth Advocate Act*, Chapter C-11.5).

#### **5. A mature minor's rights to confidentiality**

Once a minor is deemed a mature minor for the purposes of consenting for services, they correspondingly have authority to manage the disclosure of health information associated with the care for which they provided consent. The parent/guardian does not have an automatic right of access to the mature minor's confidential information unless the mature minor provides written consent.

Once the mature minor doctrine is conferred upon a minor, it does not automatically apply to all future service events while they remain a legal minor. Mature minor status must be assessed at the onset of all future access points to service with a social worker, and should be considered with the implementation of any new intervention during a period of care with a particular social worker or service agency.

### **Consent and confidentiality when a minor is not a mature minor**

#### **6. Requirements for consent when a minor is not a mature minor**

When a minor is under 14 years of age, or over 14 years of age and not deemed a mature minor, consent for services must be sought from a guardian. A person may be a guardian by virtue of meeting

one or more of the requirements under the *Alberta Family Law Act*, by virtue of an agreement, or by appointment under a court order.

**a) The following people may be guardians for the purpose of giving consent:**

- i. Natural parent - if he/she meets the co-habitation or marriage criterion under the Family Law Act.
- ii. Adoptive parent - provided the court order is current and consent has not been revoked by natural parents.
- iii. Divorced parents – if there is joint custody; access parent is still a guardian but only has the “right to know”, not a “right to be consulted.”
- iv. Common law relationship parent – (including same sex partners) – if both parents are natural parents, both are guardians. If not, then the non-natural parent is not a guardian unless appointed by court order.
- v. Guardians appointed under court order – private guardians, as well as guardians appointed for children after apprehension by a child protection authority.
- vi. Guardians appointed under a will

Step-parents are not guardians, unless there is a court order appointing them as such. Similarly, foster parents are not guardians, although they may be delegated authority to make certain decisions through an appointment.

**b) From whom *must* consent be obtained when providing services to a minor who is not a mature minor**

Section 104 of the *Health Information Act*, provides that consent of a guardian must be sought when a minor is not deemed a mature minor. Whenever there is more than one legal guardian, those rights and responsibilities are equally shared between the guardians, or differently divided between them as accorded by a specific court order.

The answer to the question of who must consent be obtained from depends on the circumstances. Who consent *must* be obtained from, as opposed to who consent *may* be obtained from, is a matter of professional judgement on the part of the social worker. Families dealing with separation and divorce may have acrimonious dynamics. Situations involving domestic violence or child sexual abuse also require professional judgement. Allowing one guardian the authority to exclusively bring a minor for services, potentially against the express wishes of the other guardian, could very well put a minor in an untenable and/or harmful position, and would arguably not be in the best interests of the child. And at the same time, refusing treatment of a minor because one guardian will not consent may be equally untenable for the minor and the guardian, and may not be in the best interests of the child.

Given that there is not one rule that will likely fit all situations, a social worker will need to assess each situation on its own merit, taking into consideration the point of view of all guardians, the nature of the services being sought, the age of the child, the status of the family, court orders in place, legal proceedings underway, and active judicial and/or child and family services investigations.

A best practice would be to obtain consent from all guardians where practicable. When this is not practicable, the social worker should determine who the most appropriate guardian is to give consent, and then obtain consent from that guardian. Of course, all decisions regarding consent for services on behalf of minors must be made in the best interests of the child, regardless of who is giving consent, and should be documented accordingly.

### **c) A minor's right to confidentiality**

Confidentiality with a minor should be considered separately from consent for services, though the two can overlap. If a minor was not deemed a mature minor for the purpose of consenting for services, then the right to confidentiality must be independently discussed and negotiated with the minor and his/her guardian. Ultimately, minors who are not mature minors do not have an unfettered right to confidentiality. As provided in Standards D.3 and D.6 it behooves a social worker to negotiate and discuss matters of confidentiality at the outset of their involvement as part of their informed consent to care when working with minors.

- D.3 A social worker working with a person under the age of majority who has not been designated a mature minor or as an adult and who has a guardian will discuss with the relevant parties where appropriate, who will have access to all or parts of the record. The discussion and any agreement reached with regard to access shall be recorded on the client file.
- D.6 A social worker working with a person under the age of majority who has not been designated a mature minor or who has a guardian will discuss with the relevant parties, where appropriate, the limit the law imposes on the right to confidentiality with respect to communications with the social worker.

**October 2015**

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Alzheimer Society of Canada has a public position statement\* on Medical Assistance in Dying (MAID) which includes the Society's position on "advanced requests". The Alzheimer Society of B.C. would like to add the following comments.

End-of-life care is a complex and highly personal issue for Canadians facing dementia. People living with dementia and caregivers will have varying opinions, experiences and feelings about MAID.

Because dementia is a progressive disease, a person's ability to communicate their needs and preferences will diminish over time. People living with dementia may worry about what their own end-of-life care will look like or their caregivers may wonder what the person they are caring for will experience. The Alzheimer Society of B.C. educates people living with dementia and families to plan ahead and access legal planning tools as soon as possible after diagnosis. It's important for families to consider care needs while their family member living with dementia is still able to express their wishes.

The ethical considerations of MAID – relating to people living with dementia – are extensive. Both making changes to legislation and then implementing those changes in the health-care system are complicated processes; the Society is not an expert in this area. If changes to implementation of this legislation were to be considered, the Society would like to see that the voices of people living with dementia and their caregivers are included in the process.

The opinions of people living with dementia vary. We have received considerable feedback from the public, our B.C. Leadership Group for People Living with Dementia and our B.C. Leadership Group of Caregivers; it is apparent that this is an important issue to them. In particular, people living with dementia want an opportunity to be part of the conversation. Many have expressed a desire to see the legislation expanded to accommodate the challenges presented by the disease, regardless of whether or not they may ultimately choose to use it.

The Society understands this legislation needs to start conservatively and expand as more is learned and thoughtfully considered. Our hope is that the process will include people living with dementia and their families.

\*[http://www.alzheimer.ca/~media/Files/national/Media-centre/asc\\_position\\_03152016\\_MAID\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Media-centre/asc_position_03152016_MAID_e.pdf)

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Alzheimer Society of Nova Scotia

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

We strongly believe that it is premature to take a position of access to MAID by persons with dementia. There is a need to clearly understand what persons living with dementia and their families and caregivers want and in that process determine the parameters in which the decisions will be limited.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Alzheimer Society of Nova Scotia

Statement of Fact- Medical Assistance in Dying

This background paper is adapted from Alzheimer Society of Canada

**Background Information**

Dementia is a progressive disease that will eventually lead to death. Because dementia is very different than other life-limiting illnesses, the needs of people with dementia at the end of life are unique and require special considerations.

Due to the progressive, degenerative nature of dementia, people with the disease will eventually become unable to make decisions about treatment and their own care. Family members and health care professionals often have to make difficult decisions on behalf of the person with dementia. People with dementia should be encouraged to make their wishes known to their family members (or a substitute decision maker in some provinces) when they are still capable. A written advance care plan can guide families when the person with dementia is no longer able to express their wishes for health and personal care decisions.

**What is medical assistance in dying?**

Medical assistance in dying (MAID) is the administration by health care teams (physicians, nurses, pharmacists and other health care professionals) of medications or substances to end the life of a person, at her/his request, in order to relieve suffering by hastening death. (Other terms used include physician-assisted death, physician-assisted dying, physician-assisted suicide, physician-hastened death, etc.)

**What is the issue?**

The significant outcome of the Supreme Court decision of February 6, 2015 is that medical assistance in dying will no longer be considered murder under the Criminal Code of Canada. It follows that a competent adult with enduring and intolerable suffering can request MAID by clearly consenting to terminate her/his life. BILL C-14; An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) passed into law May 30, 2016 with the requirement that a person be competent at the time of the act of medical assistance in dying.



## Capacity and consent

While a person with dementia may not be deemed incapable to make decisions for herself/himself immediately at the time of diagnosis, due to the progressive nature of dementia, specific skills will be lost during the course of the disease, including the capacity to consent to treatment including MAID. Therefore, a diagnosis of dementia does not necessarily render someone immediately incapable.

To consent - in this instance, to MAID - the person needs to be capable of retaining and understanding new information, analyzing the information and making an informed decision. According to current legislation, consent to MAID must be clearly expressed and voluntary, and the person's ability to make decisions must be carefully assessed to ensure that he/she is able to understand the information provided and the consequences of making a decision to end their life. Bill C-14 passed into law with the additional requirement that, in order to consent to MAID, the person must be capable of retaining and understanding new information, analyzing the information and making an informed decision at the time that MAID is carried out.

All of these abilities (i.e. retaining, understanding and analyzing information and making informed decisions) may be impaired in people with dementia and consent will not be possible at the time of medical assistance in dying or throughout the mandated period of reflection (during which a person can withdraw her/his consent).

## Our understanding

Given the progressive nature of dementia, wishes, values and beliefs may change, skills are lost and the ability to make decisions is often greatly reduced. As the law currently stands, MAID is only possible when a person is deemed competent at the time of MAID, therefore persons with dementia who lack decision-making capacity would not be eligible for MAID. Indeed, The Special Joint Committee On Physician-Assisted Dying (Parliament of Canada) has recommended "that the permission to use advance requests for MAID be allowed any time after one is diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable"<sup>1</sup>.

The Alzheimer Society believes that people with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life. People with dementia may not have the capacity to make an informed decision and consent to end their life at the later stages of the disease, when in fact this is the very time when they would want the services of MAID.

In view of this information, the Alzheimer Society of Nova Scotia:

- Aims to reduce the stigma and stereotypes around Alzheimer's disease and other dementias, stressing that living a satisfying life doesn't end with a diagnosis and that it is possible to continue to live well with the disease.

- Urges people with dementia to make their wishes for their future care known, preferably through advance care planning as soon as possible after diagnosis. It's important the person with dementia have the opportunity for their individual/personal decision making and the opportunity to fully participate with sharing their "individual" plan reflective of their values, wishes and goals with their families (in particular their SDM/delegate) and care providers to ensure the best possible quality of life up to and including end of life.

- Calls for improved quality hospice palliative care that is available to all Canadians with dementia as they near the end of their life. The right to access quality palliative care will help minimize unnecessary suffering and improve the quality of dying for people with life-limiting illnesses.

## Association for Reformed Political Action

### **1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Parliament should not expand access to “medical assistance in dying” (“MAID”). It should *not* amend the *Criminal Code* to permit doctors to euthanize or assist the suicide of mature minors and/or those with a mental illness. Parliament is responsible to pass criminal laws that prohibit societal ills such as the normalization of suicide and the devaluing of the lives of people with disabilities.

Parliament has the authority to enact criminal prohibitions on the basis of fundamental social and ethical considerations. Parliament has a duty to protect human life and defend its inherent dignity. Assisted suicide and euthanasia (consensual homicide) are inherently social acts and are, in this respect, fundamentally different than the act of suicide. Intentionally causing the death of another person is intrinsically morally wrong, it is an attack on human life and dignity. Permitting MAID at all already has an effect on the longstanding and foundational principles of medical ethics.

In regulating MAID, Parliament has the duty to consider more than individual autonomy and consider the broader question of the impact of MAID on society and especially its most vulnerable members. In *Carter*, the Court’s focus was on the particular factual situation that was before it and it explicitly tailored its conclusions to that scenario (*Carter v Canada (Attorney General)*, 2015 SCC 5 at para 127).

The *Carter* ruling did not turn “assisted death” into a purely health care matter. The Supreme Court has recognized Parliament’s authority to use the *Criminal Code* to regulate matters that are dangerous or socially harmful such as regulation of narcotics, tobacco, and abortion (*PHS Community Services Society v Canada (Attorney General)*, 2011 SCC 44 at para 58), or that raise serious moral questions.

The fact that capacity is determined a certain way for most medical procedures is not determinative when it comes to MAID, because MAID it is not just another medical procedure. Indeed, many doctors do not consider assisted death to be health care at all. There is a clear ethical distinction between suicide (assisted or otherwise) and other end of life medical choices such as palliative care or refusing further medical treatment.

Until *Carter*, no one could consent to their own death. There were many reasons for this. One of the harms stems from the reality that assisted suicide and consensual homicide are social acts – they involve the deliberate participation by one person in intentionally causing the death of another.



When considering whether to extend assisted suicide to those with mental disabilities or mature minors, Parliament is not merely concerned with whether those individuals have the capacity to consent in a traditional medical sense. Allowing assisted suicide normalizes suicide as a solution to suffering; the broader the access, the more suicide is normalized. When suicide is heralded as the dignified way to die, all of society, but specifically the most impressionable and vulnerable, are given the signal that suicide is normal. Expanding access to MAID will affect our attitudes towards the sick and disabled – which any of us could be someday – and their attitudes towards themselves.

Extending assisted suicide sends the message to those with mental illness – or any condition that is deemed to qualify for MAID – that their lives are not worth living and that if they were to be killed, we would not be as suspicious of their consent as we would with an able-bodied individual.

Parliament has the duty to consider the societal and cultural implications of permitting some to assist the suicide of others or to directly cause their death (homicide) with their consent. Assisted suicide legislation is a criminal legislation – it regulates a matter that raises serious moral questions and serious safety risks to society’s most vulnerable members. Such regulation should not be abdicated to provinces, physicians’ colleges, or individual physicians to determine who is “eligible” to have a doctor put them down or aid their suicide. Rather, with the purpose of not normalizing suicide in any form and affirming the value of all with disabilities, Parliament should maintain the legislative scheme in place.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

For additional information, see the following resources:  
[Protecting Life: How Parliament Can Fully Ban Assisted Suicide Without the Notwithstanding Clause](#)

[Stemming the Tide: How Parliament Must Mitigate the Harm of Assisted Suicide](#)

Published article (attached pdf) in the Supreme Court Law Review (2016) titled *Lethal Discrimination: A Case Against Legalizing Assisted Suicide in Canada*. Please note: this is the penultimate version and is shared with the understanding that it will not be circulated. Once the paper is made available online, it will be shared with the CCA. (The paper has been published in hard copy).

ARPA Canada’s [submissions](#) to the Standing Committee on Justice and Human Rights regarding Bill C-14.

# **Lethal Discrimination: A Case Against Legalizing Assisted Suicide In Canada<sup>†</sup>**

**André M. Schutten, HON. B.A., LL.B., LL.M.\***

*The morality of the 21st century will depend on how we respond to this simple but profound question: Does every human life have equal moral value simply and merely because it is human? Answer yes, and we have a chance of achieving universal human rights. Answer no, and it means that we are merely another animal in the forest.<sup>1</sup>*

## **I. INTRODUCTION**

I was both honoured and apprehensive to be a panelist at the Canadian Constitution Foundation's 2015 Law and Freedom conference. I was asked to speak on assisted suicide and the Supreme Court of Canada's recent treatment of the issue in *Carter v. Canada (Attorney General)*.<sup>2</sup> Assisted suicide is — according to doctors, journalists, theologians and even Supreme Court judges — a very contentious moral,

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<sup>†</sup> I wish to express gratitude to the Canadian Constitution Foundation for their kind invitation to participate in their Law and Freedom conference, and to contribute an article to this special edition law journal. The CCF has done and is doing incredible work defending the constitutional freedoms of Canadians across this country. I also want to thank my employer for giving me the opportunity to spend valuable time on this article and to my friend and colleague John Sikkema for his legal research which was of immense assistance to me.

\* Director of Law & Policy for the Association for Reformed Political Action (ARPA) Canada. André completed his undergraduate degree in 2007, obtaining an Honours B.A. in Classics and Religion from McMaster University. In 2010, he obtained a law degree from the University of Ottawa. André completed a Masters degree in Constitutional Law through Osgoode Hall Law School in the summer of 2013. Called to the Ontario Bar in June, 2011, André has already represented ARPA Canada at the Supreme Court of Canada three times, including as an intervenor in the *Carter v. Canada* case.

<sup>1</sup> Wesley J. Smith, — *The Way I See It* #127, as printed on Starbucks coffee cups.

<sup>2</sup> [2015] S.C.J. No. 5, 2015 SCC 5, [2015] 1 S.C.R. 331 (S.C.C.) [hereinafter "*Carter* (SCC)"].

legal and social issue.<sup>3</sup> And if public opinion polls are to be believed, I was (and still am) on the wrong side of the debate.<sup>4</sup> However controversial the topic, it is a fundamentally important one for society to grapple with. And since the Supreme Court released its decision on assisted suicide a month after I presented at the CCF's conference, I am thankful for the opportunity to address this topic again, now with the additional benefit of having read and analyzed the Supreme Court's judgment.

If there is just one job for the civil government to do, one reason for it to exist, it is to maintain and enforce laws that provide equal protection for the lives of its citizens so that all citizens can have equal opportunity to flourish. Legalizing assisted suicide completely undermines this ideal.

An argument for assisted suicide from a libertarian perspective may be that, "if my life belongs to me, I should be free to give it up. And if I enter into a voluntary agreement with someone to help me die, the state has no right to interfere."<sup>5</sup> However, this is a particularly narrow view of the realities of assisted suicide. Legalized assisted suicide involves much more than just the autonomous individual who wants to die, and involves

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<sup>3</sup> See, e.g., Canadian Medical Association, *CMA Policy on Euthanasia and Assisted Suicide* (Updated 2014), at 2, online: <<https://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/cma-policy-euthanasia-assisted-death-updated-2014-e.pdf>>, which states:

Euthanasia and assisted death have been opposed by many national medical associations and prohibited by the law codes of many jurisdictions. ... Physicians, other health professionals, academics, interest groups, the media, legislators and the judiciary are all deeply divided about the advisability of changing the current legal prohibition of euthanasia and assisted death. Because of the controversial nature of these practices, their undeniable importance to physicians and their unpredictable effects on the practice of medicine, these issues must be approached cautiously and deliberately by the profession and society.

See also Carolyn Coorsh, "84% of Canadians support assisted dying, new poll shows" *CTVNews.ca* (October 8, 2014), online: <<http://www.ctvnews.ca/health/84-of-canadians-support-assisted-dying-new-poll-shows-1.2045085>>. See also The Canadian Conference of Catholic Bishops and The Evangelical Fellowship of Canada, *Declaration on Euthanasia and Assisted Suicide*, online: <<http://www.euthanasiadeclaration.ca/declaration/>>, which states: "Assisted suicide and euthanasia raise profound social, moral, legal, theological and philosophical questions — questions that go to the very core of our understanding of who we are, the meaning of life, and the duty of care we owe to each other." See finally, the Supreme Court of Canada in *Carter* (SCC), *supra*, note 2, at para. 2, where the Court states that legalizing assisted suicide is "a question that asks us to balance competing values of great importance".

<sup>4</sup> See Ben Spurr, "77% of Canadians support assisted suicide, poll shows", *Toronto Star* (August 28, 2015), online: <<http://www.thestar.com/news/gta/2015/08/28/77-of-canadians-support-assisted-suicide-poll-shows.html>>.

<sup>5</sup> Michael J. Sandel, *Justice: What's the Right Thing to Do?* (New York: Farrar, Straus and Giroux, 2009), at 73 [hereinafter "Sandel"].

more than the person he or she contracts with to assist with the killing. Canadian ethicist Dr. Margaret Somerville puts it this way,

Physician-assisted suicide is a social act in which medical personnel, licensed and compensated by the state, are involved in the termination of the life of a person with the approval of the state. Allowing assisted suicide asks not that we attempt to preserve life... but that we accept and act communally upon a person's judgment that his or her life is unworthy of continuance.<sup>6</sup>

Assisted suicide is inherently social: it requires the involvement of another moral agent who will be aiding in a killing and it requires the endorsement of society through legal sanction. Assisted suicide, particularly for those with disabilities or diseases,<sup>7</sup> is also inherently value-laden. Legalizing assisted suicide for such people is a value judgment about their societal worth and is discrimination in a lethal way.

Many thousands of pages will be written to analyze, praise or critique the Supreme Court's decision<sup>8</sup> and the legislative response that is sure to follow from Parliament.<sup>9</sup> This article will be limited in its scope. I will argue that legalizing assisted suicide fundamentally undermines life and liberty because permitting some people to kill members of a

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<sup>6</sup> Margaret Somerville, *Bird on an Ethics Wire: Battles about Values in the Culture Wars* (Montreal: McGill-Queen's University Press, 2015), at 129-30 [hereinafter "Somerville"].

<sup>7</sup> Very few people indeed are advocating for the right to assisted suicide for the mildly depressed.

<sup>8</sup> Other articles have already been published, and many more will be published, on this case, analysing and critiquing it from many different angles. See, for example, the five-part symposium on *Carter* (SCC), *supra*, note 2, published in the *Saskatchewan Law Review* (2015), 78 Sask. L. Rev. 197 ——— 239, covering angles such as: the significance of the suspended declaration of invalidity and its unnecessary application (Sarah Burningham, at 201-207); the blurring of the separate analyses of ss. 7 and 1 with regards to "societal interests" (Mark Carter, at 209-216); failings in the judicial method and reasoning in *Carter* (SCC) (Dwight Newman, at 217-24); the choice of the Court to limit their declaration to "physician-assisted" dying (Doug Surtees, at 225-31); and the question of whether advanced consent will be available in any ensuing legislative scheme (Barbara von Tigerstrom, at 233-39).

<sup>9</sup> At the time of writing, no legislation has yet been tabled. However, the Report of the Special Joint Committee on Physician-Assisted Dying titled *Medical Assistance in Dying: A Patient-Centred Approach* was released in February, 2016 [hereinafter "Joint Committee Report"]. The Report makes 21 recommendations, including allowing children to be euthanized (recommendation #6), permitting advance directives (recommendation #7), and recommending against any prior review and approval process (recommendation #15). These recommendations go far beyond what was required by the Supreme Court in *Carter* (SCC). It remains to be seen which recommendations will be implemented into the new law. The entire report, with the dissenting reports, can be accessed online:

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[http://www.parl.gc.ca/Content/HOC/Committee/421/PDAM/Reports/RP8120006/421\\_PDAM\\_Rpt01\\_PDF/421\\_PDAM\\_Rpt01-e.pdf](http://www.parl.gc.ca/Content/HOC/Committee/421/PDAM/Reports/RP8120006/421_PDAM_Rpt01_PDF/421_PDAM_Rpt01-e.pdf)>.

particular class, even with their consent, undermines more fundamental rights, *i.e.*, the right to life, of other members of that class. This article will argue that liberty does not equal unbridled autonomy; a justification of assisted suicide based on autonomy stretches the bounds of autonomy too far. This article will then explore the merits of a slippery slope argument before engaging in an equality rights analysis of the legislative response demanded by the Supreme Court. I conclude that the best legislative response for Parliament is to maintain absolute prohibitions on assisted suicide, and discuss one way in which that can be achieved.

## II. *CARTER V. CANADA (ATTORNEY GENERAL)*

In *Carter* (SCC),<sup>10</sup> the Court ruled that the absolute prohibition on assisted suicide in the *Criminal Code*<sup>11</sup> violated the *Canadian Charter of Rights and Freedoms*.<sup>12</sup>

Section 241(b) of the *Criminal Code* prohibits aiding or abetting a person to commit suicide. Section 14 of the *Criminal Code* states that no person is entitled to consent to have death inflicted on him and that the consent of a person upon whom death is inflicted is no defence for the person who inflicted death upon him. Put another way, the person who inflicts death upon another individual is not innocent of criminal wrongdoing simply because that person consented. The Supreme Court declared that these two sections of the *Criminal Code* are void “to the extent that they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) who has a grievous and irremediable medical condition ... that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition”.<sup>13</sup>

The case was decided based on the Court’s application of section 7 of the Charter.<sup>14</sup> Section 7 is “engaged” when a person’s life, liberty or

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<sup>10</sup> *Carter* (SCC), *supra*, note 2. I am grateful to my friend John Sikkema for assisting me with this section.

<sup>11</sup> R.S.C. 1985, c. C-46, ss. 14, 241(b) [hereinafter “*Criminal Code*”].

<sup>12</sup> Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [hereinafter “*Charter*”].

<sup>13</sup> *Carter* (SCC), *supra*, note 2, at para. 127. This definition is particularly important, as we shall see, in the s. 15 equality rights analysis.

<sup>14</sup> *Charter*, *supra*, note 12, s. 7: “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

security of the person — the “interests” protected by section 7 — is adversely affected by the state in a manner that is not trivial or insignificant. Section 7 is *violated* where it is engaged *and* where the law or state action violates a principle of fundamental justice.<sup>15</sup>

In *Carter* (SCC), the life interest was engaged because the prohibition on assisted suicide could “force” some people to take their own lives “prematurely” for fear that they would be incapable of doing so later, when their suffering became intolerable.<sup>16</sup> The liberty and security interests were engaged because the law interfered with “fundamental personal choices” and “control over one’s bodily integrity”.<sup>17</sup>

A law may interfere with the right to life, liberty, or security of the person only if it does so “in accordance with the principles of fundamental justice”. One principle of fundamental justice developed by the Supreme Court is that a law may not be overbroad, meaning it cannot interfere with the right to life, liberty, or security of the person in ways not rationally connected to achieving the objective of the law.<sup>18</sup> The validity of the law under section 7 review depends on the relationship between means and objective. Therefore, as the Court said, the first step is “to identify the object of the prohibition on assisted dying”.<sup>19</sup>

The Supreme Court characterized the objective of the criminal prohibition on assisted suicide very narrowly. It ruled that the objective was merely to protect vulnerable persons from being induced to commit suicide at a moment of weakness.<sup>20</sup> The objective was not, in the Court’s view, to protect life broadly speaking, or even to prevent suicide.<sup>21</sup> This distinction effectively determined the outcome of the case.

The Court reasoned that, since not every person who wishes to commit suicide is vulnerable, it follows that the limitation on individual rights, at least in those particular cases, is not connected to the law’s

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<sup>15</sup> Guy Regimbald & Dwight Newman, *The Law of the Canadian Constitution*, 1st ed. (Markham: LexisNexis Canada, 2013), at 618.

<sup>16</sup> *Supra*, note 2, at paras. 57-58.

<sup>17</sup> *Id.*, at para. 64.

<sup>18</sup> Overbreadth is closely related to the principle of arbitrariness. A law is arbitrary if it deprives a person of life, liberty, or security of the person in a manner that is not rationally connected to the objective of the law. A law is overbroad where its application is connected to achieving the objective in some circumstances, but not in all circumstances to which the law applies. As the Court says in *Carter* (SCC), *supra*, note 2, at para. 85, “The overbreadth inquiry asks whether a law that takes away rights in a way that generally supports the object of the law, goes too far by denying the rights of some individuals in a way that bears no relation to the object.”

<sup>19</sup> *Carter* (SCC), *supra*, note 2, at para. 73. “Object” and “objective” are used interchangeably.

<sup>20</sup> *Id.*, at para. 78.

<sup>21</sup> *Id.*

objective of protecting vulnerable persons. Consequently, the absolute prohibition was found to deprive some persons of their section 7 rights in a manner that did not accord with the principles of fundamental justice.<sup>22</sup> The prohibition was “overbroad” and therefore violated section 7.

The Supreme Court found further that the violation of section 7 was not justified under section 1 of the Charter.<sup>23</sup> The law did not minimally impair the claimants’ section 7 rights because a complete prohibition was found to be broader than necessary to achieve the Government’s objective of protecting the vulnerable. A complete prohibition was unnecessary, they reasoned, because the Government could depend on physicians to determine whether or not someone seeking assisted suicide was actually vulnerable or subject to pressure to end his or her life.<sup>24</sup>

Those who advocate for assisted suicide are, presumably, happy with the outcome of the Supreme Court’s ruling, if not fully satisfied by the reasoning. However, this judgment raises serious concerns and leaves major gaps that need to be addressed. Much could be said about various aspects of the judgment, the blurring of the principles of fundamental justice and the section 1 reasonable limits test,<sup>25</sup> the relatively new phenomenon of high deference to a trial judge’s findings of social-scientific facts,<sup>26</sup> or the lack of deference to Parliament on complex

<sup>22</sup> *Id.*, at para. 86.

<sup>23</sup> This is not surprising. In the history of the Charter, a law that failed a section 7 analysis has *never* survived a section 1 justification analysis in a case before the Supreme Court of Canada. Section 1 of the Charter allows rights and freedoms in the Charter to be limited where to do so is “demonstrably justified in a free and democratic society”.

<sup>24</sup> *Carter* (SCC), *supra*, note 2, at paras. 27, 105-106, 121.

<sup>25</sup> See, e.g., Mark Carter, “*Carter v. Canada*: ‘Societal Interests’ Under Sections 7 and 1” (2015), 78 Sask. L. Rev. 209-216 [hereinafter “Mark Carter”].

<sup>26</sup> A constitutional lawyer and former law clerk to U.S. Supreme Court Justice Antonin Scalia argues that the:

root of the rot... is not an erroneous legal doctrine or a misconstrued Charter provision... but... how the Court finds facts in Charter cases. ... In Charter cases the relevant considerations often transcend the individual parties and relate more broadly to society as a whole. ... The Supreme Court calls these ‘social facts,’ facts about ‘society at large.’ Shockingly, it now treats them identically to ordinary adjudicative facts. ... In practice, this means that a single, anonymous trial judge is authorized to impose his social worldview on the entire country. In the *Insite* case, for example, the trial judge found as a ‘fact’ that the social benefits of the safe injection site outweighed its costs. And, in *Bedford*, the trial court found that banning solicitation did not protect women from the harms of prostitution, but rather forced prostitutes to meet clients in private, exposing them to violence. These are not ‘facts’ in any true judicial sense. They are social theories, policy conclusions, value judgments and ideological preferences. Courts were never designed to resolve these sorts of ‘fact’ disputes. Parliament was. ...The problem, in other words, is neither the Charter nor judicial review. The problem is pretending that

social issues.<sup>27</sup> However, this article will focus particularly on the discriminatory effect of legalizing assisted suicide.<sup>28</sup>

### III. LIBERTY DOES NOT EQUAL UNBRIDLED AUTONOMY

Autonomous decision-making is not an absolute right, free from any government regulation or limitation.<sup>29</sup> Unrestricted autonomy is irreconcilable with true human freedom, which is exercised best when able to thrive in an ordered society. Justice Wilson puts it aptly, "...The concept of 'right' as used in the Charter postulates the inter-relation of

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systemic consequences of laws and regulations on 'society at large' can be found as 'facts', like who punched whom in the bar fight.

Yaakov Roth, "How the courts trump Parliament", *National Post* (January 3, 2014) online: <<http://fullcomment.nationalpost.com/2014/01/03/yaakov-roth-how-the-courts-trump-parliament/>>. See also the Supreme Court in *Canada (Attorney General) v. Bedford*, *infra*, note 44, at paras. 48-56, concluding, "...I am of the view that a no-deference standard of appellate review for social and legislative facts should be rejected. The standard of review for findings of fact — whether adjudicative, social, or legislative — remains palpable and overriding error."

<sup>27</sup> As the Attorney General of Canada argued in its factum (at paras. 109 and 112), in determining whether a law is overbroad, the Court is required to give a measure of deference to legislators — *R. v. Clay*, [2003] S.C.J. No. 80, [2003] 3 S.C.R. 735, at paras. 38-39 (S.C.C.) — and the onus is on the appellants to demonstrate that the laws clearly go beyond what is necessary for the government to achieve its objectives. *R. v. Heywood*, [1994] S.C.J. No. 101, [1994] 3 S.C.R. 761, at 793-94 (S.C.C.). In *RJR-MacDonald Inc. v. Canada (Attorney General)*, [1995] S.C.J. No. 68, [1995] 3 S.C.R. 199, at para. 135 (S.C.C.), for example, McLachlin J. noted that "the situation which the law is attempting to redress may affect the degree of deference which the court should accord to Parliament's choice". And increased deference may be owed where legislative provisions concerning social values are at stake. *R. v. Sharpe*, [2001] S.C.J. No. 3, [2001] 1 S.C.R. 45, at paras. 89 (*per* McLachlin C.J.C.) and 191-192 (*per* L'Heureux-Dubé (dissenting)) (S.C.C.). See the Supreme Court's statement in *Carter* (SCC) as well, "...Parliament faces a difficult task in addressing this issue; it must weigh and balance the perspective of those who might be at risk in a permissive regime against that of those who seek assistance in dying. It follows that a high degree of deference is owed to Parliament's decision to impose an absolute prohibition on assisted death". *Carter* (SCC), *supra*, note 2, at para. 98.

<sup>28</sup> Much more should be said eventually about important issues raised in this judgment regarding the qualitative vs. the existential understandings of the right to life, proper understandings of human dignity, etc. See, for example, the problematic confusion regarding qualitative verses existential: The Supreme Court endorses the trial judge's decision to reject a qualitative approach to the right to life (*Carter* (SCC), *supra*, note 2, at paras. 59-62, citing with approval the trial judge's reasons at para. 1322), but suggests that "the existential formulation of the right to life [does not require] an absolute prohibition on assistance in dying..." (*Carter* (SCC), *supra*, note 2, at para. 63). Yet their approach is, in essence, qualitative — the exception that the Court carves out is based on qualities of life.

<sup>29</sup> *Blencoe v. British Columbia (Human Rights Commission)*, [2000] S.C.J. No. 43, [2000] 2 S.C.R. 307, at para. 54 (S.C.C.).



individuals in society all of whom have the same right. The aphorism that ‘A hermit has no need of rights’ makes the point.”<sup>30</sup>

### 1. There are Some Things We Can’t Consent To

In an ordered society, citizens cannot consent to violent forms of assault, to aggravated sexual assault or to voluntary cannibalism. The vast majority of people living in such a society would not think they are living in a “less free” state by virtue of these prohibitions — probably the opposite. The argument that suffering citizens can consent to the infliction of homicide should similarly be rejected.

There are “[s]everal instances of crimes that do not cause harm to others... found in the *Criminal Code*”,<sup>31</sup> such as laws against drug consumption. Criminal law properly prohibits gross self-victimization, and it is entirely logical that it also prohibit doing certain harmful things to another person, even with their consent. That is why the principal actor in an act of murder, assisted suicide, or aggravated assault is culpable of homicide, assisted suicide or assault causing bodily harm regardless of whether the victim consented.<sup>32</sup>

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<sup>30</sup> *Operation Dismantle Inc. v. Canada*, [1985] S.C.J. No. 22, [1985] 1 S.C.R. 441, at 488 (S.C.C.).

<sup>31</sup> *R. v. Malmo-Levine; R. v. Caine*, [2003] S.C.J. No. 79, 2003 SCC 74, [2003] 3 S.C.R. 571, at para. 117 (S.C.C.); the Court uses cannibalism as an example of an offence that does not harm another sentient being, but which is prohibited “on the basis of fundamental social and ethical considerations”.

<sup>32</sup> Barbara von Tigerstrom argues that “it would be consistent with the Court’s judgment to allow some form of advance consent and this should be provided for within the new legal regime” (at para. 1). Tigerstrom states: “...There does not seem to be any convincing reasons against allowing a person to consent in advance to physician-assisted death” (para. 3) and concludes “it would be consistent with the Court’s analysis to say that the clear, competent consent required for physician-assisted death can be given in advance, and failure to allow advance consent might be vulnerable to a constitutional challenge”. Barbara von Tigerstrom, “Consenting to Physician-Assisted Death: Issues Arising from *Carter v. Canada (Attorney General)*” (2015), 78 Sask. L. Rev. 233-239, at paras. 1 and 3. However, the most obvious reason against allowing a person to consent in advance is that it provides no right or ability of revocation, a right available to anyone else. When compared to consent in other areas of criminal law, this is clearly a very dangerous policy to advance. See, for example, *R. v. J.A.*, [2011] S.C.J. No. 28, 2011 SCC 28, [2011] 2 S.C.R. 440 (S.C.C.) [hereinafter “*R. v. J.A.*”], where the majority of the Supreme Court found the accused guilty of sexual assault for penetrating the victim while she was unconscious. The majority rejected the defence of advance consent because, without contemporaneous assessment, it “effectively negates the right of the complainant to change her mind at any point in the sexual encounter” (*Id.*, at para. 53). Despite this, the special joint committee joins voice with von Tigerstrom, arguing for the use of advance directives, even though this is not contemplated by the SCC in *Carter* (“competent adult” would

(a) *Consent and Assault Law*

The common law recognizes that a person cannot consent to the infliction of serious bodily harm.<sup>33</sup> This rule acts as a deterrent against consensual fighting and, by discouraging fighting in general, also helps to protect those who do not consent to a fight from physical aggression.<sup>34</sup> But Gonthier J. recognized another reason to vitiate consent to serious bodily harm: “Wholly apart from deterrence, it is most unseemly from a moral point of view that the law would countenance ... the sort of interaction displayed by the facts of this appeal. The sanctity of the human body should militate against the validity of consent to bodily harm inflicted in a fight.”<sup>35</sup> By deterring aggression in general, the vitiation of consent in the context of assault causing serious bodily harm has the beneficial effect of protecting the autonomy and bodily integrity of those who would not consent to a fight.

(b) *Consent and Sexual Assault Law*

Section 268 of the *Criminal Code* makes female genital mutilation (known in some cultures as female circumcision) a criminal offence. The section makes it an offence to “excise, infibulate or mutilate, in whole or in part, the labia majora, labia minora or clitoris of a person, except where ... a surgical procedure is performed, by a person duly qualified by provincial law to practise medicine, for the benefit of the physical health of the person or for the purpose of that person having normal reproductive functions or normal sexual appearance or function”. Section 268 also states that no consent to such excision, infibulation, or mutilation is valid except in cases described in the exceptions.<sup>36</sup>

Section 268 is part of the law of assault. In order to convict a person of assault, the Crown must prove that the victim did not consent to the accused’s actions. The alleged victim of the assault is obviously a key witness with respect to whether or not consent was given. However, the law does not give a person complete autonomy to consent to having harm done to them. The *Criminal Code* and common law limit the

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imply contemporaneously competent, not competent at one point in time). See *Joint Committee Report*, *supra* note 9, Recommendation #7.

<sup>33</sup> *R. v. Jobidon*, [1991] S.C.J. No 65, [1991] 2 S.C.R. 714 (S.C.C.) [hereinafter “*Jobidon*”].

<sup>34</sup> *Id.*, at para. 115.

<sup>35</sup> *Id.*, at para. 116.

<sup>36</sup> *Criminal Code*, *supra*, note 11, ss. 268(3) and (4).

circumstances in which consent is valid. The onus is on the Crown to show that no consent was obtained or, if there was apparent consent, that it was not validly obtained.<sup>37</sup>

In *R. v. J.A.*,<sup>38</sup> the Supreme Court also ruled on “whether consent for the purposes of sexual assault requires the complainant to be conscious through the sexual activity”.<sup>39</sup> The issue in this case was not whether consent was irrelevant to the crime, but whether consent can be given in advance for what would otherwise be sexual assault. A majority of the Supreme Court ruled that activity which would otherwise be sexual assault requires ongoing, active consent, thereby eliminating any possibility to give consent for sexual activity while unconscious.<sup>40</sup>

(c) *Consent and Cannibalism*

A final example of a criminal activity for which there is no defence of consent is the crime of cannibalism, prohibited in section 182.<sup>41</sup> Many lawyers might think of the famous case of Richard Parker, the poor cabin boy stranded in a lifeboat with Dudley, Stephens and Brooks in July, 1884 who was killed and eaten.<sup>42</sup> Parker was killed against his will, making the crime a murder (even though he was close to death and those who killed him argued the defence of necessity). But that is not the type of cannibalism that should be weighed here. Consider the sordid tale philosopher Michael Sandel recounts:

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<sup>37</sup> *Id.*

<sup>38</sup> *Supra*, note 32.

<sup>39</sup> *Id.*, at para. 21.

<sup>40</sup> For commentary on this particular question, see Jennifer Koshan, “Consciousness and Consent in Sexual Assault Cases”, *ABlawg.ca* (June 17, 2011), online: <[http://ablawg.ca/wp-content/uploads/2011/06/blog\\_jk\\_ja\\_june2011.pdf](http://ablawg.ca/wp-content/uploads/2011/06/blog_jk_ja_june2011.pdf)>.

<sup>41</sup> *Criminal Code*, *supra*, note 11, s. 182, which reads:

Every one who

(a) neglects, without lawful excuse, to perform any duty that is imposed on him by law or that he undertakes with reference to the burial of a dead human body or human remains, or

(b) improperly or indecently interferes with or offers any indignity to a dead human body or human remains, whether buried or not,

is guilty of an indictable offence and liable to imprisonment for a term not exceeding five years.

<sup>42</sup> See a rather entertaining telling of the story by law professor Allan C. Hutchinson, *Is Eating People Wrong? Great Legal Cases and How They Shaped the World* (New York: Cambridge University Press, 2011), at 13-40.

In 2001, a strange encounter took place in [Germany]. Bernd-Jurgen Brandes... responded to an Internet ad seeking someone willing to be killed and eaten. The ad had been posted by Armin Meiwes.... Meiwes was offering no monetary compensation, only the experience itself. Some two hundred people replied to the ad. ...[W]hen Brandes met with Meiwes and considered his proposal over coffee, he gave his consent. Meiwes proceeded to kill his guest, carve up the corpse, and store it in plastic bags in his freezer. By the time he was arrested, the “Cannibal of Rotenburg” had consumed over forty pounds of his willing victim, cooking some of him in olive oil and garlic.

When Meiwes was brought to trial, the lurid case... confounded the court. Germany has no law against cannibalism. The perpetrator could not be convicted of murder, the defense maintained, because the victim was a willing participant in his own death. Meiwes’s lawyer argued that his client could be guilty only of “killing on request”, a form of assisted suicide.... The court attempted to resolve the conundrum by convicting Meiwes of manslaughter and sentencing him to eight and a half years in prison.<sup>43</sup>

Even with the consent of the victim, the Canadian *Criminal Code* rightly criminalizes this kind of activity. Consent would be irrelevant. The harm is in the indignity done and in the risks to society. Whether it is assault causing bodily harm, aggravated sexual assault, or cannibalism, consent is not the final arbiter of things in an ordered society. There are some things we can’t consent to.

## **2. Individual Autonomy Now Trumps Societal Interests in Preserving Life**

While watching the drama of the *Carter* SCC appeal unfold in Canada’s supreme courtroom, I was struck by the strategy of the appellants challenging the absolute prohibition. Due to the reasoning in the *Bedford* prostitution decision in December 2013, the only thing they had to prove was that the absolute prohibition on assisted suicide violated the right to life, liberty or security of just one person (in this case, Ms. Gloria

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<sup>43</sup> Sandel, *supra*, note 5, at 73-74 [citations omitted]. Sandel concludes the story by noting, “In a bizarre denouement to the sordid tale, the cannibal killer has reportedly become a vegetarian in prison, on the grounds that factory farming is inhumane.”

Taylor).<sup>44</sup> If they could demonstrate that, then the onus shifts to the State to justify this infringement under section 1 of the Charter.<sup>45</sup>

Throughout the decision, societal interests in preserving life and protecting vulnerable people are juxtaposed with the individual rights of the appellants. Both the trial court and the Supreme Court admit that “the risks *inherent* in permitting physician-assisted death can be identified and *very substantially minimized* through a carefully-designed system imposing stringent limits that are scrupulously monitored and enforced”.<sup>46</sup> In this statement, both the trial judge and the Supreme Court justices admit implicitly that innocent people will die. The risks are inherent, they say. And though those risks can be *minimized*, they cannot be *eliminated*. The trial judge admitted that “none of the [other legalized] systems has achieved perfection”.<sup>47</sup> For the judges, the risks to innocent lives simply need to be balanced with the autonomous choices of others.

Two different standards emerge. A violation of the autonomy rights of just one person: totally unacceptable to the appellants and to the section 7, Charter analysis. A violation or risk of innocent people dying: an acceptable risk in “balancing rights” under section 1 of the Charter. One of the interveners, the Canadian Civil Liberties Association, also argued that the preservation of life should not trump personal autonomy.<sup>48</sup> In effect, we saw the opposite argued: the right to autonomy ought to trump the right to life.<sup>49</sup> Here are just two examples of how the

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<sup>44</sup> *Canada (Attorney General) v. Bedford*, [2013] S.C.J. No. 72, 2013 SCC 72, [2013] 3 S.C.R. 1101, at para. 113 (S.C.C.) [hereinafter “*Bedford*”], where the Court emphasizes that the focus of the section 7 analysis “remains on the individual and whether the effect on the individual is rationally connected to the law’s purpose. For example, where a law is drawn broadly and targets some conduct that bears no relation to its purpose in order to make enforcement more practical, there is still no connection between the purpose of the law and its effect on the *specific individual*. Enforcement practicality may be a justification for an overbroad law, to be analyzed under s. 1 of the Charter”.

<sup>45</sup> Charter, *supra*, note 12, s. 1, which reads: “The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.” Keep in mind, the Supreme Court has yet to uphold a law under section 1 that violates section 7.

<sup>46</sup> *Carter* (SCC), *supra*, note 2, at para. 105 quoting the trial judge, *Carter v. Canada (Attorney General)*, [2012] B.C.J. No. 1196, 2012 BCSC 886, 287 C.C.C. (3d) 1, at para. 883 (B.C.S.C.) (emphasis added) [hereinafter “*Carter* (BCSC)”].

<sup>47</sup> *Carter* (BCSC), *id.*, at para. 685.

<sup>48</sup> *Carter* (SCC), *supra*, note 2, Factum of the Intervener Canadian Civil Liberties Association, at paras. 12-18.

<sup>49</sup> See also discussion by Mark Carter on societal interests and how the objective of a law is required to do a section 7 analysis of arbitrariness, overbreadth or gross disproportionality, but in order to understand the objective, there must be an evaluation of the societal interests. It all seems very convoluted. Mark Carter, *supra*, note 25.

right to autonomy would trump the right to life: one hypothetical, the other based on the evidence at trial.

In *United States of America v. Burns*, the Supreme Court found that “capital punishment is unjust and it should be stopped” and ruled “the state’s execution of even one innocent person is one too many”.<sup>50</sup> Presumably, if an offender serving a life sentence were to request the death penalty as a preferred option over spending the rest of their life behind bars, the Charter could not compel Canada to execute them.<sup>51</sup> Yet, consistency with the justifications for legalized assisted suicide would demand exactly that.

However, autonomy trumps the right to life in more than hypothetical ways. The trial judge examined much evidence on foreign experiences with legalized assisted suicide. She found the following:

- lack of compliance with safeguards in Oregon;<sup>52</sup>
- lack of compliance with safeguards in the Netherlands;<sup>53</sup>
- lack of compliance with safeguards in Belgium;<sup>54</sup>
- difficulties with the evidence on the impact of vulnerable people in the Netherlands and Oregon;<sup>55</sup> and
- that people suffering depression may slip through the approval process, if only in “highly isolated” cases.<sup>56</sup>

It cannot be emphasized enough that these are not just theoretical possibilities if Canada is not careful enough. This is evidence that people who should not have been killed were killed, that people who were merely suffering from depression were euthanized. These patients were sick, and the doctor, instead of treating the depression, killed them.

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<sup>50</sup> [2001] S.C.J. No. 8, [2001] 1 S.C.R. 283, at paras. 84 and 102 (S.C.C.); see also paras. 70-71, 76-78.

<sup>51</sup> This example comes from the argument of the Evangelical Fellowship of Canada, *Carter* (SCC), *supra*, note 2, Factum of the Intervener Evangelical Fellowship of Canada, at paras. 18 and 19. Apart from such executions being contrary to the principles of fundamental justice, such a backdoor return of the death penalty and its mere legal possibility in any given case would create a perverse incentive which would “reward” intolerable prison conditions with more requests for death and resulting budget savings.

<sup>52</sup> *Carter* (BCSC), *supra*, note 46, at paras. 649, 653.

<sup>53</sup> *Id.*, at para. 656.

<sup>54</sup> *Id.*, at paras. 657-659.

<sup>55</sup> *Id.*, at paras. 662-663.

<sup>56</sup> *Id.*, at paras. 670-671.

As the Attorney General argued, “this is an area not amenable to deciding whether there is an acceptable level of risk”.<sup>57</sup> Autonomy now trumps the right to the full protection of life.

### 3. Whose Autonomy is It, Anyway?

Perhaps more frustrating yet is the idea that assisted suicide is even autonomous at all. If I give you a gun and say: “I consent to my death. I want you to end my life right now”; who has the power over my life? It’s not me. And, yet, the Supreme Court speaks over a dozen times of the choice and autonomy of the patient in choosing assisted death.<sup>58</sup>

Striking down the absolute criminal prohibitions on assisted suicide and euthanasia is not about autonomy; it’s about handing power over life to others, in the case of physician-assisted suicide, to state-licensed professionals. The change in the law is to protect the euthanizers, who have the final say over life, not the patient. The Supreme Court’s change to the *Criminal Code* creates a new legal defence to the charge of homicide. The Court states: “we have confined ourselves to the rights of those who seek assistance in dying, rather than of those who might provide such assistance”.<sup>59</sup> But this is a misleading statement at best and, when held to the light of the legal *effect* of the judgment, appears to be downright wrong. Because the legal effect of this ruling has no bearing on the criminal culpability of people seeking assistance in death. Rather, the legal change only provides a new criminal defence for some people (physicians) to take the lives of people in a particular class (suffering adults), as the trial judge herself conceded.<sup>60</sup> And the decision over who qualifies is made by the State, not by “autonomous individuals”.

Even when you fall seriously ill, or become clinically depressed, you will find (if ...those proposing bills to allow assisted suicide are to be believed) that your right to autonomy does not give you the right to be assisted in suicide unless you are ill *enough* or suffering *enough*, or

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<sup>57</sup> *Carter* (SCC), *supra*, note 2, Factum of the Respondent, Attorney General of Canada, at para. 96 (hereinafter “A.G. Canada Factum”).

<sup>58</sup> *Carter* (SCC), *supra*, note 2, at paras. 64-69.

<sup>59</sup> *Id.*, at para. 69.

<sup>60</sup> *Carter* (BCSC), *supra*, note 46, at paras. 1384-1393.

depressed severally and incurably *enough*—in each case ‘enough’ in the view of somebody else, *other people*.<sup>61</sup>

What appears to be patient autonomy is actually a discretionary power over life given to physicians and judges by the State.

#### 4. Unbridled Autonomy Undermines Liberty

Totally unbridled autonomy equals anarchy which is anathema to liberty. An ordered society in which freedom is possible requires some limits on autonomy or a limited view of what autonomy ought to be recognized as. The philosopher Immanuel Kant had a more limited view of autonomy.

For Kant, autonomy, which literally means ‘self-legislation,’ requires acting in accordance with one’s true self—that is, with one’s rational will determined by a universalizable, that is, rational maxim. Being autonomous means not being a slave to instinct, impulse or whim, but rather doing as one ought, as a rational being. But ‘autonomy’ has now come to mean ‘doing as you please,’ compatible no less with self-indulgence than with self-control.<sup>62</sup>

Rights, dignity, autonomy: all of these concepts need to be filtered through a lens of who we are as human beings, not merely what we can or cannot do as human beings. A living human being “is valuable as a subject of rights in virtue of what he or she is.... And so a human being remains a subject of rights, someone who has a right not to be intentionally killed, for as long as he or she exists”.<sup>63</sup> To maximize liberty for all people, an ordered society must put limits on all people. Human beings are not entitled to “unlimited liberty of action”.<sup>64</sup> Unlimited liberty is destructive of organized society.<sup>65</sup>

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<sup>61</sup> John Finnis, *The Collected Essays of John Finnis, Vol. 3, Human Rights and Common Good* (Oxford: Oxford University Press, 2011), at 255 (emphasis in original).

<sup>62</sup> Leon R. Kass, *Life, Liberty and the Defense of Dignity: The Challenge for Bioethics* (San Francisco: Encounter Books, 2002), at 216.

<sup>63</sup> Patrick Lee & Robert P. George, *Body-Self Dualism in Contemporary Ethics and Politics* (Cambridge, U.K.: Cambridge University Press, 2008), at 155.

<sup>64</sup> Mortimer J. Adler, *Six Great Ideas* (New York: Macmillan Publishing Co., 1981), at 144.

<sup>65</sup> *Id.*



### III. THE SLIPPERY SLOPE IS REAL

Some people may be hesitant to invoke the slippery slope when arguing against legalizing assisted suicide because, all too often, they are reminded that the slippery slope is a fallacy. However, as we shall see, the slippery slope is only a fallacy when argued fallaciously; the slippery slope can also be a logical argument if argued based on evidence. Further, at least some of those advocating for legalizing assisted suicide are guilty of fallacious arguments of their own, including no less than the nine Supreme Court of Canada judges.<sup>66</sup> After examining two of those fallacies, this article will explore the slippery slope argument and its effect on law and practice.

#### 1. Fallacy of False Dichotomy

The Supreme Court opens the *Carter* SCC judgment with a powerful paragraph, an evocative demonstration of literary composition which sets the stage for the legal reasoning as well as the emotional tone for the rest of the ruling. It is worth quoting in whole:

It is a crime in Canada to assist another person in ending her own life. As a result, people who are *grievously and irremediably ill* cannot seek a physician's assistance in dying and *may be condemned to a life of severe and intolerable suffering*. A person facing this prospect has two options: she can take her own life prematurely, often by *violent or dangerous means*, or she can suffer until she dies from natural causes. *The choice is cruel.*<sup>67</sup>

Apparently only cruel people could defend such a status quo. But what if there was a third option? No third option is mentioned here, but if there is a third option, then this opening paragraph, as powerful as it is, is guilty of perpetuating a fallacy of false dichotomy, more colloquially known as the either-or fallacy.<sup>68</sup>

Palliative care is an emerging area of medicine and community care, which takes place generally after a terminal diagnosis and focuses on

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<sup>66</sup> I'm not sure which judge wrote the judgment since it is a judgment of "The Court". However, we can presume that all nine of the judges signed off on it before it was released.

<sup>67</sup> *Carter* (SCC), *supra*, note 2, at para. 1 (emphasis added).

<sup>68</sup> Jill LeBlanc, *Thinking Clearly: A Guide to Critical Thinking* (New York: W.W. Norton & Company, 1998), at 160-163 [hereinafter "LeBlanc"].

pain management.<sup>69</sup> In *Carter* BCSC, the trial judge reviewed the state of palliative care and medicine in Canada,<sup>70</sup> and admitted that, “Palliative care has improved considerably in the past few decades, including with respect to pain management”<sup>71</sup> and that “palliative care can reduce requests for euthanasia or lead to their retraction”.<sup>72</sup> And though “palliative care is not a panacea”<sup>73</sup> it is “far from universally available in Canada”.<sup>74</sup> Dr. Somerville writes that “only 16 to 30 percent of Canadians who need palliative care have access to it”.<sup>75</sup> So here is that third option: effective palliative care that can eliminate or greatly reduce suffering at the end of life.

This fallacy of false dichotomy not only leads to greater risks for vulnerable lives (as will be discussed in the section 15 analysis to follow), it also leads to a constrained remedy. In the very first paragraph of the judgment, the Court hamstringing itself and, by extension, Parliament by setting up the problem as binary. Professor Newman explains that the “specificity of the declaration... speaks to the Court using the declaration to try to craft a regime of assisted suicide, rather than simply to indicate the existence of a constitutional violation to be remedied by governments”.<sup>76</sup> The result is that this third option is off the table as a creative and compassionate means by which to correct the Charter violation. The Supreme Court bars “the possibility of a dramatically improved palliative care system” as a solution, leaving to Parliament only the Court’s remedy.<sup>77</sup>

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<sup>69</sup> See, e.g., Keith G. Wilson, Harvey Max Chochinov, Christine J. McPherson, *et al.*, “Desire for Euthanasia or Physician-Assisted Suicide in Palliative Cancer Care”, (2007) 26 *Health Psychology* 3, at 314-23; Harvey Max Chochinov, Thomas Hack, Thomas Hassard, *et al.*, “Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients near the End of Life” (2005) 23 *Journal of Clinical Oncology*, at 5520-5525; Harvey Max Chochinov, “Dignity-Conserving Care – A New Model for Palliative Care: Helping the Patient Feel Valued” (2002) 287 *Journal of the American Medical Association* 17, at 2253-2260; Harvey Max Chochinov, *Dignity Therapy: Final Words for Final Days* (New York: Oxford University Press, 2012).

<sup>70</sup> *Supra*, note 46, at paras. 188-202.

<sup>71</sup> *Id.*, at para. 188.

<sup>72</sup> *Id.*, at para. 189.

<sup>73</sup> *Id.*, at para. 191.

<sup>74</sup> *Id.*, at para. 192.

<sup>75</sup> *Somerville, supra*, note 6, at 128.

<sup>76</sup> Dwight Newman, “Judicial Method and Three Gaps in the Supreme Court of Canada’s Assisted Suicide Judgment in *Carter*” (2015), 78 *Sask. L. Rev.* 217-224, at para. 10 [hereinafter “Newman”].

<sup>77</sup> *Id.*, at para. 11.

## 2. Fallacy of Equivocation

The first fallacy is tied to the second through the issue of palliative care. The Supreme Court and Smith J. confuse what is a difference in kind with a difference in degree, a form of the fallacy of equivocation.<sup>78</sup> Justice Smith accepted that there is a *legal* distinction between palliative care and euthanasia<sup>79</sup> but ruled that there is no *ethical* distinction.<sup>80</sup> Justice Smith writes of a “spectrum” of acceptable interventions at the end of life “where the likely consequence of the decision will be the death of the patient”.<sup>81</sup> The Supreme Court alludes to the same spectrum, noting that the law “allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician’s assistance in dying”.<sup>82</sup> Assisted suicide is just one choice on a smorgasbord of end-of-life options.

However, no real explanation is given for rejecting the difference between “physician-assisted death and other end-of-life practices whose outcome is highly likely to be death”.<sup>83</sup> But there is a difference that cannot be rejected: to foresee death as an inevitable result of an action chosen to relieve pain is not the same kind of thing as choosing an action with the *intention* of death as the result.<sup>84</sup> The former action can be directed at killing the pain while a person is being killed by a disease or disability, the latter action is directed at killing the patient directly in order to end her pain. This is a fundamental difference of kind, not merely a difference of degree.

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<sup>78</sup> LeBlanc, *supra*, note 68, at 136-37.

<sup>79</sup> *Carter* (BCSC), *supra*, note 46, at paras. 324, 330.

<sup>80</sup> *Id.*, at paras. 334-335, endorsed by the Supreme Court of Canada, *Carter* (SCC), *supra*, note 2, at para. 23.

<sup>81</sup> *Carter* (BCSC), *supra*, note 46, at para. 1240, endorsed indirectly by the Supreme Court of Canada, *Carter* (SCC), *id.*, at paras. 66-68.

<sup>82</sup> *Carter* (SCC), *id.*, at para. 66.

<sup>83</sup> *Carter* (BCSC), *supra*, note 46, at para. 335.

<sup>84</sup> John Keown, “A Right to Voluntary Euthanasia? Confusion in Canada in *Carter*” (2014) 28 *Notre Dame J.L. Ethics & Pub. Pol’y* 5, at para. 5: “The starting point of the [*Carter* trial] judgment should have been a clear acknowledgment that historically the law has been profoundly shaped by recognition of the intrinsic worth of the life of each human being and the principle that it is always wrong to intentionally kill innocent human beings (that is, those not involved in unjust aggression). The judgment should also have made clear that, while this principle rules out euthanasia and assisting suicide, it permits the palliation of symptoms, and the withdrawal of futile or excessively burdensome treatments, even if the hastening of death is foreseen as a side-effect.”

To clarify, the removal of exceptional medical treatment does fall within the spectrum of ethical end-of-life care options. Those opposed to legalizing assisted suicide do not believe in preserving life at all costs. There is a fundamental ethical, moral and legal difference between assisted suicide and the refusal of medical treatment. To respect a person's dignity does not mean unnecessarily prolonging life, as the trial judge incorrectly assumed.<sup>85</sup>

Finally, the imprecise nature of the terminology used by the courts also leads to confusion and fallacious argument. Professor Newman explains the troubling strategy of the Supreme Court to intentionally abandon any consistent distinction between the terms "assisted death" and "assisted suicide". The Court "meanders through the judgment, sometimes using one term and sometimes the other... without ever distinguishing between them".<sup>86</sup>

... But to simply assume without explanation that there is no distinction between 'assisted suicide' — aiding someone in ending his or her own life — and 'assisted death' — potentially extending to actively killing the person — is to assume away part of the debate at issue, to ignore long-standing societal values and the traditions of our legal system, and to simply shunt aside some of the parties without offering even the dignity of an explanation.<sup>87</sup>

### 3. The Slippery Slope Fallacy vs. the Logical Argument

Mr. Joseph Arvay, the lead lawyer for the appellants, stated emphatically during oral argument at the Supreme Court that:

if a subsequent case comes around that says, as a matter of constitutional law, the law should be extended to not just adults, or not just those who are competent... well then that's the Charter working. That's not the slippery slope. We call that the living tree in this country.<sup>88</sup>

While Mr. Arvay's perspective is popular, it is not quite accurate. There is a difference between the slippery slope fallacy<sup>89</sup> and the slippery

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<sup>85</sup> *Carter* (BCSC), *supra*, note 46, at para. 355.

<sup>86</sup> *Newman*, *supra*, note 76, at para. 12.

<sup>87</sup> *Id.*

<sup>88</sup> *Carter* (SCC), *supra*, note 2, Oral argument by Joseph J. Arvay, Q.C., appellant. Viewable online: <<http://www.scc-csc.ca/case-dossier/info/webcast-webdiffusion-eng.aspx?cas=35591>> [hereinafter "Arvay"].

<sup>89</sup> For an explanation of the slippery assimilation and slippery precedent fallacies, see LeBlanc, *supra*, note 68, at 219-22.

slope argument. The logical argument is made when demonstrating that A will lead to B either inevitably, by logical necessity or as a materially increased probability.<sup>90</sup> There is ample evidence in both law and practice that legalizing physician-assisted suicide for “a competent adult person who (1) clearly consents to the termination of life; and (2) who has a grievous and irremediable medical condition ... that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition”<sup>91</sup> will lead to the euthanasia of others outside that category.

#### 4. Slippery Slope at Work in the Supreme Court

Mr. Arvay’s oral argument in the Supreme Court listed the conditions he thought would make for acceptable assisted suicide. He mentioned, “an adult, fully competent, fully informed, exercising a truly voluntary wish to die, who wish to die”, he suggested that it “makes sense to impose a waiting period, maybe even a few years, for people disabled because of a car accident”, he cited certain qualifiers like “degenerative” and “intolerable suffering” and suggested that it be available “only in the context of where a physician is involved, where someone is suffering related to a medical illness, disease or trauma” and only for those who “literally, physically, can’t do it without assistance”.<sup>92</sup> At one point he summarized all of these qualifications: “has to be an adult, has to be competent, has to be voluntary, has to be fully informed, has to have a medical condition that is irremediable and the suffering has to be intolerable to that person”.<sup>93</sup>

However, at the same hearing, there were many other interveners already arguing for an expansion of the definition. The Attorney General of Canada summarized the broadening of the scope in his reply factum:

Underlying each factum are unstated assumptions and conflicting criteria about how a scheme of assisted suicide would operate. The HIV/Aids Legal Network contemplates a law that allows ‘those capable of making a voluntary decision to [die],’ a law that is unburdened by ‘bureaucratic barriers.’ The Unitarian Council wants a law for people who are ‘decisionally competent, terminally ill and grievously

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<sup>90</sup> Eugene Volokh, “The Mechanisms of the Slippery Slope”, 116 (2003) Harv. L. Rev. 1026, at 1028.

<sup>91</sup> *Carter* (SCC), *supra*, note 2, at para. 127. This definition is particularly important, as we shall see, in the section 15 equality rights analysis.

<sup>92</sup> Arvay, *supra*, note 88.

<sup>93</sup> *Id.*

suffering.’ The Alliance of People with Disabilities would add ‘people with a progressive disability’ to the Unitarians’ list, a highly significant expansion of the group. Dying with Dignity objects to the trial judge’s blanket exclusion of the clinically depressed. Both the HIV Network and the Farewell Foundation/AQDMD would not limit the class of potential assisters to doctors. The Farewell Foundation would not impose limitations such as terminal illness, but permit it for people who are simply ‘weary of life;’ in short, a full-fledged right to assisted suicide, which lies at the bottom of the slippery slope.<sup>94</sup>

The expansion of assisted suicide was urgently being advocated for by at least six different national organizations with highly-qualified legal counsel with complex legal arguments at the top court of the country. But more important than the legal arguments of interveners on appeal is the practical evidence on the ground.

## 5. Slippery Slope at Work in Practice

Mr. Arvay’s list of qualifications may seem reasonable to most. But on what foundation can Canadian law or society impose any limits once we cross this Rubicon? Here is Mr. Arvay’s list again: “has to be an adult, has to be competent, has to be voluntary, has to be fully informed, has to have a medical condition that is irremediable and the suffering has to be intolerable to that person”.<sup>95</sup> How do we answer the question “why?” to each of those qualifications? “The difficulty is whether any line other than a prohibition on assisted suicide can rationally stand. Once one moves away from a bright-line rule, a law on assisted suicide becomes subject to continual questioning concerning the boundary temporarily established.”<sup>96</sup>

Why an adult? On what legal or logical grounds would a State “force” a 17-year-old to suffer intolerably while allowing a 19-year-old in the exact same condition the “right” to receive a “peaceful death”?<sup>97</sup> What about a mature minor? The restriction of the Court’s declaration to

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<sup>94</sup> *Carter* (SCC), *supra*, note 2, Reply Factum of the Respondent, Attorney General Canada, at para. 10 (footnotes omitted) [hereinafter “Attorney General of Canada Reply Factum”].

<sup>95</sup> Arvay, *supra*, note 88.

<sup>96</sup> *Newman*, *supra*, note 76, at para. 7.

<sup>97</sup> And how old is an adult? Eighteen years old, as per the *Criminal Code*? But how does that compare with the 19-year-old drinking age in Ontario? To suggest that an 18-year-old is too immature to purchase alcohol but mature enough to retain assistance to kill himself is absurd.

“competent adults” seems inconsistent with their reasoning on mature minors just six years earlier.<sup>98</sup>

Why competent? On what legal or logical grounds would a state “force” a demented or mentally incapable adult to suffer intolerably while allowing an adult of the same age, in the same condition the “right” to receive a “peaceful death”? Isn’t this discrimination on the basis of mental ability?

Why medical condition that is irremediable or terminal? On what legal or logical grounds would a state “force” an adult to suffer through an intolerable period, waiting for a distant remedy to their suffering when the “remedy” of a painless death could be accessed immediately? Would this include “people with a progressive disability”, as one intervener advocated should be the case?<sup>99</sup>

Why intolerable suffering? By whose standard and on what legal or logical grounds would a state “force” an adult suffering from clinical depression to either continue treatment or be locked away in a mental health hospital while simultaneously allowing other suffering adults the “right” to receive a “peaceful death”?<sup>100</sup> Indeed, why would people simply “weary of life” be excluded?<sup>101</sup> If they want to die peacefully, then who is the Supreme Court of Canada or Parliament to take that “right” away from them?

And why a doctor? As two interveners argued,<sup>102</sup> others could do the job too. Why would anyone require “peaceful death” to be administered by a state actor, when it could be much more serene if a family member or close friend could administer the lethal dose instead? For that matter, why not allow for consent to be eaten, as in the German case of

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<sup>98</sup> See *A.C. v. Manitoba (Director of Child and Family Services)*, [2009] S.C.J. No. 30, 2009 SCC 30, [2009] 2 S.C.R. 181 (S.C.C.). And the special joint committee of Parliament has also recommended that mature minors should be able to avail themselves of legalized assisted suicide. See *Joint Committee Report*, *supra* note 9, Recommendation #6.

<sup>99</sup> *Carter* (SCC), *supra*, note 2, Factum of the Intervener Alliance of People with Disabilities, at para. 7 [hereinafter “Disabilities Alliance Factum”].

<sup>100</sup> *Carter* (SCC), *id.*, Factum of the Intervener Dying with Dignity, at para. 19. Again, the special joint committee of Parliament also recommended that a psychiatric condition should not exclude someone from being eligible for medical assistance in suicide. See *Joint Committee Report*, *supra* note 9, Recommendation #3.

<sup>101</sup> As advocated for by the Intervener Farwell Foundation, *Carter* (SCC), *id.*, Factum of the Intervener Farwell Foundation, at para. 28 [hereinafter “Farwell Foundation Factum”].

<sup>102</sup> As advocated for by the Intervener HIV/AIDS Legal Network *Carter* (SCC), *id.*, Factum of the Intervener HIV/AIDS Legal Network, at para. 26; and as advocated by the Intervener Farwell Foundation, *Farwell Foundation Factum*, *id.*, at para. 28. See also the *Joint Committee Report*, *supra* note 9, Recommendation #13.

cannibalism, discussed above? I have yet to hear or read a logically consistent answer to any of these questions that allows for some to be killed but not others. Indeed, should recommendations 2, 3, 4, 6 and 10 from the Report of the Special Joint Committee on Physician-Assisted Dying find a place in a new law, it would not be overstating the case to suggest that a depressed teenager with suicidal episodes will now be assured government-guaranteed success during her next suicidal breakdown.

The Supreme Court cites the reasons of Ms. Gloria Taylor (the applicant in the *Carter* case) for why she wants assisted suicide:

I do not want my life to end violently. I do not want my mode of death to be traumatic for my family members. I want the legal right to die peacefully, at the time of my own choosing, in the embrace of my family and friends.<sup>103</sup>

With great respect for Ms. Taylor, I don't want to die violently either. In fact, to "die peacefully, at the time of my own choosing, in the embrace of my family and friends" sounds ideal. So can I book an appointment for the day after my 75th birthday, and just check out? If not, why not? There is no compelling legal reason to deny that right any longer.<sup>104</sup>

Justice Smith's findings related to the expansion of justifications for doctor assisted suicide (the practical slippery slope) were directly contradicted by the High Court of Ireland which said that "the Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and *has drawn exactly the opposite conclusions*".<sup>105</sup> The High Court went on to review evidence

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<sup>103</sup> *Carter* (SCC), *id.*, at para. 12.

<sup>104</sup> "In one highly publicized example last year, [a Dutch euthanasia] clinic helped a 63-year-old man with severe psychiatric problems to end his life. After a very active career working for government, the patient in question could not face his upcoming retirement. ...[T]he clinic's psychiatrist, Gerty Casteelen said the man 'managed to convince me that it was impossible for him to go on. He was all alone in the world. He'd never had a partner. He did have family but he was not in touch with them...'. The man's long-term physicians had rejected his request previously. But the clinic's team evaluated him, read his medical history and decided it was time to close his case—permanently." Nadette De Visser, "The Dutch Debate Doctor-Assisted Suicide For Depression", *The Daily Beast* (March 2, 2014), online: <<http://www.thedailybeast.com/articles/2014/02/03/the-dutch-debate-doctor-assisted-suicide-for-depression.html>>.

<sup>105</sup> Text taken from the headnote summary of *Fleming v. Ireland & Ors*, [2013] I.E.H.C. 2 (H.C.), summarizing paras. 88-105 of the judgment. Judgment of the High Court of Ireland was



from the medical literature and found abuse, “disturbing” practices and cases of “life-ending acts without explicit request”,<sup>106</sup> remaining “strikingly high” in countries which have legalized assisted suicide.<sup>107</sup>

One final aspect of the slippery slope reality is the very practical hurdles that will need to be overcome. One intervener was confident that doctors would be able to distinguish between:

rational death-seekers and those with distorted thought processes; the ambivalent and the resolute; the truly consenting from the non-consenting; those whose decisions are compromised by social prejudices, internalized biases, and family pressures, and those who do not face such pressures.<sup>108</sup>

However, the Canadian Medical Association argued that “the challenges that will be faced by doctors in this regard have been ‘understated,’ having regard to factors such as resource constraints and the intricacy of the patient-doctor relationship”.<sup>109</sup> With legalized assisted suicide, it will not be easy to assess who should be killed and who should not.<sup>110</sup>

## V. EQUAL BENEFIT OF THE LAW DENIED

The equal benefit of the law is not found in having equal access to suicide.<sup>111</sup> Should we go down this road, “once some can access assisted suicide and some cannot, equality rights arguments take on a new

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upheld unanimously on appeal to the Supreme Court of Ireland, *Fleming v. Ireland & Ors*, [2013] I.E.S.C. 19 (Ireland S.C.) (emphasis added) [hereinafter “*Fleming*”].

<sup>106</sup> A stunning euphemism! Most civilized societies call this murder.

<sup>107</sup> *Fleming*, *supra*, note 105.

<sup>108</sup> The Respondent citing numerous passages from the factum of the intervener, Dying With Dignity, Attorney General of Canada Reply Factum, *supra*, note 94, at para. 11 (footnotes omitted).

<sup>109</sup> *Carter* (SCC), Factum of the Intervener Canadian Medical Association, at paras. 24, 25.

<sup>110</sup> Consider this gray zone as a case study. If a doctor is genuinely conflicted about whether a patient qualifies for physician-assisted death, which rights of the patient should take precedence? The right to life or the right to choose death? If the right to life should win out, how does that square with the Supreme Court’s analysis in *Carter* (SCC)?

<sup>111</sup> The argument for the discriminatory nature of criminalizing assisted suicide was made in the trial judge’s reasons *Carter* (BCSC), *supra*, note 46, at paras. 1009-1162; and by the applicants at the Supreme Court in their factum, at para. 87-124, responded to by the Attorney General of Canada in their factum Attorney General of Canada Reply Factum, *supra*, note 94, at paras. 120-141. However, the discriminatory effect at play here is not in the denial of assistance in suicide. The discrimination arises if assisted suicide is made legal. It is this angle that will be explored further below. There is no space to explore what I see as the wrong section 15 assertions made in the course of the *Carter* appeal.

possibility for those presently excluded”.<sup>112</sup> If we accept the line of reasoning that bans on assisted suicide are discriminatory because they deny equal access to suicide,<sup>113</sup> then, if accepted as true, this would also require “correlative obligations [of health care professionals, etc.] not to prevent people making that choice”.<sup>114</sup> In other words, society (or the State at least) would have a duty to not interfere in a suicide attempt. This is clearly wrong-headed.

The equal benefit of the law interest instead ought to be framed as having equal access to a fulsome protection of life in law. As the Attorney General wrote:

The additional risk to those with disabilities lies *not* in their capacity to make an autonomous decision, but in society’s prejudicial reaction to a request for death from such individuals. The risk is created by society’s tendency to *automatically* support such a request as a result of an assumption that the lives of individuals with disabilities are less valuable.<sup>115</sup>

If there is one role for the State, it is to protect equally in law the lives of its citizens from other people. Where some citizens are more vulnerable, that role of the State in this regard should be amplified.

## 1. *Magna Carta* and Equality Before the Law

Lord Denning, arguably one of the greatest English jurists of the past 800 years, once described the *Magna Carta* as “the greatest constitutional document of all times — the foundation of the freedom of the individual against the arbitrary authority of the despot”.<sup>116</sup>

In most history classes, the *Magna Carta* has come to symbolize the struggle between those in power with those who benefit from the equalizing force of the law. It stands for the rule of law — that all men must be treated fairly and not arbitrarily, and that no one is above the law, including the king.

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<sup>112</sup> *Newman*, *supra*, note 76, at para. 8.

<sup>113</sup> As Smith J. seems to endorse at *Carter* (BCSC), *supra*, note 46, at para. 1014, relying on Lamer C.J.C.’s dissent in *Rodriguez v. British Columbia (Attorney General)*, [1993] S.C.J. No. 94, [1993] 3 S.C.R. 519, at 549-50 (S.C.C.) [hereinafter “*Rodriguez*”].

<sup>114</sup> *Somerville*, *supra*, note 6, at 131.

<sup>115</sup> Attorney General of Canada Reply Factum, *supra*, note 94, at para. 18 (emphasis added).

<sup>116</sup> Danny Danziger & John Gillingham, *1215: The Year of the Magna Carta* (London: Hodder and Stoughton, 2004), at 278.

While much of this historic document has since been replaced or repealed by subsequent law, the ancient Carta has enduring value. In particular, one clause stands out. Clause 40 (the numbers were added centuries later by Lord Blackstone) states: “To no one will we sell, to no one will we deny or delay right or justice.”<sup>117</sup> This clause is an expression of the principle of equality before the law, cemented into Canada’s Constitution in 1982 in section 15(1) of the Charter. It reads, “Every individual is equal before and under the law and has the right to the equal protection of the law and equal benefit of the law without discrimination...”<sup>118</sup>

In *Carter* (SCC), the Supreme Court dodged the discrimination/equality claim.<sup>119</sup> By side-stepping the question of equal protection of the law, Canada’s top court abandoned a principle enshrined some 800 years ago. If Canada accepts the Court’s proposition that physician-assisted suicide should be legal in certain circumstances, we abandon Canadians with severe disabilities or limitations to a different standard of protection in law. We elevate the rights of autonomy and choice (in particular, a choice in *how* to die, not just *when* to die) of some over and above the right of others to have their lives equally valued and protected. To put it in terms of clause 40 of the *Magna Carta*, the Supreme Court of Canada has “denied or delayed right or justice” to these vulnerable people.

But, how? How does legalizing assisted suicide do this, especially if consent is required?

## 2. Consent to be Killed: Able-ism and a Two-tiered Justice System

The question of consent to be killed and the category of people to whom this legal exception applies is the key element in discovering just how discriminatory legalizing assisted suicide is.

In order to give effect to the striking down of section 241(b) (the assisted suicide prohibition) the Supreme Court also struck down section 14 of the *Criminal Code*, which states: “No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted

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<sup>117</sup> *Id.*, at 292.

<sup>118</sup> Charter, *supra*, note 12, at s. 15(1).

<sup>119</sup> *Carter* (SCC), *supra*, note 2, at para. 93. The Court says rather curtly, “Having concluded that the prohibition violates s. 7, it is unnecessary to consider this question [*i.e.*, whether the prohibition on assisted suicide violates section 15].”

on the person by whom consent is given.”<sup>120</sup> The Supreme Court invalidated both section 14 and section 241(b) because both effectively prohibit assisted suicide.<sup>121</sup> However, the Court only gave analytical attention to section 241(b), offering no interpretation of the objective of section 14. The Court simply invalidates it but *only insofar as* those provisions prevent capable adults who experience grievous and irremediable suffering from receiving “aid in dying”.<sup>122</sup>

The Court’s silence on analyzing section 14 is a terrible failure when considering one of the public policy reasons behind the section. In any homicide case, section 14 makes it unnecessary for the Crown to prove that the deceased did *not* consent to being killed. Proving beyond a reasonable doubt that a deceased person did not consent to his or her own death would be nearly impossible to prove in most situations.

Contrast this with someone charged with inter-personal crime (*e.g.*, theft, rape, assault, etc.), in which the Crown must prove lack of consent: as a rule of thumb, the victim is normally a primary witness and is available for examination and cross-examination.<sup>123</sup> And who is the main witness in a homicide? Again, it’s the victim. What’s the problem? That witness is rather unresponsive when called to the stand.

I don’t mean to be glib. Where the criminal law is changed such that some people are allowed to kill other people, and consent is now a defence to homicide, the burden of proof falls to the State to prove *beyond a reasonable doubt* that in fact the person killed did not consent

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<sup>120</sup> *Criminal Code*, *supra*, note 11.

<sup>121</sup> *Carter* (SCC), *supra*, note 2, at para. 20: “In our view, two of these provisions are at the core of the constitutional challenge: s. 241(b), which says that everyone who aids or abets a person in committing suicide commits an indictable offence, and s. 14, which says that no person may consent to death being inflicted on them. It is these two provisions that prohibit the provision of assistance in dying.”

<sup>122</sup> *Id.*, at para. 127. The Court declares that both s. 14 and 241(b) are “void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition”.

<sup>123</sup> The difficulty of proving absence of consent, however, is not the only or even the primary concern of section 14. Chief Justice Lamer references section 14 to illustrate the point that the scope of individual self-determination in our society is never absolute (*Rodriguez*, *supra*, note 113, at 560). Individual autonomy is balanced with and limited by other principles, such as the sanctity of life. It strains credibility to suggest that consent was never a defence to homicide or assisted suicide *only* because we had not yet found a way of reliably determining the presence or absence of consent.

to be killed.<sup>124</sup> And common sense and the nature of this entire assisted suicide debate dictates that those who are severely disabled are the most likely to be *assumed* to have wanted to die (creating reasonable doubt), whereas strong and healthy people won't be at risk of suffering that same assumption. In fact, the protection of section 14 remains in effect for the able-bodied.

In effect, this means that disabled Canadians, as a class of people, are provided less protection and benefit of the law *vis-à-vis* the homicide provisions in the *Criminal Code* than able-bodied Canadians when an absolute ban on killing people is removed.

Here's a thought experiment: Imagine you are on a jury in a homicide trial, and I was the murder victim. Is there any reasonable doubt that I would consent to my death? Not likely: I'm happy, healthy, young, employed, and have lots of friends on Facebook. Canadian courts will not "deny or delay right or justice" for me.

Now, however, the Supreme Court has ruled that you *can* consent to die, if — and that's a really big and telling "if" — if you are suffering. Imagine that you're on a jury for a homicide and the victim is a severely disabled, though competent adult named James.<sup>125</sup> Do you think that a unanimous jury of 12 will find someone guilty of murder for killing James if it's legal to do so as long as the deceased consented? Now is there reasonable doubt? After all, *you* don't want to live like James, so maybe... maybe James didn't want to live like James.

If we remove the absolute prohibition on some people killing other people, will the criminal law protect James the same way that it protects me? In fact, without a reasonable likelihood of conviction, most prosecutors will not bother to proceed with the prosecution at all.<sup>126</sup>

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<sup>124</sup> The accused may be the only witness to have any knowledge of what occurred and has a right against self-incrimination. The Crown would be left with no way to prove that the deceased did not consent.

<sup>125</sup> More on this man [in the section 15 analysis below](#).

<sup>126</sup> See, for example, the Ontario Attorney General's Crown Policy Manual which states:

**Reasonable Prospect of Conviction:** When considering whether or not to continue the prosecution of a charge the first step is to determine if there is a reasonable prospect of conviction. This test must be applied to all cases. If the Crown determines there is no reasonable prospect of conviction, at any stage of the proceeding, then the prosecution of that charge must be discontinued.

The threshold test of 'reasonable prospect of conviction' is objective. This standard is higher than a '*prima facie*' case that merely requires that there is evidence whereby a reasonable jury, properly instructed, could convict. On the other hand, the standard does not require 'a probability of conviction', that is, a conclusion that a conviction is more likely than not.

Consider the Robert Latimer case<sup>127</sup> — though he was found guilty of second-degree murder for killing his severely disabled daughter Tracy, a judge and jury still sentenced him to a mere one year in prison and one year probation, even though Latimer admitted to the crime.<sup>128</sup>

Legalizing assisted suicide creates a two-tiered justice system, with robust protection for the life of able-bodied Canadians, and weaker protections and assumptions about the lives of Canadians with severe disabilities. This reality betrays the able-ism embedded in the trial judgment and the Supreme Court decision. Able-ism can be defined as the “cultural, institutional and individual set of practices and beliefs that assign inferior values to people with disabilities”.<sup>129</sup> The trial judge ruled, “It is unethical to refuse to relieve the suffering of a patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm.”<sup>130</sup> In a terse reply, Amy Hasbrouck of the disability rights advocacy group Not Dead Yet writes: “I’ll have to mention that to some of my hypothetical friends who say they have been pressured by doctors, nurses and social workers to hypothetically ‘pull the plug.’ The same goes for all those folks who succumbed to the pressure; I guess they’re only hypothetically dead.”<sup>131</sup>

The problem, argues Hasbrouck, is that the trial judge (and the Supreme Court) “forgot about the ‘right to fail’; that more than 90 per cent of suicide attempts are unsuccessful”.<sup>132</sup>

To put it simply, if a non-disabled person wants to commit suicide, she’s considered irrational and mentally ill, and is treated for depression, or maybe even locked up to prevent her from hurting herself. But if a disabled person wants to kill herself, she’s told she’s

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Ministry of Attorney General, “Crown Policy Manual: Charge Screening” (March 21, 2005), online: <<https://www.attorneygeneral.jus.gov.on.ca/english/crim/cpm/2005/ChargeScreening.pdf>>.

<sup>127</sup> *R. v. Latimer*, [2001] S.C.J. No. 1, 2001 SCC 1, [2001] 1 S.C.R. 3 (S.C.C.).

<sup>128</sup> This sentence was later changed by the Supreme Court of Canada. Having been found guilty of second-degree murder, the *Criminal Code* required a sentence of life imprisonment with no eligibility of parole before 10 years.

<sup>129</sup> H. Archibald Kaiser, “The Convention on the Rights of Persons with Disabilities: Beginning to Examine the Implications for Canadian Lawyers’ Professional Responsibilities” (2012) 20 *Health L. Rev.* 2, at 26-33, at para. 20.

<sup>130</sup> *Carter* (BCSC), *supra*, note 46, at para. 315. See also *Carter* (SCC), *supra*, note 2, at para. 119: “...A theoretical or speculative fear cannot justify an absolute prohibition.”

<sup>131</sup> Amy Hasbrouck, “How about the right to cry for help? Court ruling asserting a person’s right to assisted suicide reflects discriminatory attitudes toward the disabled”, *Montreal Gazette* (July 9, 2012) [hereinafter “Hasbrouck”].

<sup>132</sup> *Id.*

making a reasonable choice, and not only has the right to do so, but is even helped to complete the act so her death is guaranteed where most other suicide attempts fail. That sounds like discrimination to me.<sup>133</sup>

In order to fully expose the value statement inherent in the Court ruling, consider section 14 *vis-à-vis* a different identity group. What if the Supreme Court had ruled that section 14 was of no force or effect for Jews or for gay men? Would that communicate a message that Jews or gay men are receiving additional protections in law, or would it send a clear message that “it’s quite understandable that you would want to die if you’re a Jew or a gay man, and therefore you have permission to have someone assist you in committing suicide”? Clearly, the message is the latter. And with that message comes another practical reality: your life as a Jew or a gay man will not have the same assumptions protecting it as the rest of the population have.

By undermining the equal benefit of the law in this way, the Supreme Court has undone the principle enshrined in clause 40 of the *Magna Carta*. Some of Canada’s most vulnerable people will lose equal access to the protections of the Canadian *Criminal Code*, due to changed assumptions about consenting to death.

### 3. Section 15 Discrimination Test Applied

Earlier in this article I referenced a man named James.<sup>134</sup> This man is not a hypothetical person. James is my cousin, a smart comedian of sorts, and his rights are directly implicated in this issue. James was diagnosed with Spinal Muscular Atrophy in his infancy.<sup>135</sup> Though he is a young,

<sup>133</sup> *Id.*

<sup>134</sup> See discussion around *supra*, note 125.

<sup>135</sup> For more on Spinal Muscular Atrophy [hereinafter “SMA”], see Mitchell Lunn & Ching Wang, “Spinal muscular atrophy” (2008) 371 *The Lancet* 9630, at 2120, where the Authors describe SMA as “an autosomal recessive neurodegenerative disease characterised by degeneration of spinal cord motor neurons, atrophy of skeletal muscles, and generalised weakness. ...[N]o medical treatment is available”. See also Jennifer Markowitz, Priyamvada Singh & Basil Darras, “Spinal Muscular Atrophy: A Clinical and Research Update” (2012) 46 *Pediatric Neurology* 1, at 1 where the Authors note that SMA is “a hereditary degenerative disorder... associated with progressive muscle weakness and atrophy, is the most common genetic cause of infant mortality.... Although no effective treatment for spinal muscular atrophy exists, ...[a]dvances in the multidisciplinary supportive care of children with spinal muscular atrophy also offer hope for improved life expectancy and quality of life”. And, see Maryam Oskoui & Petra Kaufmann, “Spinal Muscular Atrophy” (2008) 5 *Neurotherapeutics* 4, at 499, where the Authors note that SMA is “a potentially devastating and lethal neuromuscular disease frequently manifesting in infancy and childhood”.

fully aware, communicative and competent adult, he is dependent on an electronic wheelchair for mobility, dependent on a feeding tube for nutrition, dependent on a tracheostomy<sup>136</sup> for breathing, and dependent on other adults for all his other needs. However, although he clearly has a “grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering”<sup>137</sup> (thus making him eligible for assisted suicide according to the Supreme Court of Canada) he does not want assisted suicide. And yet, legalizing assisted suicide puts James at risk or, at the very least, diminishes the robust protections of the *Criminal Code* for him and other people like him.

Keeping James in mind then, let’s proceed through a section 15 analysis of a new law that abides by the Supreme Court’s decision, allowing some people (physicians) to kill other people of a particular class, assuming consent has been given.

Section 15(1) of the Charter reads:

*Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.*<sup>138</sup>

This section applies to individual members of any of the enumerated groups listed in section 15 (as well as certain analogous groups<sup>139</sup>). It protects their right not only to be treated equally before and under the law, but also guarantees the equal benefit or protection of the law. For the purposes of our analysis, James will be the individual seeking the equal protection of the *Criminal Code* without discrimination based on physical disability, in particular, being a member of the group that suffers from a “grievous and irremediable medical condition (including an illness, disease or disability)”<sup>140</sup>.

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<sup>136</sup> Colloquially known as a “trāch”, a tracheostomy is an opening surgically created through the neck into the windpipe to allow direct access to the breathing tube. A tube is usually placed through this opening to provide an airway and to remove secretions from the lungs. Breathing is done through the tracheostomy tube rather than through the nose and mouth.

<sup>137</sup> The reader will recognize this as the Supreme Court’s description of those who qualify for assisted suicide. *Carter* (SCC), *supra*, note 2, at para. 147.

<sup>138</sup> Charter, *supra*, note 12, at s. 15(1) (emphasis added).

<sup>139</sup> Professor Peter Hogg lists only three analogous grounds that have been recognized by the Supreme Court to date: citizenship, marital status, and sexual orientation. Peter W. Hogg, *Constitutional Law of Canada: Fifth Edition Supplemented*, looseleaf (Toronto: Thomson Carswell, 2007), at 55-23-55-25 [hereinafter “Hogg”].

<sup>140</sup> As per the qualifications of the Supreme Court, *Carter* (SCC), *supra*, note 2, at para. 127.



In order to demonstrate a violation of his section 15(1) Charter right, James must prove, on a balance of probabilities, four things. The first two items are preliminary, the second two are the actual section 15(1) test:

- (1) that the infringer of the right is a State actor;<sup>141</sup> and
- (2) that the infringing action constitutes “law” within the meaning of section 15(1).<sup>142</sup>

If James can demonstrate that the Charter should apply, then he must pass the two-stage section 15(1) analysis (again, on a balance of probabilities):

- (1) “whether, on its face or in its impact, a law creates a distinction on the basis of an enumerated or analogous ground”<sup>143</sup> and
- (2) “whether the impugned law fails to respond to the actual capacities and needs of the members of the group and instead imposes burdens or denies a benefit in a manner that has the effect of reinforcing, perpetuating or exacerbating their disadvantage”.<sup>144</sup>

I will deal with each question, applying the facts of this scenario to the case law before dealing with a common equality rights objection.

*(a) Parliament and the Supreme Court are Subject to the Charter and Their Statutes and Decisions Constitute “Law”*

The first two matters can be dispensed with quickly. It is trite law to state that Parliament, in passing laws, is subject to the Charter. It is perhaps more difficult to argue that the Supreme Court itself is subject to the Charter. In 1988, the Supreme Court ruled that where “the court is acting on its own motion and not at the instance of any private party” or where the Court’s motivation is “entirely ‘public’ in nature, rather than ‘private’”, a court order can be subject to Charter review.<sup>145</sup> Presumably

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<sup>141</sup> *McKinney v. University of Guelph*, [1990] S.C.J. No. 122, [1990] 3 S.C.R. 229, at 265 (S.C.C.) [hereinafter “*McKinney*”].

<sup>142</sup> Hogg, *supra*, note 139, at 55-10-55-11.

<sup>143</sup> *Kahkewistahaw First Nation v. Taypotat*, [2015] S.C.J. No. 30, 2015 SCC 30, at para. 19 (S.C.C.) [hereinafter “*Taypotat*”].

<sup>144</sup> *Id.*, at para. 20.

<sup>145</sup> *British Columbia Government Employees’ Union v. British Columbia*, [1988] S.C.J. No. 76, [1988] 2 S.C.R. 214, at 244 (S.C.C.).

then, the Supreme Court itself is subject to the Charter, and its ruling can be evaluated in light of the Charter.<sup>146</sup>

The Supreme Court stated in *Eldridge* that “it is a basic principle of constitutional theory that since legislatures may not enact laws that infringe the Charter, they cannot authorize or empower another person or entity to do so”.<sup>147</sup> The principle should carry over to Parliament and the Supreme Court: the Court cannot “authorize or empower” Parliament to “enact laws that infringe the Charter”.

The Charter therefore applies to any new assisted suicide law, including the Supreme Court’s decision, and this law may be evaluated in light of the Charter. The term “law” in section 15 “applies to the same range of governmental action as other *Charter* rights” and covers the “range of governmental action... defined in section 32” of the Charter.<sup>148</sup> Obviously, any legalization of assisted suicide, by either Parliament or the Supreme Court, also constitutes “law” within the meaning of section 15(1).

*(b) The Carter Decision (and Any Subsequent Enabling Legislation)  
Creates a Distinction Based on a Section 15(1) Enumerated Ground*

The first stage of the two-part test for analyzing whether legalizing assisted suicide violates section 15(1) of the Charter is “whether, on its face or in its impact, a law creates a distinction on the basis of an enumerated or analogous ground”.<sup>149</sup>

In *Carter* (SCC), the Supreme Court makes a distinction on the basis of disability, an enumerated ground. In particular, the decision of the Supreme Court makes a distinction between able-bodied Canadians and a new sub-category of Canadians the Court creates: adult Canadians who

<sup>146</sup> This question is probably worthy of an entire journal article on its own. It raises issues of the supremacy of the Constitution and whether the Supreme Court has exclusive jurisdiction to make final determinations as to what that Constitution says. The irony has not escaped this author of the need to cite the authority of the Supreme Court’s earlier jurisprudence to argue that the authority of the Supreme Court in the *Carter* case should be questioned.

<sup>147</sup> *Eldridge v. British Columbia (Attorney General)*, [1997] S.C.J. No. 86, [1997] 3 S.C.R. 624, at para. 35 (S.C.C.).

<sup>148</sup> Hogg, *supra*, note 139, at 55-11. Section 32(1)(a) of the Charter states:  
This Charter applies

(a) to the Parliament and government of Canada in respect of all matters within the authority of Parliament including all matters relating to the Yukon Territory and Northwest Territories...

<sup>149</sup> *Taypotat*, *supra*, note 143, at para. 19.

have “a grievous and irremediable medical condition that causes enduring suffering that is intolerable”. James fits within this category. If Parliament acts on the Supreme Court’s direction, the new law will “create a distinction on the basis of an enumerated ground”.

*(c) The Distinction Creates a Disadvantage by Perpetuating Prejudice and by False Stereotyping*

The second stage of the section 15 test asks “whether the impugned law fails to respond to the actual capacities and needs of the members of the group and instead imposes burdens or denies a benefit in a manner that has the effect of reinforcing, perpetuating or exacerbating their disadvantage”.<sup>150</sup> An earlier iteration of this stage of the test asked courts to look at whether the law “[1] perpetrat[es] disadvantage or prejudice, or [2] stereotyp[es] in a way that does not correspond to actual characteristics or circumstances.”<sup>151</sup>

The trial judge heard, and even accepted, evidence of prejudice already existing that people who suffer from extreme diseases and disabilities are living lives that are not worth living.<sup>152</sup> One of the interveners at the Supreme Court put it best:

arguments based on autonomy require that physicians, and society at large, endorse the judgments of patients that their lives are no longer worth living.... If these judgments about the worthlessness of a person’s life are to be decisive, we must remember that when a physician agrees with a patient that his or her life has no value, *that judgment is transitive*; it must logically apply to *all persons* in the same state, regardless of whether they have requested death.<sup>153</sup>

Clearly the law perpetrates disadvantage. People are categorized according to their abilities and disabilities. Judgments of some regarding their worthlessness are projected onto others. The disadvantages that result are profound: people in this category lose the benefit of the *Criminal Code* assumption of non-consent to death (as discussed above); physicians and society assume that individuals in this category prefer

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<sup>150</sup> *Id.*, at para. 20.

<sup>151</sup> *Withler v. Canada (Attorney General)*, [2011] S.C.J. No. 12, [2011] 1 S.C.R. 396, at para. 65 (S.C.C.) [hereinafter “*Withler*”].

<sup>152</sup> *Carter (BCSC)*, *supra*, note 46, at paras. 194, 811, 819, 848-853.

<sup>153</sup> *Carter (SCC)*, *supra*, note 2, Factum of the Intervener Christian Legal Fellowship, at para. 30.

death; and health care systems develop different standards of suicide response and care depending on disability and disease.<sup>154</sup> As a disability rights group in the United States argued in an amicus brief,

legalized assisted suicide sets up a double standard for how health care providers, government authorities, and others respond to an individual's stated wish to die. Some people get suicide prevention while others get suicide assistance, and the difference between the two groups is the health status of the individual.<sup>155</sup>

The Amicus Brief also notes, "Assisted suicide singles out some people with disabilities, those labeled 'terminal' or very severely impaired, for different treatment than other suicidal people receive."<sup>156</sup> As Dr. Ryan Anderson puts it, "...Government policy should seek to respect the innate dignity of the disabled by eliminating every form of unjust discrimination against them, not by expressly approving the worst form of discrimination of all."<sup>157</sup>

As per the *Taypotat* test, a law that legalizes assisted suicide for people with severe disabilities "fails to respond to the actual... needs of the members of the group and instead... denies a benefit in a manner that has the effect of... exacerbating their disadvantage".<sup>158</sup> Assistance in committing suicide is not what James needs. But if killing him becomes a legal option, why bother developing the things he *does* need: high quality, expensive palliative care?

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<sup>154</sup> Diane Coleman notes, "The primary underlying practical basis for the physician's determination that the individual is eligible for assisted suicide is the individual's disabilities and physical dependence on others for everyday needs, which is viewed as depriving them of what nondisabled people often associate with "autonomy" and "dignity", and may also lead them to feel like a "burden". This establishes grounds for physicians to treat these individuals completely differently than they would treat a physically able-bodied suicidal person." Diane Coleman, "Assisted Suicide Laws Create Discriminatory Double Standard for Who Gets Suicide Prevention and Who Gets Suicide Assistance: Not Dead Yet Responds to Autonomy, Inc.", (2010) 3 *Disability and Health Journal* 1, at 41.

<sup>155</sup> *Id.*, at 43.

<sup>156</sup> *Id.* The Brief continues: "Central to the civil rights of people with disabilities is the idea that a disabling condition does not inherently diminish one's life; rather, surrounding barriers and prejudices do so. In contrast, assisted suicide gives official sanction to the idea that life with a disabling condition is not worth living." *Id.*, at 44.

<sup>157</sup> Ryan T. Anderson, Ph.D., "Always Care, Never Kill: How Physician-Assisted Suicide Endangers the Weak, Corrupts Medicine, Compromises the Family, and Violates Human Dignity and Equality", (March 24, 2015) *The Heritage Foundation: Background*, No. 3004, at 19, online: <[http://thf\\_media.s3.amazonaws.com/2015/pdf/BG3004.pdf](http://thf_media.s3.amazonaws.com/2015/pdf/BG3004.pdf)>.

<sup>158</sup> *Taypotat*, *supra*, note 143, at para. 20.

Legalized assisted suicide not only perpetuates disadvantage, it is also “based on a stereotype that does not correspond to the actual circumstances and characteristics of the claimant or claimant group”.<sup>159</sup> The important thing to demonstrate here is impact or effect:

We must be careful not to treat *Kapp* and *Withler* as establishing an additional requirement on s. 15 claimants to prove that a distinction will perpetuate prejudicial or stereotypical attitudes towards them. Such an approach improperly focuses attention on whether a discriminatory *attitude* exists, not a discriminatory impact, contrary to *Andrews*, *Kapp* and *Withler*.<sup>160</sup>

Yvonne Peters admits that “it can be argued that much of disability discrimination is not necessarily motivated by ill will or malice”.<sup>161</sup> Certainly, no claims are being made in this article about the true attitudes of the Supreme Court judges or those advocating for assisted suicide; I presume they are all motivated by a desire to help. However, the effects of these discriminatory policies “have been nonetheless damaging and harmful to the lives of people with disabilities”.<sup>162</sup>

In *Andrews*, the Supreme Court defined discrimination as:

a distinction... based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations, or disadvantages on such individual or group not imposed upon others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society.<sup>163</sup>

As set out above, the decision of the Supreme Court, and any subsequent enabling legislation, squarely fits this definition of discrimination:

- (1) the group: Canadians with disabilities, particularly vulnerable Canadians within that group;
- (2) the personal characteristics: “a grievous and irremediable medical condition that causes enduring suffering that is intolerable”;

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<sup>159</sup> *Withler*, *supra*, note 151, at para. 36. The discussion of stereotyping by LeBel J. is helpful for understanding this point. *Quebec (Attorney General) v. A.*, [2013] S.C.J. No. 5, [2013] 1 S.C.R. 61, at paras. 201-203 (S.C.C.) [hereinafter “*Quebec v. A.*”].

<sup>160</sup> *Quebec v. A.*, *supra*, note 159, at para. 327. See paras. 325-334 for a fuller discussion on this point. See also *Taypotat*, *supra*, note 143, at paras. 24, 27-30, 33, 34.

<sup>161</sup> Yvonne Peters, “The Constitution and the Disabled” (1993) 2 *Health L. Rev.* 1, at 17-22, at para. 7.

<sup>162</sup> *Id.*

<sup>163</sup> *Law Society of British Columbia v. Andrews*, [1989] S.C.J. No. 6, [1989] 1 S.C.R. 143, at 174 (S.C.C.).

- (3) the disadvantage or limited access: a two-tiered *Criminal Code* that lacks particular protective assumptions regarding their life; and
- (4) available to others: the protections found in section 14 of the *Criminal Code*,<sup>164</sup> namely, the assumption that the individual does *not* consent to die.

(d) *The Discrimination does not Need to be Universally Applied to a Group*

Some may object to the conclusion that the legalization of assisted suicide violates James's equality rights since not *all* Canadians with disabilities are against the legalization of assisted suicide.<sup>165</sup>

The Supreme Court has addressed this objection directly. In *Quebec v. A.*, Abella J. wrote that "this Court has held that heterogeneity within a claimant group does not defeat a claim of discrimination... [and this Court] squarely rejected the idea that for a claim of discrimination to succeed, all members of a group had to receive uniform treatment from the impugned law".<sup>166</sup> Justice Abella cites Dickson C.J.C. in *Janzen* where he states,

...If a finding of discrimination required that every individual in the affected group be treated identically, legislative protection against discrimination would be of little or no value. It is rare that a discriminatory action is so bluntly expressed as to treat all members of the relevant group identically.<sup>167</sup>

Although *Janzen* was decided in the context of human rights legislation, Gonthier J. applied the principle expressed there to the Charter context years later. He wrote: "...This Court has long recognized that differential treatment can occur... despite the fact that not all persons

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<sup>164</sup> *Supra*, note 11. The section states:

**Consent to death**

**14.** No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given.

<sup>165</sup> See, for example, Disabilities Alliance Factum, *supra*, note 99, which argued in support of legalizing assisted suicide.

<sup>166</sup> *Quebec v. A.*, *supra*, note 159, at para. 354.

<sup>167</sup> *Janzen v. Platy Enterprises Ltd.*, [1989] S.C.J. No. 41, [1989] 1 S.C.R. 1252, at 1288-89 (S.C.C.).

belonging to the relevant group are equally mistreated.”<sup>168</sup> In other words, says Abella J., “even if only some members of an enumerated ...group suffer discrimination by virtue of their membership in that group, the distinction and adverse impact can still constitute discrimination”.<sup>169</sup>

It is clear then that even though some people within the disability rights community advocate for assisted suicide, nevertheless the discrimination in violation of section 15(1) has been made out in regards to those members of the disability community who do not want assistance in suicide, but whose lives are put at risk notwithstanding. Furthermore, the effect of this overt discrimination will no doubt have consequential negative effects for other members of this group due to the societal message sent by the legalization of the practice.

(i) A (Not So) Modest Legislative Proposal<sup>170</sup>

Political scientists have observed a side-effect of Charter legislative review called “policy distortion”, a phenomenon that occurs where lawmakers choose policies that may be less effective but which they believe will be more easily defensible against future Charter challenges.<sup>171</sup> Parliament may risk foregoing the best option because Members of Parliament mistakenly believe it falls outside the range of policies a court would accept under Charter review. So where the Supreme Court of Canada clearly states its intent to limit the policy impact of its ruling, as it does in *Carter* (SCC),<sup>172</sup> Members of Parliament should take note.<sup>173</sup>

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<sup>168</sup> *Nova Scotia (Workers' Compensation Board) v. Martin; Nova Scotia (Workers' Compensation Board) v. Laseur*, [2003] S.C.J. No. 54, [2003] 2 S.C.R. 504, at para. 76 (S.C.C.).

<sup>169</sup> *Quebec v. A.*, *supra*, note 159, at para. 355.

<sup>170</sup> For this last section, I borrow heavily from the work of my organization, ARPA Canada, particularly our factum to the Supreme Court of Canada and our research for Parliament's Panel on Options for a Legislative Response to *Carter v. Canada*. I am indebted to both of my colleagues Mark Penninga (for his work on the factum) and John Sikkema (for his work on the legal research for the Parliamentary Panel, especially as it is found in our publication *Protecting Life: How Parliament Can Fully Ban Assisted Suicide Without Section 33*, online: <<https://arpacanada.ca/attachments/article/2399/Assisted%20Suicide%20-%20Total%20Ban%20analysis%20FINAL.pdf>>).

<sup>171</sup> For other democratic objections to judicial review, such as those based on its capacity to discourage or distort legislative constitutional deliberation, see Mark Tushnet, “Policy Distortion and Democratic Debilitation: Comparative Illumination of the Countermajoritarian Difficulty”, (1995) 94 Mich. L. Rev. 245, at 292, 299.

<sup>172</sup> *Supra*, note 2, at para. 127.

<sup>173</sup> The Special Joint Committee report is a classic – or even extreme – case of “policy distortion”. The recommendations go so far beyond the scope of what the Supreme Court limited its reasoning to that even some euthanasia advocates are critical of their recommendations.

That being said, in light of what is at stake in legalizing assisted suicide, Parliament ought to enact a new absolute prohibition on assisted suicide, but do so without invoking the notwithstanding clause.<sup>174</sup> The legislation would need two elements to address the concerns above: It would need an explicit objective clause (to correct the very narrow reading of the law's objective on the part of the Supreme Court<sup>175</sup>); and it would need to have some mechanism for improving access to palliative care in Canada (to provide a different means to address the section 7 violation, as discussed in the false dichotomy fallacy section above).

The irony of the *Carter* (SCC) decision is in how the Supreme Court summarized the case law on the section 7 right to life: "...In short, the case law suggests that the right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly."<sup>176</sup> Yet, the evidence is plentiful that this is exactly what the Supreme Court has done: its actions have imposed "an increased risk of death on a person, either directly or indirectly"; the right to life of some people with severe disabilities have been touched. It is within Parliament's power to counter this inequality without delay; "The *Charter* should not be used to compel Parliament to quantify the number of lives that must be saved to justify the absolute prohibition."<sup>177</sup>

The objective of the existing law was a matter of debate and the Court's conclusion about its objective in *Carter* (SCC) was not the only possible interpretation or even the most reasonable. The Supreme Court acknowledged that it is *Parliament's* objective, embodied in the text of the legislation enacted by it, that is in question in the section 7

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<sup>174</sup> *Charter*, *supra*, note 12, s. 33(1), which states,

Parliament or the legislature of a province may expressly declare in an Act of Parliament or of the legislature, as the case may be, that the Act or a provision thereof shall operate notwithstanding a provision included in section 2 or sections 7 to 15 of this Charter.

<sup>175</sup> *Carter* (SCC), *supra*, note 2, at para. 78. The Court ruled that the objective was merely to protect vulnerable persons from being induced to commit suicide at a moment of weakness. The objective was not, in the Court's view, to protect life broadly speaking, or even to prevent suicide. This distinction effectively determined the outcome of the case.

<sup>176</sup> *Carter* (SCC), *supra*, note 2, at para. 62.

<sup>177</sup> A.G. Canada Factum, *supra*, note 57, at para. 116, citing *R. (Nicklinson) v. Ministry of Justice*, [2014] U.K.S.C. 38, at para. 229 (S.C.).



analysis.<sup>178</sup> Parliament can decide why to prohibit assisted suicide by communicating its objective to the courts through the text of the law.<sup>179</sup>

I agree in principle with the following points made by the Attorney General of Canada:

Although it may be motivated by compassion, physician-assisted death involves intentional acts of a third party to bring about the death of another and necessarily involves an affirmation of the subject's conclusion that his or her life is not worth living. It leads to the normalization of assisted suicide and euthanasia and denormalization of physical dependence. The re-enforcement of the societal message that death is preferable to physical dependence must be taken into account in assessing whether the protection provided by the impugned provisions creates a discriminatory distinction.<sup>180</sup>

And:

Furthermore, it is the very regulatory scheme proposed by the trial judge that, by defining which kinds of lives may be taken, sends the message which is antithetical to Parliament's objective of confirming the value of every life. Allowing for defined exceptions to the prohibitions results in some people who say that they want to die receiving suicide intervention, while others receive suicide assistance. Those who fall into the latter category will be defined by their health or disability status, sending the message that such lives are less worthy of protection.<sup>181</sup>

The Supreme Court formulated the existing prohibition's objective in a way that favoured the appellants. But the Court's interpretation of section 241(b) does not shackle Parliament. *It is the interpretation of an ordinary statute that is in question here*, not the Court's interpretation of the Charter. The Court simply plugged its preferred interpretation of the object of the assisted suicide prohibition into the section 7 framework it developed over the years.

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<sup>178</sup> As the Court says in *Carter* (SCC), *supra*, note 2, at paras. 29 and 37, a carefully designed system of safeguards could obtain *Parliament's* objective of protecting the vulnerable, the objective the Court interprets as being embodied in s. 241(b).

<sup>179</sup> There is no room to discuss this further here. See more about a possible "Charter dialogue" between the institutions of Court and Parliament in Peter W. Hogg and Allison A. Bushell, "The Charter Dialogue between Courts and Legislatures (or Perhaps the Charter of Rights Isn't Such a Bad Thing After All)" (1997) 35 Osgoode Hall L.J., at 75-124; Peter Hogg, Allison A. Bushell Thornton, & Wade K. Wright, "Charter Dialogue Revisited Or 'Much Ado' About Metaphors" (2007) 45 Osgoode Hall L.J., at 1-65.

<sup>180</sup> A.G. Canada Factum, *supra*, note 57, at para. 134.

<sup>181</sup> *Id.*, at para. 156.

Altering the framework by which judges interpret and apply section 7 of the Charter would require a constitutional amendment, but all Parliament needs to do in response to the *Carter* (SCC) ruling is amend a normal federal statute, the *Criminal Code*. Courts must interpret and apply statutes to the facts of individual cases. Legislatures cannot tell courts how to apply a statute in a given case, but legislatures can and do give courts direction on how to interpret a statute in the statute itself. The Supreme Court's interpretation of the objective of section 214(b) is binding only with respect to that provision, not with respect to future amendments, enactments, or even re-enactments of the same prohibition for a different or broader purpose.

Parliament ought to pass a bill amending the *Criminal Code* to include a complete ban on all forms of assisted suicide and euthanasia with a purpose clause stating that the purpose of the law is to protect every human life, to maintain respect for the inviolability of life, to affirm the equal worth of every life, and to prohibit as a public wrong the deliberate participation of any person in another person's suicide with or without the latter person's consent.<sup>182</sup> The same bill that gives effect to the foregoing ought to also include mechanisms for improving palliative care. As long as there is a nationalized medical care system, proper end-of-life care should be made readily available for those who desperately need it.

Absolute prohibitions of assisted suicide are necessary for upholding the sanctity of human life. Exceptions based on subjective determinations of the value of a person's life will radically destabilize the protection that law provides to the vulnerable. To assume that Canada will be the exception to every other jurisdiction that has failed to maintain adequate safeguards fails to understand that the problem is not with the particular safeguards enacted, but with the nature of safeguards themselves. Crossing the bright line and deeming some lives as unworthy of living creates an unstable regime, regardless of where the line is drawn. There is no logical or legal foundation by which to uphold any safeguards once that threshold is crossed.

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<sup>182</sup> The most important of these is the latter. Active, deliberate participation in another person's suicide is, to borrow a phrase from Sopinka J. in *Rodriguez*, *supra*, note 113, at 601, "intrinsically morally and legally wrong". Justice Sopinka's phrase, "intrinsically morally and legally wrong" captures the longstanding legal principle of the *inviolability of life* — that the *intentional* taking of human life is exceptionlessly wrong, no matter whose life it is, no matter what the circumstances. Inviolability is not the same as vitalism, the latter being the belief that society must take every possible step to prolong life.

As discussed at the trial level of this case, both the Netherlands and Belgium offer an abundance of evidence in this regard, with access to assisted suicide being broadened continually,<sup>183</sup> and now even including children.<sup>184</sup> In Canada, with the ink not yet dry on Bill 52, the secretary of Québec's College of Physicians was already publically contemplating the need to extend the law to include far more people, calling Bill 52 "only a step".<sup>185</sup> Parliament's first official response to the *Carter* (SCC) decision is 21 legislative recommendations, all but one of which is intended to expand access to assisted suicide beyond the scope of the Supreme Court's framework.<sup>186</sup>

Wesley J. Smith appropriately calls out the consequences of how we answer the question of legalizing assisted suicide:

The morality of the 21st century will depend on how we respond to this simple but profound question: Does every human life have equal moral value simply and merely because it is human? Answer yes, and we have a chance of achieving universal human rights. Answer no, and it means that we are merely another animal in the forest.<sup>187</sup>

Our society may feel obliged to grant the request of those who seek state-assisted, and society-endorsed, suicide. But doing so means constructing a new foundation that is incapable of equally upholding the right to life. If that foundation is subjective, it will ultimately mean that humanity becomes "merely another animal in the forest". In the forest, it is strength that determines superiority. The weak must learn to hide.

If there is just one job for the civil government to do, one reason for it to exist, it is to maintain and enforce laws that provide equal protection for the lives of its citizens so that all citizens can have equal opportunity to flourish. Legalizing assisted suicide undermines this ideal, putting the protection of some citizens' lives on a second tier.

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<sup>183</sup> *Carter* (BCSC), *supra*, note 46, at paras. 455-462, 505, 508-509. See also Tinne Smets *et al.*, "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases", (2010) *BMJ* 34, at c. 5174.

<sup>184</sup> *Carter* (SCC), *supra*, note 2, Affidavit of Professor Etienne Montero sworn April 23, 2014 (English translation), at paras. 79-82, 87.

<sup>185</sup> Graeme Hamilton, "As Quebec set to legalize euthanasia, doctors already looking to expand who qualifies for lethal injections", *National Post* (February 13, 2014), online: <<http://news.nationalpost.com/2014/02/13/as-quebec-set-to-legalize-euthanasia-doctors-already-looking-to-expand-who-qualifies-for-lethal-injections/>>.

<sup>186</sup> See *Joint Committee Report*, *supra* note 9.

<sup>187</sup> Wesley J. Smith, — *The Way I See It* #127, as printed on Starbucks coffee cups.

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Préambule : Au Québec, la Loi sur les soins de fin de vie visant à encadrer les soins palliatifs est entrée en vigueur le 10 décembre 2015. Elle instaurait le régime des directives médicales anticipées, instituait la Commission sur les soins de fin de vie et permettait l'aide médicale à mourir (AMM), selon certains critères d'accès :

- être assuré au sens de la Loi sur l'assurance maladie;
- être majeur;
- être apte à consentir aux soins;
- être en fin de vie;
- être atteint d'une maladie grave et incurable;
- avoir une situation médicale qui se caractérise par un déclin avancé et irréversible de ses capacités;
- éprouver des souffrances physiques ou psychiques constantes, insupportables et qui ne peuvent être apaisées dans des conditions jugées tolérables.

Nous considérons que la loi québécoise sur les soins de fin de vie est un modèle duquel le groupe d'experts devrait s'inspirer. Quant à la loi fédérale, l'AMQ émet des réserves importantes sur le droit accordé toute personne autre qu'un médecin qui aide un patient à s'administrer la substance prescrite, et ce, sans formation ou encadrement particulier sur les plans cliniques. Si de telles balises ne sont pas en place, il est alors question d'assistance au suicide et non d'aide médicale à mourir. C'est la responsabilité professionnelle du médecin d'être présent à toutes les étapes du processus d'AMM, un processus qui doit être réglementé de façon serrée.

Les enjeux relatifs à l'AMM sont complexes et délicats, mais l'AMQ estime qu'ils sont sous-jacents à une problématique beaucoup plus large que la seule question de l'accès à l'AMM, c'est-à-dire : l'accès à des soins palliatifs de qualité.

Effectivement, une profonde réflexion sur notre culture des soins de fin de vie permettrait d'arrimer plus solidement les textes de loi avec la réalité sur le terrain. Bien que la Loi sur les soins de fin de vie pointe une direction claire, son esprit ne pourra pas être pleinement servi si nos façons de faire en ce qui concerne la planification et l'organisation des soins palliatifs ne sont pas repensées. C'est ce qui nous permettra de mettre sur pied un continuum de soins efficace et cohérent. Plusieurs aspects doivent être considérés, par exemple :

- les médecins sont-ils formés et outillés adéquatement afin de savoir quand et comment mener une discussion efficace sur la planification de soins de fin de vie avec leurs patients et leurs proches?
- les niveaux d'intervention médicale sont-ils systématiquement déterminés et fréquemment révisés avec les patients?
- de quelles façons le surdiagnostic et le surtraitement affectent la qualité de vie des patients en fin de vie ?

Par ailleurs, l'AMQ salue la démarche de consultation menée par Conseil des académies

canadiennes. Voici les conclusions des réflexions effectuées par notre association sur les trois situations visées par les travaux sur l'élargissement de l'AMM.

**Demandes médicales anticipées :**

Au Québec, la Loi sur les soins de fin de vie confère au formulaire de Directives médicales anticipées (DMA) un caractère contraignant qui équivaut à un consentement verbal en cas d'inaptitude. Ce formulaire contient une liste de soins précis que toute personne apte et majeure peut prévoir accepter ou refuser. Conséquemment, il est impossible de l'utiliser afin de demander l'AMM.

Au cours de la dernière année, les médias québécois ont rapporté plusieurs témoignages de proches aidants de personnes souffrant principalement de démence ou d'Alzheimer. Ceux-ci auraient souhaité que leur proche ait eu l'occasion de formuler une demande médicale anticipée d'AMM avant de devenir inapte à consentir. Dans d'autres cas, l'évaluation médicale de certains patients a démontré leur admissibilité, mais ces derniers n'ont finalement jamais reçu le soin en question puisqu'ils ont été jugés inaptes peu de temps avant ou au moment auquel l'AMM devait être prodiguée. Ainsi, l'AMQ croit que permettre à une personne de demander l'aide médicale à mourir de façon anticipée serait une option viable afin d'améliorer l'accès à ce soin.

Pour qu'une demande anticipée d'AMM soit recevable, nous émettons la condition cette personne soit diagnostiquée d'une maladie incurable, dont les effets entraîneront inévitablement le décès, un déclin avancé et irréversible de ses capacités et des souffrances physiques ou psychologiques intolérables. En somme, les effets prévisibles de sa maladie devraient correspondre aux critères de la loi québécoise.

L'AMQ considère également que la nomination d'un mandataire serait un élément important afin de permettre la prise d'une décision éclairée quant au moment où l'aide médicale à mourir sera prodiguée.

**Mineurs matures :**

L'AMQ est d'avis qu'une personne mineure atteinte d'une maladie grave et incurable dont les conséquences satisfont les critères de la loi québécoise, et qui démontre la maturité nécessaire pour effectuer des choix importants en lien avec sa santé devrait pouvoir faire une demande d'AMM.

Actuellement, la mécanique de la loi québécoise oblige le médecin à consulter les proches ainsi que l'équipe de soins. Nous croyons que cette exigence doit être maintenue dans le cadre d'une demande d'AMM par un mineur mature.

**Personnes souffrant de problème de santé mentale comme seule condition de santé sous-jacente :**

L'AMQ émet des réserves importantes quant à cet aspect des discussions. Néanmoins, si elle est abordée à la lumière de l'arrêt Carter, l'admissibilité à l'AMM pourrait être accordée pour des personnes aux prises avec des « problèmes de santé graves et irrémédiables (y compris une affection, une maladie ou un handicap) ».

Ainsi, l'AMQ estime que l'aide médicale à mourir devrait pouvoir être prodiguée si la maladie mentale qui affecte le patient entraîne une dégénérescence, évolue de façon irréversible et causera assurément le décès, comme dans les cas de démence sévère et d'Alzheimer. L'AMQ prétend que les demandes médicales anticipées et la nomination d'un mandataire, dans un cadre de diagnostic précis, permettraient aux patients l'accès à l'AMM et réglerait cette problématique.

Toutefois, des réticences considérables sont exprimées concernant cette possibilité pour des patients souffrant, par exemple, de dépression ou de schizophrénie. En effet, alors que les conséquences de ces maladies ne satisfont pas les critères de la loi québécoise, la procédure s'apparenterait davantage à l'euthanasie qu'à l'aide médicale à mourir.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Loi sur les soins de fin de vie  
<http://legisquebec.gouv.qc.ca/fr/ShowDoc/cs/S-32.0001>

Régie de l'assurance maladie du Québec:  
Directives médicales anticipées <http://www.ramq.gouv.qc.ca/fr/citoyens/assurance-maladie/volontes/Pages/directives-medicales-anticipees.aspx>

Institut national d'excellence en santé et services sociaux :  
Portrait de la situation : Les niveaux d'intervention médicale - niveaux de soins  
[https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/OrganisationsSoins/INESSS\\_Niveaux\\_intervention\\_medicale.pdf](https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/OrganisationsSoins/INESSS_Niveaux_intervention_medicale.pdf)

Association médicale du Québec  
Mémoire sur le projet de loi 52 - Loi concernant les soins de fin de vie  
<https://www.amq.ca/images/stories/documents/memoire-projet-loi-52.pdf>

Association médicale du Québec  
Sondage LÉGER : Enquête auprès des médecins - Mourir dans la dignité  
<https://www.amq.ca/documents/sondage-mourir-dignite-fr.pdf>

Association médicale du Québec  
Lettre d'opinion - Un droit s'accompagne toujours d'une obligation  
<https://www.amq.ca/fr/amq-en-action/nouvelles/item/757>

Département de psychiatrie, CHUM et CRCHUM  
Groupe de recherche sur la souffrance psychique et l'AMM  
<http://www.cmq.org/pdf/outils-fin-de-vie/exploration-souffrance-psychique.pdf?t=1506007807928>

Radio-Canada Informations  
Meurtre dans un centre d'hébergement : le conjoint de la victime est accusé  
<http://ici.radio-canada.ca/nouvelle/1018118/meurtre-centre-hebergement-comparution-conjoint-victime>

La Presse  
Le cri du coeur de Bonnardel  
<http://www.lapresse.ca/le-soleil/actualites/chroniques/gilbert-lavoie/201702/24/01-5073048-le-cri-du-coeur-de-bonnardel.php>

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Association of Registered Nurses of B.C. (ARNBC) is pleased to bring forward the voice of B.C. registered nurses and nurse practitioners to the CCA Expert Panel on MAiD. As one of the first nursing organizations to publish a position statement on MAiD prior to becoming law, ARNBC recognizes the need to proactively study the complexities surrounding MAiD in relation to mature minors, advance directives, and mental illness as the sole underlying condition. The nature of nursing practice, nurses' relationships with individuals, families and communities, and ethical principles of respect for autonomy, beneficence, non-maleficence, and justice, continue to position nurses as key leaders in informing MAiD policy. This submission has been informed by B.C. nurses and nurse practitioners, and provides a brief overview of the key issues identified through the nursing perspective.

**Mature Minors**

In relation to mature minors, key issues include:

- 1) Competency: One of the most important considerations when exploring this type of MAiD request is how a 'mature minor' is defined, and what factors will be considered in determining competency. Depending on the context, age may provide little information on whether a minor has the maturity and capacity to make informed decisions. There is also a need to examine when cognitive development reaches full maturity in order to enable capable decision making. Greater examination around the processes and tools required to assess competency, as well as the identification of biopsychosocial suffering parameters are required.
- 2) Involvement of parents or guardians: There is a need to consider parental or guardian consent and influence, and how this will be balanced between young individuals' own wishes. In the case of conflicting views between young individuals, parents, and/or guardians, greater examination is needed to understand the legalities and best course of action to be taken by assessors and providers of MAiD.
- 3) Nursing role: The nature of nursing practice positions nurses to be highly influential in the care and decisions of children and families. Greater examination is needed to gain a clear understanding of nursing's role throughout this process, and the mechanisms in place to support nurses in helping patients and families navigate these complex processes. There is also significant contention within the pediatric community, and issues of stigma and conflict between care providers will also need to be addressed. A greater understanding around the perspectives of potential pediatric MAiD assessors, providers and assistants will be required as this will have significant implications on access, if mature minors are eligible for MAiD.

**Mental Illness (Sole Underlying Condition)**

In relation to mental illness as the sole underlying condition, key issues include:

- 1) Competency: At times, the presence of a mental illness does impact rationality. However, nursing expertise would also suggest that mental illness and irrationality are not synonymous. As a result, there is a need to determine the type of tools, instruments, and processes required to thoroughly assess capacity in order to determine whether the decision to seek assisted dying is one that is rational or one that is being influenced by the mental illness.
- 2) Defining grievous and irremediable mental illness: It is important to recognize that mental

suffering is no less onerous than physical suffering, and contextual factors such as the structural violence experienced by marginalized individuals living with mental illness and the adequacy of mental health supports and treatments also need to be considered. Unlike physical illnesses, natural death from mental illness is often not foreseeable, as the trajectory of mental illness is usually non-linear and unpredictable. Greater examination is needed to determine how irremediable and grievous will be defined within the context of mental illness, when it is deemed appropriate to engage in MAiD, and how subjective and objective data will be balanced in order to inform decision making.

3) Nursing Role: Greater examination around the types and number of assessors that will be appropriate within the context of MAiD and mental illness will be required. For example, the use of nurse practitioners in the area of mental health across Canada continues to be small. While many nurse practitioners are not specifically trained and educated in mental health, the use of nurse practitioners may increase access in rural and remote areas. The role of nurses, especially registered psychiatric nurses (in western provinces) will also be important to consider.

#### Advance Requests

In relation to advance directives, key issues include:

1) Contemporary Competence: There may be multiple occasions where a patient's perspective may change between the time of completing an advance directive and when assisted dying would actually be enacted. While the reasoning behind contemporary competence is related to safeguarding against mistake and abuse, there also must be a balance with individual autonomy and the underlying intent of an advance directive.

2) Representation Agreements: Where patients have representation agreements in place, key issues such as decision makers' legal authority to change, adhere, and consent to the advance directive, as well as competing viewpoints and tensions between decision-makers must be further examined. Variation in provincial legislation regarding advance directives also requires further consideration.

3) Specificity of Advance Directive- There are many grey areas when opening up MAiD to advance requests including when the patient would wish to seek MAiD, and how this would be supported by MAiD providers, family or friends. Advance directives would need to be written out clearly, and greater examination is needed around the specifics required in an advance directive.

4) Nursing Role: Nurses are often the healthcare professionals who are most informed around the relationships and dynamics of families. This will require greater consideration of nursing's role in this process, and the legal considerations that will enable nurses to best support patients and families. Many individuals with neurodegenerative diseases who complete advance directives will likely be in the care of nurses in complex continuing care or residential care settings. Due to the significant role that nurses play, there is need to examine the type of ethical, legal and clinical frameworks required.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*



## Nursing Role

From a nursing perspective, there is a need for systematic reviews of jurisdictions that have implemented legal and clinical frameworks to guide MAiD practice within the context of mature minors, advance requests and those with mental illness as the sole underlying condition. Specifically, knowledge is needed around the implications for nurses within and outside of the interprofessional team.

Below is list of existing knowledge that may be considered by the CCA Expert Panel on MAiD.

## Mature Minors

Bolt, E. E., Flens, E. Q., Pasman, H., Willems, D., & Onwuteaka-Philipsen, B. D. (2017). Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatrica*, 106(4), 668-675.

Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *Jama*, 316(1), 79-90.

Hein, I. M., Troost, P. W., Broersma, A., De Vries, M. C., Daams, J. G., & Lindauer, R. J. (2015). Why is it hard to make progress in assessing children's decision-making competence?. *BMC medical ethics*, 16(1), 1.

Pousset, G., Mortier, F., Bilsen, J., Cohen, J., & Deliens, L. (2011). Attitudes and practices of physicians regarding physician-assisted dying in minors. *Archives of disease in childhood*, 96(10), 948-953.

Vrakking, A. M., Van Der Heide, A., Looman, C. W., Van Delden, J. J., Onwuteaka-Philipsen, B. D., Van Der Maas, P. J., & Van Der Wal, G. (2005). Physicians' willingness to grant requests for assistance in dying for children: A study of hypothetical cases. *The Journal of pediatrics*, 146(5), 611-617.

Vrakking, A. M., Van Der Heide, A., Onwuteaka-Philipsen, B. D., Van Der Maas, P. J., & Van Der Wal, G. (2007). Regulating physician-assisted dying for minors in the Netherlands: views of paediatricians and other physicians. *Acta Paediatrica*, 96(1), 117-121.

## Advance Directives

Menzel, P. T., & Steinbock, B. (2013). Advance directives, dementia, and physician-assisted death. *The Journal of Law, Medicine & Ethics*, 41(2), 484-500.

Tomlinson, E., Spector, A., Nurock, S., & Stott, J. (2015). Euthanasia and physician-assisted suicide in dementia: A qualitative study of the views of former dementia carers. *Palliative medicine*, 29(8), 720-726.

## Mental illness as sole underlying condition

Rousseau, S., Turner, S., Chochinov, H. M., Enns, M. W., & Sareen, J. (2017). A National Survey of Canadian Psychiatrists' Attitudes toward Medical Assistance in Death. *The Canadian Journal of Psychiatry*, 0706743717711174.

Sheehan, K., Gai, K. S., & Downar, J. (2017). Medical assistance in dying: special issues for patients with mental illness. *Current opinion in psychiatry*, 30(1), 26-30.

Autism Canada

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Autism Canada appreciates the opportunity to submit these comments to the Expert Panel on Medical Assistance in Dying (MAID).

Autism Canada does not believe autism is a mental health condition although many on the spectrum do have co-occurring mental health conditions like anxiety and/or depression as examples. Autism Canada also believes that suffering is not inherent to autism. This is not to say that people with autism do not experience hardship or pain, but that when they do suffer, they do not suffer solely and primarily due to autism. The average autistic person, given adequate resources and a supportive environment, will live a happy, healthy life that is different from but no less valuable than that of a person without autism. Therefore, autism and other similar conditions do not meet the Supreme Court of Canada's guideline of a "grievous and irremediable medical condition" in the decision of *Carter v. Canada (Attorney General)*, 2015 SCC 5, at para 127.

Autism is typically a lifelong condition, but the barriers, resource gaps, and social stigma that result in a lower quality of life for people with autism should be addressed outside the context of medical assistance in dying. Autistic people likewise have similar expected lifespans to non-autistic counterparts in the same living conditions, meaning that autism does not match the criteria of a "reasonably foreseeable" death outlined in the Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), SC 2016, c 3, s 2d.

Early death among the autistic population is largely a result of co-occurring medical conditions such as epilepsy and cardiovascular disease as well as accidental injury and certain elevated risk-factors such as poverty, malnutrition, and stress.

Further, it is notable that autism is a diagnostic grouping based on a cluster of symptomatic behavioural traits rather than a common cause. Autism, like some other disorders such as intellectual delays or depression, is actually a set of behaviours caused by underlying physiological and biological issues, not a single, specific, "one size fits all" condition.

Even in cases when diagnostic labels of this kind are associated with a higher rate of early death, it is at best unsound to extrapolate from those results to other individuals sharing the same diagnostic label. Two superficially similar patients with the same diagnostic label might, in fact, have an entirely different underlying cause to their condition, meaning that the progression of said condition will also be likewise entirely different. Without understanding the underlying cause or the development of a given condition, it is impossible to predict whether a "reasonably foreseeable death" is likely. Such judgements should be reserved for specific, known diseases, not based on ambiguous symptoms like autism. It is for the reasons above that Autism Canada opposes autism and neurological and psychological conditions similar to autism as sole cause for requesting medical assistance in dying.

It is, of course, possible that a person with autism will request medical assistance in dying for a condition other than autism. In this case, it is vital to balance respect for personal choice and autonomy with an extreme degree of caution due to the status of people with autism as a vulnerable population. Both the communication and social barriers characteristic of autism must

be taken into account in the “individual assessment of vulnerability” required by the court’s decision, *Carter v. Canada (Attorney General)*, 2015 SCC 5, at para 116.

In addition to written consent, the individual must be capable of directly expressing their request to the deciding physicians in real time, either through speech, writing, sign language, or a similar non-verbal language system. Further, due to social naivety and vulnerability to coercion, physicians should proceed with an excess of caution when assessing an autistic patient’s capacity for consent and their uncoerced, consistent desire to proceed.

With a sufficiently rigorous process to address concerning assessment and consent, autistic people with a medical condition matching the criteria set out by the Supreme Court of Canada should be granted the same right as other Canadian citizens to request medical assistance in dying.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

No response

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

We believe the current restrictions on mature minors, advance requests and people with mental illness are discriminatory and unjustly infringe on the dignity of Canadians.

Humanism is a worldview based on the recognition and advancement of human dignity. To this end we have called for the government to give all Canadians the right to freely choose a medically-assisted death. We have argued that there is no strong moral case for limiting access to just those who have "a grievous and irremediable medical condition that causes enduring suffering that is intolerable in the circumstances of his or her condition," as set out in the Supreme Court of Canada *Carter v Canada* ruling. The ruling is "a floor and not a ceiling."

Anyone mature enough, regardless of age, to give an informed and voluntary consent should be free to choose a physician-assisted death. It is the right of a competent individual to determine whether they are ready to end their life.

We commended much of the government's approach to regulating MAiD. Specifically, they sought to ensure that patients would have access through whatever means were appropriate to them. This gives Canadians the flexibility to choose the time, place and manner to end their life. However, the restrictions on mature minors, advance requests and individuals with mental illnesses have closed the door for countless individuals to access their rights.

On the question of whether to allow mature minors the right, we argue that there is no moral difference between a person on the days before and after their 18th birthday. As healthcare professionals are already tasked under the law to determine whether a patient is capable of making decisions about their own health, the age-based restriction is extraneous and serves only to deny the rights of mature minors. Our healthcare system already recognizes the rights of mature minors to make life and death medical decisions, so this restriction ought to be removed. Competency, not age, should be the test for whether a decision is free and voluntary.

Similarly, we support broadening the law to explicitly allow individuals to specify in advance the circumstances under which they would want MAiD. Prohibiting against advance requests discriminates against individuals whose diagnosis results in their loss of competency but continue to suffer. For many people, their sense of dignity is closely tied to their mental capacity. To slowly lose that is to lose their sense of identity and is a worse fate than suffering or death. Without the ability to specify in an advance request that they would prefer an assisted death, individuals facing a diagnosis of a degenerative disease are denied their dignity.

The restrictions that a person's "natural death" be "reasonably foreseeable" have been described by countless medical and legal experts as dangerously vague. This vagueness has led to a growing chill among healthcare professionals who are increasingly wary of providing MAiD. It has therefore both left countless Canadians, particularly those whose primary medical condition is mental illness, without access to MAiD and has also reduced access to those who might otherwise choose it as they may be unable to find medical practitioners willing to support their choice. This restriction further contributes to stigma against people with mental illness as it presumes that such an illness necessarily means they are perpetually unable to make competent decisions, a fact that is refuted by the lived experience of countless people with a mental illness.

Finally, while not directly in the scope of the CCA's consultation, we also wish to reiterate our concern with another barrier to accessing MAiD. That is the numerous institutions and individuals that claim so-called "conscientious objections" to the practice and thereby restrict access in many communities. In particular, healthcare institutions that receive public funds should be required to allow MAiD within the institution. Institutions that refuse should see their funding withdrawn. We've already seen in both Quebec and across the country, hospices and hospitals refuse to provide MAiD. This has led to individuals being forced to endure grueling transfers to see their rights fulfilled. Similarly, individual conscientious objections and refusals to even provide effective referrals by some religious medical associations denies patients' autonomy and dignity. Coupled together, these attempted opt-outs create systemic barriers to patients in remote areas and those with limited means to navigate an already bureaucratic healthcare system.

It's time for Canada to take a leadership role on the right to die with dignity. The current restrictions on mature minors, advance requests and on people with mental illness are discriminatory and unjust. These create barriers and a chill on healthcare professionals who might otherwise consider providing Canadians with the option for a compassionate end. Coupled with other barriers, the rights of individuals are continuing to be infringed and people are being forced to suffer needlessly.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

The BC Humanist Association has adopted the Amsterdam Declaration 2002 as our definition of Humanism. It states that "Humanism is the outcome of a long tradition of free thought that has inspired many of the world's great thinkers and creative artists and gave rise to science itself." It goes on to say that Humanism "affirms the worth, dignity and autonomy of the individual and the right of every human being to the greatest possible freedom compatible with the rights of others," among many other principles.

Humanists have long stood behind the right to choose an assisted death. Humanist Manifesto II, signed in 1973 recognized "an individual's right to die with dignity, euthanasia, and the right to suicide." The American Humanist Association passed "A plea for beneficent euthanasia" in 1974, Humanists UK has supported numerous bills and court cases seeking the right to die with dignity since 2006 (and likely many before that).

The overwhelming majority of Canadians support physician-assisted dying. This has been found by research groups including Ipsos Reid, Forum Research and Insights West. That support is nearly universal (over 95%) among Canada's non-religious community, who we represent, according to the 2014 survey by Ipsos Reid.

Fewer and fewer Canadians identify with traditional religions. According to the 2011 National Household Survey, 24% of Canadians and 44% of people in British Columbia are not religious.

This is an increase from 17% and 36% in 2001. Our own research suggests the question asked by Statistics Canada exaggerates the number of religious respondents. A survey we

commissioned from Justason Market Intelligence in 2013 found that 64% of British Columbians do not practice a religion or faith. When we asked the same question in 2016 with Insights West, 69% said they do not practice a religion or faith.

This growing non-religious constituency does not hold the same views on the sanctity of life and morality around dying as traditional religions. They strongly support an individual's free choice to live and die as they choose, so long as it doesn't harm or infringe upon others. As more Canadians leave traditional religious identities behind, they are increasingly demanding greater liberty to choose how and when they die.

While a number of religious organizations who are dogmatically opposed to physician-assisted dying have spoken out on these issues, these Bishops, Ministers and clergy are offside, not just of Canadians in general, but of the men and women in the pews of their own churches. According to the Ipsos Reid survey, 80% of Christians and 83% of Catholics support assisted dying. Religious Canadians overwhelmingly reject the arguments of their supposed moral leaders and agree that Canadians should have the right to choose an assisted death.

At the time of this submission (Sep 14, 2017), our position, as outlined in response to the first question, has been endorsed by 162 people.

[http://www.bchumanist.ca/bcha\\_cca\\_response?splash=1](http://www.bchumanist.ca/bcha_cca_response?splash=1)

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Canadian Association for Community Living (CACL) engaged IRIS – Institute for Research and Development on Inclusion and Society to undertake a review of academic and policy literature relevant to examining expanded access to MAiD. Based on that review (attached to this submission), and CACL's paper Assessing Vulnerability in a System for Physician-Assisted Death in Canada (2016), CACL raises the following concerns:

**I. CONCERNS WITH ACCESS THROUGH ADVANCE EUTHANASIA DIRECTIVES (AEDS)**

**1. Difficulty with respecting past wishes when the present is unanticipated**

Research shows that people are limited in their ability to forecast their future, and how they will cope. Persons with dementia report that their condition once it arrived was not what they feared. In the Netherlands physicians and relatives report great uncertainty about what to do if persons with AEDs appear to have adapted to their circumstances.

**2. Difficult for others to interpret intolerable suffering**

It is difficult to establish intolerable suffering in patients with advanced dementia. Requiring such judgments, as providing access through advance directives would do, provides far too much discretion when a person's life hangs in the balance.

**3. Questioning Dementia as a Cause of Suffering**

It is much less the dementia that causes suffering than the lack of support, inclusion and societal attitudes towards the disease and the needs of those requiring assistance. These factors often lead to feelings of hopelessness and loss of dignity, key factors in the experience of suffering.

**4. Communication and Determining Moment of Carrying Out AED**

Individuals with advanced-stage dementia will not be able to provide informed consent in the moment, which makes them extremely vulnerable to the judgments of others. Providing access on this basis would fundamentally undermine the duty to protect the right to life.

**5. Conflicts of Interest**

There is significant potential for family members and others to gain by a person's death – either financially or in intangible ways, such as relief from caring and feelings of guilt or loss.

**6. Balancing Autonomy and Right to Life of Vulnerable Persons**

Legalization of AEDs would set stigmatizing social norms that those with dementia are burdens and terminating their lives is justified. These norms are already taking hold. A Quebec survey of caregivers of people with Alzheimer's disease found a large majority of respondents supported MAiD for individuals with dementia and would write an AED if diagnosed.

**7. Gaps in Service**

In a context of lack of quality care, disability supports and accessible high-quality palliative care, individuals will be motivated to draft AEDs because of fears of not getting adequate care or becoming burdens on others.

**II. CONCERNS WITH ACCESS BY MATURE MINORS**

### 1. Capacity for Discernment and Decision Making

Evidence demonstrates that compared to adults, minors often lack the experience, knowledge, stable values and strong sense of self necessary to make informed decisions about MAiD.

Neuroscience suggests that minors are less able to balance emotional drives in decision making with the executive functions necessary for informed consent.

### 2. Vulnerabilities Specific to Minors

The economic and emotional dependence of minors on parents and other relatives makes them particularly vulnerable to coercion and influence, which may lead to choosing MAiD.

### 3. Gaps in Service Motivate Requests

There are major gaps in pediatric palliative care and mental health services for youth, which have been found to motivate requests. Again, there is voluminous evidence that the suffering motivating requests for MAiD largely results from inadequate supports and services.

## III. CONCERNS WITH ACCESS BASED SOLELY ON MENTAL ILLNESS

### 1. No Conclusive Evidence that Mental Health Conditions are Irremediable

There is simply no conclusive evidence that mental health conditions are irremediable, and thus should not be eligible under the Supreme Court's terms in Carter and the basic provisions of the legislation.

### 2. Capacity to Consent is Often Compromised

People with mental health conditions often, though not by definition, have significant difficulty in exercising capacity to consent. Depression and other conditions interfere with ability to weigh short-term and long-term consequences and judgment of circumstances. There is inherent indeterminacy in judging decision-making capacity in these situations.

### 3. Vulnerability Cannot be Adequately Assessed or Addressed without an End-of-Life Criterion

Research points to social determinants motivating requests and compounding the suffering associated with mental health conditions, including concern about being a burden on others, fears about losing autonomy, lack of support, and confinement to institutional facilities. It is society's response (or lack thereof), that can result in intolerable suffering.

### 4. Access Based Solely on Mental Health Conditions Undermines Equality

For advanced dementia or a mental illness to be considered eligible grounds to receive MAiD, the criterion of the reasonable foreseeability of natural death would have to be removed from the law. Any disability condition could then be considered grounds for MAiD. Other groups also at higher risk of suicide, including indigenous persons or transgender youth, for example, could legitimately access the system to die. This would deepen the problem of ableism, stigma, disadvantage and inequality in Canadian society.

### 5. Charter Equality Rights Could Not Constrain Access Only to People with Mental Health Conditions

Expanding access on this basis could not be limited to these conditions in the context of Charter equality rights. There would be a valid claim that restricting access only to persons with mental health conditions violated equality of people with other disability-related conditions. This would be a powerful motivator of stigma in society, and thus for requests for MAiD from people who are not dying.

### 6. Expanded Access Risks Major Unintended Social Consequences



History teaches that public health goals can have unintended consequences. Understanding of the inherent value of lives of people with disabilities has progressed since the eugenics movement but, as the termination of fetuses based on disability traits shows, persons with disabilities still face discrimination, exclusion, and a prevailing societal belief that their life is something to be avoided. Clearly, lessons from history can, and should be applied to critically considering MAiD and its expansion.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Attached please find two papers CACL would like to have considered by the expert panel, each reviewing and summarizing a wide body of literature relevant to the CCA's assessment:

1. Concerns with Expanding Access to Medical Assistance in Dying: A Review of Evidence (IRIS - Institute for Research and Development on Inclusion and Society, 2017)

2. Assessing Vulnerability in a system for physician-assisted suicide and voluntary euthanasia in Canada (Canadian Association for Community Living, 2016)

# Assessing Vulnerability in a system for physician-assisted death in Canada

**Issued By:**  
**The Canadian Association for Community Living**

**April 2016**  
**(Revised)**



# Table of Contents

<b>Acknowledgments.....</b>	<b>i</b>
<b>Introduction .....</b>	<b>1</b>
<b>I. Core Concerns .....</b>	<b>2</b>
<b>II. Criteria for Assessing Vulnerability among People Requesting Physician-Assisted Death .....</b>	<b>3</b>
A. Suicidality more than a ‘Well-Reasoned’ Request.....	3
B. Predominance of Psychosocial Dimensions of Suffering.....	6
C. Evidence of Inducement and Coercion.....	10
1. Disordered insight and self-stigma.....	10
2. How coercion by others can motivate requests for PAD .....	12
3. How psychodynamics of the physician-patient relationship can motivate requests .....	14
D. Degree of Resilience .....	17
E. Potential vs. Actual Vulnerability.....	18
F. Towards a ‘Vulnerability Lens’ in Requests for PAD .....	20
<b>III. Key Issues in Implementing a Vulnerability Lens .....</b>	<b>20</b>
A. Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence.....	21
B. Varying health profession guidelines for informed consent and response to vulnerable persons.....	23
C. Limitations of relying solely on physicians to assess vulnerability .....	25
D. Need for valid tools and comprehensive protocol to assess vulnerability .....	26
Summary.....	29
<b>IV. Federal legislative requirements to implement a vulnerability lens.....</b>	<b>30</b>
A. Criminal Code standard for informed consent .....	31
B. Criminal Code requirement for vulnerability assessment.....	31
C. Criminal Code requirement for prior review and determination by an independent authority .....	32
<b>Conclusion.....</b>	<b>35</b>
<b>Appendix A – Growing Vulnerability among Persons with Disabilities in Canada</b>	<b>37</b>

## List of Tables

<b>Table 1:</b> Illustration of the Accumulation of Potentiating Risk Factors and Warning Signs on Risk of Suicide.....	5
<b>Table 2:</b> Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act] Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014, Oregon, 1998-2013 .....	9
<b>Table 3:</b> Cases of coercion in physician-assisted suicide and euthanasia.....	13
<b>Table 4:</b> Inducement and Coercion in Dynamics of Patient-Physician Interactions in Requests for PAD.....	16
<b>Table 5:</b> Dynamics of Vulnerability to Inducement to Commit Suicide in Times of Weakness .....	19

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## Introduction

This report identifies criteria and approaches to assessing vulnerability that could help safeguard vulnerable persons in a system for physician-assisted death. It examines key issues in designing a pan-Canadian and consistent approach to safeguards, and recommends a federal legislative approach to addressing these issues. The report is intended to assist law- and policy-makers in designing safeguards, and to provide civil society organizations a resource to support their participation in the law reform process.

In *Carter v. Canada*<sup>1</sup> the Supreme Court recognized a constitutional right of Canadians to access physician-assisted death, where the person: 1) is an adult; 2) clearly consents to the termination of life; 3) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition; and, 4) is not vulnerable to being induced to commit suicide in a time of weakness.

The Court imposed the fourth criterion, recognizing that Parliament's objective to protect vulnerable persons is a "pressing and substantial" one. In doing so, the Court recognized vulnerable persons' constitutional right to protection of life in a system for physician-assisted death.<sup>2</sup> It also found that a "stringently limited, carefully monitored system of exceptions" would achieve the objective, but that it was Parliament's responsibility to design the system of safeguards.<sup>3</sup> To recommend ways that Parliament can fulfill this responsibility, this report draws on a wide body of research literature and is divided into four main sections.

**Section I** outlines core concerns that motivate this report.

**Section II** reviews a large body of research to identify main criteria to assess vulnerability of persons requesting physician-assisted death. These criteria constitute five dimensions of a 'vulnerability lens' to guide review and authorization of requests.

**Section III** examines issues that would need to be addressed to implement a consistent vulnerability lens for physician-assisted death in the current health care context.

**Section IV** recommends a federal legislative approach to address these issues, through three main *Criminal Code* provisions.

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<sup>1</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331.

<sup>2</sup> A recent legal opinion on the *Carter* decision outlines the constitutional protections for vulnerable persons that the decision recognizes. See Dianne Pothier (2016), "The parameters of a Charter compliant response to *Carter v. Canada (Attorney General)*, 2015 SCC 5 (Social Science Research Network eLibrary, online: <http://ssrn.com/abstract=2753167>).

<sup>3</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 at para. 29.

## I. Core Concerns

The main concern prompting this report is that a growing group of vulnerable Canadians will die under the system for physician-assisted death (PAD) in Canada because of a lack of adequate safeguards. People could be vulnerable in two main ways:

- 1) using the system to commit suicide because they are suffering intolerably from conditions in their lives other than their medical condition, or that significantly compound the suffering their medical condition causes; and,
- 2) being given an assisted death when in fact their request was neither informed nor voluntary, but instead motivated either by disordered insight or by external inducements, undue influence or coercion sufficient to negate any superficial expression of consent to the termination of their life.

Research on how people become vulnerable in these ways is reviewed in this report. It points to many factors that can motivate suicidality or render people unable to give free and informed consent to terminate their lives, for example: the experience of stigma and social rejection associated with disability; the fear of growing dependence or burden on others; hopelessness caused by a mental health issue or clinical depression; social stigma and isolation; economic insecurity; victimization and domestic abuse; family and caregiver stress; coercion or inducement by a caregiver; and subtle and unconscious inducement that can operate in patient-physician decision-making processes.

In designing a system for physician-assisted death it is important to recognize that these factors are becoming more prevalent in Canadian society. Detailed in Appendix A, they include:

- increasing prevalence and severity of disability and multiple disadvantage;
- increasing prevalence of mental health difficulties and disability;
- lack of access to disability-related supports;
- growing burden of care of family and informal caregivers;
- gaps in palliative care up to 70%;
- high rates of poverty and labour force exclusion among people with disabilities;
- high rates of violence, abuse and insecurity for people with disabilities and seniors;
- barriers to health care access for people with intellectual and other disabilities, differential treatment and poorer outcomes;
- rapid increase in cases of dementia; and
- high rates of depression among seniors in residential care.

Because people may be vulnerable in these ways does not mean that by definition they should be precluded from accessing physician-assisted death. Clear criteria of vulnerability will be required to determine if a person requesting PAD is being induced to commit suicide in a time of weakness and if other measures should be taken to address their suffering.

## **II. Criteria for Assessing Vulnerability among People Requesting Physician-Assisted Death**

Through the research review for this paper five criteria of vulnerability were identified to guide responding to and authorizing requests for PAD. These five criteria of vulnerability are:

- Indications of suicidality rather than a ‘well-reasoned’ request
- Predominance of psychosocial dimensions of suffering underlying the request
- Evidence of inducements, undue influence or coercion by others
- Low resilience to risk factors
- Evidence that the person is *actually* vulnerable, not only potentially vulnerable.

### **A. Suicidality more than a ‘Well-Reasoned’ Request**

The trial decision in *Carter* provides a helpful place to begin defining criteria of vulnerability. The decision distinguished between: 1) “sound, rational and well reasoned”<sup>4</sup> requests to die by patients at the end of life, and, 2) decision making about “suicide related to mental illness, substance use, impulsivity and other psychosocial factors”<sup>5</sup> and “by persons who are mentally ill, or whose thinking processes are affected by substance abuse, trauma or other such factors.”<sup>6</sup> The Supreme Court adopted this distinction, and found that voluntary requests motivated by a capable reasoning process could be distinguished from requests motivated by suicidality.

While some research findings suggest this distinction may be clearer in theory than in practice<sup>7</sup>, the Supreme Court makes it a legal distinction in *Carter* and in so doing defines a core criterion of vulnerability in a system for PAD. A person is vulnerable where their request to die is motivated more by suicidal ideation than by a well-

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<sup>4</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 813.

<sup>5</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 813.

<sup>6</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 814.

<sup>7</sup> Madelyn Hsiao-Rei Hicks (2006), “Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors,” *BMC Family Practice* (7:39, online: <http://www.biomedcentral.com/content/pdf/1471-2296-7-39.pdf>).



reasoned request based on enduring and intolerable suffering caused by the medical condition.

What factors are associated with suicidality, as distinct from ‘well-reasoning’? The American Psychiatric Association draws on extensive body of research evidence on risk factors to inform its practice guidelines for suicide prevention and treatment of suicidality.<sup>8</sup> As well, the U.S. Joint Commission, which accredits almost 21,000 health care facilities and programs in the U.S, identifies risk factors based on event reports from health facilities:

The risk factors common across health care settings include having previously attempted suicide; recent suicide attempt; suicidal thoughts or behaviors; a family history of suicide or psychiatric illness; on antidepressants; physical health problems, including central nervous system disorders such as traumatic brain injury; diagnosis of delirium or dementia; chronic pain or intense acute pain; poor prognosis or prospect of certain death; social stressors such as financial strain, unemployment or loss of financial independence; disability; trauma; divorce or other relationship problems; hopelessness; and substance abuse. Substance abuse may also exacerbate psychological symptoms such as depression, and the disinhibitory effects of alcohol may contribute to impulsive suicidal behavior. Older adults are prone to additional suicide risk factors including declining health, loneliness and recent bereavement.<sup>9</sup>

A number of risk assessment tools have been developed to improve identification and assessment of suicide risk among patients in the health care system.<sup>10</sup> For example, in response to growing concerns about suicide rates and hospitalization for suicidality, the Ontario Hospital Association and the Canadian Patient Safety Institute have developed a comprehensive framework to encourage standardized assessment within health care settings.<sup>11</sup> Drawing on an inventory and analysis of fifteen suicide risk assessment tools, the framework distinguishes between ‘risk factors’ and ‘warning signs’ to assist health professionals in identifying and responding to suicidal ideation and behaviour in patients (see **Table 1**).

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<sup>8</sup> American Psychiatric Association (2010), *Practice Guideline for the Assessment and Treatment of Patients with Suicidal Behaviours* (online: [http://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/suicide.pdf](http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide.pdf)); and Michael Gliatto, K Anil and MD Rai (1999), “Evaluation and Treatment of Patients with Suicidal Ideation,” *American Family Physician* 59(6), p. 1500-1506.

<sup>9</sup> The Joint Commission (2010), “The Joint Commission sentinel event alert: A follow-up report on preventing suicide: Focus on medical/surgical units and the emergency department” (Issue 46, online: [http://www.jointcommission.org/assets/1/18/SEA\\_46.pdf](http://www.jointcommission.org/assets/1/18/SEA_46.pdf)).

<sup>10</sup> R Giordano JF Stichler (2009), “Improving Suicide Risk Assessment in the Emergency Department,” *Journal of Emergency Nursing* 35:22-6; For a list and links to resources on suicide prevention and protocols see for example “Practical Tools” published by the British Columbia Ministry of Children and Family Development (online: [https://www.mcf.gov.bc.ca/suicide\\_prevention/practical\\_tools.htm](https://www.mcf.gov.bc.ca/suicide_prevention/practical_tools.htm)).

<sup>11</sup> Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: <https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf>).

**Table 1: Risk Factors and Warning Signs on Risk of Suicide<sup>12</sup>**

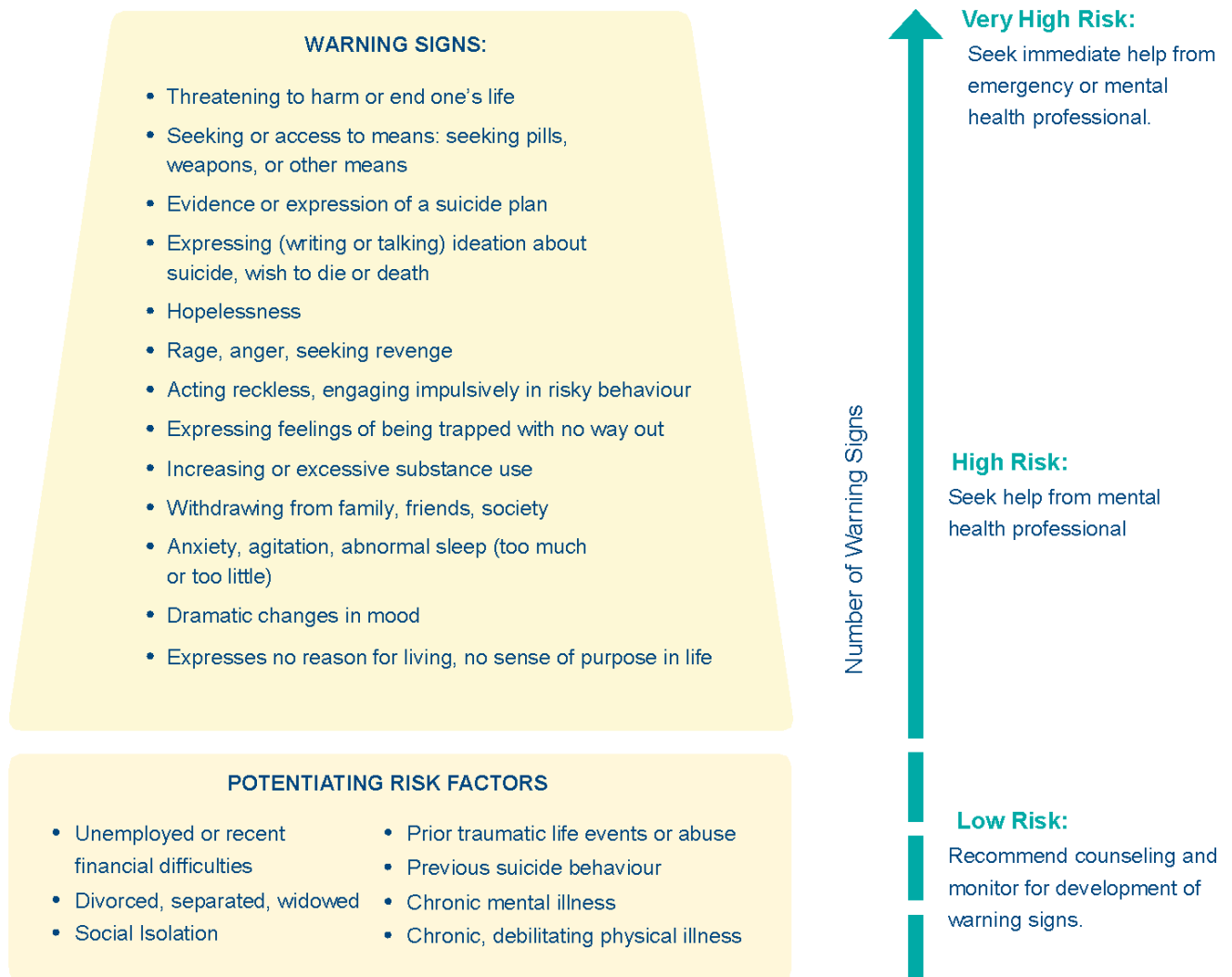


Table 1 Illustration of the Accumulation of Potentiating Risk Factors and Warning Signs on Risk of Suicide

<sup>12</sup> This table is presented in: Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: <https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf>). The table is adapted in that text from MD Rudd, AL Berman, TE Joiner, MK Nock, MM Silverman, M Mandrusiak, K Orden & T Witte (2006), "Warning signs for suicide: Theory, research, and clinical applications," *Suicide and Life Threatening Behaviour* (36, 255-62).

Research indicates suicidal ideation and intent is also associated with: onset of physical disability through traumatic injury, long-term health condition or degenerative disease;<sup>13</sup> intellectual disability when associated with other types of disability in persons with mild intellectual disability (many of whom would be able to consent to PAD); spinal cord injury; and multiple sclerosis.<sup>14</sup>

Co-presence of the factors in any particular case – for example, physical disability, plus major psychiatric syndrome, plus domestic violence, plus unmet socio-economic needs – increase the risk of suicidal ideation and intent. Even for patients who come into palliative care with a long history of disability, factors associated with their experience of prejudice, bias, disenfranchisement, and devaluation have been shown to increase their suffering and vulnerability.<sup>15</sup>

## **B. Predominance of Psychosocial Dimensions of Suffering**

Research indicates that it is often psychosocial dimensions of suffering that are primary motivators for requesting PAD, in comparison to physical dimensions of suffering. This is another criterion of vulnerability. The trial decision in *Carter* distinguished psychosocial suffering in two ways:

- as a medical condition, in and of itself; and
- as a response to a grievous and irremediable end-of-life condition.<sup>16</sup>

Justice Smith concurred with evidence presented at the trial that it was “problematic to conflate decision-making by grievously and irremediably ill persons about the timing of their deaths, with decision-making about suicide by persons who are mentally ill, or whose thinking processes are affected by substance abuse, trauma or other such factors.”<sup>17</sup> This led to her conclusion that the term “grievously and irremediably ill persons” should not “incorporate reference to “psychosocial suffering”.”<sup>18</sup> The definition was not questioned or altered by the Supreme Court of Canada in its decision in *Carter*.

By definition, then, people whose cause of psychosocial suffering is itself a psychosocial condition, should be identified as being vulnerable to being induced to commit suicide in a time of weakness. Evidence drawn from psychological autopsies of

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<sup>13</sup> D Russell, RJ Turner and TE Joiner (2009), “Physical disability and suicidal ideation: a community-based study of risk/protective factors for suicidal thoughts,” *Suicide and Life-threatening Behaviour* (V. 39 (4), p. 440-451).

<sup>14</sup> MJ Gianni, B Bermark, S Kreshover, E Elias, C Plummer and E O’Keefe (2010), “Understanding suicide and disability through three major disabling conditions: intellectual disability, spinal cord injury and multiple sclerosis,” *Journal of Disability and Health* (3(2), p. 74-78).

<sup>15</sup> D Stienstra and HM Chochinov (2006), “Vulnerability, Disability, and Palliative End-of-Life Care,” *Journal of Palliative Care* (22, 3, Autumn).

<sup>16</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 813.

<sup>17</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 814.

<sup>18</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 1390.

suicide victims show consistently that almost 100% (varying in some studies between 93 and 98 percent) had psychiatric illness, with high rates of depression, chronic alcoholism or episodes of schizophrenia, acute anxiety or other features known as “axis I” diagnosis in multi-axial assessment of mental disorders.<sup>19</sup>

In jurisdictions which provide for psychological conditions as a criterion of eligibility for access to PAD, recent research suggests growing concerns about vulnerability. For example, findings published in February 2016 on voluntary euthanasia provided to 66 patients with psychiatric conditions under the system in the Netherlands<sup>20</sup> found that depressive disorders, post-traumatic stress disorder and anxiety disorder were prominent among the cases. Over 50% of those who were euthanized had prior suicide attempts, and 80% had been hospitalized previously for psychiatric conditions. Social isolation and loneliness were significant factors motivating the requests. Research evidence indicates that all these factors are amenable particularly to psychodynamic and psychoanalytic psychotherapies.<sup>21</sup>

The prevalence of these psychosocial factors in motivating requests for PAD, particularly those related to hopelessness, depression, and fears of being a burden and losing independence, are identified throughout the research literature as indicators of vulnerability that can be addressed by other courses of action. Concern about the caregiving burden on others, and fears of losing autonomy and a sense of dignity that one may associate with physical, communicative or cognitive independence are both very real, as the data shows. These fears can become overwhelming as functional capacities decline and caregiving needs increase. However, the suffering may be caused less by the medical condition itself than by lack of: caregiver supports; adaptive capacities that could yet be developed with personal and technological assistance; environmental accommodations to one’s changing needs; and, community supports that

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<sup>19</sup> See, for example, DG Jacobs, ed. (1999), *Harvard Medical School Guide to Suicide Assessment and Intervention* (San Francisco: Jossey-Bass, pp 270–286); L Sher, MA Oquendo MA, and JJ Mann (2001), “Risk of suicide in mood disorders”, *Clinical Neuroscience Research* (1:337–344).

<sup>20</sup> Scott Y.H. Kim, Raymond G. De Vries and John R. Peteert (2016) Éuthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014”, *Journal of American Medical Association – Psychiatry* (Published online February 10, 2016).

<sup>21</sup> See, for example, A Bateman and P Fonagy, (1999), “Effectiveness of partial hospitalization in the treatment of borderline personality disorder: a randomized controlled trial”, *Am J Psychiatry* 156:1563–1569; A Bateman and P Fonagy (2001), “Treatment of borderline personality disorder with psychoanalytically oriented partial hospitalization: an 18-month follow-up”, *Am J Psychiatry* (158:36–42); J Stevenson and R Meares, (1992) “An outcome study of psychotherapy for patients with borderline personality disorder”, *Am J Psychiatry* (149:358–362); ES Paykel, J Scott, and JD Teasdale, AL Johnson, A Garland, R Moore, A Jenaway, PL Cornwall, H Hayhurst, R Abbott and M Pope (1999), “Prevention of relapse in residual depression by cognitive therapy: a controlled trial”, *Arch Gen Psychiatry* (56:829–835). For a comprehensive review of the research literature on the impact of psychotherapies in reducing suicidal ideation and behaviour, see American Psychiatric Association (2010), *Practice Guideline for the Assessment and Treatment of Patients with Suicidal Behaviours* (online: [http://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/suicide.pdf](http://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/suicide.pdf)).

respond to growing dependence on others for certain forms of self-care. As discussed below, these interventions can boost a person's resilience to deal with changing circumstances.

In this regard, the National Cancer Institute of the U.S. National Institutes of Health recommends in-depth examination of four dimensions of suffering in response to requests for PAD: physical, psychological, social and spiritual suffering. It stresses the importance of attending to psychosocial and spiritual dimensions of suffering, particularly the fear of becoming a burden and losing independence:

Physical suffering, including pain, is a less-frequent motivator than many think. In one above-noted study, pain alone was a motivator in 3% of requests; pain was one of several motivators in 46% of requests; and in the remaining 51% of requests pain was not cited as a factor at all. Nonetheless, the contribution of physical suffering is important because it is often treatable... The fear of being a burden and losing independence are the most important correlates of a desire for hastened death, and are more distressing for many patients than physical symptoms. It remains crucial to address physical symptoms in cases of requests for hastened death, but in relative terms, the psychosocial aspect is more important.<sup>22</sup>

A 2014 report on data gathered in Oregon system supports this conclusion about the relative importance of psychosocial aspects of suffering motivating requests. **Table 2** presents the findings on reasons for requesting physician-assisted suicide by patients who died from ingesting a lethal dose of medication, as authorized under the Oregon *Dying with Dignity Act*.<sup>23</sup> Over 90% of the 748 patients for whom data is available indicate that "losing autonomy" was one of the concerns motivating the request, 50% about losing control of bodily functions, and 40% were concerned about the burden on family, friends/caregivers if they continued to live. This is in comparison to a much smaller proportion (23.7%) for whom inadequate pain control or concern about pain were among the reasons.

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<sup>22</sup> National Cancer Institute, *Education in Palliative and End-Of-Life Care for Oncology: Self-Study Module 14: Physician-Assisted Suicide* (Online: <http://www.cancer.gov/resources-for/hp/education/epeco/self-study/module-14/module-14.pdf>, p. 5).

<sup>23</sup> See Oregon Public Health Division (2014). Oregon's Death with Dignity Act—2013 (Online: <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>).

**Table 2. Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act] Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014, Oregon, 1998-2013**

Year	2013	1998-2012	Total
<b>END OF LIFE CONCERNS:</b>	(N=71)	(N=677)	(N=748)
<b>Losing autonomy (%)</b>	66 (93.0)	618 (91.3)	<b>684 (91.4)</b>
<b>Less able to engage in activities making life enjoyable (%)</b>	63 (88.7)	602 (88.9)	<b>665 (88.9)</b>
<b>Loss of dignity (%)</b>	52 (73.2)	452 (81.9)	<b>504 (80.9)</b>
<b>Losing control of bodily functions (%)</b>	26 (36.6)	350 (51.7)	<b>376 (50.3)</b>
<b>Burden on family, friends/caregivers (%)</b>	35 (49.3)	264 (39.0)	<b>299 (40.0)</b>
<b>Inadequate pain control or concern about it (%)</b>	20 (28.2)	157 (23.2)	<b>177 (23.7)</b>
<b>Financial implications of treatment (%)</b>	<b>4 (5.6)</b>	<b>18 (2.7)</b>	<b>22 (2.9)</b>

*Table 1 Characteristics and End-of-life Care of 752 DWDA [Dying With Dignity Act] Patients who Died from Ingesting a Lethal Dose of Medication as of January 17, 2014, Oregon, 1998-2013*

The Oregon data are not unique. Researchers suggest there is “woefully little evidence” supporting the popular notion that physical pain is the primary motivator for PAD, and that data point much more strongly to psychological stress and mental health conditions as primary factors:

It seems that many people imagine the circumstances that might drive them to want to “end it all,” and excruciating pain comes to mind. This picture of terminally ill patients writhing in uncontrolled or even uncontrollable pain requesting euthanasia or PAS has dominated all discussions about whether euthanasia or PAS is ethical and should be legalized...

If not pain, then what motivates patient interest in euthanasia or PAS? Accumulating data support what might be called the depression thesis. Most, if not all, studies that have examined this question reveal that psychological distress, including depression and hopelessness, are significantly associated with patients' interest in hastening their own death through euthanasia and/or PAS.<sup>24</sup>

A wide range of studies over the past fifteen years reach similar conclusions, finding for example that: “For people at the end of life, depression, hopelessness, and psychosocial distress are among the strongest correlates of desire for hastened

<sup>24</sup> Ezekiel J. Emanuel (2005), “Depression, Euthanasia, and Improving End-of-Life Care”, *Journal of Clinical Oncology* (vol. 23 no. 27, 6456-6458).

death”<sup>25</sup>, including findings that 80% of patients with cancer who commit suicide have a mood disorder.<sup>26</sup>

In summary, the evidence suggests that where the reasons motivating the requests are primarily related to psychosocial suffering associated with unmet needs, there is a high risk that a person may be vulnerable to requesting PAD as a result of suicidal ideation and intent rather than a ‘well-reasoned’ request, which evidence suggests can only be made in the context of end-of-life conditions.

### **C. Evidence of Inducement and Coercion**

In addition to research on factors that can motivate suicidality and on the psychosocial aspects of suffering that underlie requests for PAD, a growing body of findings show how dynamics of inducement and coercion can motivate adult requests. Three distinct but inter-related psychological dynamics of inducement and coercion are found in the research: 1) a patient’s disordered insight and judgment caused by depression, hopelessness and/or self-stigma; 2) direct coercion by others; and 3) the psychodynamics of the physician-patient relationship. Each of these dynamics is discussed below.

#### **1. Disordered insight and self-stigma**

As evident from research cited in the preceding section, disordered insight resulting from hopelessness, depression or other mental health conditions can motivate requests for physician-assisted death. ‘Disordered insight’ refers to impairments in reasoning

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<sup>25</sup> Linda Ganzini, Elizabeth R Goy and Steven K Dobscha (2008), “Prevalence of depression and anxiety in patients requesting physicians’ aid in dying: cross sectional survey” *British Medical Journal* (v. 337, 1682). For research cited on this finding, see EJ Emanuel (2005), “Depression, euthanasia, and improving end-of-life care” *Journal of Clinical Oncology*, (23:6456-8); KG Wilson, HM Chochinov CJ McPherson, MG Skirko, P Allard, S Chary, et al. (2007) “Desire for euthanasia or physician-assisted suicide in palliative cancer care”, *Health Psychology* (26:314-23); B Rosenfeld, W Breitbart, C Gibson, M Kramer, A Tomarken, C Nelson, et al (2006) “Desire for hastened death among patients with advanced AIDS”, *Psychosomatics* (47:504-12); JL Werth Jr. (2004) “The relationships among clinical depression, suicide, and other actions that may hasten death” *Behavioural Science and the Law* (22:627-49); HM Chochinov, KG Wilson, M Enns, N Mowchun, S Lander, M Levitt et al. (1995) “Desire for death in the terminally ill”, *American Journal of Psychiatry* (152:1185-91); K Blank; J Robison, E Doherty, H Prigerson, J Duffy, HI Schwartz (2001), “Life-sustaining treatment and assisted death choices in depressed older patients” *Journal of American Geriatrics Society* (49:153-61); W Breitbart, B Rosenfeld, H Pessin, M Kaim, J Funesti-Esch, M Galletta M, et al. (2000), “Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer”, *Journal of American Medical Association* (284:2907-11); EJ Emanuel, DL Fairclough, LL Emanuel (2000), “Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers”, *Journal of American Medical Association* (284:2460-8).

<sup>26</sup> MM Henriksson, ET Isometsa, PS Hietanen, HM Aro, JK Lonnqvist (1995), “Mental disorders in cancer suicides”, *Journal of Affective Disorders* (36:11-20). Cited in Linda Ganzini, Elizabeth R Goy and Steven K Dobscha (2008), “Prevalence of depression and anxiety in patients requesting physicians’ aid in dying: cross sectional survey” *British Medical Journal* (v. 337, 1682).

capacity that include inability to connect symptoms to one's illness, to understand the risks and benefits of treatment, or to make a treatment decision based on personal goals and values.<sup>27</sup> Insight disorders are associated with brain injury and a many psychiatric conditions. A large body of research also shows how depression tends to significantly impair a patient's medical decision making, with consistent findings across diverse cultural contexts. Research has shown that depression induces feelings of hopelessness, can magnify the experience of physical pain, and impair ability to cope and other functional abilities, all of which can undermine free and voluntary requests for physician-assisted death.<sup>28</sup>

Hopelessness is another factor that can impair judgment, and it often occurs through the mechanism of self-stigma that can result when a person experiences disability-related discrimination and stigma from others.<sup>29</sup> Systematic research review has shown a strong negative relationship between levels of self-stigma and hopefulness, self-esteem and empowerment among people with mental illness.<sup>30</sup> The research suggests that stigma is internalized as self-stigma through a "regressive model" that begins with awareness of stigma toward oneself by others, and leads to self-application of the

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<sup>27</sup> K. William M. Fulford (1998), "Completing Kraepelin's Psychopathology: Insight, Delusion, and the Phenomenology of illness," in Xavier F. Amador and Anthony S. David, eds. *Insight and Psychosis Insight and Psychosis: Awareness of Illness in Schizophrenia and Related Disorders* (Oxford: Oxford University Press).

<sup>28</sup> Marsha Garrison cites a number of studies which bear out this conclusion. See citations in Marsha Garrison (2007), "The Empire of Illness: Competence and Coercion in Health-care Decision Making", William and Mary Law Review (Volume 49, Issue 3, 781-843), including: G. Magni et al. (1994), "Prospective Study on the Relationship Between Depressive Symptoms and Chronic Musculoskeletal Pain", *Pain* (56); C. Dickens and F. Creed (2001), "The Burden of Depression in Patients with Rheumatoid Arthritis", *Rheumatology* (50, 1327); P.P. Katz and E.H. Yelin (1993), "Prevalence and Correlates of Depressive Symptoms Among Persons with Rheumatoid Arthritis", *Journal of Rheumatology* (20, 790); Daniel Weintraub et al. (2004), "Effect of Psychiatric and Other Nonmotor Symptoms on Disability in Parkinson's Disease", *Journal of American Geriatrics Society* (52, 784); N.J. Rubin (1993), "Severe Asthma and Depression," *Archives of Family Medicine* (2); Mark D. Sullivan (2003), "Hope and Hopelessness at the End of Life", *American Journal of Geriatric Psychiatry* (11, 393); Harvey Chochinov (2006), "Dying, Dignity, and New Horizons in Palliative, End-of-Life Care", *CA: A Cancer Journal for Clinicians* (56, 84); Aaron T. Beck et al. (1990), "Relationship Between Hopelessness and Ultimate Suicide: A Replication with Psychiatric Outpatients" *American Journal of Psychiatry* (147, 190); Aaron T. Beck et al. (1985) "Hopelessness and Eventual Suicide: A 10-Year Prospective Study of Patients Hospitalized with Suicidal Ideation", *American Journal of Psychiatry* (142, 559).

<sup>29</sup> See, for example, L Patterson, K McKenzie and B Lindsay (March 2012), "Stigma, social comparison and self-esteem in adults with an intellectual disability", *Journal of Applied Research in Intellectual Disability* (25(2):166-76); [A Ali, A Hassiotis, A Strydom and M. King](#) (Nov-Dec 2012), "Self stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review", *Journal of Intellectual Disability Research* (33(6):2122-40); Elaine Brohan, Rodney Elgie, Norman Sartorius and Graham Thornicroft (2010), "Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study", *Schizophrenia Research*(Volume 122, Issues 1-3:232-238).

<sup>30</sup> James D. Livingston, Jennifer E. Boyd (2010), "Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis", *Social Science & Medicine* (Volume 71, Issue 12:2150-2161).



stigma, negative impact on self-esteem and self-efficacy, shame and self-discrimination.<sup>31</sup>

Because psychological conditions of disordered insight, depression, hopelessness and self-stigma can motivate requests to die, experts recommend there should be “provision for an exploration of the motivation in patients who make such a request”<sup>32</sup> and consideration of other alternatives. In other words, these motivations are signs of vulnerability which should trigger further examination prior to approving a request.

## **2. How coercion by others can motivate requests for PAD**

Research findings also raise concerns about direct coercion motivating requests for PAD. A review of actual cases demonstrates the validity of these concerns, including documentation of coercion in requests for physician-assisted death in both Oregon and Netherlands (see **Table 3** for examples).

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<sup>31</sup> Patrick W. Corrigan, Benjamin G. Druss, and Deborah A. Perlick (2014), “The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care”, *Psychological Science in the Public Interest* (Vol. 15(2) 37–70).

<sup>32</sup> Philip R. Muskin (1998), “The Request to Die; Role for a Psychodynamic Perspective on Physician-Assisted Suicide” *The Journal of the American Medical Association* (279(4):323-328).

Table 3 – Cases of coercion in physician-assisted suicide and euthanasia<sup>33</sup>

Case 1, Oregon: An 85-year-old cancer patient with worsening dementia requests PAS but her psychiatrist believes that she is being pressured by family. Nevertheless, she is then approved for PAS by a psychologist and receives assisted suicide.

Case 2, Oregon: Louise, who has a degenerative neurological disease, requests PAS. As her disease progresses, those in her network who support her suicide become increasingly anxious that she will become too mentally or physically incapacitated to act on her request. This includes her doctor, her mother, a friend who will be present at her suicide, and the Oregon Compassion in Dying PAS advocate who has arranged for a New York Times reporter to fly in and cover the suicide. Louise says she is almost ready but not quite. She wants a week to relax and be with her mother. On learning indirectly that her doctor thinks she will not be able to act if she waits, she appears startled. Her mother tells her, "It's OK to be afraid." She replies: "I'm not afraid. I just feel as if everyone is ganging up on me, pressuring me. I just want some time".

Case 3, The Netherlands: A wife who no longer wishes to care for her sick, elderly husband gives him a choice between euthanasia and admission to a nursing home. Afraid of being left to the mercy of strangers in an unfamiliar place, he chooses euthanasia. His doctor ends his life despite being aware that the request was coerced.

Case 4, The Netherlands: Cees requests euthanasia one month after being diagnosed with ALS (MND). As required, his request is assessed by the primary doctor who will carry out the euthanasia and by a consultant. During their assessments, both doctors allow Cees' apparently resentful wife to answer all the questions directed to him, even though his speech is still understandable and he can type on a computer. His ambivalence about euthanasia is expressed by repeatedly pushing the date back. It is also expressed by weeping in response to the doctor's pro forma question of whether Cees is sure he wants to go ahead with euthanasia. His wife quickly answers affirmatively for him and then tells the doctor to move away from Cees, saying it is better to let him cry alone. At no point does a doctor ask to talk with Cees alone before his euthanasia.

Table 2 Cases of coercion in physician-assisted suicide and euthanasia

<sup>33</sup> These cases are drawn from Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: <http://www.biomedcentral.com/content/pdf/1471-2296-7-39.pdf>).

### 3. How psychodynamics of the physician-patient relationship can motivate requests

The research also indicates that “[r]equests for PAS and doctors’ decisions to assist suicide can be influenced by coercion and by unconscious motivations in doctors, patients and caregivers.”<sup>34</sup>

The psychiatric literature points to ways the psychological dynamics of “transference and countertransference” can operate coercively between patient and physician in the context of requesting, considering and approving a request for PAD:

Transference and countertransference feelings are normal and can occur in any doctor-patient relationship. When these feelings heighten around emotionally intense issues, they can exert coercive pressure on clinical decision-making with an obligatory quality that is difficult to resist. Recognition is complicated by the frequent involvement of unacceptable feelings and urges that both doctor and patient wish to deny.<sup>35</sup>

The U.S. National Cancer Institute stresses the importance of physicians having insight about how countertransference can operate in this encounter:

To respond effectively to the needs of the patient, the physician must be aware of his or her own biases and the potential for counter-transference. If the idea of suicide is offensive to the physician, the patient may feel his or her disapproval and worry about abandonment. Conversely, if the physician feels it would be best for everyone if the patient were to die soon, the patient may sense this and become more concerned about being an unwelcome burden.<sup>36</sup>

Documented examples of how transference and countertransference, or unconscious motivations can operate on part of both the physician and the patient in the request process for PAD are presented in **Table 4**. For example, one study reporting on this dynamic states: “The patient’s experience of the physician’s guilt and the physician’s unchallenged acquiescence to the patient’s request to die confirm the patient’s guilty experience of being bad and unworthy of the physician’s healing power.”<sup>37</sup> The research findings point to the need to be sensitive to the fact that the patient-physician relationship, the patient’s psychological condition, and the patient’s health care context

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<sup>34</sup> Madelyn Hsiao-Rei Hicks (2006), “Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors,” *BMC Family Practice* (7:39, online: <http://www.biomedcentral.com/content/pdf/1471-2296-7-39.pdf>).

<sup>35</sup> Madelyn Hsiao-Rei Hicks (2006), “Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors,” *BMC Family Practice* (7:39, online: <http://www.biomedcentral.com/content/pdf/1471-2296-7-39.pdf>).

<sup>36</sup> National Cancer Institute, *Education In Palliative And End-Of-Life Care For Oncology: Self-Study Module 14: Physician-Assisted Suicide* (Online: <http://www.cancer.gov/resources-for/hp/education/epeco/self-study/module-14/module-14.pdf>).

<sup>37</sup> Philip R. Muskin (1998), “The Request to Die; Role for a Psychodynamic Perspective on Physician-Assisted Suicide” *The Journal of the American Medical Association* (279(4):323-328).

can influence the request. Moreover these influences can be, as the trial judge in *Carter* found, “subtle and exercised at an unconscious level.”<sup>38</sup>

This body of research raises very serious concerns about how such factors would be identified in a system where physicians undertake both the assessment of eligibility and the authorization of the request. The validity of these concerns is borne out by compelling evidence from the Netherlands. A survey of psychiatrists involved in consulting on requests for PAD in that country found that in their assessment issues of transference and countertransference influenced 25% of the requests in which they had provided psychiatric consultation. And in 19% of cases of PAD, it was authorized by physicians even though the psychiatrist had advised that issues of transference or countertransference appeared to be influencing the decision.<sup>39</sup>

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<sup>38</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 815.

<sup>39</sup> JH Groenewoud, A van der Heide, AJ Tholen, WJ Schudel, MW Hengeveld, BD Onwuteaka-Philipsen, PJ van der Maas, and G van der Wal, (2004), “ Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide” *General Hospital Psychiatry* (26:323-330).

Table 4 – Inducement and Coercion in Dynamics of Patient-Physician Interactions in Requests for PAD<sup>40</sup>

Transference is when a patient relates to the doctor in a way that primarily replicates other important, usually parental, relationships. It frequently acts on an unconscious level to covertly affect the patient-doctor interaction. As a general example, patients may relate to the doctor as an omnipotent parental authority figure. Their communications and behaviour may express a wish for approval, a wish for comfort and restoration, fear of abandonment, or rage at perceived abandonment. In any suicidal patient, including the terminally ill, the request to die can be a plea for help or an attempt to be given a reason to live. A request for PAS can be an entreaty for the doctor to take the terminally ill patient's situation or despair more seriously, or a test of the doctor's true feelings about the patient's value now that he is nearing death. One patient's request for euthanasia was described as *"the patient's way of 'testing' the medical team...to make sure they would not be abandoned. Moreover, as the patient had a difficult relationship with their family – who had asked for euthanasia to be carried out – this request enabled the patient to hear that they still had a certain value in the eyes of the medical team"*.

Another example is that of Mr. C., a 72-year-old man with severe obstructive lung disease. This patient asked his doctor, "Can't you do something to just bring it to an end? ...Just put me out of my misery. It would save everyone a lot of trouble." His doctor replied rather awkwardly, "Even though you feel like a burden, I can't do that." Mr. C. asks, "Why not? You'd do it for your dog." His doctor answers, "Because you aren't a dog, Mr. C. You're my patient and I'm your doctor, and I'm trying to help you. And I'll keep trying to help you as long as I have to." Mr. C. took the doctor's hand in both of his and said, "Thank God. I thought everyone had given up on me".

Rene Diekstra, a pioneer of PAS in the Netherlands, described how some doctors coming before a committee that reviewed PAS cases were prematurely ready to provide PAS when feelings of helplessness about the patient's condition influenced them to overestimate the rationality or inevitability of the patient's suicide. Fear of inadequacy and of abandoning patients by denying the PAS request can be observed in... interviews with Oregon doctors. One doctor favorable to PAS said, *"...I think I would just feel really uncomfortable if I couldn't help"*. Whether or not a doctor chooses to provide PAS, the patient's request for PAS can be perceived as a rejection or a condemnation of the doctor's inadequacy. As one doctor said, *"It's almost as if your treatments and attempts to make the patient comfortable have been a complete failure if they're going to ask for that"*. And another: *"I feel like there's something with physician assisted suicide, personally, where I see it as a rejection of care...some- how the patient is saying, 'Whatever you're doing isn't good enough. It's not meeting my needs."*

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<sup>40</sup> The information in this Table is drawn from Madelyn Hsiao-Rei Hicks (2006), "Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors," *BMC Family Practice* (7:39, online: <http://www.biomedcentral.com/content/pdf/1471-2296-7-39.pdf>).

Some doctors feel deep disgust towards disease and can have a profound fear of death and the helplessness that accompanies illness. Dr. Lewis Thomas writes, in an unusually naked portrayal of these feelings, "*Death is shocking, dismaying, even terrifying...A dying patient is a kind of freak...an offense against nature itself*". Some individuals become doctors as a way of dealing with their death anxiety. Doctors' fears of death and of other issues around PAS can contribute to their avoiding much-needed discussions with patients about their impending death, both in doctors who support and who reject PAS. An Oregon doctor said about a PAS request, "*I kind of dealt with the medical issues and I didn't square up with it...I avoided it*". This reaction can lead to doctors giving PAS prescriptions to patients without adequate evaluation...

Table 3 Inducement and Coercion in Dynamics of Patient-Physician Interactions in Requests for PAD

## D. Degree of Resilience

Health research suggests that individuals' resilience to suicide risk factors is essential in understanding the dynamics of vulnerability. An extensive review of the literature defines resiliency as:

the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity.<sup>41</sup>

People's resilience in coping with their vulnerabilities varies and depends upon factors such as "the availability or lack of intimate and instrumental support; and neighborhood and community resources that may facilitate or hinder personal coping and interpersonal relationships."<sup>42</sup> Personal, psychological and social assets have also been shown to be important predictors of vulnerable individuals "bouncing back" from trauma and stress. For this reason, extent of resilience is also identified as a factor in suicide risk assessment and response in the health care context<sup>43</sup> and is an important determinant of whether a person's *potential* vulnerability to being induced to commit suicide makes them *actually* vulnerable and calls for protective or other responses.

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<sup>41</sup> Gill Windle (2011), "What is resilience? A review and concept analysis," *Reviews in Clinical Gerontology* (21, 2).

<sup>42</sup> David Mechanic and Jennifer Tanner (2007), "Vulnerable people, groups, and populations: societal view," *Health Affairs* (V. 26(5): 1220-1230 (Online: [http://www.jenniferltanner.com/docs/HA\\_vulnerablegroupsetc\\_MechanicTanner.pdf](http://www.jenniferltanner.com/docs/HA_vulnerablegroupsetc_MechanicTanner.pdf))). Also see, C Grabovschi, C Loignon and M Fortin (2013), "Mapping the concept of vulnerability related to health care disparities: a scoping review," *BMC Health Services Research* (V. 13, March, Published online: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3626765/>).

<sup>43</sup> Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: <https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf>).

## E. Potential vs. Actual Vulnerability

A number of the risk factors identified above may be present in the circumstances of a person who makes a request for physician-assisted death. However, they may not leave the person at such a high risk of *actual* vulnerability that the person is unable to freely and voluntarily consent. Therefore, assessing vulnerability requires distinguishing between ‘potential’ and ‘actual’ vulnerability to being induced to commit suicide.

A recent synthesis of a wide body of research on vulnerability factors presents an understanding of vulnerability as a function of two intersecting dimensions – ‘sources’ of vulnerability (inherent, situational or pathogenic) and potential (dispositional) or actual (occurrent) ‘states’ of vulnerability.<sup>44</sup> Applied to the question of vulnerability to being induced to commit suicide in a time of weakness, the framework would suggest the following:

- **Sources of vulnerability** would include:
  - Inherent vulnerability (a grievous and irremediable medical condition that causes a person enduring suffering that is intolerable in the circumstances and is motivating a request to die, makes the person at least potentially vulnerable to being induced to commit suicide);
  - Situational vulnerability (factors present in the person’s circumstances are associated with suicidal risk – i.e. social isolation – but are not pathogenic per se);
  - Pathogenic vulnerability (the person is in relationships where they are being exploited, neglected, abused, discriminated against or stigmatized).
- **Potential and actual states of vulnerability** would include:
  - Potentially vulnerable (that the range of inherent, situational and pathogenic factors a person is subject to potentially make them vulnerable to being induced to commit suicide)
  - Actually vulnerable (that these factors *actually* are making the person vulnerable to being induced to commit suicide in times of weakness).

**Table 5** provides a typology of these sources and states of vulnerability. Drawing on research findings cited above, the typology suggests indicators of potential states of vulnerability and actually occurring states of vulnerability to being induced to commit suicide through a system of physician-assisted death.

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<sup>44</sup> Catriona Mackenzie, Wendy Rogers and Susan Dodds (2014), “What Is Vulnerability, and Why Does It Matter for Moral Theory?” in Catriona Mackenzie, Wendy Rogers and Susan Dodds, eds., *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford: Oxford University Press).

Table 5 – Distinguishing Potential and Actual Vulnerability

SOURCES of Vulnerability	STATES of Vulnerability	
	POTENTIALLY Vulnerable to being induced to commit suicide in a time of weakness	ACTUALLY Vulnerable to being induced to commit suicide in a time of weakness
<b>INHERENT sources of vulnerability</b> (to the person)	Patient has a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the person in the circumstances.	If situational and/or pathogenic sources of vulnerability are operating.
<b>SITUATIONAL sources of vulnerability</b> (in the person's context)	Patient is in a situation of: <ul style="list-style-type: none"> <li>• unmet needs for medical, financial, psychological, social or caregiving support; or</li> <li>• concern or fear about loss of autonomy or dignity, growing dependence, caregiving burden, limited financial or other resources.</li> </ul>	Patient request for PAD is motivated by: <ul style="list-style-type: none"> <li>• unmet needs resulting from lack of positive interpersonal relationships and social isolation;</li> <li>• lack of needed services and supports;</li> <li>• lack of insight or understanding about alternative courses of action; and</li> <li>• has low resilience to these factors.</li> </ul>
<b>PATHOGENIC sources of vulnerability</b> (caused by exploitation, neglect, abuse, discrimination or social stigma)	Others are stigmatizing, exploiting, neglecting or abusing the patient (psychologically, physically, sexually, or financially).	Patient request for PAD is motivated by: <ul style="list-style-type: none"> <li>• stigma, exploitation, neglect or abuse;</li> <li>• coercion inflicted or inducements offered by others;</li> <li>• discrimination in access to needed health and social supports as a result of physical, financial, cultural, communicational, or attitudinal barriers; or</li> <li>• negative psychodynamics in the physician-patient relationship; and,</li> <li>• has low resilience to these factors.</li> </ul>

Table 4 Dimensions of Vulnerability to Inducement and Coercion to Commit Suicide in Times of Weakness



## **F. Towards a ‘Vulnerability Lens’ in Requests for PAD**

Research reviewed for this report point to five criteria of vulnerability that motivate requests for physician-assisted death: suicidality, predominance of psychosocial causes of suffering, dynamics of inducement or coercion, low resilience, and actually occurring states of vulnerability. Framed as questions, these criteria constitute five dimensions of an evidence-based ‘vulnerability lens’ to guide review and authorization of requests.

1. Is this a well-reasoned request or is the person suicidal because of factors other than the medical condition associated with the request?
2. Are there psychosocial factors that are motivating this request, which could be addressed by alternative courses of action?
3. Are dynamics of inducement and/or coercion underlying this request – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient’s relationship to health care or social service professionals and systems?
4. Does the person have low resilience to factors that could be motivating this request, other than the medical condition itself, and if so are there alternative interventions that could be used to boost resilience?
5. Is the person *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is the person *actually* vulnerable as a result of these factors?

The purpose of this report was not to develop comprehensive indicators and tools for applying this lens. Rather, it was to synthesize findings and evidence on vulnerability in the context of physician-assisted death to determine if a coherent set of criteria emerge from that analysis. The research reviewed identifies a consistent set of evidence-based criteria across diverse sources. Further work is needed by health care professionals and regulatory bodies to translate this set of criteria into assessment tools and protocols for application in the system for PAD. The next section turns to implementation issues that should be anticipated in doing so.

## **III. Key Issues in Implementing a Vulnerability Lens**

To provide consistent application of the vulnerability lens to considering and authorizing requests for PAD, a number of legal, policy, practice and institutional issues would need to be addressed. These issues are outlined below, and include:

- Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence;

- Varying health profession guidelines for informed consent and response to vulnerable persons;
- Limitations of relying solely on physicians to assess vulnerability; and,
- Need for valid tools and comprehensive protocol to assess vulnerability.

### **A. Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence**

In the *Carter* trial decision, Justice Smith specifies the standards of informed consent that must be met for an authorization of PAD to obtain the constitutional protection of an exception to the ban:

[M]y conclusion is that the unconstitutionality of the legislation arises from its application to competent, fully-informed, non-ambivalent adult persons who personally (not through a substituted decision-maker) request physician-assisted death, are free from coercion and undue influence and are not clinically depressed...<sup>45</sup>

Can the current law, policy and practice framework for informed consent and capacity assessment in Canada ensure that this legal standard – the adult person is non-ambivalent, free from coercion and undue influence and is not clinically depressed – is consistently applied in a system for PAD?

Research findings, including the findings and reports released since the *Carter* trial, suggest substantial reform is required. Only five provincial/territorial jurisdictions in Canada have a statutory framework for health care consent for adults – British Columbia, Ontario, Québec, Prince Edward Island, and the Yukon. New Brunswick has provisions for medical consent for minors.<sup>46</sup> Other provinces/territories have provisions related to a test for legal capacity to make health, personal care and property decisions.

However, none of the statutory provisions incorporate the standard for undue influence and coercion as specified in the *Carter* decision and international codes. The Québec *Act Respecting End-of-Life Care* does provide for “making sure that the request [for PAD] is being made freely, in particular by ascertaining that it is not being made as a result of external pressure.”<sup>47</sup> However, it does not reference the indirect and

<sup>45</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 1390.

<sup>46</sup> British Columbia, *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, Chapter 181, ss. 6, 13; Ontario, *Health Care Consent Act*, S.O. 1996, Chapter 2, Schedule A, s. 11; Québec, *An Act Respecting End of Life Care*, chapter S-32.0001, s. 29, and *An Act Respecting Health Services and Social Services*, S-4.2, ss. 8, 9, 10; Prince Edward Island, *Consent to Treatment and Health Care Directives Act*, R.S.P.E.I. 1988, Cap. C-17.2, s. 6; Yukon Territory, *Decision Making, Support and Protection to Adults Acts: Schedule B Care Consent Act*, SY 2003, c.21, amended by SY 2008, c.1 and SY 2012, c.17, s. 5; New Brunswick, *Medical Consent of Minors Act*, SNB 1976, c M-6.1, s. 3.

<sup>47</sup> Québec, *An Act Respecting End of Life Care*, chapter S-32.0001, s. 29(1)(a).

internalized forms of coercion operating through distorted insight and the psychodynamics of the physician-patient relationship that the research finds are powerful inducing forces.

The existing statutes do make reference to ensuring that health care consent is given “freely” or is “voluntary” and in all the jurisdictions, except Québec, that it is not “obtained by fraud or misrepresentation”. In this sense, most current statutory standards in Canada emphasize what has been referred to as “coercive informational influences” (i.e., withholding or misrepresentation of information relevant to a health care decision), but they do not account for the “noninformational forms of coercion and undue influence” which are known to motivate requests for PAD, as the findings cited earlier in this report make clear.

Although the informed consent claim takes account of coercive *informational* influences, it does not address mental, contextual, or emotional factors that might overpower the decision maker's will, like those recognized in the undue-influence and insane-delusion doctrines [in determination of testamentary capacity]... The medical decision induced by grief, shock, or despair is enforceable to the same extent as one induced by a careful appraisal of the patient's long-term goals and values.<sup>48</sup>

In response to this gap in consent and capacity law as it applies to authorizations for PAD, U.S. legal scholar Marsha Garrison has proposed that in order to better protect vulnerable patients, doctrines from the law of wills and testator capacity be incorporated into the legal framework. This would include the doctrines of ‘delusion’ and ‘undue influence’ to protect those “suffering from the corrosive emotional influence exerted by depression and hopelessness”:

Vulnerable patients need, and deserve, protection from the coercive effects of distorted perception and motivation just as much as vulnerable testators need and deserve protection against scheming gold-diggers. It is time to reform the law of medical decision making to ensure that it provides such protection. Patient health-and life itself-hang in the balance.<sup>49</sup>

In the Canadian context, the legal doctrine applying to testamentary capacity is that of “suspicious circumstances.” In *Vout v. Hay*, the Supreme Court of Canada set out three types of suspicious circumstances: “(1) suspicious circumstances raised by events surrounding the preparation of the will; (2) events tending to call into question the capacity of the testator; and (3) coercion or fraud.”<sup>50</sup> These factors are now

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<sup>48</sup> *Ibid.*, 797-798.

<sup>49</sup> Marsha Garrison (2007), “The Empire of Illness: Competence and Coercion in Health-care Decision Making”, *William and Mary Law Review* (Volume 49, Issue 3, 781-843).

<sup>50</sup> See M. Scott Kerwin (2010), *Probate Actions – Estate Litigation Basics* (Vancouver: Continuing Legal Education Society of British Columbia, online: <https://www.cle.bc.ca/PracticePoints/WILL/11-ProbateActions.pdf>). Suspicious circumstances doctrine defined in *Vout v. Hay*, [1995] 2 S.C.R. 876 at para. 25.

incorporated into understanding of testamentary capacity in Canadian law.<sup>51</sup> In the health care context, the concepts have been defined by a Canadian health law expert as follows:

**Voluntariness:**

refers to the need to ensure that consent is obtained without influences that undermine autonomous choice. Influences can be explicit or implicit, and external or internal. Coercion, undue influence, and fraud or misrepresentation are factors which most commonly affect voluntariness.<sup>52</sup>

**Coercion can be defined to:**

characterize an offer that is intentionally made to a person who is extremely vulnerable due to distress, need, or poverty, and who would, under the most basically fair conditions, never accept such an offer. In those circumstances of particular vulnerability, the recipients of the offer may feel that that they have no other option but to accept... Coercion, the intentional use of psychological pressure, physical force, or threat, is more clearly deemed to vitiate consent.<sup>53</sup>

**Undue influence:**

Undue influence is commonly used in testamentary law, where several conditions have been identified that relate to the vulnerability of the person, the relation of dependency, and the likelihood that the pressure may have had an effect... Undue influence is seen as impacting more subtly on voluntariness than coercion does... It has been suggested that influence is undue when it makes people ‘act against their better judgment’ or “when it leads to distortions of the risks and benefits of participation”.<sup>54</sup>

The absence of statutory standards for informed consent that specify the obligation to assure against any forms of coercion or inducement is particularly concerning given the strong evidence that these factors can motivate requests for PAD in complex and not always conscious ways.

## **B. Varying health profession guidelines for informed consent and response to vulnerable persons**

The Canadian Medical Association’s (CMA) “Principles-based Recommendations for a Canadian Approach to Assisted Dying”, published in January 2016, set a standard for competence and informed consent, much more in line with *Carter*. The principle on “Voluntariness” states:

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<sup>51</sup> See, for example, discussion of ‘undue influence’ and ‘suspicious circumstances’ in British Columbia Law Institute (2013), *Report on Common-Law Tests of Capacity*. Vancouver: Author.

<sup>52</sup> Trudo Lemmens (2015), “Informed Consent”, In *Routledge Handbook of Medical Law and Ethics*, edited by Yann Joly and Bartha Maria Knoppers (New York: Routledge).

<sup>53</sup> *Ibid.*

<sup>54</sup> *Ibid.*

The attending physician must be satisfied, on reasonable grounds, that all of the following conditions are fulfilled: – The patient's decision to undergo assisted dying has been made freely, without coercion or undue influence from family members, health care providers or others. – The patient has a clear and settled intention to end his/her own life after due consideration. – The patient has requested assisted dying him/herself, thoughtfully and repeatedly, in a free and informed manner.<sup>55</sup>

Earlier guidelines by the Canadian Medical Protective Association (CMPA) also emphasize the necessity to guard against any form of compulsion in providing informed consent:

Patients must always be free to consent to or refuse treatment, and be free of any suggestion of duress or coercion. Consent obtained under any suggestion of compulsion either by the actions or words of the physician or others may be no consent at all and therefore may be successfully repudiated. In this context physicians must keep clearly in mind there may be circumstances when the initiative to consult a physician was not the patient's, but was rather that of a third party, a friend, an employer, or even a police officer. Under such circumstances the physician may be well aware that the patient is only very reluctantly following the course of action suggested or insisted upon by a third person. Then, physicians should be more than usually careful to assure themselves patients are in full agreement with what has been suggested, that there has been no coercion and that the will of other persons has not been imposed on the patient.<sup>56</sup>

The Federation of Medical Regulatory Authorities of Canada (FMRAC) – a federation of the various provincial/territorial colleges and medical councils of physicians and surgeons – stipulate the standard of voluntariness as follows:

The attending physician must be satisfied, on reasonable grounds, that all of the following conditions are fulfilled: The patient's decision to undergo physician-assisted dying has been made freely, without coercion or undue influence from family members, health care providers or others; The patient has a clear and settled intention to end his or her own life after due consideration; and, The patient has requested physician-assisted dying him/herself, thoughtfully and repeatedly, in a free and informed manner.<sup>57</sup>

It is encouraging to see professional practice guidelines attentive to a higher standard of voluntariness than statutory provisions for informed consent. However, there are important differences among the guidelines presented. The CMA and FMRAC do emphasize that the request must be “without coercion or undue influence” and reflect “a clear and settled intention.” The CMPA standard focuses primarily on external third party “compulsions” on the patient. The only national standard to reference vulnerable persons or the wide range of factors known to result in vulnerability and risk of suicidal

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<sup>55</sup> Canadian Medical Association (2016) *Principles-based Recommendations for a Canadian Approach to Assisted Dying* (online: [https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma-framework\\_assisted-dying\\_final-jan2016.pdf](https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma-framework_assisted-dying_final-jan2016.pdf)).

<sup>56</sup> Canadian Medical Protective Association (2006), *Consent: A Guide for Canadian Physicians* [Fourth Edition] (online: [www.cmpa-acpm.ca/-/consent-a-guide-for-canadian-physicians#voluntary consent](http://www.cmpa-acpm.ca/-/consent-a-guide-for-canadian-physicians#voluntary%20consent)).

<sup>57</sup> Federation of Medical Regulatory Authorities of Canada (December 2015), *Physician-Assisted Dying Guidance Document* (online: <http://fmrac.ca/wp-content/uploads/2015/12/FMRAC-Guidance-Document-Physician-Assisted-Dying.pdf>).

ideation is the CMA statement in a principle that states: “Protection of patients: Laws and regulations, through a carefully designed and monitored system of safeguards, should aim to minimize harm to all patients and should also address issues of vulnerability and potential coercion.” Neither the statutory or regulatory framework in Canada currently meets this test.

### **C. Limitations of relying solely on physicians to assess vulnerability**

Justice Smith did find that “coercion and undue influence can be detected as part of a capacity assessment.” However, she also found that:

To be accurate and reliable, clinicians who perform such assessments would have to be aware of the risks of coercion and undue influence, of the possibility of subtle influence, and of the risks of unconscious biases regarding the quality of the lives of persons with disabilities or persons of advanced age.<sup>58</sup>

How widespread is this knowledge and expertise base across physicians and other health professions? The Federal External Panel on Options for a Legislative Response to *Carter v. Canada* found widely divergent views by health profession associations and others consulted about whether physicians generally have the training and expertise to discern the sometimes complex dynamics of inducement and coercion<sup>59</sup>; which, as noted above, can include their own participation in such dynamics. This finding is reflected in a U.S. survey of family physicians in relation to detecting for elder abuse and neglect, which concluded: “Despite this expected increased demand for expertise [for detection and assessment], physicians generally lack training, experience, education, and adequate guidelines for the assessment and management of abuse. Less than 2% of reports of elder abuse and neglect... come from physicians.”<sup>60</sup>

Health profession regulators in Canada do not appear to be addressing this concern, opting instead it appears, at least for some, a position that declares that by definition physicians are able to undertake this assessment. For example, the College of physicians and surgeons of Manitoba simply relies on the statement by the SCC that “Physicians are capable of reliably assessing patient competence and it is possible to detect vulnerability, coercion, undue influence, and ambivalence as part of the

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<sup>58</sup> *Carter v. Canada (Attorney General)*, 2012 BCSC 886, at para. 814.

<sup>59</sup> Federal External Panel on Options for a Legislative Response to *Carter v. Canada* (2016), *Consultations of Physician-Assisted Dying: Summary of Results and Key Findings: Final Report* (Ottawa: Department of Justice Canada, pgs. 64-69, online: <http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf>,

<sup>60</sup> Robert M. Hoover and Michol Polson (2014) “Detecting Elder Abuse and Neglect: Assessment and Intervention”, *American Family Physician* (Volume 89, Number 6, p. 453).

assessment process for informed consent and medical decision making capacity.”<sup>61</sup> In this case, a finding at both the trial and the Supreme Court decisions in *Carter* that “it is possible” for physicians to detect vulnerability, coercion, undue influence and ambivalence, stands in for evidence that this is what all physicians have the skills, training, time and expertise to actually do. The evidence does not bear out this interpretation of the Court’s assertion of possibility the declaration.

In response to the concerns about how vulnerability assessment will be conducted, the Canadian Nurses Association recommends ensuring “that requests for PAD are addressed through a comprehensive assessment process by an interprofessional team.” This could include, the association recommends, nurses, psychologists, pharmacists and social workers. The CNA stresses that a “reductionist” approach to assessment for vulnerability, relying exclusively on physician assessment of voluntariness and competence is too risky. They recommend an independent assessment by nurses as an important safeguard and one which recognizes the more fulsome relationships that nurses may form with patients, given their greater likelihood of prolonged and intimate observation as patients negotiate illness, relationships and decision-making.<sup>62</sup>

Thus, even among health professionals in Canada, there is vast disagreement about capacity to undertake adequate assessment of vulnerability in people requesting PAD.

#### **D. Need for valid tools and comprehensive protocol to assess vulnerability**

In addition to concerns about lack of expertise and training and an interdisciplinary approach to vulnerability assessment, valid tools for assessing vulnerability in relation to the request for PAD are lacking. In fact, standard capacity or competency assessment tests *are not designed* to capture “coercion and undue influence”, “clinical depression” or the negative impact on decision making capacity of the psychological mechanisms and dynamics discussed above. This limitation includes the MacArthur Competence Assessment Tool-Treatment (MacCAT-T), which a Canadian review of competency

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<sup>61</sup> College of Physicians and Surgeons of Manitoba (2016), “Physician-Assisted Death: Schedule M attached to and forming part of By-Law No. 11 of the College” (online: <http://cpsm.mb.ca/cji39alckF30a/wp-content/uploads/PAD/PADSchMa.pdf>).

<sup>62</sup> Canadian Nurses Association (October 2016), “Physician-Assisted Death: Brief for the Government of Canada’s External Panel on Options for a Legislative Response to *Carter v. Canada* (2015)” (online: [https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/physician-assisted-death\\_brief-for-the-government-of-canadas-external-panel-on-options-for-a-legislative-response-to-carter-v-canada.pdf?la=en](https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/physician-assisted-death_brief-for-the-government-of-canadas-external-panel-on-options-for-a-legislative-response-to-carter-v-canada.pdf?la=en)).

assessment tools refers to as the “gold” standard of competency assessment.<sup>63</sup> The difference between this tool and the Scale to Assess Unawareness of Mental Disorder (SUMD), for example, has been noted specifically in relation to requests for PAD because, unlike the MacCAT-T, the SUMD evaluates the various dimensions of insight, including awareness of symptoms, retrospective awareness, and psychosocial consequences.<sup>64</sup> Thus, a recommended ‘gold standard’ for competency assessment by health professionals in Canada does not incorporate attention to those dimensions of capable decision making which the evidence indicates are critical in assessing disordered insight.

No comprehensive set of vulnerability assessment tools have been designed or tested for assessing the extent to which any, or some combination, of these factors may be operating to make a person vulnerable to requesting PAD as a way to commit suicide in a time of weakness. Nonetheless, there is growing concern and attention in the health care system to vulnerability of patients, and to risk of suicide in particular. A number of these instruments and protocols could be drawn upon and tested by health researchers and professionals to develop a comprehensive assessment protocol for the purposes of assessing and responding to vulnerability of patients requesting PAD.

For example, and as noted above, the Ontario Hospital Association and the Canadian Patient Safety Institute have developed a comprehensive framework to encourage standardized assessment of suicide risk within health care settings, drawing on an inventory and analysis of fifteen suicide risk assessment tools.<sup>65</sup> A number of these tools could be considered and adapted for assessing vulnerability in response to requests for physician-assisted death.

As well, more general vulnerability assessment tools have been designed that could also be adapted for the context of physician-assisted death. For example, a “Vulnerability Assessment Tool” has been designed to identify extent of instability in living conditions of homeless persons. It identifies ten domains of vulnerability, and has

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<sup>63</sup> See Deborah O’Connor (2009), *Incapacity Assessments: A Review of Assessment and Screening Tools: Final Report*, Prepared for the Public Guardian and Trustee of British Columbia (Online: [http://www.trustee.bc.ca/documents/STA/Incapacity\\_Assessments\\_Review\\_Assessment\\_Screening\\_Tools.pdf](http://www.trustee.bc.ca/documents/STA/Incapacity_Assessments_Review_Assessment_Screening_Tools.pdf)).

<sup>64</sup> Marsha Garrison (2007), “The Empire of Illness: Competence and Coercion in Health-care Decision Making”, *William and Mary Law Review* (Volume 49, Issue 3, 781-843).

<sup>65</sup> Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: <https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf>). See also, Registered Nurses Association of Ontario (January 2009), *Nursing Best Practice Guideline Assessment and Care of Adults at Risk for Suicidal Ideation and Behaviour* (online: [http://rnao.ca/sites/rnao-ca/files/Assessment\\_and\\_Care\\_of\\_Adults\\_at\\_Risk\\_for\\_Suicidal\\_Ideation\\_and\\_Behaviour\\_0.pdf](http://rnao.ca/sites/rnao-ca/files/Assessment_and_Care_of_Adults_at_Risk_for_Suicidal_Ideation_and_Behaviour_0.pdf)).



been both validity- and reliability-tested.<sup>66</sup> While not designed for assessing vulnerability to being induced to commit suicide in times of weakness, it does assess some of the same factors the research identifies for vulnerability to suicidal ideation and intent. Moreover, it provides helpful scales of the degree of vulnerability in each of the domains it assesses, which could be adapted in designing assessment tools for the purposes outlined here.

In the area of older persons, the “Elder Abuse Suspicion Index” has been validated in health care settings and could be adapted as part of a comprehensive protocol for vulnerability assessment in responding to requests for PAD.<sup>67</sup>

The British Medical Association’s “Safeguarding Vulnerable Adults – a Tool Kit for General Practitioners”<sup>68</sup> is not designed specifically for vulnerability assessment in the context of PAD, but it is informed by concern for the types of vulnerability factors identified above. It could be a helpful template for vulnerability assessment in PAD.

There may also be factors in the adult’s experience of health care treatment which are identified as needing more in-depth inquiry. For example, there is increasing use of ‘patient reported outcomes’ (PROs) to assist health professionals in assessing the impact of health care events, symptom burden, functioning, health status, and health-related quality of life.<sup>69</sup> Some PRO assessment tools look specifically at the impact of ‘events’ in the health care system over a period of time, and the “dynamics of care” which may have a cumulative impact on the patient’s perception of quality of life, especially those with complex health needs.<sup>70</sup> A growing body of research is finding that patient perception of care is a predictor of patient quality of life. In this regard, health care researchers in treatment of HIV/AIDS note that patient-oriented outcomes

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<sup>66</sup> Downtown Emergency Service Center, “Vulnerability Assessment Tool for Determining Eligibility and Allocating Services and Housing for Homeless Adults” (Seattle, WA: Author, Online at: [http://www.desc.org/documents/06.30.2015.DESC.Intro to Vulnerability Assessment Tool.incl%20VAT%20&%201-page%20validity.pdf](http://www.desc.org/documents/06.30.2015.DESC.Intro%20to%20Vulnerability%20Assessment%20Tool.incl%20VAT%20&%201-page%20validity.pdf)).

<sup>67</sup> MJ Yaffe and B Tazkarji (2012), “Understanding elder abuse in family practice”, *Canadian Family Physician* (58(12), pgs. 1336-1340).

<sup>68</sup> British Medical Association (2011), *Safeguarding Vulnerable Adults – A Tool Kit for General Practitioners* (London: Author, Online at: [https://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAAahUKEwjS4v6\\_-urlAhUGpx4KHdPzAU4&url=http%3A%2F%2Fbma.org.uk%2F%2Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethics%2Fsafeguardingvulnerableadults.pdf&usg=AFQjCNEVOS5NTs1Xmn\\_kAp7lb0idVbCdEw](https://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAAahUKEwjS4v6_-urlAhUGpx4KHdPzAU4&url=http%3A%2F%2Fbma.org.uk%2F%2Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethics%2Fsafeguardingvulnerableadults.pdf&usg=AFQjCNEVOS5NTs1Xmn_kAp7lb0idVbCdEw)).

<sup>69</sup> Neil Aaronson, Thomas Elliott, Joanne Greenhalgh, et al (2015), *User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice* (International Society for Quality of Life Research, online: <http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf>).

<sup>70</sup> See, for example, Bruce Rapkin, Elisa Weiss, Rosy Chhabra, et al (2008), “Beyond satisfaction: Using the Dynamics of Care assessment to better understand patients’ experiences in care,” *Health and Quality of Life Outcomes* (6:20 March).

assessment “sheds light on concerns that may not make it into care because of patients' sense of futility, embarrassment, or independence.”<sup>71</sup>

Such assessments also point to a patient's resilience in the face of factors that may make them vulnerable, as discussed above. A number of tools for assessing resiliency are being developed for use in vulnerability assessment in health care contexts.<sup>72</sup> As such, they provide another source for developing a comprehensive assessment protocol to determine the extent of vulnerability to being induced to commit suicide in a time of weakness.

Particularly applicable in the context of assessing potential vs. actual vulnerability is what has been termed “Focused Risk Assessment.” The goal is to “establish an open and therapeutic rapport with the person”, and explore in detail the adult's plans, ideation, strengths and supports available that may moderate the risk.<sup>73</sup>

## Summary

In summary, there are a wide range of existing health practice guidelines and tools for both suicide risk assessment and vulnerability assessment more generally. However, no specific set of protocols have been developed for vulnerability assessment in the context of PAD. The research suggests that a range of factors may coerce requests, including psychological factors of depression, hopelessness and self-stigma that can disorder insight, direct coercion by others, and the psychodynamics of patient-physician relationships that evolve in the context of requests for PAD. The “informational” focus of the current legal and practice framework for obtaining consent does not appear to be adequate in surfacing these more complex psychological factors and dynamics.

There is a clear need for investment by health authorities, professional associations and health regulators to develop and validate needed assessment tools and protocols, and to ensure they are part of health care professionals' obligations, with clear practice guidelines for this purpose.

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<sup>71</sup> Bruce Rapkin, Elisa Weiss, Rosy Chhabra, et al (2008), “Beyond satisfaction: Using the Dynamics of Care assessment to better understand patients' experiences in care,” *Health and Quality of Life Outcomes* (6:20 March).

<sup>72</sup> Gill Windle, Kate M Bennett and Jane Noyes (2011), “A methodological review of resilience measurement scales,” *Health Quality Outcome* (9:8).

<sup>73</sup> Ontario Hospital Association and Canadian Patient Safety Institute, *Suicide Risk Assessment Guide: A Resource for Health Care Organizations* (online: <https://www.oha.com/KnowledgeCentre/Documents/Final%20-%20Suicide%20Risk%20Assessment%20Guidebook.pdf>, p. 68). The notion of this ‘focused’ and more indepth stage of risk assessment is drawn from P. Barker and P. Buchanan-Barker (2005) *The Tidal Model: A Guide for Mental Health Professionals* (New York, NY: Routledge).

It is critically important to recognize, however, that the system for physician-assisted death will be introduced in Canada long before any such comprehensive tools have been designed, clinically tested or systematically evaluated for this purpose. **Absence of a clinically proven evaluation protocol to assess vulnerability to being induced to commit suicide in a time of weakness, in the context of requests for PAD, suggests extreme caution should be exercised.**

#### **IV. Federal legislative requirements to implement a vulnerability lens**

A safeguards system for PAD must be designed to minimize as much as possible the abuse and error that would result if adults received PAD when they were vulnerable to being induced to commit suicide; while at the same time ensuring equitable access for eligible adults. Both objectives must be achieved, with policy architecture and institutional mechanisms that ensure an appropriate balancing is made in assessing and authorizing any request.

This report has drawn on extensive evidence to identify elements of a vulnerability lens to ensure adequate safeguards in decision making in PAD. This lens gives attention to the unmet needs, inducements and coercive forces which make people vulnerable in this context. The analysis has pointed to key limitations in the current legal, regulatory, policy and practice environment in Canada which suggest that the health care system for applying this lens to identify or address vulnerability in a reliable and consistent manner across provincial/territorial jurisdictions.

A national standard for vulnerability assessment in responding to, considering and authorizing requests for PAD is therefore urgently needed. Federal leadership for this purpose is essential. Only with a uniform standard across Canada will provincial/territorial health authorities, health professionals and health care regulators have clarity about the specific legal obligations and needed policies/practices to obtain informed consent in a manner that protects vulnerable persons from being induced to commit suicide in a time of weakness.

Through what means should a national standard be established for this purpose? Because the Supreme Court of Canada mandated that the ban on assisted suicide could be lifted in the exceptional circumstances it defines, a *Criminal Code* amendment seems most appropriate for this purpose. It is the legal framework in which to define the conditions under which assisted suicide, which otherwise remains prohibited under the *Criminal Code*, could be legally authorized. The findings and analysis in this report

point to three core elements of a national standard to protect vulnerable persons that could be embedded in the *Code*:

### **A. Criminal Code standard for informed consent**

The statutory standard should require that a person not be vulnerable to being induced to commit suicide in a time of weakness, and that the person make a non-ambivalent, voluntary request, free from coercion, inducement or undue influence. Applying the standard should require:

- a. Two physicians to independently assess the medical condition and suffering and capacity for informed consent, with at least one physician having clinical expertise in diagnosis, prognosis and treatment of the medical condition. This need for at least two independent assessments has been recognized by both the Provincial/Territorial Expert Advisory Group and the Parliamentary Joint Special Committee report on physician-assisted dying.<sup>74</sup>
- b. Independent psychiatric or psychological evaluation where there is any concern that factors external to the condition underlay the suffering and the motivation for the request, including: 1) psychological stressors of distorted insight, depression, hopelessness or self-stigma; 2) coercion by others; and/or 3) the psychodynamics of the patient-physician relationship.
- c. Physician liability for not triggering a more indepth inquiry when there is even minimal concern that a person may be vulnerable to being induced to commit suicide in a time of weakness.

### **B. Criminal Code requirement for vulnerability assessment**

Provisions should require mandatory vulnerability assessment to be undertaken by health and social service professionals and require, in particular:

- a. Vulnerability assessment to be conducted in response to each request, drawing upon designated health professionals within the clinical or health care team whose responsibility, training, and expertise it is to assess vulnerability.
- b. Application of a vulnerability assessment lens that assesses:

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<sup>74</sup> Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying Final Report (November 30, 2015), *Final Report* (Toronto: Ontario Ministry of Health and Long-term Care); Parliament of Canada (42<sup>nd</sup> Parliament, 1<sup>st</sup> Session), Special Joint Committee on Physician-Assisted Dying (February 2016), *Medical Assistance in Dying: A Patient-Centred Approach: Report of the Special Joint Committee on Physician-Assisted Dying* (Ottawa: Author).

- i. whether the person may be suicidal because of factors other than the medical condition associated with the request;
  - ii. predominance of psychosocial factors motivating this request, which could be addressed by alternative courses of action;
  - iii. any dynamics of inducement, undue influence and/or coercion underlying the request – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient’s relationship to health care or social service professionals and systems;
  - iv. whether the person has low resilience to factors that could be motivating the request, other than the medical condition itself and, if so, if there are there alternative interventions that could be used to boost resilience;
  - v. the extent to which the person is *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is person *actually* vulnerable as a result of these factors.
- c. That, if any member of the health team expresses any concern that the adult may be vulnerable, indepth assessment is conducted and consideration given to the range of factors that may be inducing or coercing the request.
- d. That, if it is determined that the risk is too high that the person is vulnerable to committing suicide in a time of weakness, then alternative courses of action must be taken, with referrals to adult protection services, community supports, or police, as may be required by prevention and response protocols or legal obligations, depending on the particular situation.

### **C. Criminal Code requirement for prior review and determination by an independent authority**

Provision should be established in the *Criminal Code* requiring prior independent review of all requests, either through a provincial/territorial Superior Court judge, a revised mandate of provincial/territorial mental health review boards already established under the *Code*, or through existing or newly established tribunals at the provincial/territorial level.

There are a number of rationales for prior independent review of requests for PAD, as one of the safeguards to protect vulnerable persons:

- ***Inconsistent or absent statutory standards for informed consent*** – With health regulators using different professional practice standards for assessing voluntariness, coercion and undue influence in medical decision making, in the context of varying or completely absent statutory standards, a mechanism that can consistently apply national standards is required. This would ensure that vulnerable persons have equal access to constitutional protections of the right to life.
- ***Evidence that health professionals disagree about validity of requests*** – With evidence from other jurisdictions that physicians disagree about validity of requests for PAD, and that unconscious factors may operate in the physician-patient relationship that can distort insight and the reasoning process, a more independent mechanism is required for authorization of requests.
- ***No reliable and clinically proven tools for vulnerability assessment*** – Lack of consistent and reliability- and validity-tested tools for vulnerability assessment make it impossible without an independent mechanism that can operate according to consistent guidelines, to meet the legal requirement laid down by the Supreme Court of Canada to protect vulnerable persons.
- ***Health care system not designed to make the authorizations*** – Physician-assisted death is not a health treatment decision. It is a decision to take a lethal dose of substances intended to terminate life, upon a capable decision to refuse health treatments. Such an intervention may be provided by health professionals, but that is a policy choice about how to deliver the intervention, not a determination of the meaning of the intervention. Moreover, eligibility for PAD may be determined in part through clinical assessments of a person's medical condition and ways to alleviate suffering. These roles fall within the purview of health professionals' competencies and mandates. Authorization of an intervention intended to terminate the life of a person can only be provided as an exception to the *Criminal Code* prohibition. While the intervention may be funded as an 'insured service' under provincial health insurance plans, its authorization as an exception to criminal liability that would otherwise be imposed, is a different matter subject to legal determination.
- ***Consistent with Canada's obligations under international law*** – Prior review is consistent with Canada's obligations under international law to protect the inherent right to life of vulnerable persons. The United Nations Human Rights Committee, which is responsible for monitoring Canada's and other state parties' obligations to protect the "inherent right to life" recognized in Article 6 of the *International Covenant on Civil and Political Rights*, has urged that in approving

requests for PAD independent review be provided for in order to “guarantee that this decision was not the subject of undue influence or misapprehension.”<sup>75</sup> The Committee calls for “independent review by a judge or magistrate” because of the potential for violation of the right to life.

- ***Provisions already exist in the Criminal Code for prior independent review and for mandating vulnerability assessments*** – Current provisions in the Criminal provide for provincial/territorial Review Boards to determine who cannot be held criminally responsible due to a mental disorder and to make placement decisions to ensure that such individuals can access needed mental health services. Detailed legislative proposals for adapting existing Boards for the purpose of prior review and authorization for PAD have been developed in light of the Carter decision.<sup>76</sup>

This could include adaptation of existing tribunals like the Ontario ‘Consent and Capacity Board’ which currently has a mandate to adjudicate on matters of capacity, consent, civil committal, substitute decision making, disclosure of personal health information and mandatory blood testing. In 2014-15 the Board received over 6800 applications and drawing on a roster of part-time lawyers, psychiatrists and public members, convened over 3,500 hearings, with over 500 hearings done by video-conferencing.<sup>77</sup>

Provisions already exist in the *Criminal Code* for receiving and ordering assessments, with respect to placement decisions by mental health review boards currently mandated under the *Criminal Code* (in ss.672.1 to 672.21) and could be adapted for the purpose of ordering additional vulnerability assessments where warranted.

Under such a system, provision could be made for expedited decision making as may be needed where the adult may be close to death or the adult’s state of suffering requires urgent decision.

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<sup>75</sup> U.N. Human Rights Committee, Consideration of Reports Submitted by States Parties Under Article 40 of the Covenant, para. 7, U.N. DOC. CCPR/C/NLD/CO/4 (Aug. 25, 2009). See also U.N. Human Rights Committee, Concluding Observations of the Human Rights Committee: Netherlands, para. 5–6, U.N. DOC. CCPR/CO/72/NET (Aug. 27, 2001).

<sup>76</sup> See David Baker and Gilbert Sharpe (2015), Draft Federal Legislation to Amend the Criminal Code to be Consistent with *Carter v. Canada (Attorney General)* 2015 SCC 5. Toronto: bakerlaw (Online: [http://www.cacl.ca/sites/default/files/uploads/Baker-Sharpe%20An%20Act%20to%20Amend%20the%20Criminal%20Code%20\(Physician%20Assisted%20Suicide\).pdf](http://www.cacl.ca/sites/default/files/uploads/Baker-Sharpe%20An%20Act%20to%20Amend%20the%20Criminal%20Code%20(Physician%20Assisted%20Suicide).pdf)).

<sup>77</sup> Ontario, Consent and Capacity Board (2015), “Consent and Capacity Board: Annual Report 2014-2015” (online: <http://www.ccboard.on.ca/english/publications/documents/annualreport20142015.pdf>).

## Conclusion

The Supreme Court of Canada decision in *Carter* upheld the ban on physician-assisted suicide and voluntary euthanasia for adults who may meet the medical for access, but who are nonetheless ‘vulnerable to being induced to commit suicide in times of weakness.’ In doing so, the Court recognized constitutional obligations to protect and safeguard vulnerable persons in the strictest manner. However, it left design of a framework for identifying and safeguarding vulnerable persons up to Parliament.

The research findings reviewed for this report point to five main dimensions of a ‘vulnerability lens’ to identify persons who may be vulnerable in a system for PAD:

1. Is this a well-reasoned request or is the person suicidal because of factors other than the medical condition associated with the request?
2. Are there psychosocial factors that are motivating this request, which could be addressed by alternative courses of action?
3. Are dynamics of inducement, coercion or undue influence underlying this request – whether through disordered insight and self-stigma, direct coercion or inducement by others, or because of the psychodynamics of the patient’s relationship to health care or social service professionals and systems?
4. Does the person have low resilience to factors that could be motivating this request, other than the medical condition itself, and if so are there alternative interventions that could be used to boost resilience?
5. Is the person *potentially* vulnerable to being induced to commit suicide in a time of weakness because of the range of factors that could motivate the request for PAD, or is the person *actually* vulnerable as a result of these factors?

A reliable system of checks and balances to assure consistent application of this lens for vulnerability assessment is essential. Without such attention, there is very real risk that people will die in a manner that violates criminal prohibition. This includes adults who may appear to meet the criteria for PAD but whose suffering is, in fact, substantially related to other factors that induce suicidal ideation and intent and which may underlie an adult’s experience of enduring and intolerable suffering. It also includes adults who, because of other factors in their lives or in the dynamics of the relationship with their physician, are actually victims of subtle, unconscious or explicit inducement or coercion in the request for PAD. Such outcomes would not only be an ethical and moral failure of health care and justice systems of immense proportions. Under *Carter*, they would also be a criminal violation.

A number of issues must be addressed in ensuring consistent application of this lens in responding to, considering and authorizing requests for PAD, including:

- Incomplete and inconsistent statutory obligations for health care consent and to assure absence of coercion, inducement and undue influence;



- Varying health profession guidelines for informed consent and response to vulnerable persons;
- Limitations of relying solely on physicians to assess vulnerability; and,
- Need for valid tools and comprehensive protocol to assess vulnerability.

In order to establish a nationally-consistent system for PAD that can address these limitations in the current health care delivery system, this report recommends embedding key safeguard requirements in the *Criminal Code*, including: 1) a legal standard for informed consent that requires a person make a non-ambivalent, voluntary request, free from coercion, inducement and undue influence; 2) mandatory vulnerability assessment; and, 3) prior review and determination by an independent authority.

These recommendations are sensitive to the Supreme Court's imperative that any safeguard system must balance the competing values of protecting the autonomy and dignity of an adult's right to choose, and the need to protect vulnerable persons. To do anything less would be to prioritize the value of autonomy over protecting the vulnerable, and the Supreme Court provided no such avenue in its decision in *Carter*. Given the very real risk to vulnerable persons that could result from a system for physician-assisted suicide and voluntary euthanasia, it is of the utmost urgency and import to develop robust, transparent and consistent safeguards in which all Canadians can trust.

## Appendix A – Growing Vulnerability among Persons with Disabilities in Canada

Increasing prevalence in Canadian society of many of the factors associated with vulnerability and suicide risk among people with disabilities in particular, signals the urgent need for a reliable vulnerability assessment process in a system for PAD:<sup>78</sup>

- **Severity of disability, and multiple disadvantage** – Almost 14% of the adult population in Canada has a disability and this prevalence rate is growing year by year. Women are over-represented in almost all age groups.<sup>79</sup> Among Aboriginal persons, the prevalence of disability is over 30%, with this higher rate due to significant environmental and trauma-related disabilities.<sup>80</sup> Overall there is an increasing prevalence of people with ‘severe’ or ‘very severe’ disabilities, currently estimated at 1.8 million adults in Canada.<sup>81</sup> This is a group particularly vulnerable to abuse, social exclusion, and stigma especially those multiply-disadvantaged by gender or ethno-racial-cultural status.
- **Lack of access to disability-related supports** – A growing gap in needed disability-related supports affects both people with disabilities and families. Statistics Canada reports that unmet need for support increases with severity of disability, with 49% of people with severe disabilities needing help or not receiving enough help. For people with disabilities not living alone, 80% rely on families for needed support. For those living alone, 56% rely on their families.<sup>82</sup> With the aging of the population this gap will grow substantially – because of increased disability prevalence and more limited capacity of aging family caregivers.
- **Gap in palliative care** – up to 70% of Canadians are not able to access palliative care.<sup>83</sup> This will become a growing issue as annual deaths increase

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<sup>78</sup> The following discussion of vulnerability in Canadian society is drawn from CACL’s earlier report, Canadian Association for Community Living (2015), *Protecting Choice and Safeguarding Inclusion: A Proposal to Regulate Physician-Assisted Suicide and Voluntary Euthanasia in Canada* (Online: <http://cacl.ca/sites/default/files/uploads/CACL%20-%20Choice%20and%20Inclusion%20-%20%20%28english%29.pdf>).

<sup>79</sup> Statistics Canada, Social and Aboriginal Affairs Division (2013). Disability in Canada: Initial findings from the Canadian Survey on Disability: Fact Sheet. Ottawa: Statistics Canada.

<sup>80</sup> Douglas Durst (2006). Urban First Nations People with Disabilities Speak Out. *Journal of Aboriginal Health* (September 2006).

<sup>81</sup> For a comparison of 2001 and 2006 disability rates in these population groups, see Statistics Canada, *Participation and Activity Limitation Survey: Analytical Report* (Ottawa: Statistics Canada, 2007), online: <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm> (last accessed: 24 September 2014).

<sup>82</sup> Rubab Arim (2015). A profile of persons with disabilities among Canadians aged 15 years or older, 2012. Ottawa: Statistics Canada.

<sup>83</sup> The Honourable Sharon Carstairs (2010). *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Ottawa: Senate of Canada, at p. 24.

from the current rate of 260,000 deaths per year to more than 425,000 per year by 2036.<sup>84</sup> Lack of access contributes to the stress that both patients and family caregivers face at end-of-life, which may contribute to suicidal ideation and intent or coercion, as discussed above.

- **Increasing prevalence of mental health difficulties** – A study for the Mental Health Commission of Canada estimates 20% of Canadians experience mental health difficulties annually, including mood disorders, anxiety disorders, schizophrenia, attention deficit/hyperactive disorders (ADHD), personality disorders, substance use disorders or dementia. It estimates that within a generation more than 8.9 million Canadians will be living with a mental illness.<sup>85</sup> People with disabilities who experience rates of violent victimization much higher than the general population are also more likely to self-rate poor or fair health status, as well as sleep disorders and use of antidepressants or sedatives, at rates 50% to 90% higher than the general population.<sup>86</sup>
- **Mental health disability and other disabilities co-related** – Statistics Canada estimates there are over 1 million Canadians with mental health disabilities, which are defined for population surveys as a long-term condition that limits daily activities. Of this group, almost 92% also report having at least one other type of disability.<sup>87</sup>
- **Poverty and labour force exclusion** – Working-age adults with disabilities are about twice as likely to live in poverty as the general population (20.5% versus 11%). Almost 40% of Aboriginal persons with disabilities live in poverty. Persons with severe disabilities are multiply disadvantaged, with over 50% living in poverty. Employment rates are far lower for working age adults with disabilities (51.3%) than those without (75.1%). Among working age people with intellectual disabilities, labour force participation is only 30%.<sup>88</sup> As noted above, in a study of those requesting PAD in Belgium

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<sup>84</sup> Quality End-of-Life Care Coalition of Canada (2010). *Blueprint for Action: 2010 to 2020*. Ottawa: Author, at p. 1.

<sup>85</sup> P. Smetanin, D. Stiff, C. Briante, C.E. Adair, S. Ahmad and M. Khan (2011). *The Life and Economic Impact of*

*Major Mental Illnesses in Canada: 2011 to 2041*. Toronto: RiskAnalytica, on behalf of the Mental Health Commission of Canada.

<sup>86</sup> See Samuel Perrault (2009). *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems*. Ottawa: Statistics Canada.

<sup>87</sup> Christine Bizier, Carley Marshall and Gail Fawcett (2014). *Mental health-related disabilities among Canadians aged 15 years and older, 2012*. Ottawa: Statistics Canada.

<sup>88</sup> Cameron Crawford (2013). *Looking Into Poverty: Income Sources of Poor People with Disabilities in Canada*. Toronto: IRIS - Institute for Research and Development on Inclusion and Society, 2013. Online: <http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/income-sources-of-poor-people-with-disabilities>; Crawford, C. (2013 version). *Disabling Poverty & Enabling Citizenship: Understanding the Poverty and Exclusion of Canadians with Disabilities*. Winnipeg: Council of Canadians

because of psychological suffering, 73% had been found medically unfit to work.<sup>89</sup>

- **Violence, abuse and insecurity<sup>90</sup>** – People with disabilities are twice as likely as non-disabled persons to be victims of violence. People with some form of cognitive or mental disability, including intellectual disability, are four times more likely to be victimized than those without. Women with disabilities are sexually assaulted at a rate at least twice that of the general population of women in Canada. Almost two thirds (65%) of violent crimes against persons with activity limitations were committed by someone who was known to the victim. Persons with disabilities are 2 to 3 times more likely to be victims of the most severe forms of spousal violence, including being sexually assaulted, beaten, struck or threatened with a weapon. It is estimated that 80% of psychiatric inpatients have been abused in their lifetimes.<sup>91</sup> Moreover, people with disabilities who are victims of violence are less likely than other victims to be satisfied with the police response and with the ability of courts to deal with the incidents in a timely manner. With the rate of sexual abuse experienced by Aboriginal persons with disabilities at five times the general population,<sup>92</sup> aboriginal persons with disabilities are particularly vulnerable.
- Barriers to preventive and acute health care – People with intellectual disabilities are three to four times more likely to die preventable deaths because of barriers to needed health care and other supports.<sup>93</sup>

Add to these factors the rapid aging of the Canadian population. This will mean a growing proportion of people with disabilities in the decades ahead and an increasing incidence of financial and other forms of abuse against persons with

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with Disabilities.

Online: <http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/understanding-poverty-exclusion>.

<sup>89</sup> Lieve Thienpont, Monica Verhofstadt, Tony Van Loon, Wim Distelmans, Kurt Audenaert and Peter P De Deyn (2015), Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study,” *BMJ Open* (5, online: <http://bmjopen.bmj.com/content/5/7/e007454.full>).

<sup>90</sup> For statistics referenced in this section, see Samuel Perrault (2009), *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems* (Ottawa: Statistics Canada).

<sup>91</sup> National Clearing House on Family Violence (2004), “Violence Against Women with Disabilities.” (Ottawa: Minister of Public Works and Government Services Canada).

<sup>92</sup> Larry Chartrand and Celeste McKay (2006), *A Review of Research on Criminal Victimization and First Nations, Métis and Inuit Peoples 1990-2001* (Ottawa: Department of Justice Canada).

<sup>93</sup> See P. Heslop et al (2014), “The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study,” *The Lancet*; 383: 9920, 889–895; and Stacey Atkinson, Joanne Lay, Su McAnelly, Malcolm Richardson (eds.) (2015), *Intellectual Disability in Health and Social Care* (New York: Routledge).

disabilities including older persons, especially with the large inter-generational transfer of wealth currently underway:

- **Rapid increase in cases of dementia** – The almost half a million Canadians with dementia in 2008 will increase 2.3 times by 2038 to over 1,125,000 individuals, at which point there will be 250,000 new cases diagnosed each year.<sup>94</sup>
- **High rates of depression among seniors** – The Canadian Institute for Health Information reports that over 40% of seniors living in residential care in Canada have either been diagnosed with depression or show symptoms of depression.<sup>95</sup>
- **Elder abuse** – Estimates of elder abuse prevalence range from 4-10% of the population, with financial abuse being the leading form.<sup>96</sup>

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<sup>94</sup> P. Smetanin, P. Kobak, C. Briante, D. Stiff, G. Sherman, G. and S. Ahmad (2010), *Rising Tide: The Impact of Dementia in Canada 2008 to 2038* (Toronto: Alzheimer Society Canada).

<sup>95</sup> Canadian Institute for Health Information (2010). *Depression among Seniors in Residential Care: An Analysis in Brief*. Ottawa: Author.

<sup>96</sup> See, for example, E. Podnieks (2008), Elder abuse: the Canadian experience. *Journal of Elder Abuse and Neglect*, (20(2):126-50); Charmaine Spencer (1998), *Diminishing Returns: An Examination of Financial Abuse of Older Adults in British Columbia* (Vancouver: Gerontology Research Centre, Simon Fraser University).

# Concerns with Expanding Access to Medical Assistance in Dying

## *A Review of Evidence*

Prepared by  
IRIS – Institute for Research and Development on Inclusion and  
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# Table of Contents

<b>Introduction .....</b>	<b>1</b>
<b>I. Concerns with Access through Advance Euthanasia Directives .....</b>	<b>1</b>
1. Continuous Identity and Respecting Past vs. Present Wishes .....	2
2. Others Interpreting Intolerable Suffering .....	3
3. Questioning Dementia as a Cause of Suffering.....	3
4. Communication and Determining Moment of Carrying Out AED .....	4
5. Conflicts of Interest .....	4
6. Balancing Autonomy and Right to Life of Vulnerable Persons .....	4
7. Gaps in Service .....	5
<b>II. Concerns with Access by Mature Minors .....</b>	<b>5</b>
1. Capacity for Discernment and Decision Making .....	5
2. Vulnerabilities Specific to Minors .....	6
3. Gaps in Service Motivate Requests.....	6
<b>III. Concerns with Access Based Solely on Mental Illness.....</b>	<b>6</b>
1. No Conclusive Evidence that Mental Health Conditions are Irremediable .....	6
2. Capacity to Consent is Often Compromised .....	7
3. Vulnerability Cannot be Adequately Assessed or Addressed without an End-of-Life Criterion .....	7
4. Access Based Solely on Mental Health Conditions Would Undermine Equality of People with Disabilities and Promote Ableist Stereotypes in Violation of MAiD Objectives.....	9
5. Charter Equality Rights Could Not Constrain Access Only to People with Mental Health Conditions .....	9
6. Expanded Access Risks Major Unintended Social Consequences.....	10
<b>Conclusion.....</b>	<b>11</b>
<b>References .....</b>	<b>13</b>



## Introduction

This paper reviews a wide body of research and evidence to critically consider expanding access to medical assistance in dying (MAiD) in the Canadian context. In adopting amendments to the *Criminal Code* in June 2017, Parliament committed to studying implications of expanding access to MAiD by providing for eligibility for mature minors, through advance directives and based solely on a mental health condition, which would mean removing the end of life requirement currently in the legislation.

The paper reviews literature from academic sources in psychology, bio-ethics, clinical studies, social policy and disabilities studies. As well, it draws on a wide range of policy research. The aim of this paper is to focus on literature and evidence which raises concerns with expanding access.

The review is organized into three main sections:

- Concerns with Access through Advance Euthanasia Directives
- Concerns with Access by Mature Minors
- Concerns with Access Based Solely on Mental Illness

### I. Concerns with Access through Advance Euthanasia Directives

Advanced directives (ADs) are statements and/or directions written by an individual about which medical treatments should or should not be performed if the individual becomes incapable of decision making (Downie & Lloyd-Smith, 2015). ADs have been developed to ensure that an individual's autonomy and preferences are respected throughout their life (de Boer, Droës, Jonker, Eefsting, & Hertogh, 2010b). ADs can offer individuals comfort and reassurance that they will retain control of their end-of-life health care, even when they are no longer able to communicate (Gastmans & De Lepeleire, 2010). ADs can be useful tools in advancing Supported Decision Making; they allow individuals to make medical treatment decisions in advance, that is, for a time when their decision-making capacity may be impaired. In this sense ADs help support Supported Decision Making's principle of autonomy.

ADs are justified as a mechanism both to protect exercise of negative liberty rights – i.e., refusing specific intervention – and to protect positive rights to specific interventions (de Boer et al., 2010b). ADs have been critiqued based on lack of clarity, ability of individuals to predict their future wishes, and possible interference with a physician's judgment, although some suggest that about certain interventions and situations ADs can be justified to respect individual autonomy (Gastmans, 2013; Hertogh, de Boer, Droës, & Eefsting, 2007; Mitchell, 2010).

In the context of assisted dying, Advanced Euthanasia Directives (AEDs) are a means to exercise positive rights: they request physicians to perform interventions intended to cause death at a certain point in the future. The Netherlands is the only country in which AEDs can be carried out for patients with advanced dementia (Belgium allows for AEDs but the individual must no longer be conscious and the AED must have been written at least five years before the start of

incapacity) (Downie & Lloyd-Smith, 2015). Netherland's *Termination of Life on Request and Assisted Suicide Act 2002* states that an individual deemed capable can draft an AED to be carried out when they reach a state of unbearable suffering, and that physicians may follow the directive so long as the due-care criteria set out in the act are met (Bolt, Snijewind, Willems, van der Heide, & Onwuteaka-Philipsen, 2015; van Delden, 2004).

In the case of AEDs, in which death is the specific intent (compared to non-treatment directives that permit the potential of death), it has been argued that these concerns are intensified and the potential for harm is too great to overcome (Francis, 1993; Vogelstein, 2017). These arguments draw on the concept of the sanctity of life, concluding that it is worse to end someone's life when they did not explicitly consent to its termination, than not end their life when they wanted it to end (Vogelstein, 2017).

Thus, there is a crucial difference in both legal and moral terms between ADs and AEDs. While it is legally acknowledged that patients have the right to refuse treatment, the positive right to have an intervention performed that is intended to cause a person's death constitutes a weaker claim on the state. Moreover, the rights of physicians to refuse to perform a treatment they believe is ethically inappropriate or harmful is an ethically stronger claim (Vogelstein, 2017).

Most literature and research on AEDs focuses on how they are to be applied to individuals with dementia and whether an individual should be permitted to draft an AED that requests MAiD to be carried out when they reach an advanced stage of dementia and no longer have the capacity to make the request or provide informed consent for the intervention.

The research and ethics literature points to seven main concerns with allowing AEDs for individuals with dementia.

### **1. Continuous Identity and Respecting Past vs. Present Wishes**

There is an unresolved philosophical question (based on Ronald Dworkin's (1993) concepts of critical and experiential interests) about whether the person making the AED at a certain point in time can bind their future self to its terms when it is impossible to anticipate how that future self will change through the various stages of dementia (Dresser, 1995; van Delden, 2004). Dworkin's well-known argument suggests that the self making the AED has absolute authority to make decisions for future selves, even if they may develop a different set of desires and values (Menzel & Steinbock, 2013; Mitchell, 2010). However, there is clear evidence that an individual may adapt and be content to live in an advanced stage of dementia that they previously thought would be intolerable (Cohen-Almagor, 2016; de Boer Droës, Jonker, Eefsting, & Hertogh, 2010a; Dresser, 1995; 1999).

Biomedical and psychological research do not provide conclusive evidence to justify the moral and legal authority of AEDs; in fact, quite the opposite. Research shows that people are limited in their ability for affective forecasting (predicting future emotional states), often underestimating how quickly they cope with negative circumstances when confronted with them in the future (Gastmans, 2013; Halpern & Arnold, 2008; Wilson & Gilbert, 2005). Research

has found that persons with dementia have reported that the experience of their condition was not what they feared it would be (Bolt, Pasman, Deeg, Onwuteaka-Philipsen, 2015; Cohen-Almagor, 2016; Hertogh, 2009; Menzel & Stenibock, 2013).

Moreover, studies in the Netherlands have found that physicians and relatives of persons with dementia report hesitation about what to do if the patient seems to have adapted to their situation and also uncertainty about determining the exact moments to carry out AEDs (de Boer et al., 2010a; Kouwenhoven et al., 2015; Tomlinson, Spector, Nurock, & Stott, 2015). Physicians and family members are thus placed in an almost impossible position. How are they to determine whether the current situation meets the criteria set by the person who authorized the AED in the past, at a time they were unable to anticipate what would come to pass, or to anticipate their experiential interests at an undetermined point in the future (Gastmans, 2013; Hertogh et al., 2007)? Given these obvious concerns, most physicians in the Netherlands choose only to use the AED as a non-treatment, or withdrawal of treatment, directive (de Boer, Droës, Jonker, Eefsting, & Hertogh, 2011).

## **2. Others Interpreting Intolerable Suffering**

The *Medical Assistance in Dying Act* states that an individual must be experiencing “intolerable suffering” to be eligible for assisted death, but the term is never clearly defined. Concerns have been raised about such wide scope for interpreting eligibility criteria in the context of assisted death, because it can lead to manageable levels of suffering being considered intolerable (Hertogh, 2009). Even if strictly defined, establishing the presence of intolerable suffering is difficult, particularly in the case of dementia patients, who may not be able to express themselves in ways that others understand (Hertogh et al., 2007; Rietens, van Tol, Schermer, & van der Heide, 2009). This places immense pressure on family members and physicians to determine whether an individual is truly suffering from their condition, as they feared they would be when they drafted the AED, and whether the suffering can be relieved through other means, such as expanded and enriched social relationships and rehabilitation interventions (Goering, 2007; Rietens et al., 2009). Moreover, AEDs reference an undetermined future in which the directive can be carried out, which increases the scope for uncertainty in interpretation and application (Francis, 1993; Franklin, 2015; Mitchell, 2010).

## **3. Questioning Dementia as a Cause of Suffering**

The idea that dementia is the cause of unbearable suffering can also be questioned. It can be argued that it is not the condition itself that causes suffering to be unbearable but rather the lack of inclusion and societal attitudes towards the elderly and those requiring assistance that lead to feelings of hopelessness and loss of dignity (Goering, 2007; Mitchell, 2010). Studies on interventions and therapies that promote the inclusion of persons with dementia, such as music programs, contact with nature and their neighbourhood, and life story workshops, show that quality of life can be enhanced and sense of dignity can be preserved (Eldirdir Osman, Tischler, & Schneider, 2016; Gillard & Marshall, 2011; McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Phinney, Kelson, Baumbusch, O'Connor, & Purves, 2016; Tranvåg, Petersen, & Nåden, 2015).

#### **4. *Communication and Determining Moment of Carrying Out AED***

The *Medical Assistance in Dying Act* states that individuals must be able to express consent immediately before MAiD is carried out. For individuals with advanced-stage dementia, this is often not possible, as they are often unable to communicate fully and may be lacking the cognitive abilities and insight to fully understand the nature and consequences of the decision. Physicians in the Netherlands report that adherence to the due care criteria set out in the law rests on their ability to communicate with the patient and go through a process of shared decision making, but that such communication is impossible in cases of patients with advanced dementia (Bolt et al., 2015; de Boer, Droës, Jonker, Eefsting, & Hertogh, 2011). This lack of communication makes it difficult for physicians to determine when the AED should be carried out and whether the individual's current state resembles the situation described in the AED (Gastmans & De Lepeleire, 2010; Hertogh, 2009; Mitchell, 2010). It opens up the very real risk that MAiD could be carried out against an individual's contemporaneous wishes (Gastmans, 2013; van Delden, 2004).

#### **5. *Conflicts of Interest***

Studies in the Netherlands have found that physicians work with family members to determine whether to carry out AEDs and when to do so (de Boer et al., 2010b). This raises the potential that family members with something to gain from the death of their relative choose to carry out an AED too early. The gain may be tangible, such as an inheritance, or it may be intangible, and even unconscious, such as the relief from providing care, feelings of guilt, or ongoing loss of their relative.

#### **6. *Balancing Autonomy and Right to Life of Vulnerable Persons***

Respect for an individual's autonomy is an important goal in decision making, but it must be balanced with the recognition that persons with advanced-dementia are vulnerable. AEDs have the potential to increase the vulnerability of an individual because they give relatives and physicians power to determine when MAiD should be performed (Gastmans, 2013; Gastmans & De Lepeleire, 2010; van Delden, 2004). As well, AEDs can potentially increase the vulnerability of persons with dementia as a whole, particularly those that live in group living settings; if one person chooses to write an AED, it may weaken the resiliency of those around them with a similar condition by promoting the idea that life with advanced dementia is not worth living. The legalization of AEDs may also increase the prevalence of the idea that those with dementia are burdens and have a "duty" to society to choose to die, which could in turn work to further increase the stigma against persons with dementia in our society and work to threaten the provision of quality of care, thus pressuring persons who would not normally choose to write an AED to do so (Benbow & Jolley, 2012; Gastmans & De Lepeleire, 2010; Gastmans & Denier, 2010; Johnstone, 2013). Indeed, a recent survey of caregivers of people with Alzheimer's in Quebec found that 91 percent of respondents supported MAiD for individuals with dementia who are at the terminal state of their illness, showing signs of distress and who have an AED and that 77 percent of respondents reported that they would write an AED if diagnosed with dementia, signaling that this trend may already be taking root (Derfel, 2017).

## **7. Gaps in Service**

Research suggests that individuals may be motivated to draft AEDs because of the quality of care and/or gaps in needed services which can underlie fears that dementia brings an inevitable loss of dignity, a burden to relatives, and social stigma. An AED motivated by such fears may not accurately reflect the wishes of an individual (Cohen-Almagor, 2016; Gastmans, 2013; Mitchell, 2010). Significant investment in and transformation of services and supports for individuals with dementia is required to diminish the concerns associated with dementia in the current context (Franklin, 2015; Gastmans & De Lepeleire, 2010; Menzel & Steinbock, 2013).

## **II. Concerns with Access by Mature Minors**

The legal ability of minors to make decisions regarding medical treatment varies across Canada. Quebec and New Brunswick have legislated the age of medical consent to be 14 and 16, respectively. In the other provinces and territories there is no defined age of consent and the “mature minor doctrine” is generally applied (MacIntosh, 2016). In legal terms, this means that minors between 16 and 18 years old are usually considered capable of making medical treatment decisions (Schuklenk, van Delden, Downie, McLean, Upshur, & Weinstock, 2011). This capability is questioned when the decision is considered to be at odds with the minor’s best interest (most often this involves cases of treatment refusal). In such cases, the court may override the minor’s decision if it believes that the minor does not appreciate the nature and consequences of their decision (Arshagouni, 2006; MacIntosh, 2016). The most relevant legal case in Canada is *A.C. v. Manitoba*, in which a 15-year-old refused consent to a life-saving treatment. The Supreme Court decided that the right to make decisions varies in accordance with a minor’s level of maturity and the degree to which the maturity is scrutinized intensifies in accordance with the severity of potential consequences of the treatment and its refusal (*A.C. v. Manitoba*, 2009).

The research points to three over-riding concerns about extending access to mature minors.

### **1. Capacity for Discernment and Decision Making**

The *Medical Assistance in Dying Act* requires that an individual be able to give “informed consent” before receiving MAiD. In order to provide informed consent, one must have the capacity to understand and fully appreciate the situation they are in and the consequences of their decision. However, psychological and neuroscience literature questions whether mature minors can fully meet this test because of an inherent lack of life experience, especially when it comes to major life decisions like MAiD. (Cuman & Gastmans, 2017; Friedel, 2014; Giglio & Spagnolo, 2014; Raus, 2016). This evidence suggests that compared to adults, minors may lack the experiential knowledge, stability of values and preferences, and sense of self that is necessary to make decisions about MAiD (Kaczor, 2016; Siegel, Sisti, & Caplan, 2014; Wolf, 1998).

Furthermore, evidence from neuroscience and brain development suggests that minors tap into different patterns of brain structures and pathways in making decisions than adults. Because

the frontal lobe (the area responsible for governing executive functions such as decision-making and abstract reasoning) develops last and after earlier developing limbic system responsible for emotional response, minors tend to over-rely on the latter structures for decision making. It has been found that minors have a propensity to discount long-term consequences and have more difficulty regulating emotional systems in their decision making. Therefore, even though a minor may have the capacity to understand the circumstances of their situation, they may not have the ability to fully reason and make informed judgments about life and death situations (Arshagouni, 2006; Diekema, 2011; Mendelson, 2014).

## ***2. Vulnerabilities Specific to Minors***

The economic and emotional dependence of minors on parents and other relatives makes them particularly vulnerable to coercion and influence, which may lead to choosing MAiD (Giglio & Spangnolo, 2014; Wolf, 1998). Even if parents do not explicitly tell their child to request MAiD, a minor may feel pressure to relieve their parents of emotional and financial burdens (Cuman & Gastmans, 2017; Kaczor, 2016). As well, a child who has yet to fully develop executive functions associated with frontal lobe development may be more sensitive to the opinions of their parents and want to satisfy their parents' expectations (Kaczor, 2016; Keeling, 2017). For children and youth with disabilities these concerns are compounded as they have been found to be more likely to be in the child welfare system (Lightfoot and Hill, 2009), have suicidal ideations and behaviour (Gianni, et al., 2010), and live in households dealing with poverty (Statistics Canada, 2008).

## ***3. Gaps in Service Motivate Requests***

Pediatric palliative care and mental health services for youth have been found to be under serviced (Dan, 2015; Friedel, 2014; Widger et al., 2007). Physicians argue that if better palliative care and mental health services were provided, minors would not be compelled to request MAiD (Cuman & Gastmans, 2017; Giglio & Spangnolo; Khader & Mrayyan, 2017; Silva & Nunes, 2015).

# **III. Concerns with Access Based Solely on Mental Illness**

Research points to six main concerns in providing access to MAiD based solely on a mental health condition.

## ***1. No Conclusive Evidence that Mental Health Conditions are Irremediable***

An extensive literature on mental illness and the question of irremediability of conditions suggests that the apparent 'futility' of medical psychiatric treatments in a particular case should not be equated with a conclusion that the condition is in and of itself irremediable (Bilkshavn, Husum, & Magelssen, 2017; Broome & de Cates, 2015; Claes et al., 2015; Kim & Lemmens, 2016; Miller, 2015; Olié & Courtet, 2016; Rousseau, Turner, Chochinov, Enns, & Sareen, 2017; Shaffer, Cook, & Connolly, 2016). Cases in the Netherlands and Belgium have highlighted the impossibility of making a conclusive finding that an individual's condition is treatment-resistant. Many individuals whose request has been approved later withdraw their request after receiving

alternative treatment and/or therapy (Claes et al., 2015; Dierickx et al., 2017; Kouwenhoven, 2013; Lemmens, 2016).

The Canadian Mental Health Association has recently issued a background paper informing its position that access to MAiD should not be provided solely on the basis of a mental health condition (Canadian Mental Health Association, 2017). The basis of its position is that the research evidence is simply not conclusive that any mental health condition is by definition irremediable.

## ***2. Capacity to Consent is Often Compromised***

No blanket statement is justified that mental health conditions, by definition, undermine capacity to consent, and jurisprudence in Canada and internationally affirms this. However, particular conditions, for specific individuals, in certain circumstances can compromise an individual's ability to assess a situation and make reasoned decisions (Charland, Lemmens, & Wada, 2016; Claes et al., 2015; Lemmens, 2016; Shaffer, Cook, & Connolly, 2016). Clinical depression has been found to interfere with an individual's weighing of short-term and long-term consequences and judgment of their circumstances (Broome & de Cates, 2015; den Hartogh; Frati, Gulino, Mancarella, Cecchi, & Ferracuti, 2014; Kim & Lemmens, 2016; Olié & Courter, 2016).

In this context, it might be assumed that the standards for informed consent and capacity assessment become more rigorous. However, evidence about practice suggests the opposite. While physicians report difficulties in determining whether individuals with mental health conditions have the capacity to consent to assisted death, reviews of such cases have found that physicians generally require only a low threshold be met before a request for MAiD is approved (Doernberg, Peteert, & Kim, 2016).

Concerns have also been raised about cases where an individual, whose initial request had been denied by their primary physician, is later approved for assisted death another physician less familiar with the person and their situation. As well, there are cases in which physicians have disagreed about an individual's capacity to consent and/or their prognoses, but an medically-assisted death was nonetheless administered (Kim, De Vries, & Peteet, 2016).

Cognizant of these concerns, both the Royal Dutch Medical Association and the Dutch Association of Psychiatry have issued guidelines calling for extreme caution when dealing with requests for assisted death from individuals with mental health conditions. There is inherent indeterminacy in judging decision-making capacity in these situations, and especially in a context where evidence suggests psychoanalytic transference and counter-transference with presiding physicians can operate to compromise the process of obtaining informed consent free of inducement or external pressure (Pols & Oak, 2013).

## ***3. Vulnerability Cannot be Adequately Assessed or Addressed without an End-of-Life Criterion***

In the regimes for assisted death in Belgium and the Netherlands, individuals with mental health conditions are permitted to request assisted death solely on that basis. In Belgium, in addition to fulfilling the general criteria of being in a state of constant and unbearable suffering that cannot be reasonably alleviated as deemed by two physicians and possessing full competence, individuals with a mental health condition must also undergo consultation with an independent psychiatrist and wait at least one month between the date of the written request and the date the request is carried out (Lemmens, 2016; Naudts et al., 2006).

In the Netherlands, assisted death for individuals with mental health conditions has been permitted officially since 2002, but had been practiced prior based on jurisprudence authorizing the practice (Cowley, 2013; Pols & Oak, 2013; Kissane & Kelly, 2000). The 2002 legislation set out no additional criteria for individuals with mental health conditions to meet. General criteria are applied in all cases, including: that the individual's request is voluntary and well considered; the individual is suffering unbearably without prospect of improvement or reasonable treatment alternative; the individual is informed about their situation; and, at least one other physician has been consulted (Kim, De Vries, & Peteet, 2016).

In Belgium, from 2002 when the practice was legalized, to 2013, there were 117 reported cases in which a psychosocial disability was the sole diagnosis, with an uptake in cases being reported in more recent years (Dierickx, Deliens, Cohen, & Chambaere, 2017). In the Netherlands, 66 cases of assisted death were reported for individuals with mental health conditions between 2011 and 2014 (Doernberg, Peteert, & Kim, 2016). In both countries, depression and personality disorders are the most common disability reported, but cases of individuals with Asperger's Syndrome, ADHD, intellectual disability and eating disorders have also been reported (Charland, Lemmens, & Wada, 2016; Dierickx et al., 2017; Thienpont et al., 2015; Kim, De Vries, & Peteet, 2016).

In the study of the cases in the Netherlands (Kim, De Vries and Peteert, 2016) many vulnerability factors were observed, including the prominence depressive disorders, post-traumatic stress disorder and anxiety disorders. The majority of those who were euthanized under the system had already attempted suicide, and 80% had been hospitalized previously for psychiatric conditions. Social isolation and loneliness characterized those making the requests.

This and other research evidence points to social determinants motivating requests and compounding the suffering associated with the medical condition, including such factors as concern about being a burden on others, fears about losing autonomy, lack of support, and confinement to institutional facilities.

Thus, it is the societal response (or lack thereof), that can result in intolerable suffering for people living with mental health and other disability-related conditions. Research from the Netherlands, Belgium, and Switzerland find that individuals are turning to assisted death because of inadequate social and community support and because it is becoming an acceptable solution to challenges faced by vulnerable populations, particularly individuals with disabilities and the elderly (Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2016). Findings from the



recent survey in Quebec (Derfel, 2017) suggests that prospectively we could anticipate similar outcomes if the end-of-life condition requirement were no longer in place.

In a system for MAiD where eligibility can depend only on mental health conditions, what prevents those most at risk of suicidal ideation and behavior because of a lack of social determinants of health in their lives – persons with disabilities, indigenous persons and transgender youth to name just three of many examples – from accessing the system to die?

#### **4. Access Based Solely on Mental Health Conditions Would Undermine Equality of People with Disabilities and Promote Ableist Stereotypes in Violation of MAiD Objectives**

Providing access to MAiD based solely on a mental health condition would mean radically changing a key component of the definition of a “grievous and irremediable medical condition” as it is defined in the *Medical Assistance in Dying Act* – that, among other criteria, a person must be in a condition in which their natural death is “reasonably foreseeable.” For advanced dementia or a mental illness to be considered eligible grounds to receive MAiD, the criterion of the reasonable foreseeability of natural death would have to be removed. The presence of this eligibility criteria currently works to limit a number of otherwise serious and incurable conditions as eligible grounds for receiving MAiD. Removing this criterion would open the possibility that any incurable and irremediable long-term condition—including a disability condition—could be considered grounds for MAiD, if the person finds their suffering intolerable.

Although any disability can be managed if supported, persons with disabilities can suffer intolerably when proper support and social inclusion is lacking. Accepting that a disability condition is a reason for ending a life would, as a consequence, reinforce the ableist notion that life with disability is not worth living. Even if such a policy did not result in explicit coercion of people with disabilities to request MAiD, it would reinforce discriminatory attitudes and negative social stigma toward people with disabilities (Gill, 2010). Further, the “choice” of MAiD might reduce the pressure on society to provide services and support for persons with disabilities and their families (Golden & Zoanni, 2010).

#### **5. Charter Equality Rights Could Not Constrain Access Only to People with Mental Health Conditions**

While there is discussion in the Canadian context of whether access to MAiD should be extended to people solely on the basis of mental health conditions, expanding access on this basis could not likely be constrained to those parameters in the context of *Charter* equality rights.

Evidence from Switzerland, Belgium and the Netherlands shows alarming consequences of expanding access beyond end-of-life requirements. In the Netherlands and Switzerland, any suffering that is unbearable and without any prospect of improvement is an eligible criterion, and there is no requirement for a diagnosable condition (Fischer et al., 2009; Legemaate & Bolt, 2013). Belgian law does require evidence that the persistent and unbearable suffering (physical

or psychological) stems from a serious and incurable condition, but that condition does not need to be an end-of-life condition (Raus & Sterckx, 2015).

The consequence of these broad eligibility criteria has been that individuals with a range of physical and mental disabilities and even vague conditions have been able to request—and receive—assisted deaths. In all three countries, reviews of cases have found that interpretation of the criteria have now expanded to include individuals whose claim of being “tired” or “weary” of life has been used to justify assisted death (Miller, 2016; Rurup et al. 2005). Other documented reasons in these jurisdictions for requesting and receiving assisted death are weariness of treatment, social isolation, decreased capacity to engage in activities, loss of concentration, loss of self, fear of future suffering, increased dependency, loss of autonomy, becoming a burden, loneliness, and hopelessness (Dees, Vernooij-Dassen, Dekkers, Vissers, van Weel, 2011; Fischer et al., 2009, Frei et al., 2001; Snijdwind, Willems, Deliens, Onwuteaka-Philipsen, & Chambaere, 2015). Assisted death is also being approved for persons with a range of disability-related conditions including Asperger’s Syndrome, autism, ADHD, intellectual disability and eating disorders.

Under *Charter* equality rights there would be a very strong case to be made that that restricting access only to people with mental health conditions is discriminatory on the grounds of mental and physical disability. The evidence from Switzerland, Belgium and the Netherlands makes clear that a much broader range of disability-related conditions can be associated with suffering sufficient to legally justify assisted death in those jurisdictions. Crossing the threshold of access based on mental health conditions in the Canadian context will inevitably open up access on a much broader basis, with the very likely result that internal and socialized stigma based on disability will have very fertile ground.

## **6. Expanded Access Risks Major Unintended Social Consequences**

It is also critically important to contextualize consideration of expanded access in an historic context. There are other points in history in which public health goals have been equated with the termination of certain forms of life, in the name of population health, compassion and reduction of suffering. These examples teach that delivering on such aims can have unintended social consequences. These examples do not necessarily imply that widespread termination of life of people with disabilities would be inevitable if, for example, the reasonable foreseeability criterion was removed from the legislation, but they do encourage pause, and serve as a reminder that what may first appear to be valid public health goals can have unintended and negative consequences.

The first example is the eugenics movement of the 20<sup>th</sup> century. In Canada, support for eugenics—that is, the notion of improving a population by controlled breeding—came from the belief that eugenic interventions (i.e. forced sterilization of certain individuals could rid the population of “feeble-mindedness” and mental deficiency, considered as they were to be causes of social ills (McLaren, 2015). This understanding led to persons with disabilities being unjustly and forcibly subjected to segregation and sterilization (Acevedo Guerrero, 2015; Grekul, Krahn, & Odynek, 2004).

The second example is the Nazi eugenically-based extermination program, which took these policies further; the program, which began with the goal of carrying out acts of mercy on persons with disabilities (Gallagher, 1990) and started with forced sterilization, ended with the mass murder of hundreds of thousands of persons with disabilities and individuals with mental illnesses (Bachrach, 2004; Strous, 2006).

The third example is the use of prenatal testing for genetic disability-related conditions which has been used to encourage termination of certain fetuses thought to be carrying disability-related traits (de Graaf, Buckley, & Skotko, 2015; Steinbach, Allyse, Michie, Liu, & Cho, 2016). Social assumptions about what constitutes pre- and post-natal ‘normalcy’ strengthen the social foundations for viewing people with disabilities as abnormal and deficient, thus contributing to pervasive stigma which people can internalize in self-judging ways (Asch, 1999; Asch, 2000; Browner & Press, 1995; Hubbard, 2013; Saxton, 2000).

Understanding of the inherent value of lives of people with disabilities has progressed since the eugenics movement and Nazi programs, but, as the termination of fetuses with disability traits shows, persons with disabilities still face discrimination, exclusion, and a prevailing societal belief that their life is something to be avoided. Clearly, lessons from history can, and should be applied to critically considering MAiD and its expansion (Frazee, 2017).

## **Conclusion**

The Supreme Court of Canada in the *Carter* decision required that Parliament, in designing a system for exemptions to the prohibition on assisted suicide, strike a balance between the right to autonomy of a competent adult with a grievous and irremediable medical condition experiencing intolerable suffering, and the need to protect vulnerable persons (*Carter v. Canada*, 2016, para. 2). Evidence reviewed in this paper clearly suggests that expanding access through advance directives, approval of requests from mature minors, and eligibility solely on the basis of a mental health condition would pose significant risk to managing that balance in practice. Moreover, the removal of the “reasonable foreseeability of natural death” criterion that would come with providing access solely on the basis of a mental health condition would itself significantly expand access far beyond mental health conditions. The equality rights framework in Canada would undoubtedly be used to successfully challenge restricting access to mental health conditions, once the end-of-life criterion is removed. This would pose significant structural and long-term disadvantage to the status of people with disabilities in the Canadian context.

The research reviewed for this paper points to a large body of evidence that overwhelmingly finds that the intolerable suffering motivating requests for assisted death is often caused by social factors amenable to intervention. Deeply entrenched and for many, internalized, social stigma still equates loss of physical and psychic independence, and dependency on others for personal care, with inherent indignity and loss of autonomy. These equations are by no means inevitable. Rather, they result from well-documented, persistent gaps in access to needed

disability-related supports and palliative care and lack of valued social and economic status for those defined by disability-related conditions. Expanding access to MAiD in the name of public health would appear, in fact, to significantly risk further entrenching the negative disability-related stereotypes that the MAiD legislation explicitly seeks to guard against in its statutory objectives. Thereby, and based on evidence from other jurisdictions, the very criteria for eligibility and access to MAiD would come to constitute social norms that devalue the lives and needs of people with disabilities. This would be a tragic outcome for a group whose equality rights were to be protected and whose structural and historic disadvantage was to be redressed, not further entrenched, under Canada's *Charter of Rights and Freedoms*.

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Canadian Association of MAID Assessors and Providers

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached letter and survey results.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached letter and survey results.



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September 2017

To: The Council of Canadian Academies

CAMAP welcomes the opportunity to provide information to the panels. As the only association of assessors and providers of medical assistance in dying (MAID) in the world, CAMAP has an important role to play in helping determine best medical practice and is in a unique position to provide feedback to regulators and other health practitioners about MAID. Our current membership has representation from ten provinces and two territories.

Limited data exists on MAID and even less information on the specific issues the Council seeks to study. Rather than just the experienced opinion of the CAMAP Board, in this submission and the attached supporting documentation we will provide you with data from a survey of active assessors and providers of MAID.

**Mature minors**

MAID should be permissible for minors. Our member survey shows that 95% of current assessors and providers agree, as there is no difference in the intolerability of suffering of a child with advanced incurable cancer and that of an adult with the same condition. For the law to disallow MAID for the younger person seems cruel. Robust safeguards would need to be in place as already exist for MAID in Canada, and for other treatment decisions for minors around the world. Belgium has a system of graded involvement of parents with parental consent necessary up until a certain age, and involvement of parents required but their consent not necessary beyond that age.

Our member survey suggests 82% of current assessors and providers would be willing to assess mature minors for MAID and 70% would be willing to provide MAID to a mature minor deemed eligible.

**Advance requests**

Advance requests for MAID is something that Canadians wish to have available. In an Ipsos Reid poll in February 2016, 80% of Canadians said that patients with a serious illness should be able to make advance requests for physician assisted dying. 76% of Christians, 76% of health



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professionals and 88% of the disability community are in favour. 71% of Canadians support allowing a person who does not yet have a serious illness to make an advance request.

The CAMAP poll shows 82% of current assessors and providers would be willing to assess patients who have made an advanced request for MAiD but have lost the capacity to make their own health care decisions and 76% would be willing to provide MAiD for them if deemed eligible.

### ***Advance requests for those who have already been found eligible for MAiD***

Current law requires that a person must have capacity at the time of the MAiD procedure itself. We have witnessed many patients forego painkillers and sedatives during the days before their scheduled MAiD date in order to reduce the risk of loss of capacity. Our membership strongly believes that advance requests must be made permissible for those who have already requested and been deemed eligible for MAiD.

Our survey shows 94% of active assessors and providers agree that if such an individual loses capacity due to illness progression or secondary to the effects of necessary analgesics or sedatives then MAiD should be allowed to proceed.

This is not a theoretical problem. Across Canada many providers have experienced the gruelling situation of having to tell the patient and their family that although they have requested MAiD and been found eligible, they may now not receive the release they have sought because they have lost capacity. Loss of capacity does not mean there is a loss of the ability to suffer.

### ***Advance requests for those whose suffering is not yet intolerable and for those who do not yet have a grievous and irremediable condition causing intolerable suffering***

Even within groups and organizations supportive of advance requests debate exists regarding the circumstances under which this should be permitted. Most agree that dementia or any other capacity-diminishing condition, once it has reached the point of causing loss of capacity, is a grievous and irremediable condition and that the person is in an advanced state of irreversible decline in capability, as required by the law. Disagreement arises as to what constitutes enduring physical or psychological suffering. Some argue that the person should be permitted to define in their advance request the circumstances that they assert would qualify as causing intolerable suffering, such as not being able to toilet themselves, recognize family, speak, or mobilize independently. This is a common viewpoint amongst the general public. Others, including we believe a greater proportion of physicians than of the general public, contend that a person with capacity does not necessarily know what will cause them to suffer when they have lost capacity.



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The nature and extent of suffering could instead be determined by MAID clinicians (physicians or nurse practitioners) trained in the assessment of individuals in this state.

CAMAP supports advance requests for MAID for those who have already requested MAID and been deemed eligible but who lose capacity. We urge the panel to consult widely on the issue of the circumstances in which it should be permitted for others.

### **Mental illness as the sole underlying medical condition**

The only restriction in the current law that affects persons with mental illness as the sole medical condition is section 241.2(2)(d) which requires that the person's natural death has become reasonably foreseeable. As very few mental illnesses will lead to natural death in the foreseeable future it is rare that a person with only mental illness will be found eligible for MAID.

The constitutionality of this sub-section is an issue wider than simply the effect on persons with mental illness and it is already being challenged in the *Lamb* case currently before the courts in British Columbia. If this clause were to be dropped, MAID would more likely become available for patients with mental illness as the sole underlying medical condition. Determining eligibility in such circumstances is not yet within our expertise but something our membership is willing to consider.

### **Attached (supplementary documents)**

1. CAMAP membership survey results
2. Collection of Comments from Individual Assessors and Providers



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### **CAMAP Survey results August 2017**

135 Assessors and Providers were surveyed from within our larger membership list. Those who did not go on to self-describe as either an active assessor or an active provider (or both) were excluded.

We do not claim or suggest that the remaining respondents are in any way a complete roster of MAiD assessors and providers in Canada but do believe they reflect the most active assessors and providers across the country (with the exception of those in Quebec who are not well represented herein).

79 responses were recorded:

18 respondents described themselves as an active assessor for MAiD

2 respondents described themselves as active providers of MAiD and

59 respondents described themselves as both an assessor and provider of MAiD

#### **Questions and results:**

**1. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow mature minors to request and receive MAiD under certain circumstances, would you be willing to assess mature minors for MAiD? (yes/no)**

14 answered No (18%)

65 answered Yes (82%)

**2. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow mature minors to request and receive MAiD under certain circumstances, would you be willing to provide MAiD for mature minors? (yes/no)**

22 answered No (29%)

55 answered Yes (70%)

2 did not answer

**3. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow advanced requests for MAiD such that a person who has lost capacity to make their own health care decisions can make an application for**





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**MAiD, would you be willing to assess patients who no longer have capacity to make their own health care decisions but are now presenting for MAiD? (yes/no)**

14 answered No (18%)

65 answered Yes (82%)

**4. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow advanced requests for MAiD such that a person who has lost capacity to make their own health care decisions can make an application for MAiD, would you be willing to provide MAiD for patients who no longer have capacity to make their own health care decisions but are now presenting for MAiD? (and presumably have been deemed eligible under the law) (yes/no)**

17 answered No (22%)

60 answered Yes (76%)

2 did not answer

**5. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow MAiD in patients where mental health is the sole underlying medical condition, would you be willing to assess patients for MAiD where mental health is the sole underlying medical condition? (yes/no)**

23 answered No (29%)

55 answered yes (70%)

1 did not answer

**6. Given that you currently assess and/or provide for MAiD, if federal law were to change to allow MAiD in patients where mental health is the sole underlying medical condition, would you be willing to provide MAiD for patients where mental health is the sole underlying medical condition? (and presumably have been deemed eligible under the law) (yes/no)**

24 answered No (30%)

51 answered Yes (65%)

4 did not answer



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**7. Leaving aside for the moment the question of mature minors exercising their right to MAiD without parental consent, please consider the following statement:**

**‘In the uncommon situation where a child suffers from a grievous and irremediable condition, as defined in current Canadian law as it relates to MAiD, and in the even more uncommon circumstance that parents and child agree that MAiD is their preferred option, I believe it should be legal and available.’**

35 Strongly agree (44%)

40 Agree (51%)

4 Disagree (5%)

0 Strongly disagree

**8. In the specific situation where a patient has requested MAiD and been deemed eligible, and in the circumstance that they go on to lose capacity to make this request due to disease progression or appropriate analgesic needs, they should be allowed to use their properly completed request as an advanced directive and receive MAiD as planned**

56 Strongly agree (70%)

19 Agree (24%)

3 Disagree (4%)

0 Strongly disagree

1 did not answer

Canadian Bar Association

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*



October 5, 2017

Via email: [reviews@scienceadvice.ca](mailto:reviews@scienceadvice.ca)

The Honourable Justice Marie Deschamps, C.C., Ad.E  
Chair, Expert Panel on Medical Assistance in Dying  
Council of Canadian Academies  
180 Elgin St., Suite 1401  
Ottawa, ON K2P 2K3

Dear Justice Deschamps:

**Re: Call for input on Medical Assistance in Dying - advance requests, requests by mature minors, and requests where mental illness is the sole underlying medical condition**

I am writing on behalf of the Canadian Bar Association's End-of-Life Working Group (CBA Working Group) in response to the call for input from the Council of Canadian Academies' Expert Panel on Medical Assistance in Dying.

The CBA is a national association of 36,000 lawyers, Québec notaries, law teachers and students, with a mandate to promote improvements in the law and the administration of justice. The CBA Working Group comprises a cross-section of members drawn from diverse areas of expertise, including criminal justice, constitutional and human rights law, health law, wills, estates and trusts law, elder law, children's law, corporate counsel, privacy law, dispute resolution and equality issues. The members include lawyers in private practice, the public sector, and in-house counsel.

End-of-life care issues touch all Canadians, but for CBA members there is an additional professional dimension. Lawyers across Canada write wills, health care directives and powers of attorney for our clients, who increasingly request legal advice on medical assistance in dying as part of their estate planning. Our members advise health care providers who are called on to make referrals to, or to administer, medical assistance in dying, and also advise related professions and industries.

In 2015, the CBA called for a framework to clarify the law about end-of-life decision-making and, after the Supreme Court of Canada decision in [Carter v. Canada \(Attorney General\)](#),<sup>1</sup> stressed the importance of a pan-Canadian approach. In August 2016, the CBA considered the three areas under review by the Expert Panel, namely advance requests, requests by mature minors, and requests where mental illness is the sole underlying medical condition. The CBA policies are attached.

<sup>1</sup>

[2015] 1 SCR 331, 2015 SCC 5

The CBA Working Group appreciates that the Expert Panel has not been tasked with making recommendations. Our comments elaborate the CBA policies and identify directions for research by the Expert Panel.

## **A. MATURE MINORS**

### **1. The legal status of mature minors**

In [\*A.C. v. Manitoba \(Director of Child and Family Services\) \(A.C.\)\*](#),<sup>2</sup> the Supreme Court of Canada made it clear that a mature minor can make an informed decision about their life and death. The Criminal Code excludes MAID as an option for any person under 18 years of age. The CBA believes the Code must be amended to respect the constitutional rights of mature minors.

Mature minors are a disenfranchised group with limited agency to retain legal counsel. Mature minors who are ill are even less able to engage counsel to argue their position. Given their vulnerability, the CBA Working Group reiterates the importance of proceeding with a constitutionally-grounded perspective on the right of mature minors to make medical decisions regarding their life and death.

### **2. Research**

The effect of the A.C. decision is that a person under the age of 18 must have the right to demonstrate mature medical decisional capacity, or the statute that precludes it will be found to be unconstitutional. However, the SCC noted that these are complex situations requiring a careful assessment of the young person's individual capacity for autonomous choice.

In those most serious of cases, where a refusal of treatment carries a significant risk of death or permanent physical or mental impairment, a careful and comprehensive evaluation of the maturity of the adolescent will necessarily have to be undertaken to determine whether his or her decision is a genuinely independent one, reflecting a real understanding and appreciation of the decision and its potential consequences.<sup>3</sup>

Consequently, appropriate tools to assess and confirm consent and capacity of minors in relation to MAID need to be developed. Lawyers are on the front lines of advising the full range of participants in MAID. The development of clear guidelines and requirements to assist lawyers and others determine whether a minor has mature medical decisional capacity for MAID or is adequately consenting to MAID is imperative. Research directed at these issues would be most helpful.

### **3. Relevant Authorities**

*A.C. v. Manitoba (Director of Child and Family Services)*, [2009] 2 SCR 181, 2009 SCC 30

Provincial statutes which contain a capacity- rather than age-based approach for purposes of health care (e.g. Ontario's *Health Care Consent Act, 1996*)

[United Nations Convention on the Rights of the Child](#)

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<sup>2</sup> 2009 SCC 30, [2009] 2 S.C.R. 181

<sup>3</sup> See note 2, at para. 95

## B. PSYCHIATRIC CONDITIONS

### 1. The legal status of individuals with psychiatric illness

In *Canada (Attorney General) v E.F.*,<sup>4</sup> the Alberta Court of Appeal concluded that persons whose medical condition is psychiatric in nature were not precluded from MAID, provided they otherwise met the criteria under the *Carter* decision. There is no consensus that the current MAID regime precludes the eligibility of these persons.<sup>5</sup> The CBA believes that current legislation should be amended to clarify that, with appropriate safeguards, persons suffering from psychiatric illness only are eligible for MAID.

### 2. Research

Similar concerns exist for persons with psychiatric illness as for mature minors, namely the need to develop appropriate assessment tools and clear guidelines and requirements to assist lawyers and others to determine whether a person with psychiatric illness has capacity to make a decision about MAID or whether a person has adequately consented to MAID. Research directed at these issues would be most helpful.

### 3. Relevant Authorities

*Canada (Attorney General) v. E.F.*, 2016 ABCA 155

Jocelyn Downie and Justine Dembo, *Medical Assistance in Dying and Mental Illness under the New Canadian Law*, JEMH · 2016 · Open Volume

## C. ADVANCE REQUESTS

### 1. The legal status of advance requests

A substantial majority of Canadians support advance requests, that is, that individuals should be permitted to consent to MAID in advance of losing their capacity to do so.<sup>6</sup> The Provincial-Territorial Advisory Group on Physician-Assisted Dying recommended that advance requests be permitted at any time following the diagnosis of a grievous and irremediable condition when suffering becomes intolerable. The Special Joint Committee on Physician-Assisted Dying<sup>7</sup> (Special Joint Committee) recommended that advance requests for MAID be allowed at any time after one is diagnosed with a condition that is reasonably likely to cause loss of capacity or after diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable.<sup>8</sup> The CBA supports these recommendations.

Some individuals who wish medical assistance in dying, but fear they will lose capacity before they can exercise their choice, may take their own life at an earlier point in time. The constitutional right to liberty includes “the right to make fundamental personal choices free from state interference.”<sup>9</sup>

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<sup>4</sup> 2016 ABCA 155

<sup>5</sup> See, e.g. Jocelyn Downie and Justine Dembo, *Medical Assistance in Dying and Mental Illness under the New Canadian Law*, JEMH · 2016 · Open Volume (<http://www.camapcanada.ca/dd2016.pdf>)

<sup>6</sup> See, e.g. February 2016 Ipsos research conducted for *Dying with Dignity*. (<http://ow.ly/B4pF30fCftj>)

<sup>7</sup> *Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying* (<http://ow.ly/5WL730fCfHD>)

<sup>8</sup> *Medical Assistance In Dying: A Patient-Centred Approach* (<http://ow.ly/HyGT30fCfTO>)

<sup>9</sup> See note 1, at para 64.

In *Carter*, the SCC acknowledged that the constitutional right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly.<sup>10</sup>

## 2. Research

Legislative safeguards need to be developed, consistent with the criteria recommended by the Provincial-Territorial Advisory Group and the Special Joint Committee. These include the right of a person to change their mind and to refuse MAID, regardless of capacity, and guidance on the role of the substitute decision-maker and health practitioner when implementing an advance request. Research directed at these issues would be most helpful.

In addition, the issue of advance requests would benefit from study of international experiences, including questions related to:

- Eligibility criteria for advance requests
- Mechanisms to ensure validity of advance requests
- Duration of advance requests
- Enforcement mechanisms

A review of mechanisms to facilitate coordinated, or preferably, harmonized approaches across jurisdictions in Canada would also be helpful.

## 3. Relevant Authorities

*Carter v. Canada (Attorney General)*, [2015] 1 SCR 331, 2015 SCC 5

Provincial-Territorial Advisory Group on Physician-Assisted Dying, Final Report (November 30, 2015)

Special Joint Committee on Physician-Assisted Dying, Medical Assistance in Dying: A Patient-Centred Approach (February 2016)

Please don't hesitate to let us know how we might further assist the Expert Panel in its work.

Yours sincerely,

*(original letter signed by Tina Head for Kimberly J. Jakeman)*

Kimberly J. Jakeman  
Chair, CBA End of Life Working Group

encl.

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<sup>10</sup> See note 1, at para 62.

## Clarifying Law About End of Life Decision-Making

**WHEREAS** end of life decision-making in health care is legally, ethically and emotionally challenging;

**WHEREAS** the lack of clarity in the law on the rights and obligations of patients, substitute decision-makers (SDMs) and health care providers leads to conflict and moral distress;

**WHEREAS** initiatives promoting advanced care planning should be encouraged while recognizing that not all disputes can be resolved through advanced planning;

**WHEREAS** it is critical that health care organizations have robust, compassionate and responsive dispute resolution mechanisms when patients or SDMs disagree with the health care being proposed;

**BE IT RESOLVED THAT** the Canadian Bar Association:

1. Urge provincial and territorial governments, in collaboration with stakeholders, to develop a framework to facilitate end of life health care decision-making that respects the following fundamental principles:
  - a. Patients and SDMs must be properly informed of the health care choices available to them and consent must be obtained prior to medical treatment being provided;
  - b. Except in certain public health matters, a competent patient has a right to refuse treatment even if it will lead to severe consequences including death;
  - c. A properly appointed SDM also has the right to refuse such treatment subject to and in accordance with their authority under the relevant document and legislation;
  - d. Neither a competent patient nor a SDM should have the right to demand treatment that is not offered because the health provider, acting in accordance with ethical and legal obligations, determines such treatment not to be clinically indicated, medically appropriate, or in the patient's best interests;

## Préciser le droit relatif aux décisions de fin de vie

**ATTENDU QUE** les décisions de fin de vie en matière de soins de santé sont difficiles sur les plans juridique, éthique et émotionnel;

**ATTENDU QUE** le manque de précision du droit relativement aux droits et obligations des patients, des mandataires spéciaux (MS) et des fournisseurs de soins de santé donne naissance à des conflits et à de la détresse morale;

**ATTENDU QUE** les initiatives favorisant la planification avancée des soins devraient être encouragées même s'il est reconnu que les différends ne peuvent pas tous être réglés au moyen de la planification avancée;

**ATTENDU QU'IL** est essentiel que les organismes de soins de santé disposent de modes de règlement des différends rigoureux, compatissants et adaptés lorsque les patients ou les MS sont en désaccord avec les soins de santé proposés;

**QU'IL SOIT RÉSOLU QUE** l'Association du Barreau canadien :

1. Exhorte les gouvernements provinciaux et territoriaux, en collaboration avec les parties prenantes, à élaborer un cadre pour faciliter la prise de décisions de fin de vie en matière de soins de santé, qui respecte les principes fondamentaux suivants :
  - a. Les patients et les MS doivent être convenablement informés des choix dont ils disposent en matière de soins de santé et le consentement à un traitement médical doit être donné avant que ce traitement ne soit reçu;
  - b. Sauf dans certains cas de santé publique, le patient capable a le droit de refuser un traitement même si ce refus entraînera de graves conséquences, notamment la mort;
  - c. Le MS dûment nommé a aussi le droit de refuser un tel traitement conformément au pouvoir que lui confèrent le document et la législation pertinents;
  - d. Le patient capable et le MS ne doivent pas avoir le droit d'exiger un traitement qui n'est pas offert parce que le fournisseur de soins de santé, agissant conformément à ses obligations déontologiques et légales, estime que ce traitement n'est pas indiqué sur le plan clinique, qu'il n'est pas approprié sur le plan médical ou qu'il



**Resolution 15-02-M**

- e. When more than one medically appropriate course of treatment is offered, a competent patient or SDM may decide the course of treatment even if it is not the course of treatment recommended by the health providers;
  - f. Health care organizations should be encouraged to put in place patient-focused, compassionate dispute resolution policies and procedures for use when there are disagreements about health care to be provided to patients;
2. Urge governments in provinces and territories without existing structures to put mechanisms in place for quick access to the courts (or specialized boards) when disputes cannot be resolved without assistance;
  3. Urge provincial and territorial governments, in consultation with the federal government, to ensure that valid SDM appointments under legislation in one province or territory are recognized and enforceable in other jurisdictions in Canada.

**Certified true copy of a resolution carried by the Council of the Canadian Bar Association at the Mid-Winter Meeting held in Ottawa, ON, February 21-22, 2015.**

**Résolution 15-02-M**

n'est pas dans le meilleur intérêt du patient;

- e. Lorsque plus d'un traitement approprié sur le plan médical est offert, le patient capable ou le MS peut décider du traitement même s'il ne s'agit pas de celui recommandé par les fournisseurs de soins de santé;
  - f. Les organismes de soins de santé doivent être incités à mettre en place des politiques et procédures de règlement des différends compatissantes et axées sur les patients en cas de désaccord au sujet des soins de santé à fournir aux patients;
2. Exhorte les gouvernements dans les provinces et territoires qui n'ont pas déjà de tels mécanismes en place à établir des mécanismes d'accès rapide aux tribunaux (ou à des commissions spécialisées) lorsque les différends ne peuvent pas être tranchés sans aide;
  3. Exhorte les gouvernements provinciaux et territoriaux, en consultation avec le gouvernement fédéral, à veiller à ce que toute nomination de MS qui est valide conformément à la législation d'une province ou d'un territoire soit reconnue et exécutoire dans les autres provinces et territoires du Canada.

**Copie certifiée d'une résolution adoptée par le Conseil de l'Association du Barreau canadien, lors de l'Assemblée de la mi-hiver, à Ottawa (ON), du 21 au 22 février 2015.**

**John D.V. Hoyles  
Chief Executive Officer/Chef de la direction**

## Physician-Assisted Dying

**WHEREAS** in *Carter v. Canada (Attorney General)*, the Supreme Court of Canada unanimously declared *Criminal Code* sections 241(b) (assisted suicide) and 14 (consent to death) to be unconstitutional and “void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition”;

**WHEREAS** the Court suspended the declaration of invalidity until February 2016;

**WHEREAS** a pan-Canadian approach to physician-assisted dying would be desirable;

**WHEREAS** legislators and regulators should consult with vulnerable people, including persons with disabilities and groups who represent them, as well as the Canadian Bar Association, in crafting a harmonized legislative approach to physician-assisted dying;

**BE IT RESOLVED THAT** the Canadian Bar Association:

1. urge the federal government to amend the *Criminal Code* to align with the *Carter* decision;
2. urge provincial and territorial governments to enact harmonized legislation establishing:
  - (a) clear pathways for timely access to physician-assisted dying;
  - (b) clear procedural safeguards that protect individuals who seek physician-assisted dying but do not impose unreasonable restrictions that would prevent those meeting the SCC criteria from accessing physician-assisted dying; and
  - (c) a system of oversight that ensures meaningful retrospective review of cases and the collection and public reporting of data on physician-assisted dying in Canada;

## Aide médicale à mourir

**ATTENDU QUE** dans l'arrêt *Carter c. Canada (Procureur général)*, la Cour suprême du Canada a déclaré, dans une décision unanime, que l'alinéa 241**b**) (aide au suicide) et l'article 14 (consentement à la mort) du *Code criminel* sont inconstitutionnels et « sont nuls dans la mesure où ils prohibent l'aide d'un médecin pour mourir à une personne adulte capable qui (1) consent clairement à mettre fin à sa vie; et qui (2) est affectée de problèmes de santé graves et irrémédiables (y compris une affection, une maladie ou un handicap) lui causant des souffrances persistantes qui lui sont intolérables au regard de sa condition »;

**ATTENDU QUE** la Cour a suspendu la prise d'effet de la déclaration d'invalidité jusqu'en février 2016;

**ATTENDU QU'**une approche pancanadienne à l'égard de l'aide médicale à mourir serait souhaitable;

**ATTENDU QUE** le législateur et les organismes de réglementation devraient consulter les personnes vulnérables, notamment les personnes handicapées et les groupes qui les représentent, ainsi que l'Association du Barreau canadien, dans le but d'adopter une action législative harmonisée relativement à l'aide médicale à mourir;

**QU'IL SOIT RÉSOLU QUE** l'Association du Barreau canadien :

1. exhorte le gouvernement fédéral à modifier le *Code criminel* de manière à le rendre compatible avec la décision dans l'arrêt *Carter*;
2. exhorte les gouvernements provinciaux et territoriaux à adopter des lois harmonisées qui établissent :
  - (a) des démarches claires pour permettre l'accès en temps opportun à l'aide d'un médecin pour mourir;
  - (b) des garanties claires en matière de procédure qui protègent les personnes sollicitant l'aide d'un médecin pour mourir, mais qui n'imposent pas de limites déraisonnables qui empêcheraient ceux et celles qui satisfont aux critères établis par la CSC de pouvoir se prévaloir de cette aide médicale à mourir; et
  - (c) un mécanisme de supervision qui assure un examen rétrospectif satisfaisant des cas et la collecte, ainsi que la publication de rapports destinés au public, de données concernant l'aide médicale à mourir au Canada;

**Resolution 15-01-A**

3. urge provincial and territorial governments and regulatory bodies of physicians and other health care professionals who may be involved in physician-assisted dying to review and, if necessary, enact legislation and standards of practice to address necessary aspects of implementation, including appropriately reconciling the Charter rights of patients, health care professionals who conscientiously object to participating in physician-assisted dying, and health care professionals who are willing to participate in physician-assisted dying.

**Certified true copy of a resolution carried  
by the Council of the Canadian Bar Association  
at the Annual Meeting held in Calgary, AB  
August 13, 2015.**

**Résolution 15-01-A**

3. exhorte les gouvernements provinciaux et territoriaux et les organismes de réglementation des médecins et des autres professionnels de la santé qui pourraient participer dans le cadre de l'aide médicale à mourir à examiner la législation et les normes existantes, et s'il le faut, à adopter des lois et des normes de pratique qui abordent les aspects nécessaires liés à la mise en œuvre, notamment la conciliation convenable des droits garantis par la Charte des patients avec ceux des professionnels de la santé qui refusent, en raison de leurs convictions, de participer à l'aide médicale à mourir et avec ceux des professionnels de la santé qui acceptent d'y prendre part.

**Copie certifiée d'une résolution adoptée  
par le Conseil de l'Association du Barreau canadien,  
lors de son Assemblée annuelle, à Calgary, AB  
le 13 août 2015.**

**John D.V. Hoyles  
Chief Executive Officer/Chef de la direction**

## Advance Requests for Medical Assistance in Dying

**WHEREAS** the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying recommended that the federal government amend the *Criminal Code* to permit a request for medical assistance in dying (MAID) at any time following the diagnosis of a grievous and irremediable condition when suffering becomes intolerable;

**WHEREAS** the Special Joint Committee on Physician-Assisted Dying recommended that advance requests for MAID be allowed at any time after one is diagnosed with a condition that is reasonably likely to cause loss of capacity or after diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable;

**BE IT RESOLVED THAT** the Canadian Bar Association:

1. urge the federal government to amend the *Criminal Code*:
  - a) to permit advance requests for medical assistance in dying consistent with the criteria recommended by the Provincial-Territorial Advisory Group and Special Joint Committee; and
  - b) to exempt from liability all persons assisting in the discussion of end of life choices, including MAID, in the context of an advance request.
2. urge each province and territory to review and, where necessary, enact legislation to permit MAID pursuant to a valid advance request, and to consider and address:
  - a) consistency across provinces and territories;
  - b) measures that adequately safeguard individuals where capacity is an issue, but do not impose undue barriers for eligible individuals who wish to make an advance request for MAID;

## Demande anticipée d'aide médicale à mourir

**ATTENDU QUE** le Groupe consultatif provincial-territorial d'experts sur l'aide médicale à mourir a recommandé au gouvernement fédéral de modifier le *Code criminel* afin qu'une personne puisse formuler une demande d'aide médicale à mourir (AMM) à tout moment après avoir été diagnostiquée d'une affection grave et irrémédiable lorsque les souffrances deviennent intolérables;

**ATTENDU QUE** le Comité mixte spécial sur l'aide médicale à mourir a recommandé que le recours aux demandes anticipées d'aide médicale à mourir soit autorisé à tout moment après qu'une personne ait reçu un diagnostic de problème de santé qui lui fera vraisemblablement perdre ses capacités ou un diagnostic de problème de santé grave ou irrémédiable, mais avant que les souffrances ne deviennent intolérables.

**QU'IL SOIT RÉSOLU QUE** l'Association du Barreau canadien :

1. exhorte le gouvernement fédéral à modifier le *Code criminel* :
  - a) afin d'autoriser les demandes anticipées d'aide médicale à mourir conformément aux critères recommandés par le Groupe consultatif provincial-territorial d'experts sur l'aide médicale à mourir et par le Comité mixte spécial sur l'aide médicale à mourir; et
  - b) que les personnes prenant part aux discussions des options de fin de vie, y compris l'aide médicale à mourir, dans le contexte d'une demande anticipée, soient dégagées de toute responsabilité.
3. exhorte chaque province et territoire à réviser sa législation et, le cas échéant, à adopter de la législation en vue d'autoriser la prestation d'aide médicale à mourir en vertu de demandes anticipées valides, et à aborder les points suivants :
  - a) la cohérence dans l'ensemble des provinces et des territoires;
  - b) l'adoption de mesures qui protègent, de façon adéquate, les personnes dont la capacité est en cause, sans pour autant qu'elles imposent des embûches trop contraignantes pour les personnes admissibles qui souhaitent formuler une demande anticipée d'aide médicale à mourir;

**Resolution 16-02-A**

- c) clear requirements to determine the validity of an advance request for MAID;
- d) a prohibition against providing MAID based on an advance request if the grantor is capable;
- e) retaining the right of every individual who has made an advance request to refuse the administration of MAID regardless of capacity; and
- f) who is legally bound to comply with an advance request for MAID.

**Certified true copy of a resolution carried  
by the Council of the Canadian Bar Association  
at the Annual Meeting held in Ottawa, ON,  
August 11, 2016.**

**John D.V. Hoyles  
Chief Executive Officer/Chef de la direction**

**Résolution 16-02-A**

- c) la mise en œuvre d'exigences claires pour déterminer la validité d'une demande anticipée d'aide médicale à mourir;
- d) l'interdiction du recours à l'AMM basée sur les demandes anticipées si le mandant est capable;
- e) le maintien du droit de toute personne ayant formulé une demande anticipée de refuser l'aide médicale à mourir, sans égard à la capacité de cette personne;
- f) la détermination, sur le plan légal, de la personne qui est tenue de respecter les termes d'une demande d'AMM.

**Copie certifiée d'une résolution adoptée  
par le Conseil de l'Association du Barreau canadien, lors de  
son Assemblée annuelle, à Ottawa (ON), le 11 août 2016.**

## Medical Assistance in Dying and Psychiatric Conditions

**WHEREAS** the Supreme Court of Canada in *Carter v. Canada (Attorney General)* extended the right to medical assistance in dying to competent and consenting adults with a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to them in the circumstances of their condition;

**WHEREAS** the Alberta Court of Appeal in *Canada (Attorney General) v. E.F.*, stated that the *Carter* decision should be interpreted as including persons with a psychiatric condition if they otherwise fit the criteria for medical assistance in dying;

**WHEREAS** the Joint Parliamentary Committee on Physician-Assisted Dying recommended that individuals not be excluded from medical assistance in dying based on the fact that they have a psychiatric condition;

**WHEREAS** the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying did not recommend excluding individuals with psychiatric conditions, but encouraged the development of better assessment tools for consent and capacity, especially in relation to vulnerabilities associated with the lack of support for persons living with disabilities;

**WHEREAS** persons with psychiatric conditions should not be presented with additional barriers to access medical assistance in dying;

**BE IT RESOLVED THAT** the Canadian Bar Association:

- urge the federal government to ensure that amendments to the *Criminal Code* align with all of the criteria established by the Supreme Court of Canada in *Carter*, including the eligibility of persons with a psychiatric condition;
- urge federal, provincial and territorial governments to ensure that persons with psychiatric conditions who seek medical assistance in dying are not faced with additional barriers by virtue solely of their psychiatric condition;

## Aide médicale à mourir et troubles psychiatriques

**ATTENDU QUE** la Cour suprême du Canada, dans l'arrêt *Carter c. Canada (Procureur général)*, a statué que le droit à l'aide médicale pour mourir s'applique à une personne adulte capable, qui consent à mettre fin à ses jours, étant atteinte de problèmes de santé graves et irrémédiables (y compris une affection, une maladie ou un handicap) lui causant des souffrances persistantes qui lui sont intolérables au regard de sa condition;

**ATTENDU QUE** la Cour d'appel de l'Alberta, dans l'affaire *Canada (Attorney General) v. E.F.*, a déclaré que l'arrêt *Carter* devrait être interprété de façon à inclure les personnes atteintes d'une maladie psychiatrique, dans la mesure où ils répondent aux critères de l'aide médicale à mourir;

**ATTENDU QUE** le Comité mixte spécial sur l'aide médicale à mourir a recommandé que l'on ne juge pas inadmissibles à l'aide médicale à mourir les personnes atteintes d'une maladie psychiatrique en raison de la nature de leur maladie;

**ATTENDU QUE** le Groupe consultatif provincial-territorial d'experts sur l'aide médicale à mourir n'a pas recommandé que les personnes atteintes d'une maladie psychiatrique soient jugées inadmissibles à l'aide médicale à mourir, mais a plutôt recommandé l'élaboration de meilleurs outils d'évaluation de capacité et de consentement, plus particulièrement à l'égard des vulnérabilités liées au manque de soutien social des personnes ayant des handicaps;

**ATTENDU QUE** les personnes atteintes de maladies psychiatriques ne devraient pas être confrontées à des obstacles supplémentaires avant de pouvoir avoir recours à l'aide médicale à mourir;

**QU'IL SOIT RÉSOLU QUE** l'Association du Barreau canadien :

- exhorte le gouvernement fédéral à faire en sorte que les modifications apportées au *Code criminel* concordent avec tous les critères établis par la Cour suprême du Canada dans l'arrêt *Carter*, y compris l'admissibilité des personnes atteintes d'une maladie psychiatrique à l'aide médicale à mourir;
- exhorte les gouvernements fédéral, provinciaux et territoriaux à faire en sorte que les personnes atteintes d'une maladie psychiatrique qui ont recours à l'aide médicale à mourir ne soient pas confrontées à des obstacles supplémentaires par le seul fait qu'elles sont atteintes d'une maladie de cette nature;

**Resolution 16-03-A**

- urge federal, provincial and territorial governments to facilitate the development of appropriate assessment tools for consent and capacity, relying on a patient-centric approach.

**Certified true copy of a resolution carried  
by the Council of the Canadian Bar Association  
at the Annual Meeting held in Ottawa, ON,  
August 11, 2016.**

**John D.V. Hoyles  
Chief Executive Officer/Chef de la direction**

**Résolution 16-03-A**

- exhorte les gouvernements fédéral, provinciaux et territoriaux à faciliter l'élaboration d'outils appropriés aux fins de l'évaluation du consentement et de la capacité, en se fondant sur une approche centrée sur les patients.

**Copie certifiée d'une résolution adoptée  
par le Conseil de l'Association du Barreau canadien, lors  
de son Assemblée annuelle,  
à Ottawa (ON), le 11 août 2016.**

## Medical Assistance in Dying for Competent Minors

**WHEREAS** Canada has ratified the United Nations *Convention on the Rights of the Child*, which recognizes the right of all children to express their views freely in all matters affecting them and to give due weight to those views in accordance with their age and maturity;

**WHEREAS** the Supreme Court of Canada stated in *AC v. Manitoba (Director of Child and Family Services)* that “it would be arbitrary to assume that no one under the age of 16 has capacity to make medical treatment decisions”;

**WHEREAS** the rationale in the Supreme Court of Canada decision in *Carter v. Canada (Attorney General)* applies equally well to any competent and consenting minor with a grievous and irremediable medical condition causing enduring suffering that is intolerable to them;

**WHEREAS** the exclusion of competent minors from medical assistance in dying (MAID) on the basis of age is arbitrary and would likely be subject to constitutional challenge;

**WHEREAS** the Joint Parliamentary Committee on Physician-Assisted Dying recommended that the federal government immediately facilitate a study of issues and appropriate competence standards for those under the age of 18;

**BE IT RESOLVED THAT** the Canadian Bar Association urge the federal government to:

2. Immediately commission a Child Rights Impact Assessment to:
  - a) study the developmental, medical and legal issues related to competent minors (also referred to as mature minors) and MAID;
  - b) undertake broad-based consultations;
  - c) recommend safeguards to ensure that the substantive criteria for MAID are satisfied, including appropriate tools to assess competence and consent for children and youth;

## L'aide médicale à mourir et les mineurs capables

**ATTENDU QUE** le Canada a ratifié la Convention des Nations Unies relative aux droits de l'enfant, qui reconnaît le droit de l'enfant d'exprimer librement son opinion sur toute question l'intéressant, les opinions de l'enfant étant dûment prises en considération eu égard à son âge et son degré de maturité;

**ATTENDU QUE** la Cour suprême du Canada a énoncé ce qui suit dans l'arrêt *AC c. Manitoba (Directeur des services à l'enfant et à la famille)* : « il serait arbitraire de présumer qu'aucune personne de moins de 16 ans n'a la capacité de décider de son traitement médical »;

**ATTENDU QUE** le raisonnement dans la décision de la Cour suprême du Canada dans l'arrêt *Carter c. Canada (Procureur général)* vaut tout aussi bien pour la personne mineure qui est capable et y consent, étant atteinte de problèmes de santé graves et irrémédiables lui causant des souffrances persistantes qui lui sont intolérables;

**ATTENDU QUE** le fait d'exclure les mineurs capables à l'aide médicale à mourir (AMM) en raison de leur âge est arbitraire et fera vraisemblablement l'objet d'une contestation sur le plan constitutionnel;

**ATTENDU QUE** le Comité mixte spécial sur l'aide médicale à mourir a recommandé au gouvernement fédéral qu'il s'engage sans tarder à ce que soit réalisée une étude des questions entourant les personnes âgées de moins de 18 ans et des critères relatifs à la capacité qui leur seraient applicables;

**QU'IL SOIT RÉSOLU QUE** l'Association du Barreau canadien exhorte le gouvernement fédéral :

1. à commander, immédiatement, une étude des incidences sur les droits de l'enfant, qui :
  - a) analysera les aspects d'ordre médical et juridique, ainsi que ceux connexes au développement, se rattachant à la question des mineurs capables (aussi appelés « mineurs matures ») et l'aide médicale à mourir;
  - b) engagera une consultation à grande échelle;
  - c) fera des recommandations quant aux protections à mettre en place afin de s'assurer que les conditions de fond liées à l'aide médicale à mourir sont satisfaites, y compris l'établissement d'outils appropriés aux fins de l'évaluation de la capacité et du



**Resolution 16-04-A**

- d) make recommendations for legislation permitting MAID for competent minors.
2. Introduce legislation by June 2017 to permit competent minors to be eligible for MAID.

**Certified true copy of a resolution carried  
by the Council of the Canadian Bar Association  
at the Annual Meeting held in Ottawa, ON,  
August 11, 2016.**

**John D.V. Hoyles  
Chief Executive Officer/Chef de la direction**

**Résolution 16-04-A**

- consentement chez les enfants et les adolescents;
- d) fera des recommandations quant à la législation autorisant le recours à l'aide médicale à mourir chez les personnes mineures capables;
2. à déposer un projet de loi, au plus tard en juin 2017, permettant que les personnes mineures capables soient admissibles à l'aide médicale à mourir.

**Copie certifiée d'une résolution adoptée  
par le Conseil de l'Association du Barreau canadien, lors  
de son Assemblée annuelle,  
à Ottawa (ON), le 11 août 2016.**

Canadian Coalition for the Rights of Children

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*



**Medical Assistance in Dying in Canada:  
Denial of Rights to End Intolerable Suffering of Mature Minors**

Submission to the Council of Canadian Academies  
by the Canadian Coalition for the Rights of Children  
September 22, 2017

Introduction

This submission provides a rights-based analysis for consideration by the Council as part of its deliberation on requests by mature minors. It draws on both the Canadian Charter of Rights and the UN Convention on the Rights of the Child, which Canada and all provinces ratified more than 25 years ago. It considers legal precedence in Canada and analyzes implications and related concerns from a rights-based perspective.

The Canadian Coalition for the Rights of Children works for full realization of all rights in the Convention of the Rights of the Child as an integrated framework to guide public policy. Below are significant provisions for reference in this analysis:

Article 12 of the UN Convention of the Rights of the Child states:

*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*

The Canadian Charter of Rights and Freedoms states:

*Section 7: Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.*

*Section 15: Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, **age** or mental or physical disability.*

### Legal Context in Canada

In 2015 the Supreme Court of Canada, in *Carter v. Canada (Attorney General)*, considered the right to medical assistance in dying for competent and consenting adults with a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to them in the circumstances of their condition. It found criminal code prohibitions against providing aid unconstitutional. They did not consider mature minors.

The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (November 30, 2015) recommended that the federal government amend the Criminal Code to permit a request for medical assistance in dying (MAID) at any time following the diagnosis of a grievous and irremediable condition when suffering becomes intolerable. The expert panel did not find it appropriate, legally, ethically or medically, to exclude otherwise capable people based on age alone.

Bill C-14 (Medical Assistance in Dying) received Royal Assent on June 17, 2016. To qualify for medical assistance in dying two health care professionals must evaluate the individual request and **the individual must be over 18 years of age.**

The Supreme Court of Canada stated in *AC v. Manitoba (Director of Child and Family Services)* that “*it would be arbitrary to assume that no one under the age of 16 has the capacity to make medical treatment decisions.*”<sup>1</sup>

### Analysis

In an ideal world no child would ever suffer from a terminal disease. They would not endure intractable pain or face the indignity of losing control over one’s own body and mind; nor would their parents have to watch their child suffer, knowing death was inevitable.

Despite advances in health care, in particular palliative care and pain management, there are cases where suffering cannot be alleviated. This was recognized by the Supreme Court of Canada, and accordingly the criminal prohibition against providing assistance was struck down. Further, physical suffering alone is not the sole motive of those who seek an end to life. Loss of

dignity and autonomy as one's body succumbs to disease and injury, leaving one incapable of any form of communication or thought, are most often stated as reasons to control how and when the end comes, alongside intractable pain. While ever increasing doses of medication may control pain, many also express fear over such things as choking or slow suffocation, all contributing to the underlying desire for medical assistance in dying.

In 2015 the Supreme Court of Canada held that a law which prohibits a person from pursuing physician-assisted death “*interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty. And, by leaving people .... to endure intolerable suffering, it impinges on their security of the person.*”<sup>2</sup> While this case considered only adult appellants, the Supreme Court has on several occasions recognized the fundamental rights of fully capable or “mature minors” with respect to medical decision making.

In *A.C. v. Manitoba (Director of Child and Family Services)*, a majority of the Supreme Court held that:

*“The more a court is satisfied that a child is capable of making a mature, independent decision on his or her own behalf, the greater the weight that will be given to his or her views....” “If, after a careful and sophisticated analysis of the young person’s ability to exercise mature, independent judgment, the court is persuaded that the necessary level of maturity exists, it seems to me necessarily to follow that the adolescent’s views ought to be respected.”*<sup>3</sup>

Furthermore, the Supreme Court of Canada stated in *AC v. Manitoba* that “*it would be arbitrary to assume that **no one under the age of 16** has capacity to make medical treatment decisions.*” [emphasis added]

Legally and ethically there is no proper reason to exclude mature minors from the rationale in the Supreme Court of Canada decision in *Carter v. Canada (Attorney General)*. It applies equally well to any competent and consenting minor with a grievous and irremediable medical condition causing enduring suffering that is intolerable to the young person.

Current laws in Canada, across provinces and territories, allow mature minors, based on their capacity, not age, the right to request the removal of life-sustaining medical equipment such as ventilators, refuse artificial nutrition and hydration, and refuse life -saving treatments such as dialysis or chemotherapy even though such treatments may prolong their life. While some



provincial and territorial laws have presumptive ages for capacity, all of them allow the minor to prove capacity in order to have the autonomous right to medical decision making, with the exception of Quebec (no capacity below age 14). It is legally incoherent to acknowledge the equal rights of capable mature minors to consent to end or refuse medical treatment, even treatment that could extend their lives, improve the quality of their lives, or result in a premature death, but not extend to them the same right to assistance in ending their suffering from a “grievous and irredeemable dying,” as adults have.

### Protection of the Vulnerable

Denial of the right of fully capable minors to seek assistance to end their life of intolerable suffering is often mistakenly characterized as “protecting the vulnerable” or “best interests of the child.” As the Supreme Court of Canada noted in *A.C. v. Manitoba*, it is in the best interests of minors, [like all other people] to recognize their right to bodily integrity and therefore respect their wishes on healthcare decisions, according to their capacity, not age.

When it enacted the current law, Parliament unfortunately took a paternalistic approach to all of those under 18 years old, including those whose experience and understanding of illness, pain, suffering and mortality may far exceed that of the very decision makers who would deny them the same rights as all other capable Canadians. The decision may have been influenced by ignorance of cognitive development, extreme discomfort in facing the reality that young people die, or political or personal reasons. There is no evidence that the intolerable suffering of mature minors, who are equally aware of their current condition and what they face in the future, is any more tolerable than that of the similarly situated capable person over 18 years of age. Palliation is available as a choice for adults, as it is for minors, and there is no reason to assume it is any more or less a means to alleviate intolerable suffering based on age alone. Whatever the opinion of legislators or health care-providers, the Supreme Court of Canada has ruled that palliation is not sufficient to alleviate suffering in all cases. Therefore, the only remaining legal and ethical question is one of whether to deny equal access to that which is a fundamental right and benefit to those dying and suffering without hope.

### Test for Capacity

The test for capacity in all cases must ensure that the person making the decision understands his or her medical condition, what treatment is offered, and what the consequences of the medical decisions are. It must also ensure that the person making the decision is not unduly influenced by others. A fulsome examination of capacity for all patients is essential since many who face end of life decisions are vulnerable. However, this should not preclude anyone, whether elderly, disabled, homeless or young, from equal access to MAID if they are capable and otherwise meet the medical criteria. The concerns about vulnerable populations are not age dependent, nor should concerns about adequate safeguards justify denying the most basic rights to the citizens of a country. This includes the right of bodily integrity and security of the person as it applies to ending an unwanted life dominated by intolerable and hopeless suffering, according to the Supreme Court of Canada.

### Denial, not deferral of a right

Medical assistance in dying is not a spontaneous decision, in which impulse controls are at issue. It is considered, unhurried and reasoned decision making, overseen by medical professionals. To refuse this right to any capable person based on age alone is a most grievous expression of denying fundamental rights based on a purely arbitrary category. Further, unlike other less fundamental rights such as driving and marijuana consumption, which unfortunately are often brought forward as analogous deferred rights in debates on MAID, the section 7 right to medical assistance in dying is a fundamental Charter right which cannot be deferred. The right to choose when to end intolerable suffering by the mature minor with an irremediable medical condition (i.e. a reasonably foreseeable death,) is not an instance of ‘wait to become an adult and you too will have this right.’ The right is not deferred, it is forever denied.

### Other factors for consideration

Further, the right to MAID can in itself provide some solace to the young person, as well as others, at a time when little else is available. In a study among parents whose children were dying of cancer, 19% considered requesting a hastened death. While it is not clear how many loving parents would have in the end supported such a decision by their dying child, one father whose boy died of cancer made the following request of his physician: if the child's soft-tissue

tumor ever threatened to choke his son to a "horrible, horrible" death, "can we just get it over with quickly?"<sup>4</sup> This study showed that the mature minor is as aware as the parent or a patient over 18 would be of what their death might entail. They are, in legal terms, fully informed.

While it is expected that the numbers of young people who chose MAID will be low, that is not an argument to deny the right to the few. Nor is it the only benefit of the right. To deny MAID is not only to deny them alleviation from suffering they find intolerable at the end of their life; it also denies them the solace of a better dying, knowing that there is a "way out" in their control, should it become intolerable. To deny a fully capable and therefore knowing young person the same right to a lessening of fear of what lies ahead in their dying, is a most fundamental violation of their equal rights. It is an expression of cruel and unusual punishment that cannot be cloaked in "best interests."

### Summary

While the state has a legitimate interest in protecting those who are vulnerable, choosing an arbitrary age to deny or grant the right to assistance to end the intolerable suffering of prolonged dying in a fully capable person cannot stand up to scrutiny under the Charter nor the *UN Convention on the Rights of the Child*. Nor should it be protected under section 1 of the Charter.

As shown by an Alberta Government survey, the majority of respondents support MAID for those under 18 years, as long as they have legal capacity to make the decision.<sup>5</sup> It is expected that the support rate among those under 18 years would be higher. An informal survey of young persons in 2015 found that, of those who supported physician-assisted death, 77.7% believed that it should be equally available to capable youth.<sup>6</sup>

The Canadian Coalition for the Rights of the Child presents this evidence to show why the existing legislation needs to be amended to recognize the Charter rights of young people as well as their rights under the UN Convention on the Rights of the Child. The evidence shows why the right to medical assistance in dying to alleviate intolerable suffering needs to be based on capacity rather than the arbitrary indicator of chronological age.

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<sup>1</sup> A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181, para. 107.



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<sup>2</sup> Carter v. Canada (Attorney General), 2015 SCC 5, at para. 66.

<sup>3</sup> A.C. v. Manitoba, para. 87.

<sup>4</sup> Archives of Paediatric & Adolescent Medicine Journal 2010 Mar; 164(3):231-7. doi: 10.1001/archpediatrics.2009.295. **Considerations about hastening death among parents of mature minors who die of cancer.**

Dussel V, Joffe S, Hilden JM, Watterson-Schaeffer J, Weeks JC, Wolfe J.

<sup>5</sup> Alberta Health-What We Heard: Medical Assistance in Dying May, 2016. 54.12% in support, 6.7% no opinion

<sup>6</sup> Fundamental Freedoms Conference, C C L A; workshop by Lee Ann Chapman PBO at SickKids.

Canadian Federation of Catholic Physicians' Societies, Canadian Physicians for Life, and Christian Medical and Dental Society of Canada joint submission

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

This document is a joint submission of Canadian Physicians for Life, Canadian Federation of Catholic Physician's Societies and Christian Medical and Dental Society of Canada.

I attach the submission in PDF format for your review. While it is slightly over your 1000 word limit, we are hoping that we will be granted some leeway because of the fact that three organizations have combined their efforts in this document. We would also like to note that the submission was personally endorsed by 247 health care professionals.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

You will note that our submission has numerous citations of scholarly articles as well as another list of articles at the end of the submission. We hope that our research will be helpful for your deliberations.

## Joint Submission to the Council of Canadian Academies' Expert Panel on Medical Assistance in Dying

- on behalf of Canadian Physicians for Life, Canadian Federation of Catholic Physicians' Societies and Christian Medical and Dental Society of Canada - October 6, 2017<sup>1</sup>

Our main concern about the proposed expansion of the MAID criteria is the protection of vulnerable patients. In order for a patient to qualify for MAID, the current legislation requires that the patient's death must be "reasonably foreseeable". This clause is being litigated in British Columbia, and has already been redefined in a high profile case in Ontario.<sup>2</sup> If this clause is struck down, reinterpreted, or if the MAID criteria are expanded, the main surviving test will be whether the patient has a "grievous and irremediable condition". This is not a medical term, and does not have a precise definition. The *Carter* decision and subsequent legislation have defined irremediable as a condition that cannot be treated *by any means that is acceptable to the patient*. As the requirement for intolerable suffering is also subjective, physicians conducting assessments will be hard pressed to refuse MAID requests since there will no longer be objective benchmarks to measure criteria. *The end result will be state sponsored suicide on demand*. The expansion of the MAID criteria to include each of these groups of vulnerable patients needs to be considered in this context.

### CHILDREN

When providing medical care to children and adolescents, a key concern is that capacity may not be present. According to the standards of Canadian medicine, acting on decisions made by a patient without capacity is not ethical conduct. Capacity is the ability to understand and appreciate the consequences of a decision. The standard for capacity is higher than usual when decisions are life altering or life threatening. Factors influencing capacity in minors include immature neurophysiological development, which results in biologically mediated difficulty with appreciating future consequences, psychological immaturity, ongoing evolution of identity, and vulnerability to peers and the media.<sup>3</sup> Previous experience demonstrates that the process of determining capacity in minors (such as children refusing life-saving chemotherapy) is a high-resource and painful endeavor. Capacity assessment of minors often requires expertise from clinical ethics, psychiatry, child protection, and the law. It is an emotionally charged issue for

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<sup>1</sup> Canadian Physicians for Life, Canadian Federation of Catholic Physicians' Societies, and Christian Medical and Dental Society of Canada represent 5,000 physicians in Canada. This response was drafted by physician members and friends of our organizations, who treat patients who are children, have psychiatric conditions, or who have an advanced directive (vulnerable people).

<sup>2</sup> See article on the AB case <https://www.thestar.com/news/crime/2017/08/10/woman-at-centre-of-ontario-assisted-death-case-dies.html> The following article explains how the AB case is already being used as justification for MAID when the patient does not have a terminal condition. <http://www.cbc.ca/news/canada/british-columbia/assisted-dying-law-canada-moro-1.4294809?cmp=rss&partner=skygrid>

<sup>3</sup> Casey BJ, Jones RM, Hare TA (2008). The adolescent brain. *Ann N Y Acad Sci* 1124: 111-126. Johnson SB, Blum RW, Giedd JN (2009). Adolescent maturity and the brain: The promise and pitfalls of neuroscience research in adolescent health policy. *J Adolesc Health*. 45: 216-221.

families, medical staff, and the general public. Determining capacity around the issue of medical assistance in dying is a high-stakes decision that is more serious than discontinuing treatment; as MAID involves actively taking a human life. In addition, previously identified general concerns about MAID, such as wrongful deaths in other permissive jurisdictions, are of greater concern in minors, given society's obligation to protect our most vulnerable. Overall, there is much less experience with MAID for minors on an international level, resulting in less reassurance regarding governments' ability to mediate potentially negative consequences. Furthermore, we are concerned that extension of MAID to minors would jeopardize a population already known to have a high incidence of both suicidal ideation and peer pressure, and that effects might be particularly pronounced in subsets of young people with special vulnerabilities.<sup>4</sup>

Society recognizes the lack of neuroanatomical maturation in areas like voting and driving. Proponents for MAID for minors will need to answer why children are incapable of voting or driving, but yet are capable of choosing to die.

### PATIENTS WITH A PRIMARY DIAGNOSIS OF MENTAL ILLNESS

Suicidal ideation is normally an indicator of serious mental illness. Society has given physicians the legal right to admit someone to hospital against their will to be treated for suicidal ideation. Keeping a patient against their will, while extremely rare in other circumstances, is allowed in the case of the suicidal patient because their desire to harm themselves is evidence of their irrationality and incompetence. Suicidal ideation and refusal of treatment are consequences of under-treated mental illness.

Depression afflicts those who have both long-term mental health diagnoses and the remainder of the population intermittently.<sup>5</sup> Its effects are pervasive; it affects the brain, the mind and the way that people think and feel. Thinking patterns of depressed people are distorted; they are prone to pessimism, all or nothing thinking and often cannot see past the current moment. A key determinant of eligibility for MAID is how the patient perceives his/her situation, but in a depressed individual, perception is seen through a dark lens. At the same time, it is possible to be erroneously deemed competent while

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<sup>4</sup> Among Canadians aged 15 to 34, suicide is the second leading cause of death. Cf. Navaneelan T (2017). Suicide rates: An overview. Statistics Canada. Accessible at [www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm](http://www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm).

Gould M, Wallenstein S and Kleinman M (1990). Time-space clustering of teenage suicide. *Am J Epidemiol* **131**: 71-78.

D'Augelli AR, Herschberger SL, Pilkington NW (2001). Suicidality patterns and sexual orientation-related factors among lesbian, gay, and bisexual youths. *Suicide Life-Threatening Beh* **31**: 250-265.

Kielland N and Simeone T (2014). Current issues in mental health in Canada: The mental health of First Nations and Inuit communities. Library of Parliament Research Publications. 2014-02-E. [www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm](http://www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm)

<sup>5</sup> One particularly high-risk population is First Nations communities. Some First Nations communities have suicide rates that are 800 times the national average. Cf. Kielland N and Simeone T (2014) (ibid.) Approval of MAID for people who have mental health challenges may be seen as a government endorsement of suicide. The lack of sufficient mental health services puts those communities at great risk.

suffering from depression. Patients can be rational about some aspects of their lives, and not others, so the request for MAID may appear to be a rational decision. Competence assessments are often suboptimal,<sup>6</sup> and unless the assessor has an appropriate level of suspicion, he/she may not recognize the cognitive distortion. Furthermore, depression often involves rigid and restricted thinking, such that an individual who wants something other than what he/she is experiencing, may insist on being euthanized, for lack of being able to conceive of another option.<sup>7</sup> Similar concerns exist for other psychiatric diagnoses as well.

Offering death for mental illness is unwise, since the most common reason for a request is clinical depression, which almost always resolves without medication within 6 months to two years.<sup>8</sup> Other jurisdictions, such as Belgium, require the illness to be unresponsive to all possible treatments, while Canada currently does not require the patient to undertake any treatment.

When a patient is receiving mental health care, the greatest treatment their physician can provide is hope, caring for them, and imparting the message that life is worth living. How can the physician conduct an assessment to prevent suicide and provide care when that same assessment may also be used as a means to provide suicide?<sup>9</sup> “Safeguards” will not protect people suffering solely from psychological illness because the tools mental health professionals use to protect and treat these individuals will be rendered ineffective in a permissive regime.

#### ADVANCE DIRECTIVES:

Advance directives pose additional problems. It is impossible to predict one’s experience of the illness trajectory. Palliative care professionals observe patients’ perceptions about dependence on others becoming less negative as they become more dependent.<sup>10</sup> Moreover, dementia patients have stable quality of life ratings as their

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<sup>6</sup> Appelbaum, P.S. 2007. Assessment of Patients’ Competence to Consent to Treatment. *New England Journal of Medicine*:357:1834-1840. There is no standard assessment process or specific measures of competence.

<sup>7</sup> Clarke, D. M.(1999);*Journal of Medical Ethics* 25(6), 457-462.

<sup>8</sup> J. L &Lacasse, J.R.2012. The controversy over Antidepressant Drugs in an era of evidence-based practice. *Social Work in Mental Health* 10:445-463.

<sup>9</sup> This concern is emphasized in the following excerpt: “For many psychiatrists, however, assisting patients to die is incompatible with the way in which the therapeutic relationship between physician and patient should function to contain, understand, and manage despair and suicidality (Koerselmans, 1995, 2011). Indicating that they are willing to consider a patient’s assisted suicide request after a therapeutic intervention were to fail would undermine the therapeutic process from the beginning.”

Pols, H., Oak, S. 2013. Physician-assisted dying and psychiatry: Recent developments in the Netherlands. *International Journal of Law and Psychiatry*. 36:506-514 [p. 511].

<sup>10</sup> Canadian Society of Palliative Care Physicians. “Submission to Special Joint Committee on Physician-Assisted Dying.” (January 27, 2016) Retrieved from <http://www.cspcp.ca/wp-content/uploads/2014/10/CSPCP-Submission-to-the-Special-Joint-Committee-on-Physician-Assisted-Dying-National-Secretariat.pdf>

disease progresses. In the Netherlands, possessing an advance directive for euthanasia does not predict completion of euthanasia,<sup>11</sup> and such advance directives are rarely carried out for incompetent patients because of difficulty assessing the presence of voluntariness and unbearable suffering in this population.<sup>12,13</sup> Patients may resist euthanasia when they reach their previously-defined conditions for it. In this case, would we respect the patient's previously anticipated wish and ignore her current subjective experience because it is deemed to come from an incompetent mind? Would this not be an annihilation of the rights of the incompetent person? The implications of a scenario in which a proxy ultimately decides to proceed with the euthanasia of another person must be fully evaluated. Proxy ratings of quality of life (QOL) for dementia patients tend to be worse than patients' own ratings,<sup>9,14,15</sup> and caregiver ratings of patient QOL have been associated with caregiver mood.<sup>16</sup> Moreover, the assessment of QOL in dementia in general is acknowledged in the literature to be problematic.<sup>13,14,17</sup> These factors render an autonomous decision about euthanasia impossible to achieve via advance directives, and introduce significant risk that factors other than the best interests of the patient will motivate decision-making where the potential for secondary gain exists.

## CONCLUSION

The expansion of the MAID mandate to include these vulnerable patients challenges the main philosophical underpinning of the legalization of euthanasia and assisted suicide – autonomy. Autonomy is only one of the four factors that make up modern medical ethics. Beneficence is another. If a patient tells their care team that they want to die what does it mean to do good for the patient? Does it mean to give them a lethal injection or to find an alternative?<sup>18</sup> To simply let the patient decide begs the question.

<sup>11</sup> Bolt, E., Pasman, R., Deeg, D., Onwuteaka-Philipsen, B. 2016. From Advance Euthanasia Directive to Euthanasia: Stable Preference in Older People? *Journal of the American Geriatrics Society*. 64(8): 1628–1633.

<sup>12</sup> Kouwenhoven, P. et al. 2015. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. *BMC Medical Ethics*. 16:7

<sup>13</sup> Hertogh, C., de Boer, M., Drees, R., Eefsting, J. 2007. Would We Rather Lose Our Life Than Lose Our Self? Lessons From the Dutch Debate on Euthanasia for Patients With Dementia. *The American Journal of Bioethics*, 7(4): 48–56.

<sup>14</sup> Parker B, Petrou S, Underwood M, et al. Can care staff accurately assess health-related quality of life of care home residents? A secondary analysis of data from the OPERA trial. *BMJ Open* 2017;7:e012779. doi:10.1136/bmjopen-2016-012779.

<sup>15</sup> Buckley et al, "Predictors of Quality of Life Ratings for Persons with Dementia Simultaneously Reported by Patients and their Caregivers: The Cache County (Utah) Study", *Int Psychogeriatr*. 2012 July ; 24(7): 1094–1102.

<sup>16</sup> Schiffczyk, C., et al. 2010. Generic quality of life assessment in dementia patients: a prospective cohort study. *BMC Neurology*. 10:48

<sup>17</sup> Hongisto et al. 2015. Self-Rated and Caregiver-Rated Quality of Life in Alzheimer Disease with a Focus on Evolving Patient Ability to Respond to Questionnaires: 5-Year Prospective ALSOVA Cohort Study. *Am J Geriatr Psychiatry* 23(12): 1280-1289.

<sup>18</sup> This was played out in Quebec when emergency physicians were faulted for not treating patients who came to their emergency department after having attempted suicide because they were "confused" about their duties. (Cf. Hamilton, G. "Some Quebec doctors let suicide victims die though treatment was available: college", *National Post*, March 17, 2016. <http://nationalpost.com/news/canada/some-quebec->

Various personal vulnerabilities and influences can make the patient unable to act in their own best interests. The current system of MAID assessment requires two physicians, neither of whom need to be intimately acquainted with the patient, to determine whether or not the patient is capable of consent and whether or not there is coercion. Coercion can be subtle and difficult to detect. Competency measures are very difficult to assess with each of these three groups of patients. It is not practically possible to expand the MAID mandate without a significant risk of wrongful death for some patients. In the end, it is not worth the risk.

*A list of relevant articles are included after the endorsements.*

The following three physicians' organizations have jointly submitted this document. Together they represent approximately 5,000 Canadian physicians. 247 individuals have asked that their names be attached to the document as a personal and public endorsement. *Reference to positions held by individuals does not imply organizational endorsement.*

1. Faye Sonier, Executive Director  
Canadian Physicians for Life  
Ottawa, ON

2. Dr. James Lane, President  
Canadian Federation of Catholic Physicians' Societies  
Family Physician  
Vancouver, BC

3. Dr. Donato Gugliotta, President  
Christian Medical and Dental Society of Canada  
Family Physician  
Trenton, ON

4. Dr. Thomas Bouchard MD  
Family Medicine Physician  
Calgary, AB

5. Dr. Lilian Lee Yan Vivas MD  
Physical Medicine and Rehabilitation Resident  
Toronto, ON

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[doctors-let-suicide-victims-die-though-treatment-was-available-college](#)) "Psychiatrists who fail to take reasonable care that their patients do not commit suicide, including by failing to order their involuntary hospitalization in order to prevent them committing suicide, can be liable for medical malpractice (negligence), unprofessional conduct (they lose their medical licenses), and even, in extreme cases, criminal negligence." (Somerville, M, *Bird on an Ethics Wire* [McGill-Queen's University Press, 2015], pg. 131)

6. Dr. Anthony Marchie, MD, MPhil, FRCSC  
Orthopaedic Surgeon  
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7. Dr. Natalia Novosedlik MD, CCFP(PC)  
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8. Dr. Davina Lansing MD, CCFP  
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Bowmanville, ON

9. Dr. Kiely Williams MD, CCFP  
Family Physician  
Calgary, AB

10. Dr. Betty Anne Story MD  
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11. Dr. Maria Wolfs MD, MHSc, FRCPC  
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13. Dr. Jonathan Chia-ho Lee, MD, FRCPC  
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14. Dr. Will Johnston, MD  
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15. Dr. Sandra Tigchelaar MD, CCFP, FCFP  
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16. Dr. Wesley J. Reimer, MD, FCFP, MSc  
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17. Phil Drijber MD, PhD, CCFP (F), CBOM (associate)  
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18. Dr. Mary Ellen Haggerty, MD  
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20. Dr. Althea Burrell MD, FRCP(C)  
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25. Dr. Richard R.J. Smyth MBBS, FRCS, FRCS(C)  
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Clinical Instructor in Otolaryngology, UBC  
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26. Dr. Margaret M Cottle, MD, CCFP (CAC Palliative Care)  
Palliative Care Physician  
Clinical Assistant Professor, UBC, Faculty of Medicine  
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27. Dr. Michael Koke MD, CCFP, CoE  
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28. Dr. Sandra Brickell MD, FRCPC  
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29. Dr. Jane Dobson MD, CCFP  
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30. Dr. David Chan MD, CCFP  
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33. Dr. Rene Leiva MD CM, CCFP, FCFP (CoE)  
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34. Dr. Melissa Ng MD  
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35. Helen McGee RN, MN, CPMHN(C)  
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36. Dr. Dale Hoffman MD  
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37. Dr. Duncan Etches MD  
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Vancouver, BC
38. Dr. John Kraulis, MD  
General Surgeon  
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39. Dr. Adrienne Vraets MD, MSc, FRCPC  
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40. Dr. Paul Yong MD, PhD, FRCSC  
Chronic pelvic pain specialist  
Vancouver, BC
41. Dr. Jillian Lusina MD  
Family Medicine  
Vancouver, BC
42. Dr. Cyril Chan MD  
Family Physician (Retired)  
Vancouver, BC
43. Dr. James Yeung MD, FRCPC  
Richmond, BC
44. Dr. Bevan Voth MD, CCFP FCFP  
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45. Dr. G. Vivian Walker MD, CCFP (CAC - PC)  
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50. Dr. H. Edward Wiens MD  
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73. Dr. Kevin Sclater MD, CCFP(PC)  
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75. Dr. Robert Kidd MD, CM  
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Renfrew, ON

76. Dr. Vincent Tang MD  
Family Medicine  
Vancouver, BC

77. Dr. Robin Cottle MD  
Ophthalmology  
Vancouver, BC

78. Dr. Victoria Haines MD  
Family Medicine  
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79. Dr. Kami Kandola  
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80. Dr. Robert W Adams MD  
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81. Dr. Kelley Minish MD, CCFP  
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82. Dr. Don Paetkau MD, FRCP(C)  
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83. Dr. Bryan Dias MD, FRCPC  
Cardiologist  
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84. Dr. Joel Emery MD  
Gastroenterology and Hepatology  
Kamloops, BC

85. Dr. Brad Burke MD, FRCPC  
Physical Medicine & Rehabilitation  
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225. Dr. Bruce Hiller MD  
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Comox, BC
226. Dr. Chris Newcombe MA  
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Nanaimo, BC
227. Dr. Patrick MacGillivray MD, MSc, CCFP  
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228. Dr. Chantale Demers MD, CCFP (CAC Palliative Medicine)  
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Winnipeg, MB
229. Dr. Timothy Dowdell MD, FRCPC, CCFP  
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231. Dr. Frank Fornasier MD, FCFP  
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232. Dr. Kenneth Fung MD, MB., FRCS (Lon)  
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236. Dr. Natalia Pastuszevska MD  
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237. Dr. Mary de Porres Ilo MD, CCFP-EM  
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244. Dr. Christopher J Ryan MD  
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245. Dr. Luke Savage BKin(Hons), MD, CCFP  
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246. Dr. Vincent Fung MD  
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247. Dr. Mary OConnor MD  
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*The following resources may be helpful in the deliberations of the committee. We are providing them in the form of an annotated bibliography for ease of use.*

1. **De Lima, L., Woodruff, R., Pettus, K., Downing, J., Buitrago, R., Munyoro, E., et al. (2017). International association for hospice and palliative care position statement: Euthanasia and physician-assisted suicide. *Journal of Palliative Medicine*, 20(1), 8-14. doi:10.1089/jpm.2016.0290 [doi]**

This is the most current position statement from the International Association for Hospice and Palliative Care.

2.
  - a. **Foley, K. M. (1991). The relationship of pain and symptom management to patient requests for physician-assisted suicide. *Journal of Pain and Symptom Management*, 6(5), 289-297.**
  - b. **Foley, K. M. Pain (1995) Physician-assisted Suicide, and Euthanasia. *Pain Forum* 4(3): 163-178**
  - c. **Foley, K. M. (1997). Competent care for the dying instead of physician-assisted suicide. *The New England Journal of Medicine*, 336(1), 54-58. doi:10.1056/NEJM199701023360109 [doi]**

In these papers by Dr. Foley, she essentially makes an argument that the application of proper palliative care makes physician assisted suicide unnecessary. She is a world leader in the area of palliative care (writing extensively on the topic).

3. **Jones, D. A., & Paton, D. (2015). How does legalization of physician-assisted suicide affect rates of suicide? *Southern Medical Journal*, 108(10), 599-604.**

This paper finds there is an increased rate of suicide in jurisdictions where physician assisted suicide is practiced.

4. Keizer, A. A. (2013). Euthanasia in advanced dementia: A moral impossibility. [Euthanasie bij gevorderde dementie: een morele onmogelijkheid] *Nederlands Tijdschrift Voor Geneeskunde*, 157(25), A6407.
5. Kissane, D. W.; Kelly, B. J. Demoralisation, depression and desire for death: problems with The Dutch guidelines for euthanasia of the mentally ill (2000) *Australian and New Zealand Journal of Psychiatry*; 34:325–333.

This paper concludes that “Dutch guidelines for physician-assisted suicide in the mentally ill generate serious concern given the uncertainty of prognosis, potential range and variability of outcome of treatments of suicidality and the boundary violations that are involved for the psychiatrist. The guidelines have the potential to dangerously alter the practice of psychiatry and should be condemned”.

6. Mendelson, D., & Haywood, I. (2014). Minors' decision-making capacity to refuse life-saving and life-sustaining treatment: Legal and psychiatric perspectives. *Journal of Law and Medicine*, 21(4), 762-773.

The capacity of minors to make decisions related to euthanasia is questioned in this paper.

7. Oduncu, F. S., & Sahm, S. (2010). Doctor-cared dying instead of physician-assisted suicide: A perspective from germany. *Medicine, Health Care, and Philosophy*, 13(4), 371-381. doi:10.1007/s11019-010-9266-z [doi]

The authors conclude that: “Euthanasia and PAS as practices of direct medical killing or medically assisted killing of vulnerable persons as “due care” is to be strictly rejected. Instead, we propose a more holistically-oriented palliative concept of a compassionate and virtuous doctor-cared dying that is embedded in an ethics of care.”

8. Somerville, M. A. (1999). Euthanasia is wrong: Legalizing it would have a dangerous impact on society *The Gazette*; Montreal, Que. [Montreal, Que]15 May: B5.
9. Van Norman, G. A. (2014). Physician aid-in-dying: Cautionary words. *Current Opinion in Anaesthesiology*, 27(2), 177-182.

This paper warns that vulnerable populations maybe at risk with PAS and euthanasia policies.

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**Introduction**

The Canadian Medical Association (CMA) is pleased to provide this submission to the Council of Canadian Academies in response to the call for input by the Expert Panel on Medical Assistance in Dying. The submission identifies the main considerations identified by physicians concerning requests for medical assistance in dying (MAiD) by mature minors, advance requests, and where mental illness is the sole underlying medical condition.

Representing more than 85,000 members, the CMA has an ongoing commitment to developing policies and positions through member consultation to represent the national voice of the medical profession in Canada. This submission is no exception and is a result of research, consultation and deliberation with CMA members and key stakeholders. In preparation for this submission, members were asked to explore and reflect upon the clinical implications, risks and safeguards associated with the three types of requests.

**MAiD requests by mature minors**

In considering providing MAiD for mature minors, physicians recognize the need for appropriate safeguards that account for the individual situation of each minor.

**(i) Role of the parent/primary caregiver/caregiver**

The role and extent of parental/caregiver involvement in the decision of a mature minor to request MAiD is deemed to be important but requires clarification, especially to navigate cases when parents disagree with the child's request. The need for parental/caregiver involvement is important, but limits must exist as parents should not make the decision for the mature child.

**(ii) Assessing capacity and maturity**

There is a need for clear guidelines to assess the child's capacity and maturity to consent. Clinicians qualified to perform specialized capacity assessments are required. These assessments should take into consideration the unique circumstances of each minor.

**(iii) Involving a multi-professional approach**

When considering requests by mature minors, there is a need for a multi-professional team to ensure adequate counselling, accurate information, and an assessment of the child's best interests.

**(iv) Minors with mental illness**

The irreversibility of MAiD, young age and inadequate access to child psychiatrists merits a cautious approach to allowing mature minors to access MAiD where mental illness is the minor's sole underlying condition.

**Advance Requests for MAiD**

Physicians supported advance requests for MAiD, but as access evolves, guidelines are needed to support health care providers in light of the provincial and territorial variability in advance care planning requirements.

**(i) Variability in interpretation of eligibility**

The variability in the understanding of the eligibility criteria for accessing MAiD, e.g., grievous



and irremediable medical conditions, is a concern. Moreover, there is a need for greater clarity in the requirements and level of specificity necessary for a valid advance directive that includes MAiD.

(ii) Determining whether the patient's situation meets the conditions expressed in the advance request

Clarity in the expression of the circumstances that prompt the provision of MAiD was seen as imperative. Without clear guidelines, the potential variability in the progression of an illness may make it challenging to determine when a patient's situation has met the conditions outlined in the request. Further, timely and accurate assessment of the patient's progression will be required.

(iii) Changes in a patient's wishes over time

A significant clinical challenge is present when patients make an advance request when capable, but later refuse the administration of MAiD while incapable. Clear guidelines are required to address situations where patients refuse the administration of MAiD when they are deemed to be incapable, after having made an advance request when capable.

(iv) The role and involvement of third parties

Conflict and challenges are likely to arise when the role and extent of the involvement of third parties, e.g., family members or substitute decisions makers, is unclear where there is an advance request for MAiD.. Clear guidelines, safeguards, standards and/or dispute resolution mechanisms are required to resolve these conflicts and respect the patient's decision.

Requests for MAiD where mental illness is the sole underlying condition

Physicians were divided regarding requests for MAiD where mental illness is the sole underlying condition due to what are deemed to be the significant risks, clinical challenges and nature of mental illnesses.

(i) The broad scope of mental illnesses

A significant challenge with requests where mental illness is the sole underlying condition is the broad scope of conditions captured by the term 'mental illness.' Without specificity, there is a risk of generalizing decisions for a group of people whose illnesses are highly nuanced and individualized.

(ii) Determining eligibility

The management of mental health conditions has improved dramatically in recent years, but barriers to accessing adequate care remain, e.g., systemic deficiencies and the effect of social determinants of health. While mental illnesses may indeed be grievous or unbearable, determining whether such illnesses are irremediable in light of a lack of access to care is difficult.

(iii) Assessing capacity

Assessing a patient's capacity to consent to MAiD in this context is difficult. For example, the desire to die is sometimes a characteristic of particular mental illnesses. Moreover, the possibility of compounded vulnerability, e.g., due to homelessness or lack of access to mental health care, further complicate capacity assessments.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

We will be submitting some additional considerations at the end of the week.

Thank you for your understanding.

## Medical Assistance in Dying

### Using Artificial Intelligence to Study Canadian Opinions

ASSOCIATION  
MÉDICALE  
CANADIENNE



CANADIAN  
MEDICAL  
ASSOCIATION

1867–2017

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The Canadian Medical Association (CMA) is the national voice of Canadian physicians. Founded in 1867, the CMA's mission is empowering and caring for patients.

On behalf of its more than 85,000 members and the Canadian public, the CMA performs a wide variety of functions. Key functions include advocating for health promotion and disease/injury prevention policies and strategies, advocating for access to quality health care, facilitating change within the medical profession, and providing leadership and guidance to physicians to help them influence, manage and adapt to changes in health care delivery.

The CMA is a voluntary professional organization representing the majority of Canada's physicians and comprising 12 provincial and territorial divisions and over 60 national medical organizations.

## Overview

The Canadian Medical Association (CMA) employed Artificial Intelligence (AI) to generate reports that measure the level of response to medical assistance in dying (MAiD) with respect to requests made by mature minors, advance requests, or where mental illness is the sole underlying condition. These reports help us understand Canadian physicians' and the general population's opinion on the three types of requests.

Using AI to generate reports is similar to using traditional polling techniques. However, there are significant advantages to using AI to measure opinions. First, AI reports the level of engagement and support or opposition for a topic, indicating how informed and interested the population is in that topic. Second, using AI allows for amplified sample sizes. For example, the physician population includes 8,100 Canadian physicians, while the sample size for the general population was 140,600 individuals residing in Canada. Last, using AI to gauge opinions provides an unbiased assessment, as engagement is not garnered by calling people and asking for an opinion. Rather, opinions and data are generated from online conversations about MAiD, while respecting the privacy of individuals.

The study focused on determining the level of support for the three requests as well as the considerations that make providing MAiD acceptable both from the perspectives of physicians and the general population. The recommendations and statistics presented are the results of the data and opinions that AI reports.

## Methodology

### I. Sampling and demographics

The AI algorithm crawls online networks to create a sample of people that is representative of the overall population. The sample generated by the algorithm is identical to Random Digit Dialling but amplified to include thousands to hundreds of thousands of people.<sup>1</sup>

The demographics for each individual is assessed and assigned by the AI using specific attributes of the online profile to determine gender and age. For example, gender is determined by examining the profile, the individual's first name and avatar image. The data is then assessed against a combination of birth records and actuarial tables.

Further, AI is able to determine whether individuals are physicians or part of the general population.

For this study, the algorithm was restricted to individuals residing in Canada. The study period is January 2016 to September 2017. The sample size for studying the general population's opinion was 140,600 individuals. The sample size for studying physician opinion was 8,100. The AI is not able to determine if the physicians are CMA members.

## **II. Topic and stance detection**

Unlike traditional polling, AI produces an unbiased result. The approach does not ask individuals in the sample any questions. Therefore, individuals are neither forced to take a stance on an issue nor is the response biased through the wording of the question.

Instead, AI examines the online communications of the person in the sample to determine if it matches the topic. Once the communication matches the topic, the AI assesses the communication to determine if a person opposes or supports the given topic. This is achieved through algorithms to build a statistical model of each topic. AI 'learns' the subject matter, *i.e.*, MAiD, by 'reading' current literature, including articles, studies and reports. This allows the AI to determine if a person's online communication relates to the learned topic. AI's matching is unbiased because it reflects the language within the current literature. AI then measures the semantic polarity of the communication in the context of the topic to determine the level of opposition or support to the given topic.

## **I. Privacy**

The CMA respects privacy, the use of AI to identify opinions, challenges and recommendations reflects this respect.

The mined data are taken from public online sites where the user has allowed open access to their accounts and data. The AI's data mining complies with each site's terms and conditions. AI will not mine the data of individuals who wish their information to be private.

Once AI processes the demographics, any identifiable information for each individual is removed from the stored data. Further, the online communications for each user are not available for analysis or to researchers. Only the aggregate data, without the actual message of the communication, is returned. AI protects privacy, only returning aggregated queries when five or more individuals match, preventing analysts from identifying a single specific user based on a specific query

## **IV. Response Rate and Engagement**

Traditional polling refers to the response rate within the sample.<sup>2</sup> The response rate for AI's method is technically 100% as there is enough information within the sample to determine if a person is discussing the topic and their stance.

Engagement is an alternative measure of response rate that determines how many people were engaged with the topic and discussing the topic online. The engagement rate indicates how interested the population is in the topic without prompting a response from the survey taker. Engagement is an unweighted aggregation of the probability that a person is discussing a topic.

## Findings

The study surveyed the Canadian physicians and the general population to identify the level of support for the three requests, as well as the associated considerations, challenges and recommendations discussed. For the considerations, challenges and recommendations, AI first determines the number of Canadians discussing the various points then gauges the level of support or opposition for each. Thus, the results reflect the current online conversations for each population.

### I. Requests by mature minors

#### a. Population opinion

The study revealed that 59% of Canadian physicians support MAiD requests by mature minors. In contrast, the general Canadian population showed a higher level of support, with 65% supporting MAiD requests by mature minors.

#### b. Challenges

Canadian physicians were actively discussing the challenges associated with MAiD request by mature minors. The identified challenges included assessing the mature minor's competence and parental/caregiver objection.

From the sample population, 500 physicians discussed the accurate assessment of a mature minor's competence, 84% of whom agreed that this is the biggest challenge to providing MAiD for mature minors. Further, between 700 and 800 physicians discussed parental/caregiver objection, 56% of whom identified this as the biggest challenge.

Comparatively, the study revealed that amongst the general population, a low number of Canadians discussed the challenges associated with MAiD requests by mature minors (25,600–29,100 individuals). However, in these discussions, assessing competence and parental/caregiver objections were perceived as the biggest challenges for MAiD requests by mature minors (87% and 74%, respectively).

#### c. Recommendations

Both physicians and the general population supported using a combination of an age threshold as well as a competence-based threshold to determine access to MAiD for mature minors.

Physicians supported using a combination of both an age and competence threshold (85%) rather than an age threshold alone (29%) or a competence threshold alone (43%) as the eligibility criteria for mature minors. Comparatively, amongst the general population, 68% supported using a combination of both an age and competence threshold, while 38% supported an age threshold alone, and only 29% supported a competence threshold alone.

## **II. Advance Requests for MAiD**

### **a. Population opinion**

The study indicates that both physicians and the general population show support for advance requests for MAiD. 62% of physicians are willing to provide MAiD through an advance request, and 65% of the general population believe that advance requests for MAiD should be provided.

Between 800 to 1000 physicians discussed the provision of MAiD through an advance request when the patient was in an 'irreversible state.' A strong majority of these physicians (94%) would provide MAiD if the patient is in an 'irreversible state' and had made an advance request. 200 physician conversations focused on the validity period of an advance request, with 82% agreeing to provide MAiD where the advance request was made within the past five years.

Comparatively, 77% of physicians argue against MAiD when they are not confident that the patient was competent to make the decision when creating the advance request. Further, 68% of physicians hesitate to provide MAiD when a power of attorney/next of kin/substitute decision maker objects to carrying out the advance request. Similarly, amongst the general Canadian population, 63% believe an advance request for MAiD should not be honored when an individual's competence to make the advance request is in question.

### **b. Challenges**

According to the findings, 75% of physicians believe that the biggest challenge to providing MAiD through an advance request is determining when the patient's circumstances meet the criteria in the advance request.

### **c. Recommendations**

Both physicians and the general population discussed how best to make an advance request for MAiD. Physicians identified that amongst the various ways to make an advance request, a video recording made by the individual (75%), a legal notarized document (70%), an audio recording made by the individual (72%) or a standardized MAiD form (54%) are best. For the general population, a standardized MAiD form (84%), a video recording made by the individual (74%), an audio recording made by the individual (71%) or a legal notarized document (69%) are best.

## **III. Requests where mental illness is the sole underlying condition**

### **a. Population opinion**

Of the three types of requests, MAiD where mental illness is the underlying condition received the least support both from physicians and the general population. Within the sample population of physicians, only 27% support providing MAiD where mental illness is the sole underlying condition. Comparatively, only 21% of the general population supports MAiD where mental illness is the sole underlying condition.



Despite the opposition, physicians discussed the circumstances in which they would provide MAiD where mental illness is the sole underlying condition. These circumstances include where all treatment options have been exhausted, and the patient still believes that they have no quality of life (82%), and where requests are made by individuals who have a mental illness for many years, without successful treatment (56%).

### **b. Challenges**

The findings show that between 1,000 and 1,100 physicians discussed the challenges associated with providing MAiD where mental illness is the sole underlying condition. Of these physicians, 57% believe that assessing whether the patient is capable of consenting is the biggest challenge to providing MAiD where mental illness is the sole underlying condition. In the general population, 68% of Canadians believe that the biggest challenge for this request is understanding the definition of mental illness.

### **c. Recommendations**

The study did not reveal online conversations that discussed recommendations.

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<sup>1</sup> Li G. "Sampling Graphical Networks via Conditional Independence Coupling of Markov Chains" in Khoury R, Drummond C (eds) *Advances in Artificial Intelligence*. Springer, Cham, 2016 p 298-303.

<sup>2</sup> Keeter G, Hatley N, Kennedy C, et al. What Low Response Rates Mean for Telephone Surveys. *Pew Research*. 2017 May 15. Available: <http://www.pewresearch.org/2017/05/15/what-low-response-rates-mean-for-telephone-surveys> (accessed 2017 Sep 30).

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The CMPA is a not-for-profit mutual defence organization and the principal provider of medical-legal assistance to approximately 98,000 physician members. The most obvious expression of the CMPA's assistance to its members is the provision of legal representation in medical-legal matters including the provision of appropriate compensation to patients proven to have been harmed through negligent medical care. The CMPA also plays an integral role in providing risk management advice and services to its members on issues related to the practice of medicine.

Since the Supreme Court of Canada's decision in *Carter* and the introduction of Bill C-14 legalizing medical assistance in dying ("MAID") in certain circumstances, the CMPA has received frequent and numerous calls from members with questions about MAID. With the assistance of our legal counsel, we have assisted many members across the country who have received requests from patients for MAID. It has been our experience to date that there continues to be uncertainty about the interpretation and application of some of the existing Criminal Code requirements for MAID, including amongst physicians, patients, legal counsel and others.

The CMPA does not take a position on whether Parliament should or should not decide to expand eligibility to MAID to mature minors, advance requests, and/or cases where mental illness is the sole underlying medical condition. Rather, our principal recommendation is that if the government decides to expand eligibility, it should be done through a thoughtful and balanced approach and with additional clearly understood and effective criteria and safeguards.

The CMPA has consistently stated in the context of MAID that effective safeguards are important to protect patients while also minimizing the medical-legal risks for physicians. Safeguards should be clear to ensure that those involved understand how to apply them, thereby avoiding uncertainty that could impede patient access to MAID. In this regard, the CMPA welcomes the work CCA is doing in gathering and assessing relevant information and evidence that will inform Parliament's reflection on whether to revise the MAID framework.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

**a. Mature Minors**

In all provinces and territories except Québec, the determinant of a minor's capacity to consent to medical care is the extent to which the person's physical, mental, and emotional development allows for a full appreciation of the nature and consequences of the proposed care.

If Parliament were to expand eligibility to MAID to mature minors, it would be necessary to address how patient competence will be assessed in the specific context of MAID. The current general test to determine whether a minor is competent to provide consent is subjective and may be particularly difficult to implement in the context of decisions that may result in the

person's death. This issue was recognized in the Supreme Court of Canada decision, *A.C. v. Manitoba (Director of Child and Family Services)*, in which the majority of the Court held that "mature adolescents have strong claims to autonomy, but these claims exist in tension with a protective duty on the part of the state that is justified by the difficulty of defining and identifying 'maturity'. Any solution to this tension must be responsive to its complexity."

One option may be for Parliament to create additional safeguards in the Criminal Code when the patient requesting MAID is a minor. For example, mature minors in Belgium can access MAID if they meet certain criteria in addition to those applicable to adults. While Belgian adults can access MAID if they suffer from irremediable physical or psychological suffering, MAID is only accessible to mature minors if they suffer from irremediable physical suffering, and only if their medical condition will result in death in the short term. In addition, a consultation must be held with a child psychiatrist or psychologist concerning the minor's competency and a written report must be prepared which must be discussed with the minor's parents. The parents also need to provide written consent to the minor's request for MAID.

In the Netherlands, mature minors between the ages of 16 and 18 may access MAID if they meet the eligibility requirements and their parents have been involved in the decision process. Mature minors between the ages of 12 and 16 may only access MAID with their parents' consent.

Special consideration will need to be given by Parliament to the unique issues that can arise when the minor requesting MAID is suffering from a mental illness. In this regard, the issues identified above will need to be considered in combination with the issues discussed below regarding mental illness, particularly when the minor's request for MAID is based solely on his/her mental illness.

#### b. Advance Requests

Without taking a position on whether or not they should be permitted, in the event that Parliament considers advance requests for MAID, unique and complex legal issues related to informed consent will need to be addressed. It will also be important to ensure that there are clear and effective safeguards to protect vulnerable patients, including clearly defining when such requests can be given and what will be required in the request. The process and circumstances in which a physician can rely on an advance request should be clearly defined, particularly when family members or substitute decision-makers do not consent to proceeding with MAID. The legislation should also protect from criminal or civil prosecution physicians who reasonably rely on a properly executed advance request.

The issues related to advance requests in the context of MAID are not purely theoretical. We are aware of a number of cases to date in which patients have changed their mind about receiving MAID after making the initial request. According to the report of the Québec's Commission sur les soins de fin de vie, amongst the 253 requests for MAID made in Québec institutions between December 10, 2015 and June 9, 2016, patients changed their minds about receiving MAID in 24 of these cases.

The issues for consideration will vary, in part, on the conditions in which Parliament may allow advance requests. For example, the issues will likely be different if the advance request was made prior to the diagnosis of the incurable condition, as compared to after the diagnosis of the incurable condition that is likely to evolve into a grievous and irremediable medical condition. We are aware that some individuals are being encouraged to include in their wills, prior to any

diagnosis being made, a provision confirming their desire to receive MAID if they develop a grievous and irremediable medical condition at some point in the future but lack the mental capacity to provide contemporaneous consent to MAID. In some cases, this provision is being included in anticipation of the possibility that eligibility for MAID will be expanded in the future to permit advance requests.

Where the advance request for MAID is received prior to a diagnosis being made, how informed consent will be obtained needs to be considered. The law generally expects that in obtaining informed consent in most cases, physicians address the likely evolution of an incurable condition, available and reasonable options to relieve and manage suffering (such as palliative and other end-of-life care options), and whether these treatments are acceptable to the patient. If no incurable condition has been diagnosed at the time the advance request is made, it will be important that physicians understand the expectations for obtaining informed consent where the request is, by its nature, hypothetical and speculative.

In cases where the advance request is made after the diagnosis, it might not necessarily be made before the patient experiences the required enduring and intolerable suffering. In these cases, there will need to be a process and clear expectations for determining when the circumstances expressed in the advance request are met, whether the directive remains the patient's current wish, and when to proceed with MAID. For example, a patient suffering from dementia could ask to receive MAID when he/she is no longer able to recognize family members. Amongst the issues a practitioner must assess in these circumstances is how to determine when that condition is met – when the patient can no longer name some or all family members or when he/she no longer appears to derive comfort from their visits? Despite no longer recognizing family members, should MAID still be administered if the patient still appears to enjoy a quality of life?

A patient who satisfies all of the eligibility criteria for MAID could instruct the practitioner in advance that MAID be administered at a predetermined date or circumstance (e.g. unable to eat solid foods), even if he/she no longer has the capacity to consent at the time of the administration. In such a case, assuming the patient was capable of providing consent at the time the request was made, the issue of informed consent and whether the request remains the patient's wishes at the time of administration may appear less concerning. However, consideration should be given to situations where the patient may no longer have the capacity to consent to MAID, but may still be able to express wishes and preferences which might contradict the content of the advance request.

In those circumstances, should the practitioner proceed to honour the patient's wishes as expressed in the advance request? How would the practitioner determine whether the patient's suffering is intolerable to him/her if the patient has limited abilities to express himself/herself because of the progression of the illness? Consideration should also be given to a forum for adjudicating disputes that would inevitably arise where a patient's substitute decision maker does not support the advance request for MAID.

Should Parliament consider allowing advance requests for MAID, the challenges posed by the existing legal framework around informed consent will need to be thoroughly considered when developing clear and robust criteria and safeguards. Consultations with the medical and legal community at that time will be essential to determine what safeguards would be most appropriate to protect vulnerable patients and to consider the legal and practical situations physicians will face when trying to implement advance requests in the context of MAID.

### c. Mental Illness

Expanding access to MAID to persons whose sole underlying medical condition is a mental illness raises many complex challenges. If Parliament considers expanding access to MAID to these patients, the medical and legal communities working in the area of mental health should be thoroughly consulted to ensure clear and effective criteria and safeguards are developed to mitigate the associated risks to vulnerable persons and professionals asked to carry out such requests.

As discussed above, ensuring patients have the requisite capacity to consent to MAID and that their request is voluntary are important issues to consider in discussing the possibility of allowing individuals to request MAID based solely on a mental illness. Assessing a patient's capacity can be particularly challenging when the patient is a minor or suffering from a mental illness that affects his/her insight required to provide informed consent. For example, patients with severe depression may not be able to see the potential for improvement in their condition if they underwent treatment. If those patients were to request MAID, would their decision be considered truly voluntary or does it result from symptoms of the psychiatric illness? Would they have the capacity to consent to MAID if their reasoning was distorted by the psychiatric illness?

Another consideration that arises in this context relates to determining when a psychiatric illness is "irremediable". In a letter to the Federal Minister of Health dated April 11, 2016, the Canadian Psychiatric Association ("CPA") suggested "there is no established standard of care in Canada, or as far as CPA is aware of in the world, for defining the threshold when typical psychiatric conditions should be considered irremediable." While treatment options for physical conditions can be limited, there are generally a wide variety of possible psychiatric medications and psychotherapeutic approaches that can be considered for psychiatric disorders. The CPA adds that "not only do the standards for defining irremediability not exist, with current jurisdictional mental health legislations, there is also the risk of individuals declining potentially remediating treatments because of cognitive distortions of illness, but being able to access the PAD/MAID framework on the grounds that their symptoms are irremediable given the lack of treatment."

The CMPA is also aware of the ongoing debate concerning whether the eligibility criteria in the Criminal Code that the patient be in an "advance state of irreversible decline in capability" requires an irreversible decline in physical capability, or whether it should be interpreted broadly so as to include those suffering only from a decline in mental capability. While the CMPA interprets the provision based on the information currently available as requiring an advance state of irreversible decline in physical capability, clarity is required on this issue.

With this in mind and to be consistent with the objective of protecting vulnerable individuals, clear criteria and robust safeguards must be implemented if Parliament agrees to expand MAID to this group. For example, will psychiatric assessments be mandatory? Is an extended "reflection period" (beyond the 10 clear days required currently by the Criminal Code) required in such cases during which practitioners verify that the patient's wishes are persistent? Should MAID be restricted to patients suffering from a severe, treatment-resistant mental disorder? Should the requirements around informed consent, including exploring treatment options, be heightened in the context of these cases? What additional criteria or safeguards are required, if any, when the patient requesting MAID based solely on a mental illness is a minor.

### Conclusion

We trust that these comments will be of assistance to the CCA. If the CMPA's national experience with the medical-legal issues in this context might be of further assistance, we would be pleased to consider providing other information or input as may be required.

Yours sincerely,


Hartley S. Stern, MD, FRCSC, FACS  
Executive Director/Chief Executive Officer

Canadian Mental Health Association

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*



# Canadian Mental Health Association's Position Paper on **Medical Assistance in Dying (MAiD)**

AUGUST 2017



CMHA National  
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Toronto, ON M5T 2Z5



# The Canadian Context - Overview of Bill C-14

On April 14, 2016, Bill C-14 (the Bill) received first reading in the House of Commons of Canada and was formally passed into law on May 30, 2016. The Bill primarily sets out to decriminalize medical assistance in dying (MAiD) by amending portions of the Criminal Code that otherwise prohibit it. Additionally, it addresses eligibility and procedural elements of MAiD. The Bill follows the Supreme Court of Canada 2015 decision in *Canada v. Carter*, which legalized MAiD in Canada by striking down the Criminal Code provisions associated with the act.

Beyond providing detailed eligibility criteria, the Bill is most notable for its definition of ‘grievous and irremediable’ medical condition that includes a “reasonably foreseeable natural death”. The Bill aims to maintain the Criminal Code’s prohibition of assisted suicide, while creating an exemption for MAiD so as to protect medical practitioners. The counselling or assistance of suicide remains against the law in any circumstance outside of MAiD. Importantly, criminal sanctions are outlined for medical or nurse practitioners that do not comply with the procedural requirements set out in the Bill, acting as a key safeguard for ensuring the responsible implementation of this legislation. The Bill will amend the *Criminal Code of Canada*, the *Pension Act*, the *Corrections and Conditional Release Act*, and the *Canadian Forces Members and Veterans Re-establishment and Compensation Act*.

Bill C-14 does not, however, explicitly include mental illnesses in the eligibility criteria. The Bill provides a narrow definition of a ‘grievous and irremediable’ medical condition:

(s.241)

## Grievous and irremediable medical condition

A person has a grievous and irremediable medical condition if

- A. they have a serious and incurable illness, disease or disability;
- B. they are in an advanced state of irreversible decline in capability;
- C. that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- D. their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The first criterion uses the word ‘incurable’, which could easily exclude most mental illnesses based on the availability of treatment and recovery-based philosophies of mental health agencies such as CMHA. Subsection (b) requires a ‘state of irreversible decline in capacity’, which would also likely exclude mental illnesses, as they often fluctuate in symptoms and are remediable with appropriate treatment. Finally, Subsection (d) requires that a natural death be reasonably foreseeable, subsequently setting a very high threshold that will not likely be met solely on the basis of a mental illness.

In legalizing physician-assisted dying in the *Carter* decision, the Supreme Court indicated that its intention was to address a very small number of eligible patients. The Supreme Court found that there was no evidence to show that physician-assisted dying had negatively impacted vulnerable populations in other jurisdictions where it is legal, nor was there an increased risk of people with disabilities wanting to access it. The ruling allows for competent adults living with a “grievous and irremediable medical condition that causes enduring and intolerable suffering” to end their

life with the assistance of a physician. The Supreme Court did not, however, define “grievous and irremediable,” raising the questions of whether or not mental illnesses and addictions can be defined that way and what the implications of doing so would be in this context.

End-of-life care is a relevant issue to all Canadians, meaning that the regulation of this new law must adequately address the needs and well being of a diverse and complex population. The questions surrounding mental health are complex ones, requiring careful navigation in order to properly address people living with mental health conditions. While there may be some question as to whether mental illnesses can be included in the term “grievous and irremediable medical condition,” it is our position that the Supreme Court of Canada specifically distinguished their ruling from the laws of other countries such as Belgium which includes “euthanasia for minors or persons with psychiatric disorders or minor medical conditions” (para. 111 of Carter). This very important distinction attempts to distance Canada’s legal framework on this issue from other nations that have raised controversy due to their broad policies and administration of the practice. Upon comparison of other jurisdictions that allow for psychiatric- Euthanasia/Assisted Suicide, CMHA’s position that mental illness not be included in this definition becomes clear.

## Other Jurisdictions – A Case Review of the Netherlands and Belgium

As Canada continues to debate the particularities of the legalization of MAiD, it is important to look towards our international neighbours who have forged the way before us. Beyond Canada, euthanasia or assisted suicide (EAS)<sup>1</sup> is now legal in some form in Belgium, the Netherlands, Switzerland, Luxembourg, and several American states.<sup>1</sup> In regards to this report, however, it is essential to analyze the countries that have legalized EAS for non-terminally ill patients suffering *solely* from mental illnesses. Here, we will assess this practice in the Netherlands and Belgium, focusing on data from two specific studies that analyzed cases of psychiatric EAS within their respective countries.

The Netherlands (NL) and Belgium (BE) have constructed a set of “due care” criteria that must be met for EAS to be legally performed. The most striking difference between their standards and the Canadian law is that death need not be foreseeable to perform EAS in the Dutch and Belgian cases, hence why psychiatric- EAS may be performed. Tinne Smets et al. have organized the Dutch and Belgian substantive and procedural requirements as follows:<sup>2</sup>

- The patient’s request must be voluntary and well considered; it must be repeated, and may not be the result of any external pressure (BE/NL).
- The patient must be in a medically futile state of constant and unbearable physical or psychological suffering, which cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident (BE).
- The patient’s suffering must be lasting and unbearable (NL).
- The physician must inform the patient about his/ her health condition and prospects (BE/ NL).
- The physician must terminate life in a medically and technically appropriate way (NL).

<sup>1</sup> Note: EAS is the term used interchangeably in the Belgium and the Netherlands context, while in Canada MAiD is used; however, both terms are referencing physician-assisted death.

- The treating physician must consult another physician before proceeding (BE/ NL).
- The physician must notify the case of euthanasia for review (BE/ NL).

Beyond these official, legislative similarities, it is important to highlight the social, normative similarities as well. In both countries, psychiatric-EAS appears to be on the rise—Since 2006 it has increased by an average of 15% a year, nearly three times the 2002 figure [meaning] that today about one in 25 deaths in the Netherlands is the result of psychiatric-EAS.<sup>8</sup> Similarly, a Belgian statistic claims that, since 2002, the number of EAS reported deaths has increased each year, “rising from 742 in 2004/2005 to 2086 in 2010/2011,” although it should be noted that this may also reflect better reporting.<sup>9</sup> The social normalization of this practice is alarming upon realization of the systemic flaws highlighted by the Belgian and Dutch studies that analyzed psychiatric EAS cases in both countries.

Through a comparison of the two studies conducted by Lieve Thienpont et al. (2015) in Belgium and Scott Kim et al. in the Netherlands, some issues with EAS reporting become clear. The Belgium study analyzed 100 cases of EAS requests, procedures and outcomes between 2007 and 2011, while the Dutch study compared 66 cases of *completed* EAS cases between 2011-2014. While the Dutch study is null here as all procedures were completed, the Belgian study highlights important findings in psychiatric EAS—mentally ill patients have a high likelihood of *changing their minds*. Out of the 48 patients who were approved for EAS, 11 (excluding 1 patient who postponed due to imprisonment) either postponed or cancelled their procedures.<sup>10</sup> Additionally, of the 52 patients who were not accepted, 38 withdrew their requests before a decision was made.<sup>11</sup> Therefore, 48% of patients (38 withdrew + 10 who postponed) in this study changed their minds. This is a concerning statistic as it reveals the high likelihood that, with more time and support, a patient requesting psychiatric EAS may retract their decisions. Follow up data collected a year later further supports this claim: Of the 57 patients who were still alive (35 died by EAS, 6 by suicide, 2 by other health issues), only 9 patients still had EAS requests being processed.<sup>12</sup> Meanwhile, in the remaining 48 patients, “their requests were on hold because they were managing with regular, occasional or no therapy”.<sup>13</sup> These patients who were successfully coping and functioning, just one year later, may have otherwise already died due to the practice of psychiatric EAS. Most patients suffering with depression or other psychiatric disorders may struggle to find coping techniques for long periods of their lives; however, our position is that death need not be the solution. This study suggests evidence of this, highlighting that psychiatric EAS requests may be part of the natural symptoms of many mental illnesses, particularly depression. In fact, “depression is more influential on the desire to hasten death than physical pain”.<sup>14</sup> And, where a desire to die is often part of a patient’s disorder, “the competence of [a] decision and the intractability of their suffering are much more difficult to assess”.<sup>15</sup> It is difficult to justify supporting a “wish to die” if that wish is a known symptom of a patient’s mental illness and if said symptoms are treatable.

CMHA also notes the changing social norms in Belgium and the Netherlands surrounding this issue. The increases in requests of psychiatric-EAS may be attributed to “continuing attitudinal and cultural shifts; values of autonomy and self-determination have become more prominent, and acceptance of euthanasia continues to increase in the population at large”.<sup>16</sup> After the Dutch data revealed that 20% of patients had never had psychiatric hospitalization, that there was a high ratio of women to men (2.3 to 1), and that social isolation and or loneliness was a key observation in 56% of the reports,<sup>17</sup> a red flag was raised: psychiatric-EAS may intersect with larger social issues. We must be careful to avoid the use of psychiatric-EAS as a “substitute for effective psychosocial intervention and support”.<sup>18</sup> However, while psychiatric-EAS may be on the rise, it still remains an unfavourable option to the majority of the population. A Dutch survey (2012) revealed that a minority of healthcare professionals (35-36%) and the general public (28%) agreed with providing EAS to patients with chronic depression.<sup>19</sup>

Upon analysis, it is clear that the existing state policies on psychiatric-EAS in Belgium and the Netherlands allow for substantial gaps in their standards and compliance mechanisms. The Dutch and Belgian data validates CMHA's position that psychiatric-EAS does not have a place in the current Canadian context.



## Canadian Mental Health Association (CMHA) – Our Vision, Mission and Values

Founded in 1918, the Canadian Mental Health Association (CMHA) is the most established, most extensive community mental health organization in Canada. Through a presence in hundreds of neighbourhoods across every province, CMHA provides advocacy and resources that help to prevent mental health problems and illnesses, support recovery and resilience, and enable all Canadians to flourish and thrive.

Visit the CMHA website at [www.cmha.ca](http://www.cmha.ca).

# Mental Health and Recovery

Mental health affects us all and mental health conditions may occur across the life span, regardless of gender, race, sexual orientation or other social factors. For numerous reasons CMHA believes that psychiatric-MAiD should remain illegal, the most important of which is the core belief that any such mental health condition is treatable, recovery is always possible, and that in order to be inclusive, a society must support people with mental illnesses and addictions.

## i. Belief in Recovery

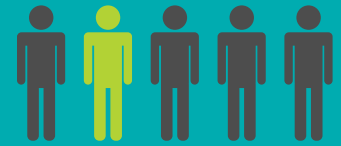
Recovery is the process by which people with lived experience of mental health and addictions issues gain control, meaning and purpose in their lives. Recovery is a unique, personal experience, involving different paths for different people. For some, recovery may mean the complete absence of the symptoms of a mental illness while, for others, recovery entails developing effective coping strategies for ongoing symptoms in an effort to maintain an active, full life within the community.<sup>23</sup>

Many mental health and addictions services and supports now promote recovery-oriented philosophies in their practices. Growing evidence shows that people can and do improve and recover from mental illness and addictions, effectively renouncing the outdated medical assumptions that mental illnesses only worsen over time. Now, new and more effective medical, social and community services and supports have been developed and implemented with the goal of recovery at the forefront.

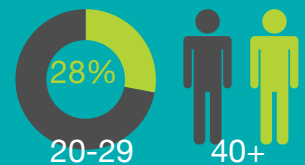
Recovery involves changes in the way individuals with mental health and addictions conditions think, act and feel about themselves and their lives. It also requires changes in the ways services are funded and organized, mental health professionals are trained, and success is measured. Recovery is about transforming the mental health and addictions system so that it truly puts the person at the centre.

## ii. Loss of Hope

It is important to discuss the potentially negative impact of a psychiatrist's or medical practitioner's approval of MAiD for their patient. Presenting MAiD as a viable option may "reinforce loss of hope and demoralization"<sup>24</sup> in struggling patients. It is argued that, "by answering a death request of a psychiatric patient positively, a central therapeutic element in the doctor-patient relationship, namely the instrument of hope, is removed".<sup>25</sup> Also related is the argument that these discussions "about the possibility of (assisted suicide) between doctor and patient may reinforce feelings of desperation and demoralization in the patient". The doctor-patient relationship is of key importance as patients often look to their doctors for answers. If the doctor—the patient's advisor and power figure—agrees or supports the



One in five Canadians experiences a mental health issue in any given year.<sup>20</sup> Currently, more than 6.7 million people are living with a mental health condition in Canada.<sup>21</sup>



More than 28% of people aged 20-29 experience a mental illness in a given year, and by the time people reach 40 years of age, 1 in 2 people in Canada will have had or have a mental illness.<sup>22</sup>

wish to die for reasons of mental illness, it is an indirect admission that the patient will never recover and that they cannot recover from their mental health condition. As CMHA firmly believes in recovery and the treatment of mental illnesses and addictions provided the proper supports and resources, this “loss of hope” is considered very detrimental.

### iii. Non-discrimination

CMHA supports that non-discrimination between mental illness and physical illness be upheld. If a patient with a reasonably foreseeable natural death *a/so* has a mental illness, that mental illness should not preclude them from being able to access MAiD. Whether or not the patient was afflicted by a mental illness before or after the physical illness, in an effort to prevent discriminatory practises in public health, the physical illness must take precedence if it meets the eligibility criteria as put forth by bill C-14.

## Our Position

As a recovery-oriented organization, CMHA does not believe that mental illnesses are irremediable, though they may be grievous or unbearable.

We recognize that people with mental illnesses can experience unbearable psychological suffering as a result of their illness, but there is always the hope of recovery.

CMHA’s position on medical assistance in dying in Canada, is that people with a mental health problem or illness should be assisted to live and thrive.



# Recommendations

As a recovery-oriented organization, CMHA makes the following recommendations to the Government of Canada:

## 1. Support Recovery

CMHA believes that every person living with mental health and addictions issues must be actively supported in their journey of recovery. With the right supports and resources, research suggests that recovery is possible regardless of the mental health diagnosis.<sup>26</sup> Recovery-oriented practice, or one that places the patient at the centre of care, is essential for a high performing mental health and addictions system in Canada.

## 2. Continue to invest in community mental health and addictions services and supports

We need governments to ensure there is access to a full continuum of mental health services and supports for all Canadians, in all communities across Canada. Although there have been significant new investments in mental health and addictions, Canada still lags behind all of the other G7 countries. Before we assist people in dying, we should assist people to live and thrive – this starts with making sure that all Canadians have equitable access to mental health and addiction services. The overall well-being and resilience of Canadians with lived experience of mental health issues will improve if their basic needs for income security, affordable and safe housing options, and opportunities to secure supported employment are met; and if a range of community-based, traditional and/or alternative mental health and addictions services and supports are available to them.

### Equity

- » It is well established that some groups (or populations) in society experience social and economic disadvantage – inequities – due to the unequal distribution of power, wealth and resources. The social determinants of health both determine and deepen inequities.
- » Marginalized groups are more likely to experience poor mental health and in some cases, mental health conditions. In addition, marginalized groups have decreased access to the social determinants of health that are essential for recovery and positive mental health.
- » Our marginalized communities are at a greater disadvantage in terms of access to care compared to non-marginalized groups. The principles of equitable provision must inform our mental health and addictions system.

## 3. Develop a national suicide prevention strategy

Though Canada has a national mental health strategy, *Changing Directions, Changing Lives: the Mental Health Strategy for Canada*<sup>27</sup>, we currently lack a comprehensive suicide prevention strategy. A national strategy for suicide prevention is necessary to coordinate the existing suicide prevention efforts currently underway in provinces and territories across Canada, and to bring evidence-informed practices for suicide prevention to every community in our country. CMHA recommends that a national suicide prevention strategy be developed to promote mental health recovery for all Canadians.

#### **4. Invest in research to accurately predict and understand the course of illness in mental health and substance use**

Our understanding of mental health and addictions issues and our implementation of practises/solutions, are quite underwhelming. There is a shortcoming here that needs to be addressed and we encourage investment in research to better understand these issues.

*Approved by the Canadian Mental Health Association National Board of Directors, August 2017*





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## End Notes

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2017



**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

While the three areas are important, the Canadian Psychiatric Association has provided input particularly where mental illness is the sole underlying medical condition. As the House of Commons and the Senate considered Bill C-14, the CPA recommended to the federal government that additional time was needed to allow the development of proper standards and guidelines prior to regarding any consideration of psychiatric illnesses in a MAID framework. It is important to make the distinction between cases of irremediable physical illness leading to grievous and intolerable suffering concurrent with psychiatric illness, versus situations where the person applies for MAID on the grounds of an irremediable psychiatric illness. In the former situation, established principles of capacity assessment would apply as they do already; in the latter situation, there are currently no established standards of care to guide clinical assessment and decision-making.

Key amongst guidelines needing development in any MAID framework is establishing a standard of care for the concept of irremediability in cases of psychiatric illness. As far as the CPA is aware, there is no established standard of care for defining the threshold when typical psychiatric conditions should be considered irremediable in Canada, or the world. In addition, symptoms of psychiatric illnesses themselves may impact decision making in unique ways, and psychosocial factors can significantly impact suffering in psychiatric illnesses, further complicating potential MAID assessments. More work needs to be done in these important areas as they relate to the MAID legislation.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

On September 14, 2017, the Canadian Psychiatric Association (CPA) released results from a member survey completed earlier this year (Attachment A). It was developed by the CPA Task Force on MAID. The 13 question survey covered key concepts related to MAID including the three questions identified by CCA. The Task Force is planning on administering a more detailed survey to better understanding member views on each issue.

The CPA has also developed a draft CPA Guidance on Medically Assisted Dying (Attachment B). Once finalized, the draft will be circulated to members and external stakeholders for input. Once this step has been completed, it will be forwarded to the CPA Board for approval. If granted, it will be released as a public document (and at that time we can forward the final document to CCA).

As part of the federal government's legislative process, the CPA has also submitted its views to the following bodies:

1. The Senate Committee on Legal and Constitutional Affairs on May 11, 2016 (Attachment C).
2. The Special Joint Committee on Physician-Assisted Dying on January 27, 2016 (Attachment

D).

3.The External Panel on Options for a Legislative Response to Carter v. Canada on November 5, 2015 (Attachment E).

4.The Provincial-Territorial Expert Advisory Group on Physician Assisted Dying on November 5, 2015.

## CPA Guidance on Medically Assisted Dying

### CPA Task Force on MAiD

**\*DRAFT document\***

The Canadian Psychiatric Association Task Force on Medical Assistance in Dying (MAiD) has developed this document to provide members with background and guidance on MAiD policies and processes. This is a newly evolving area, with further federal review coming within at least five years, and potentially earlier changes depending on outcome of pending legal challenges to the current legislation.

The body of this document is divided into four sections: Background, Mental Illness and Assisted Dying Policies, Role of the Psychiatrist and Future Directions. Appendices include relevant portions of Bill C-14 and changes to the Criminal Code of Canada, and links to MAiD related resources.

#### **A. Background/Context**

##### *Carter v. Canada*

Following the landmark Supreme Court *Carter v. Canada* ruling in February 2015, the federal government was given a one year timeline (later extended by four months to June 2016) to develop legislation to allow for MAiD (NB: at the time referred to as Physician Assisted Dying (PAD) with subsequent change in terminology to Medical Assistance in Dying (MAiD), as referred to hereinafter) in certain cases of medical illness<sup>1</sup>. The Court ruled that in situations where a patient has a **grievous and irremediable medical condition**, is in a state of **intolerable and enduring suffering**, and is a **competent adult** they should be able to access MAiD. The Court ruled that the existing prohibition against MAiD at the time, in such circumstances, constituted infringement of Section 7 of the Charter of Rights and Freedoms.

Section 7 of the Charter provides for the right to life, liberty and security of the person<sup>2</sup>. The Court reasoned that in cases of grievous illness and progressive physical decline, patients may predict getting to a future point of being unable to physically act to take their lives while being in a state of intolerable suffering, and if MAiD were not available at that time they may choose to act prior to that point, while they still retained agency, to end their lives earlier than they otherwise would. The Court concluded that “The right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly” and thus this infringed on the right to life. Likewise, the Court ruled that “an individual’s response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition [against MAiD] denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty”, and that “by leaving them to endure intolerable suffering, it impinges on their security of the person”, thus the blanket prohibition against MAiD also infringed on the person’s liberty and security, respectively.

Following the *Carter v. Canada* ruling, several processes were established to inform government policy, including the External Panel on Options for a Legislative Response to *Carter v. Canada*<sup>3</sup> and the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying<sup>4</sup> prior to the October 2015 federal election, and a joint Commons/Senate committee, the Special Joint Committee on Physician-Assisted Dying<sup>5</sup> following the election. The Canadian Psychiatric Association (CPA) testified before each of these groups<sup>6, 7</sup> in addition to the Senate Standing Committee on Legal and Constitutional Affairs<sup>8</sup>.

Considering the Supreme Court stipulation requiring an irremediable medical condition for MAiD, prior to the introduction of Bill C-14 the CPA also wrote to the Minister of Health and Minister of Justice regarding the current lack of standards for defining irremediability of psychiatric illnesses, specifically stating that “there is no established standard of care in Canada, or as far as CPA is aware of in the world, for defining the threshold when typical psychiatric conditions should be considered irremediable” and requesting further time to study the issue of mental illnesses and MAiD<sup>9</sup>.

## **B. Mental Illness in Assisted Dying Policies and Practices**

As of 2016, MAiD has been legalized or decriminalized in over a dozen jurisdictions around the world<sup>10</sup>. While eligibility criteria and indications vary by jurisdiction, MAiD on the grounds of sole criterion psychiatric illness is allowed for only in Belgium, Luxemburg, the Netherlands and Switzerland.

A recent review of the experience in the Netherlands showed the following.<sup>11</sup> Between 2011 and 2014 there were 66 completed cases of MAiD in the Netherlands for applications based on primary criterion psychiatric illness. Of these, 70% were women. In the majority of cases the patient suffered from depression or anxiety, other diagnoses included psychotic disorders, PTSD, somatoform disorder, substance abuse, eating disorders, prolonged grief, autism and other disorders. In addition to the psychiatric diagnoses, social isolation or loneliness was present in most cases. In addition, 24% of cases involved disagreement amongst consultants regarding suitability for MAiD and in 11% of cases no independent psychiatric expert was involved despite the application criterion being a psychiatric illness.

In terms of Canadian jurisprudence, under the current implementation of MAiD with Bill C-14 and amendments to the Criminal Code, MAiD applications in Canada based on sole criterion psychiatric illness are essentially not envisioned in current policy/practice (see commentary to Criminal Code amendment 241.2(2) in Appendix I below). Other legal issues regarding the possibility of future applications and policies for MAiD on the basis of mental illness remain unclear.

The *Carter v. Canada* February 2015 Supreme Court ruling acknowledged that psychological suffering must be taken into consideration, but was silent on the specific issue of psychiatric illness or diagnoses. The specific diagnoses examined by the Court were other physical medical conditions (spinal stenosis and amyotrophic lateral sclerosis). The implications of the specific Section 7 infringements ruled on by the Court also remain unclear with respect to psychiatric illnesses, as the vast majority of psychiatric



illnesses do not typically remove a person's agency to act physically, which formed a key part of the basis of one Section 7 infringement.

Following the *Carter v. Canada* ruling and prior to the introduction of Bill C-14, applications for MAiD in Canada were considered provincially on an independent consideration basis. During this time, in the case of *Canada v. E.F.*<sup>12</sup>, the Alberta Court of Appeal (COA) allowed for MAiD on the grounds of a diagnosis of Conversion Disorder (now called Functional Neurological Symptom Disorder). Although the criterion for this application was a DSM-IV diagnosis, the COA ruling emphasized the suffering was from physical symptoms, explicitly stated depression was not present and that E.F. had full capacity, and acknowledged the uniqueness of the case, stating each authorization "is specific to that person and their unique circumstances" and "the antithesis of precedential". According to the Court ruling, a psychiatrist opined in the case but they only reviewed the medical file and did not examine E.F. personally.

### **C. Role of the Psychiatrist**

#### **Overview**

Given the requirement that "natural death has become reasonably foreseeable", current federal legislation essentially does not encompass MAiD applications for sole criterion mental illness, but does not preclude applications for MAiD if mental illness is present.

The CPA Task Force has developed this document and the recommendations below in consultation with other stakeholders, and with feedback received from CPA members through a number of means, including a MAiD session at the fall 2016 CPA Annual Conference, results from a MAiD survey sent to all members, and individual member feedback. Psychiatrists should be familiar with federal legislation, provincial policies and regulations including those of their respective regulatory bodies, and local hospital/institutional policies regarding MAiD [see APPENDIX II].

#### *Should a psychiatrist be involved in assessment of every MAiD application?*

Psychiatrists do not need to be involved in every MAiD application if mental illness is not present. However, given how mental illness symptoms may affect decisions regarding MAiD requests, psychiatrists should be involved in assessment of MAiD applications if mental illness is present, or suspected to be present. Additionally, if the treatment team has concerns or uncertainty regarding capacity, the threshold for involving psychiatrists in the assessment process should be low, especially as the MAiD framework and processes are in early stages of implementation and familiarity for all medical practitioners.

#### *What factors need to be considered when mental illness is present?*

In addition to a formal capacity assessment, it is important to do a comprehensive assessment of how symptoms of mental illness may be affecting cognitions, including ability to engage in future oriented

thinking, affect and emotional resilience, sense of self, insight and judgement. In addition, suffering due to psychosocial factors should be identified and assessed. This is particularly important since, even if the primary medical condition for which MAiD is being applied for is deemed irremediable, if the impact of concurrent mental illness and/or psychosocial factors can be alleviated to reduce patient suffering, this could impact the patient's decision making process and whether they find their suffering to be intolerable.

*What factors need to be considered in a capacity assessment for MAiD?*

The accepted principles and standard of care for capacity assessments also apply to capacity assessments for MAiD. Awareness of standardized approaches and principles in structured capacity assessment tools may be helpful (for example, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T)<sup>13</sup> or the Joint Centre for Bioethics Aid to Capacity Assessment (JCB-ACE)<sup>14</sup>), and such tools may be useful for assessment and documentation especially in challenging cases.

*What if the patient's capacity changes after they have requested MAiD?*

The patient is required to have capacity when they make the MAiD request, and prior to MAiD being provided. The requirement for at least 10 clear days between the request and provision of MAiD is intended to provide a reflection period, and to ensure the decision for MAiD is not a transient one being made in a particular moment of vulnerability. As per 241.2 (3) (g), this period may be shorter than 10 days if both assessors agree that death or loss of capacity is imminent. The exemption allowed for in provision 241.2 (3) (g) is intended to be used if there is predictable progressive decline that will imminently lead to death or persistent loss of capacity, but should not be used for situations of fluctuating delirium with clearly fluctuating capacity.

*Do I have to see a patient as part of a MAiD assessment, or can I just review the chart?*

Capacity cannot be assessed without communicating with the patient. Ideally the assessment should be done in person if possible, but at a minimum via video/teleconference with the patient. Chart review alone would not satisfy the standard of care for a capacity assessment.

*If the Most Responsible Physician (MRP) is not involved in the MAiD application process, should information be sought from them as part of the psychiatrist's assessment?*

It is recommended that, to enhance understanding and context of the patient's primary medical condition for which MAiD is being sought, the psychiatrist communicate with the MRP. Even if the MRP has declined to be involved in the MAiD assessment on grounds of "conscientious objection", the MRP should provide medical information relevant to the patient's illness course and prognosis (as they would be required to for any other situation involving patient care). Conscientious objection regarding involvement in the MAiD process should not lead to an abandonment or dismissal of regular care.

*Who is the most appropriate person to be involved in MAiD assessments?*

It is important to ensure the right person with the right expertise provides MAiD related assessments. This includes both the medical practitioners assessing the primary medical illness upon which the MAiD application is based (to assess the “grievous and irremediable” nature of the condition), and also the psychiatrist if a psychiatric assessment is required (for example, a geriatric psychiatrist, or psychiatrist with expertise in relevant clinical areas in suitable circumstances). When uncertainty regarding capacity exists, physicians or health care professionals with particular expertise in capacity assessments should be involved. When preservation of capacity is clearly apparent there is no routine need for this advanced level of expertise.

*Should close family/supports be contacted as part of the MAiD assessment?*

As above, information from family and close social supports would be helpful to enhance understanding of the patient’s situation and factors impacting their decision making process. Communication with such individuals is recommended unless the (competent) patient specifically objects to such contact (and in such cases the reasons for refusing contact should be explored).

#### **D. Future Directions**

While not currently encompassed by the MAiD framework, Bill C-14 calls for further review and study of MAiD requests where mental illness is the sole underlying medical condition, requests by mature minors and advance requests. The CPA Task Force is planning for further consultation with members and stakeholders on these issues, including a second MAiD survey to members expanding on these issues.

As the MAiD framework remains quite new, experience and further policy development will need to address some as yet unresolved issues, including:

- approaches to conflict resolution (i.e. when there are differing opinions regarding appropriateness of MAiD)
- education and training of assessors
- data tracking, including to inform development and implementation of best practices

## APPENDICES

### **Appendix I: Relevant portions of Bill C-14 and Amendments to the Criminal Code of Canada, *with commentary***

Bill C-14, an Act to amend the Criminal Code and to make related amendments to other Acts with respect to Medical Assistance in Dying (MAiD) received Royal Assent on June 17, 2016<sup>15</sup>.

Among other provisions, Bill C-14:

- creates exemptions from the offences of culpable homicide, of aiding suicide and of administering a noxious thing, in order to permit medical practitioners and nurse practitioners to provide medical assistance in dying and to permit pharmacists and other persons to assist in the process;
- specifies the eligibility criteria and the safeguards that must be respected before medical assistance in dying may be provided to a person;
- creates new offences for failing to comply with the safeguards, for forging or destroying documents related to medical assistance in dying, for failing to provide the required information and for contravening the regulations.

Bill C-14 amended the Criminal Code of Canada<sup>16</sup> to allow for MAiD under certain conditions, including enacting the following changes to the Criminal Code:

Section 241.2 (1), stating that a person is eligible for MAiD only if they meet all the following criteria:

- (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

***Commentary: Note that while various health acts may not specify specific age of consent required for medical treatments, under the current federal legislation MAiD services can only be provided to those 18 years of age or older.***

Section 241.2 (2), stating a person has a grievous and irremediable medical condition if:

- (a) they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;

- (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

***Commentary: The requirement that natural death has become reasonably foreseeable for all intents and purposes essentially precludes MAiD applications on the sole criterion of a psychiatric diagnosis, but the presence of a concurrent psychiatric diagnosis does not preclude applications for MAiD for other medical conditions so long as all the other criteria are met.***

Section 241.2 (3), outlining safeguards required:

Before a medical practitioner or nurse practitioner provides a person with medical assistance in dying, the medical practitioner or nurse practitioner must:

- (a) be of the opinion that the person meets all of the criteria set out in subsection (1);
- (b) ensure that the person's request for medical assistance in dying was
  - (i) made in writing and signed and dated by the person or by another person under subsection (4), and
  - (ii) signed and dated after the person was informed by a medical practitioner or nurse practitioner that the person has a grievous and irremediable medical condition;
- (c) be satisfied that the request was signed and dated by the person — or by another person under subsection (4) — before two independent witnesses who then also signed and dated the request;
- (d) ensure that the person has been informed that they may, at any time and in any manner, withdraw their request;
- (e) ensure that another medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all of the criteria set out in subsection (1);
- (f) be satisfied that they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are independent;
- (g) ensure that there are at least 10 clear days between the day on which the request was signed by or on behalf of the person and the day on which the medical assistance in dying is provided or — if they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are both of the opinion that the person's death, or the loss of their capacity to provide informed consent, is imminent — any shorter period that the first medical practitioner or nurse practitioner considers appropriate in the circumstances;
- (h) immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying; and
- (i) if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision.

***Commentary: The above requirements require two independent practitioners to assess the person and ensure that the requirements for MAiD are met, including the patient having a grievous and irremediable medical condition, and the patient being capable of making decisions. A minimum of 10***

***clear days is required (unless both practitioners are of the opinion the person's death or loss of capacity to provide informed consent is imminent) between the date of the person's request and provision of MAiD (note: there do not have to be 10 days between the practitioner's assessments). The person must retain capacity to make treatment decisions at the time MAiD is provided.***

**Areas not covered by Bill-14 and amendments:** Bill C-14 calls for further review of requests where mental illness is the sole underlying medical condition, in addition to further review relating to requests by mature minors for medical assistance in dying and to advance requests (currently in Bill C-14 advance requests are not possible, as the person must retain capacity throughout). As the person requesting MAiD is required to have capacity to request MAiD and capacity at the time MAiD is provided, Bill C-14 does not allow substitute decision makers to make a MAiD request on behalf of another person (note that the amended Section 241.2 (4) allows another person to sign on behalf of the patient, if the patient themselves is unable to sign, however the patient themselves must retain capacity and be expressly directing the person signing on their behalf, thus the person signing is not acting as a substitute decision maker). Bill C-14 further provides for a parliamentary review of its provisions and of the state of palliative care in Canada to commence at the start of the fifth year of the Bill.

## **Appendix II: MAiD related resources**

Separate "living" document/e-document

- list of references/weblinks to processes and resources in different jurisdictions (eg provincial regulatory body and/or association policies/frameworks, CMPA, Health Canada, etc)

## **REFERENCES**

<sup>1</sup> Carter v. Canada (Attorney General), 2015 SCC 5

<sup>2</sup> *Canadian Charter of Rights and Freedoms*, s 7, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

<sup>3</sup> External Panel on Options for a Legislative Response to Carter v. Canada, 2015

<sup>4</sup> Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, 2015

<sup>5</sup> Canada, Parliament, 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament, Special Joint Committee on Physician-Assisted Dying (PDAM), 2016

<sup>6</sup> Canadian Psychiatric Association Submission to External Panel for Options on a Legislative Response to Carter v Canada. 2015 November

<sup>7</sup> Canada, Parliament, 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament, Special Joint Committee on Physician-Assisted Dying (PDAM), Evidence, 27 January 2016, 1935 (Dr. K. Sonu Gaiind, President, Canadian Psychiatric Association)

<sup>8</sup> Canada, Parliament, 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament, Senate, Standing Committee on Legal and Constitutional Affairs, Evidence, 11 May 2016 (Dr. K. Sonu Gaiind, President, Canadian Psychiatric Association)

<sup>9</sup> K. Sonu Gaiind (President Canadian Psychiatric Association) to Honourable Jane Philpott (Minister of Health) and to Honourable Jody Wilson-Raybould (Minister of Justice and Attorney General of Canada), *Re: CPA Interim Response to Report of the Special Joint Committee on Physician Assisted Dying*, 11 April 2016

<sup>10</sup> Sheehan K, Gaiind KS, Downar J. Medical assistance in dying: special issues for patients with mental illness. *Curr Opin Psychiatry*. 2017 Jan;30(1):26-30. PubMed PMID: 27798486.

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<sup>11</sup> Kim, S. Y. H., De Vries, R. G., & Peteet, J. R. (2016). Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands 2011 to 2014. *Journal of the American Medical Association Psychiatry*, 73(4), 362-368. doi: 10.1001.

<sup>12</sup> Canada (Attorney General) v E.F., 2016 ABCA 155

<sup>13</sup> MacArthur Competence Assessment Tool for Treatment (MacCAT-T), Grisso & Appelbaum, 1998

<sup>14</sup> Aid to Capacity Assessment, Joint Centre for Bioethics, University of Toronto

<sup>15</sup> Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament.

<sup>16</sup> Criminal Code, R.S.C., 1985, c. C-46



Canadian Psychiatric Association  
Association des psychiatres du Canada

# Task Force on Medical Assistance in Dying

# 2016

## MEMBER SURVEY RESULTS



The views represented herein represent the views of survey respondents, and do not necessarily reflect the policies and opinions of the Canadian Psychiatric Association.

## **SUGGESTED CITATION**

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# ABOUT THE TASK FORCE

The Canadian Psychiatric Association (CPA) Board of Directors formed the Task Force on Medical Assistance in Dying (MAID) in 2016 to assist the CPA in developing policy and influencing legislation regarding MAID, and to develop guidance for Canadian psychiatrists on how to apply and use any MAID framework.

## CHAIR

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## MEMBERS

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## STAFF

Ms. Katie Hardy, Director, Professional and Member Affairs



# BACKGROUND

The Canadian Psychiatric Association's Task Force on Medical Assistance in Dying (MAID) asked CPA members for feedback on some key concepts related to MAID to help inform the interim guidance it is preparing on behalf of the profession.

The survey was fielded Dec. 12, 2016 and data collection closed Jan. 20, 2017. A total of 2,536 members received the survey, and 332 responded (13%). The survey was available for completion in English or French.

The data from the online survey that follow are compared to the top-line results from an earlier survey that had been fielded Sept. 23, 2016 during the CPA Annual Conference (n=30). In situations where the online member survey question was slightly rephrased compared to the annual conference survey, the original (annual conference) phrasing has been noted. The annual conference survey did not include a "maybe" response option, but since it was a paper-based questionnaire, some respondents wrote in this answer, so counts and percentages have taken this into account.

# EXECUTIVE SUMMARY

QUESTION		Yes		No		Unsure	
		#	%*	#	%*	#	%*
1.	In principle do you support the availability of medical assistance in dying (MAID)?	239	73%	50	15%	35	11%
2.	Do you support the current exclusion of mental illness as a sole indication for MAID, consistent with federal legislation Bill C-14?	173	54%	88	27%	60	19%
3.	Do you support MAID for mental illness if 1) clarity were established for the interpretation of “irremediability,” 2) psychosocial issues were identified and addressed, 3) access to appropriate treatments were ensured, and 4) capacity and consent issues were fully assessed?	151	47%	104	33%	65	20%
4.	Do you feel that a psychiatric assessment should be required as part of every MAID assessment, even in the absence of known or suspected mental illness?	114	36%	169	53%	37	12%
5.	Should a psychiatric assessment be required when a mental illness is either known or suspected to be comorbid with the primary illness in MAID applications?	249	78%	30	9%	41	13%
6.	Is a chart review and discussion with individuals other than the patient sufficient to inform an adequate psychiatric assessment (either clinical or capacity assessment) for MAID (i.e., no direct face-to-face or telemedicine interaction with the patient)?	16	5%	273	85%	31	10%
7.	If the most responsible practitioner treating the patient for their primary illness declines to be involved in a MAID application, should there be a requirement to contact the most responsible practitioner for the purposes of enhancing the understanding of the patient’s current clinical situation and relevant background health issues? (The rationale for this is to address concerns arising internationally where itinerant or travelling physicians are doing MAID assessments without long term knowledge of patients.)	237	75%	29	9%	52	16%
8.	Should a close family member(s) be contacted to provide input for all MAID assessments, unless a patient specifically objects to such contact? (If the principle of “patient autonomy” is applied in a narrowly interpreted manner then input from family should not be required, but family input may provide valuable information, enhanced confidence regarding MAID decisions, and appropriate respect for the role of family.)	234	74%	33	10%	50	16%
9.	In addition to legislatively required assessments by physicians, or nurse practitioners, should a multidisciplinary “team” of health care workers be required to provide a formal assessment for all MAID applications?	96	31%	144	46%	73	23%
10.	Should capacity assessments be guided by generally accepted principles for assessing capacity contextually applied to MAID with flexibility for assessors to choose from a variety of appropriate assessment tools or formats (as opposed to a prescribed tool)?	232	74%	25	8%	56	18%
11.	Do you support allowing mature minors to qualify for MAID?	100	32%	145	46%	68	22%
12.	Do you support advanced directives for MAID in anticipation of capacity being lost and with clear criteria for activation of the MAID request?	203	65%	70	22%	40	13%
13.	Do you support a tracking process for MAID applications so that, in the event of multiple and diverging opinions as to the nature of the illness or decisional capacity, all opinions are considered?	266	85%	21	7%	26	8%

\* Percentages may not add to 100 due to rounding

# RESPONDENT DEMOGRAPHICS

The demographic information below applies only to the online member survey. Corresponding data from the annual conference presentation survey are not available.

SEX	COUNT	PERCENT
Male	167	50%
Female	159	48%
Unknown	5	2%

AGE	COUNT	PERCENT*
21 – 30	20	6%
31 – 40	47	14%
41 – 50	45	14%
51 – 60	67	20%
61 – 70	77	23%
71 – 80	43	13%
81 – 90	24	7%
Not available	8	2%

PROFESSION	COUNT	PERCENT*
Psychiatrist	282	85%
Other physician	8	2%
Resident	33	10%
Medical Student	8	2%

MEMBER TYPE	COUNT	PERCENT*
Active	207	63%
Life	55	17%
Associate	8	2%
Honorary	1	0%
International	5	2%
Member-in-Training	33	10%
Early career psychiatrist 1	4	1%
Early career psychiatrist 2	5	2%
Early career psychiatrist 3	5	2%
Medical Student	8	2%

REGIONAL DISTRIBUTION	COUNT	PERCENT*
British Columbia	37	11%
Alberta	30	9%
Prairies	31	9%
Ontario	149	45%
Quebec	44	13%
Atlantic	34	10%
Foreign	6	2%

\* Percentages may not add to 100 due to rounding



# MEMBER SURVEY RESULTS

## 1. In principle do you support the availability of medical assistance in dying (MAID)?

### COMMENTS FROM YES RESPONDENTS:

- Mais je crains qu'un accès croissant et plus facile contribue à faire passer au second plan la priorité à accorder aux soins palliatifs.
- I think it is humane to help a terminally dying patient to die a painless death.
- Choosing to go on living no longer is not, ipso facto, a sign of a major psychiatric illness. It should be an option for those who can make a choice about the future quality of their lives, and whether they wish to continue on. In saying this, we have to be aware that misery—from a variety of triggers—may be an emotional state, but is not a psychiatric illness.
- Within the current legislated criteria.
- I do support the program.
- I think there needs to be very clear criteria, however, with a lot of checks and balances.
- Only as a total last resort.
- Who else but a physician can determine if a person needs to die and needs help to do it.
- I have been involved in two MAID assessments so far.
- But only for the terminally ill who are incapable of killing themselves.
- Terminal illness when death is near.
- Medically and ethically necessary.
- Seulement pour les malades en fin de vie et souffrant.
- I'd like to see substitute decision making in the future for patients with dementias who when competent wanted MAID after a certain symptom load.
- Yes! I would want it for myself and loved ones and feel others deserve this right if they wish. People with contrary views also have the right to refuse it for themselves but not others.
- Independent medical opinion should be sought.
- I think it should be a right for appropriate cases.
- under the condition it is part of a continuum of care and an alleviation of suffering as belonging to the spectrum of medical care.
- Yes, but hesitant to provide assessment for this given limited guidelines, or involvement of a committee.
- Mourir dans la dignité est un droit.
- Am opposed to leaving a patient with intolerable suffering with no hope of improvement.
- Under very restricted circumstances.
- C'est un droit strict en autant que la personne est apte à la demander.
- There is a philosophical and ethical problem with the concept of providing means for someone to end their life that goes back to Hippocrates and is reinforced by all our philosophical, ethical and religious beliefs in the Western world. Yet profound changes in the practice of medicine in the last century have created new ethical dilemmas for all of us. In everyday life we have always faced these challenges and physicians have responded in a variety of ways short of actually administering the lethal dose. I recognize this but I want to be sure that everything has been tried to reduce suffering and effect a cure before I would consider this. This is particularly difficult in psychiatry where depression is a treatable

YES = 239 (73%)

NO = 50 (15%)

UNSURE = 35 (11%)

NO ANSWER = 2 (1%)

### ANNUAL CONFERENCE SURVEY

YES = 26 (87%)

NO = 4 (13%)

disease and the impulsive actions of borderline patients should not be supported. Also in cases of progressive dementia, the suffering is more often by the family than by the patient. Access to MAID in psychiatry must be very restricted.

- It helps clarify a murky area of patient care and legitimizes and guides what good doctors have been indirectly doing for decades.
- For certain illnesses whose treatments' are well funded in our system.
- In circumstances of terminal illness, persisting pain, when life is no longer wanted.
- A dear friend developed ALS and after a year of growing paralysis wanted to die. She lives in California now and when I visited her last fall I was left in dismay that nothing could be done for her then fortunately MAID became legal and her GP was able to assist her dying in November. I was left with appreciation for MAID and support it, and appreciate it is now legal in Canada/BC.
- There are many potential problems and pitfalls of assisting someone in dying, however, in cases where someone is suffering and also of clear mind, and has had time to come to a decision consistent with their values, it seems unethical not to provide them with assistance to end their life.
- For terminally ill patients.
- As a doctor who was trained sixty years ago, I long supported the traditional view that assisting someone to die was unethical. But in recent years the experience of having two brothers, who died after long and painful struggles with metastatic cancer, has changed my view. I now support medically assisted death in appropriate cases.
- I think it is a good idea for a very select population.
- Not for mental health.
- I think good palliative care can do a lot but there are human situations that assistance in dying is an important option for a person meeting the guidelines. I think the guidelines being restrictive at first was a good idea to get a complete grasp of easier decisions and move into more difficult and controversial.
- It can be cruel not to assist in certain circumstances.

## COMMENTS FROM NO RESPONDENTS:

- I am not opposed to choice of dying, rather the burden of carrying out the action of killing to the medical profession.
- I believe it is wrong in principle, and especially wrong for the medical profession to be involved. It is against our basic medical, Hippocratic ideals.
- I don't want to be keeping people alive unnecessarily but I don't want to be helping people die who are suffering from mental illness or are otherwise fairly healthy and well.
- I think that there should be a specific separate group that provide assistance and that it should not have the term medical attached.
- The role of a doctor does not involve taking of life.
- For longstanding medical ethics and for religious reasons.
- I feel the government has moved forward with this too quickly. In psychiatry, we try to prevent suicide, not assist it. There is a need for better palliative care, and better treatment availability for depression, and that should be worked on before allowing euthanasia.
- Incompatible avec la profession de médecin.
- I believe in providing good medical care and a maximum of comfort, but my role is not to kill, euphemistically called "assistance in dying."
- Doctors are trained to learn about illnesses and the treatment thereof (including alleviation of suffering but not of killing as a method of alleviation of suffering). If politicians and lawyers decide that suffering can be terminated by ending life then they should do it or mandate that from now onwards, part of medical training will include ending people's lives. This is not continuing medical education; it is a clear change in treatment modality that should not fall to physicians. The politicians, legal experts and other citizens (including physicians) who think it appropriate should find a way of dealing with it and leave physicians out of it. You do not need to be a physician to know how to end life. The Internet provides information on that.



- As an Orthodox Jew, my religion forbids me to support it and as a human being, I wonder what kind of moral society we are heading towards on this slippery slope.
- I prefer wide availability of good quality palliative care.
- I support medical assistance in providing optimal comfort and support until natural death.
- It is a major decision to take a life.
- I feel this option can be very open to abuse no matter what the rules. I entered medicine to try to treat and alleviate people's suffering and health conditions, not to take their lives.
- I have profound problems with a policy that might allow distressed patients, possibly inadequately treated for depression to potentially be assisted to die when they might readily respond to appropriate psychiatric care and intervention. I am also extremely concerned about the potential "slippery slope" which might in the future see patients deemed to be burdensome such as the intellectually delayed or the chronically mentally ill assisted to die.
- Do no harm. Intentionally taking a life is wrong. Physicians are privileged to help and heal. Suffering does not make a life less valuable.
- It is unethical in a world where we do not have enough support for good palliative care. People who have access to it will be led to chose MAID to avoid burden. It also gives a hierarchy between physical debilitating diseases and psychological chronic refractory psychiatric disease.
- Doctors assist people in living. I'm appalled that doctors would, and would sanction, the intentional termination of life. Equally applied that the representative doctors' organizations would become complicit in socially sanctioned killings. Spineless.

#### COMMENTS FROM UNSURE RESPONDENTS:

- I believe good palliative care can replace the need for MAID.
- It depends so much on the circumstances.
- Initially I thought slightly more favourably of the topic, however when I think back over my career I am not so sure about it. When I started practice I worked treating patients with HIV/AIDS who had psychiatric symptoms (many suicidal/depressed). Within the time frame of about six months, a disease that was tantamount to a death sentence became and has remained a treatable/manageable disease. Initially those patients may have met criteria for MAID, but would not have four to six months later. How many other medical conditions out there may have a cure or better outcome in the foreseeable future?
- I believe that the option of assisted dying should be present; however it conflicts with our mandate as physicians to promote death in an active way. Perhaps someone who is not a physician could be trained to do it. Physicians are often asked to determine capacity. However, the administration of death does not seem compatible with the physician's mandate.
- Perhaps in very limited, carefully prescribed circumstances.
- There is much room for it to be misused.
- En principe, nous devons suivre les recommandations du collège quelque soit notre opinion personnelle. En pratique, nous attendons la loi concernant l'aide médicale à mourir (AMAM) appliquée aux maladies mentales, et en théorie, je suis à l'aise avec la disponibilité de l'AMAM au niveau des idées en général.
- Depends upon the circumstances. For progressive terminal illness, I have no issue with it. For the rest (chronic conditions, but non-terminal), I am much more ambivalent, as I think it becomes a slippery slope, it is a very grey area, and at what point are we interfering with nature or trying to play God?
- I will never be sure if my choice or support for assistance in dying was right.
- Though I can imagine scenarios in which it would be the most humane option, I expect excellent palliative care/spiritual support could make most requests unnecessary. I find it ridiculous that our hospital has developed a rapid response to MAID responses, I gather to avoid having the patient die before they can be killed?!?! (that is a bit Monty Python-esque, non)
- Palliative care needs to be available to everyone before I can fully endorse MAID. I worry that people choose MAID because they are afraid of suffering, when palliative care would have relieved that suffering.

- Dying itself is very hard to define, and ending someone's life at their request is an action fraught with potentials for abuse.
- Of course, all possible assistance should be afforded to anyone who is dying, including palliative care. Including measures to shorten life or hasten death among permissible actions will sooner or later expose the health-care system and its members to conflicts of interest (mostly over cost) which will become very difficult to resolve.
- I staunchly believe in provision of skilled palliative care for patients in the end stage of their life.
- Probably yes, but under very specific and limited circumstances of irremediable suffering, and not at the expense of investing all we can in good palliative care.
- The whole impetus for MAID stems from a failure to adequately support people who have a terminal illness, psychologically, and in terms of adequate symptom relief. I believe people have the right to decide about their dying, but the co-opting of physicians into this process is again a failure to respect our fundamental role as healers. Also there are political and financial motivators that our leaders are not honest about, advanced directives and open discussion about death and its inevitability is a further societal failure.



## 2. Do you support the current exclusion of mental illness as a sole indication for MAID, consistent with federal legislation Bill C-14?

YES = 173 (54%)
NO = 88 (27%)
UNSURE = 60 (19%)

### COMMENTS FROM YES RESPONDENTS:

- I think psychiatrist and psychologist be involved in the assessment of a mentally-ill patient before his wish be met.
- As intractable as some conditions are, remissions do occur.
- As a psychiatrist, I see many people who see no other option than suicide when they are ill, yet who see things very differently when they recover. Most people I have seen who survive a suicide attempt are ultimately grateful that they did not succeed.
- I worry that it will be incredibly difficult to determine whether we should be preventing suicide or helping with the patient's suicide if mental illness is no longer excluded.
- This opens a big can of worms!
- The Supreme Court was clear. If you are able to kill yourself, that is your option. We respect it but neither encourage nor condone it. Suicide is understandable, but never the best answer to life's problems. Outside of terminal illness, all life is a struggle. One should never ask another person to kill you. It is neither a doctor's duty, nor a patient's option.
- Wish for death can be short term or long term and can be still helped with pharmacotherapy and psychotherapy and changes in personal circumstances. Even in cases that I thought this would never resolve it has.
- In general, I believe that the current limits protect from the "slippery slope" concerns. Inclusion of mental illness invites a real "slippery slope," and invites the question for the practitioner faced with a suicidal patient: "do I certify and admit, or do I assist you to die." I do not believe that we are ready to deal with such complex dilemmas.
- I have seen many patients who seemed to have a hopeless prognosis get better to advocate for assisted dying for mental disorders.
- What we can't cure today may be curable in future.
- Yes and no. I think there should be demonstrated evidence of physical harm from the psychiatric illness as well and then I'd agree fully.
- With the improvement in outcomes in psychiatry I think it's a slippery slope to include mental illness as an indication for MAID.
- The wish to die can be a symptom of psychiatric illness, and needs to be treated, not assisted.

ANNUAL CONFERENCE SURVEY
YES = 25 (83%)
NO = 5 (17%)



- Les soins en santé mentale ne sont pas prodigués au maximum de ce qui pourrait être fait, souvent pour des questions de logistiques, de disponibilités, de finances, de professionnels, etc. Alors pour le moment je suis pour cette exclusion tant que tout n’a pas été fait dans le cadre de propositions de soins aux patients. Après, on pourra raisonnablement discuté d’exclure cette exclusion.
- Mental illness should be excluded as a sole indication for MAID.
- Many psychiatric conditions are amenable to adequate therapy and expert care. An adequate psychiatric consultation and assessment is always necessary in these circumstances before MAID is considered.
- The definitions used were not precise enough to guide decisions with regard to mental illness and hence too subject to individual interpretation. They did not distinguish between illness secondary to its being refractory and that secondary to lack of access to adequate treatment.
- I don’t think we should be part of transforming suicide into MAID.
- I think that MAID is suicide, but physician-assisted and societally acceptable suicide. The context may be different (illness, suffering, intolerable symptoms, etc), but it is still suicide. I am concerned that people have access to MAID, but not to caring and competent psychiatric care. We need to advocate for good psychiatric care for those with mental illness alone seeking MAID.
- MAID goes against our work preventing suicides.
- Our whole practice of psychiatry is predicated on the relief of psychic suffering, the provision of hope, and saving people from committing suicide. How can we then turn around from certifying someone under the MHA as a danger to themselves, and then agree they can have MAID?
- “Mental illness” in the present day, with the rapid development of treatment, can never be said to be irreversible or “irremediable.”
- Yes, especially when people are incapable (e.g., demented, intellectually disabled), and potential for undue influence is high.
- Many people with psychological pain often seek an out through suicide, but once their illness is treated they usually have a change of heart. A mental illness changes the way a person looks at the issue of death.
- I believe treatment for mental illness is grossly underfunded and until we have a medical system that is better funded I do not think this is a worthwhile path to go.
- Definitely.
- Suicidality is part of some mental illnesses and patients’ views may change over time with adequate treatment of major mental illness and personality pathology.
- As a psychiatrist, suicide prevention is a goal. Many patients suffer with intractable symptoms as well as stigma from society-at-large. Perhaps some investment in social programs, building less competitively driven work programs can help people living with chronic severe mental illness live with dignity and a sense of being respected by their community.
- MAID becomes very murky and complex when illness effects cognitive capacity, emotional reactivity and impulsiveness, psychological outlook and judgment so the bar for this must be customized, and more rigorous for safety.
- This is an area that is very complex and requires a lot of review and consultation and in my mind should be the last option to be considered.
- I was very relieved that the exclusion was made while we examine the question further. We have not yet worked out all the ramifications of this legislation if applied to mental illness, as I wrote in a LinkedIn post introducing Dr. Sonu Gaind’s article on the topic: [Excerpt:] [re MAID]: “Typically we think of cases like that of Sue Rodriguez, in which a person of sound mind with an irreversibly deteriorating condition seeks to exercise control over the timing and manner of his or her inevitable death, and requests help in doing so. These would appear to be the types of situations most readily addressed by last year’s Supreme Court ruling which struck down the prohibition against physician-assisted dying. However, that ruling does not adequately address the special complexities inherent in situations where the illness causing the suffering is a psychiatric one. Suffering caused by mental illness is real, can be extreme, and at times can appear intractable. But is it different from ALS or terminal cancer, for example, when it comes to the development of legislation around assisted suicide? Certainly there are mental illnesses such as dementia, in which a person has a progressive neurodegenerative disease which—much like other degenerative conditions—gradually depletes the person’s capacity to exercise control, and ultimately will be terminal if no other illness intervenes. This is perhaps a different scenario than a chronic mental

illness which does not end in death, but in which a sense of hopelessness and the wish for death may in fact be symptoms of the illness itself. How do we approach the person with severe chronic depression which has been resistant to current treatments, who suffers greatly, and who asks for help in dying? When are cognitive distortions (which may be features of the disease) impacting on the person's free choice? How and when could family members or those involved in the person's care switch their focus from doing everything in their power to prevent suicide, to actively assisting? And is it even necessary to involve others in the decision, and in carrying it out, if the person remains capable of ending his or her own life? These and many other complex questions underscore the need for particular care and consideration—even if it means further extension of the time frame for legislation around cases involving psychiatric illness. In his recent article for the *Globe & Mail*, Canadian Psychiatric Association president Dr. Sonu Gaind explores this issue and makes the case for proceeding with caution—not as a form of discrimination against those with mental illnesses, but in fact as an expression of special concern that they be treated justly—and with safeguards against risk of harm in situations where they may be particularly vulnerable.” (Dr. K. Sonu Gaind, *Globe & Mail*, May 30, 2016)

- Hopelessness, lack of insight and chronic characterological traits impact the ability to make an informed decision about such a final act. Suicide exacts a huge toll on families and is a tragedy, but becoming party to euthanasia undermines our role as physicians.

## COMMENTS FROM NO RESPONDENTS:

- Truly suicidal people do not tell us their plans. It is usually a surprise. If a depressed and suicidal person knows they may obtain MAID, maybe they will request it, and we will have a better understanding of the depth of their hopelessness, and a more useful dialogue will result.
- Unless mental disorders are not considered medical conditions it does not make sense to exclude them arbitrarily from MAID.
- This area needs more study, and strict criteria.
- I have patients who suffer from recurrent illnesses who, during the period of quiescence, and knowing their future with current medical options, can make a conscious decision that they do not wish the future as they see it. They should be as entitled as anyone else to make such a decision.
- I believe that where mentally-ill people are competent they deserve some choice.
- Mental illness must not be excluded as a reason for MAID.
- It is discriminatory against people with mental illness. If we want parity with physical health we have to go all in, you cannot cherry pick.
- Psychiatrically ill are not necessarily unable to form the intent to die and still should be eligible to medical assistance.
- I think people suffering from dementia should be allowed to decide to end their lives while able to do so with capacity.
- It is as difficult to endure suffering from severe mental illness as it is from any other severe illness.
- If the person is capable of making treatment decisions then they should not be excluded, but this whole exercise should not be Medical Assistance In Dying (MAID); it should/could be “National” or “Conscientious” or “Legal” Assistance In Dying (NAID or CAID or LAID).
- I think that long-term mental illness, resistant to accepted methods of treatment and causing unbearable suffering should be an indication for MAID provided the person is competent to make such a choice.
- Too broad. Many who are mentally ill and able or are competent to make important decisions should be included.
- Subject to competent decision-making.
- NO—it's discriminatory at present. Each case needs individual consideration.
- Dementia should be given consideration.
- Je ne vois pas en quoi ces exclusions sont justifiées.
- Although it would be rare, I can foresee situations where everything has been tried or where comorbid chronic medical illness makes the possibility of recovering from mental illness impossible. There would need to be proof that all possibilities have been exhausted and that the patient is competent to make the decision about their treatment.
- C'est de la discrimination; par ailleurs, l'aptitude doit être établie ainsi qu'une stabilité du choix.



- I would like to see consideration for serious and persistent mental illness as an indication, with appropriate safeguards for vulnerable patients.
- For most mental illnesses, I support the exclusion. The presence of mental illness can directly impact a person's ability to make judgments. However, an early diagnosis of a dementia would be something that I think could be an indication for MAID.
- Intolerable suffering can arise from mental illness in addition to physical illness. Wanting to die does not by definition make someone mentally ill, although in our current culture of practice the two seem to be often conflated, often to the detriment of patients who are hospitalized involuntarily. Excluding patients with mental illness from MAID is quite arguably discrimination and takes a position of reducing the rights of a disenfranchised population.
- In recent years there have been definite advances in the treatment of depression, although I recognize that treatment resistant depression remains a serious problem. My concern is that, suicidal ideas being common symptoms of depression, allowing assisted suicide in such cases, might result in its being used too frequently.
- But a psychiatric assessment would be mandatory before this could be considered.
- A blanket exclusion would seem extreme, though currently defining which mental health conditions and under what circumstances is difficult and requires research. Perhaps a temporary no would be appropriate until consensus emerges regarding the mental-health-related situations that can be supported.

## COMMENTS FROM UNSURE RESPONDENTS:

- I don't think that depression should be a sufficient sole indication, but I do think that dementia with a pre-written advance directive should be accepted as a sole indication.
- Given that mental illness is an illness why should it be treated differently? On the other hand, I also recognize the impact that mental illness can have upon decision-making.
- This is tricky. The availability of competent psychiatric care in all regions of Canada is a concern. If this could be assured, I would be more comfortable with MAID for some psychiatric conditions.
- Again, it depends on circumstances.
- Generally, yes I do. There is a part of me that feels that doctors should only be involved in suicide if the patient is physically incapable of carrying it out (i.e., advanced ALS). I'm not sure how I feel about having to do it for a patient if that patient is able to do this themselves (i.e., why do I need to be involved?). It may sound petulant, but I think that's a question that's important to explore with patients, and the public—why do doctors need to be involved in an action that the layperson can do themselves?
- There is also a big part of me that is very, very worried that many people who are looking for MAID with a mental illness may not have had access to the best treatments, because of underfunding in both research and service provision, and that other causes that we as a society need to address may also be at play (i.e., social isolation, a big factor for many of the patients involved in Belgium with mental illness and MAID). I also work with Indigenous people, with a high level of suffering and suicide—I don't think the answer is MAID. It's reversing the trauma of colonization. I would feel highly ethically compromised to offer this to my Indigenous patients, and I feel like this treatment option, which is quite cheap compared to others, may detract from doing the harder work of getting to the root of people's distress. The situations I can see being a good fit for MAID are more things like severe, refractory symptoms in illnesses like schizophrenia or OCD.
- Perhaps long-term illness with poor response to treatment should not be excluded.
- Unsure of its meaning.
- I am concerned that in time the availability of MAID for relatively treatment-resistant depression would encourage its use even before treatments have been fully explored.
- The presence of psychiatric disorder does not equal impaired judgement. When psychiatric disorder is the sole indication, evaluation procedure might need to be adjusted, e.g., by adding a test of capacity.
- There are many people who would not want to stay alive if they suffered from severe dementia.
- Needs to be circumscribed and well-articulated. Risks of overuse appear greater than with physical terminal illness.
- Not sure of question.
- Il faudrait définir des critères pour les types de conditions mentales acceptables pour donner accès au programme.

- I agree there is something daunting about including mental illness, but I can't see how we could allow it to be excluded after psychiatry as an institution has pushed so much for distressing psychological experiences to be construed as being caused by biological malfunctions, and against stigma surrounding such mental illnesses.
- As a psychiatrist I'm not sure about assessing capacity for those with mental illness. I have done a second opinion assessment on one person and was able to confirm she did not have a mental illness, which led to her getting MAID.
- I think it is wise for now to exclude it until parameters are clear. I worry about a slippery slope and would have a hard time myself with it if one of my patients wanted it. I would always very much worry about capacity, and future available breakthroughs.
- I don't think psychiatric patients should be stigmatized through exclusion, but obviously need closer evaluation than those without psychiatric diagnoses.
- Not sure how to answer this—for the following reasons that anyone, least of all a doctor, would contemplate intentionally terminating the life of someone suffering a mental disorder, strains credulity. Hopefully the CPA will refuse to participate at any level in this shameful process, on the principled grounds that doctors don't intentionally kill patients, and psychiatrists too don't intentionally kill patients.



### 3. Do you support MAID for mental illness if 1) clarity were established for the interpretation of “irremediability,” 2) psychosocial issues were identified and addressed, 3) access to appropriate treatments were ensured, and 4) capacity and consent issues were fully assessed?

YES = 151 (47%)
NO = 104 (33%)
UNSURE = 65 (20%)

#### COMMENTS FROM YES RESPONDENTS:

- Irremediability would need to be assured for the illness at hand.
- Good luck with assuring that all of these conditions are met! Will cost \$\$\$\$\$.
- Given MAID (which I disagree with)—yes, if the above are established, no reason not to.
- I agree.
- IF all these were possible. But they are not.
- However I do not believe that these conditions can be met given that they are not currently available to most suffering from mental illness. Provide these to everyone and go from there.
- Pain and unnecessary suffering justify MAID, there are several mental illnesses that fulfill the criteria.
- The bar for it would have to be high.
- I believe these four components should inform every MAID assessment and not just mental illness.
- These are sufficient safeguards.
- Patients with brain illnesses—whether “psychiatric” or other neurological—should not be stigmatized if safeguards and consistency are in place.
- ALL four.
- See my answer on previous page!
- For dementia certainly.
- Tout à fait légitime la maladie mentale est très souffrante.

ANNUAL CONFERENCE SURVEY*
YES = 16 (62%)
NO = 9 (35%)
MAYBE = 1 (4%)

\* Percentages may not add to 100 due to rounding



- As above.
- But very difficult to do.
- Extreme psychiatric expertise will be necessary if MAID is to be considered, since most severe psychiatric conditions are amenable to adequate therapy, unless terminal organicity is a factor.
- Mental anguish is as painful as physical pain and often is a significant factor in a request for MAID for physical illness, which is covered.
- At very least those issues need to be addressed.
- There should, in particular, be an option for advance request for MAID in the event of irreversible dementia. Safeguards would, of course, be needed.
- Must be sure that the above are done by qualified persons in appropriate specialty areas.
- These conditional criteria address my uncertainty and I would support this.
- Capacity and consent issues are the most important for us as physicians. The rest is up to the patients themselves to determine what they want to address or leave unaddressed: what is “irremediable” or “appropriate treatment” to them.
- We know access to treatments are a concern. Strategically this might be a CPA leverage for better resources and access to mental health treatment.
- Chronic treatment resistant serious mental illnesses/severe cognitive impairment.

## COMMENTS FROM NO RESPONDENTS:

- Therapeutic nihilism is never good and many “hopeless,” “refractory” patients have been helped by appropriate treatment.
- To be completely blunt, and probably massively politically incorrect, if people are physically capable of ending their lives (i.e., not bedridden, etc) then if they want to make this choice, they can do so without needing to involve the medical system. It is a huge responsibility and ethical burden which patients are placing on us, and one which I willingly shoulder, but not if the patient is able to take that responsibility on for themselves and simply unwilling to do so. There are medical conditions which, were I to be diagnosed with them, would cause me to want to end my life. However, if I were physically able to do it myself, I wouldn’t dream of asking someone else to help me.
- I wonder how access to appropriate treatments were ensured. At this time, the majority of people in Canada cannot access one of the most proven treatments for depression, CBT, in a timely manner.
- Même si le critère d’irrémediabilité était clairement défini dans la loi, il resterait très difficile à définir cliniquement lors de l’évaluation du patient atteint d’un trouble mental.
- Slippery slope problems will arise if above implemented.
- In no circumstances should psychiatric disorders be grounds for MAID because psychiatric conditions are subjective opinions and not based on pathophysiological evidence like cancer, severe heart disease or severe degenerative neurological illnesses.
- Leave physicians out of it.
- This is very tricky. Must a patient have tried and exhausted all available appropriate treatments—it seems that access should not be sufficient.
- Given some cases that I have already read/heard about, I doubt there would be a consensus as to what constitutes “irremediability” and “access to appropriate treatments.” I am struck that some doctors have been willing to sign-off on cases that clearly have not exhausted all treatment options.
- Too difficult to clarify and address all those issues, also impossible to predict outcomes.
- This is a judgement call. Sometimes the compassionate actions of individual physicians are hard to fit into a structured position statement. There is a limit to how many complex rules or guidelines you can have before the “black swan” effect sets in.
- I would like to see the actual wording before I could give it wholehearted support.
- I am concerned that patients would worry a psychiatrist wouldn’t help them through a difficult time and want them to choose MAID. I am concerned that access to MAID for mental illness would undermine the doctor-patient relationship, even if the psychiatrist did not support MAID.

- This is far too subjective an issue and the deliberate ending of the life of another person is an action that should either not be undertaken or only if the person is within days of dying. If there is a chance for the person to recover and live, so if the illness would not necessarily lead to death, then we should never deliberately kill the person.
- I do not support under any conditions.
- There are very few circumstances in which it would be justified. Suicide is prevented by reducing access to the means. Why on earth would we even offer a method!?
- Not at this time.
- Capacity to consent would by definition fall to the treating psychiatrist to assess. In my current clinical group there is now psychiatrist amongst us willing to do such a capacity assessment were it to lead to the eventual termination of a patient's life by medically assisted dying.
- Even with these safeguards, I have rarely seen a case where I have felt everything possible has been done and the patient is justified in ending his life
- Under no circumstances. If society, rather than seven judges, thought assisted suicide was a good idea, I would fiercely oppose the medical profession having any role in it—let society farm out mercy killing to others, killing is not what doctors do.
- My response to these laudable hurdles is to say we are not capable of addressing such subtle and complex concerns in our humanity.
- Ces questions sont trop complexes pour être codifiées. Il s'en suivrait des confrontations constants avec des patients à savoir s'ils rencontrent (ou non) les critères, cette question pourrait se transformer en une lutte de pouvoir qui risquerait de drainer beaucoup d'énergie qui devrait être investie dans un plan thérapeutique.
- These are not terminal illnesses.

#### COMMENTS FROM UNSURE RESPONDENTS:

- I wonder if accepting implies untreatable, intractable, hopeless surrender vs optimism.
- Difficile de combattre le suicide et de prôner l'AMAM pour des raisons psychiatriques en même temps.
- I work in the field of patients with affective disorders and feel very uncomfortable if a patient who has expressed suicidal thoughts requests MAID. I think that item #4 (capacity and consent) has to be specifically clarified due to the irreversibility of this decision.
- What would we do with people whose decisions were impacted by low SES, poor housing, difficulty with employment? Is the government going to ensure that all of this type of care is going to be provided?
- I suspect that it would be difficult to define #1 and #4 in particular.
- Not sure that the above criteria can be met.
- Perhaps.
- The risk of well-motivated cleansing appears at stake and eroding the role and perception of medicine as an encompassing discipline involved in the caring of human beings. The notion of irremediability is evolving for a number of pathologies through time.
- Understanding of mental illness is far from clear. Consensus among psychiatrists on diagnosis or treatment is poor.
- In my ten years of treatment, I don't think I've ever encountered this situation. We have poor access to treatments and there are always some sort of psychosocial stressors. So I think the question is unrealistic.
- I suppose it would depend on what the interpretation of "irremediability" was clarified as being.
- Too many unresolved questions to allow a provisional decision to be put forth.
- Yes would be comfortable with it so long as the criteria phrased as above were met, but I do not think that psychiatry as a scientific discourse and a clinical praxis has the conceptual capacity to do so. Embedded in the criteria you designed are issues of trust, dependency, social justice, sacredness, loss and mourning that are not amenable to a technocratic response by the medical institution. I am also afraid that society at large may not realize this, may blindly trust in our scientific capacity to make determinations about the value of lives, and that this may somehow backfire against us down the road.



- Perhaps, but we until we have addressed these issues then I can not say for sure. Ask me again once these issues have been adequately addressed.
- I am not sure that these issues can be fully addressed. And since suicidality is a symptom of chronic mental illness, how can this symptom be separated from the other issues mentioned. I am particularly concerned with the definition of “irremediability” and “chronic” as it pertains to people in their 20s who may fit such definitions but are still in active brain developmental stages.
- These are certainly critical areas and I would be more open to consideration if these all were met. I’m still thinking although these are important, I say unsure that area should be approached with great caution.
- As per my previous comment, we may want to look separately at brain diseases like dementia (progressive and irreversible) vs. illnesses like chronic depression, where irremediability may be difficult to determine, as it is not progressive or necessarily terminal, and new treatments could be on the horizon. I believe we cannot approach in the same manner the situation of 1) hastening death in a manner that relieves otherwise intractable suffering in a person who is—with certainty—dying, and 2) “putting someone out of their suffering” who would not otherwise be terminal.



#### 4. Do you feel that a psychiatric assessment should be required as part of every MAID assessment, even in the absence of known or suspected mental illness?

YES = 114 (36%)*
NO = 169 (53%)
UNSURE = 37 (12%)

##### COMMENTS FROM YES RESPONDENTS:

- As with certain other medical conditions—suitability for transplants, suitability for organ donation, etc.
- Risk of depression or psychosis needs to be evaluated to see if the person really has the capacity to make the choice.
- As in the case of every major medical procedure, capacity needs to be assessed and MAID is no different.
- I think it is important to rule out a treatable depression before assuming that suffering from a terminal illness is “natural.”
- However, this should be done AFTER an assessment by the treating physician for the illness they are suffering from has providing information about the prognosis of the illness, treatment efforts, etc. For example, I don’t want to be in the position of judging whether a patient is correct in believing they won’t ever get better from their cancer. That information would have to be provided to me, and I would want the input of the team that actually knows the patient well.
- La corrélation entre désir de mourir et trouble psychiatrique est trop grande.
- If someone is that desperate then that itself is reason to pause and carefully consider.
- Yes if MAID becomes a reality. I oppose this reality.
- To make sure that treatable emotional illnesses are excluded.
- Even though the primary question is a moral and not medical question.
- It’s important to ensure a patient is competent to give permission and comprehends all options.
- Most important in order to document mental status and possibly decreasing suffering. In order for psychiatrists to acquire some knowledge relative to different mental status as someone is facing/is in the process of no-return decision-making.
- To ensure that there is not comorbid mental illness affecting the patient’s ability to tolerate the “physical” suffering.
- Preferable to rule out hasty decisions.
- Often psychiatrist issues are kept secret.

ANNUAL CONFERENCE SURVEY
YES = 13 (43%)
NO = 17 (57%)

\* Percentages may not add to 100 due to rounding

- As physicians get more experience providing MAID, confidence will rise, and if there are not safeguards put into place that are predictable, standardized, and designed to increase patient safety, then more people will be assisted to die than otherwise.
- At least the absence of mental illness should be documented.
- The person should be assessed ideally by more than one person on separate occasions to get a sense of whether the person appears to be making a values-informed decision, that they are capable of making this decision, that they have given consideration to the effects on other people, and that they have fully considered all of the implications about ending their life.
- The presence of a remediable depressive disorder, for example, needs to be ruled out.
- Though I fundamentally disagree with this entire initiative, an assessment would at least identify the individuals with untreated psychiatric illness and could potentially lead to treatment rather than inevitable death.
- Formal capacity assessment and rule out undue influence from others. Most of the literature indicates that capacity has not been addressed.

## COMMENTS FROM NO RESPONDENTS:

- This makes the unwarranted assumption that our colleagues cannot screen for mental illness, and refer if necessary.
- Give our colleagues some credit, please.
- Psychiatric assessment only required when suspected or when screened positive by another physician like for any other “treatment” decision. Even if the “treatment” is death.
- Family doctors should be able to assess routine capacity issues in patients with medical illness.
- I do believe that the medical doctor evaluating the physical condition is good enough.
- The workload would be excessive for psychiatrists as well who will pay for this?! If there are mental or addiction issues, that is different.
- The physician who has the most experience treating the irremediable condition is in the best position to decide if a patient’s assessment of their circumstances is in keeping with the typical progress and outcome of the condition. If that physician feels the patient’s assessment appears driven by inexplicable hopelessness or nihilism or amplification of negatives, then involving a psychiatrist might make sense.
- Although screening should occur.
- Only in cases where a potentially treatable psychotic motivation probably underlies the patient’s request for assistance in dying.
- Only if there is concern that psychiatric illness may be impacting decision-making.
- This could overburden the demand for consults, and be a disservice and potential delay for those with more clear-cut MAID cases.
- Des médecins autre que psychiatres peuvent évaluer la capacité à consentir au traitement. Une évaluation psychiatrique est nécessaire seulement s’il y a une suspicion d’une maladie mentale.
- I refuse to be a rubber stamp for a person of sound mind who has made his/her decision. Insulting and obstructive to their free will, and a waste of time for me.
- Not if those providing the service are carefully screening for complicating factors of influence. I fear some advocates for MAID may be too hasty in their assessment.
- It shouldn’t be required if no one is requesting it, but it should be required if any interested party requests it.
- Not needed in certain cases, e.g., ALS diagnosed by a specialist in the area and managed by them.
- Only if there are grounds for concern for mental illness, ambivalence or coercion.
- Les psychiatres sont formés pour diagnostiquer des maladies mentales pas pour certifier la normalité et entre absence de maladie mentale et normalité, il y a une zone grise.
- Je ne pense que c’est nécessaire pour les cas de maladie physique.



- A psychiatric assessment is not required de facto for withdrawal of care, surgeries with low risk of success, refusal of lifesaving treatment, etc, so I see no reason why a different standard should be applied here. Of course if there is suspected mental illness, a psychiatric assessment is appropriate.
- We have to trust the judgements of other physicians.
- But may be a part of the full assessment in many cases, especially those where the treating doctor does not have a long-term relationship with the patient. A good family doctor or palliative care specialist should not need an opinion from a psychiatrist.
- We don't have enough psychiatrists to see patients who want to recover and lead productive lives. I would consider this a waste of resources in cases where there is no known or suspected mental illness.
- Some cases are clearly medical such as cancer or ALS and there are no psychiatric issues.
- For us to make such a broad recommendation to society implies that we, from the strict evidence-based, scientific and medical ethos that we have adopted for ourselves over the last few decades, are somehow intellectually skilled to make some core determination about any sick person's view on the finality of their lives, which I think, to put it bluntly, would be a fraud. It would be more acceptable to me if the purpose of our intervention was clearly specified as something like: "ruling out a clinical syndrome impairing the patient's cognitive faculties and her or his ability to make that decision."
- All physicians who work with people who are dying and eligible for MAID should be able to do a MAID assessment. Dying is a universal issue! Why create extra work for psychiatrists and plug up the mental health system.
- I do not support MAID.
- From what I have heard of the New Zealand experience, this process was resented by patients and became largely meaningless. I see the potential for many inappropriate requests for MAID from psychiatric patients and don't want to be involved in the process in any capacity.
- I think most family doctors are competent to assess for the presence or absence of a severe psychiatric contributor to a MAID request for another medical condition.
- This would be a huge challenge for psychiatry and other physicians can make these decisions using their skill set and using the guidelines.
- In selected cases, yes.
- Psychiatry should not participate in the process in any way.
- The system will be overloaded and the wait times will become even longer.

## COMMENTS FROM UNSURE RESPONDENTS:

- An assessment by either one of the following specialties should be required though: psychiatry, palliative care, geriatrics.
- We must presume capability; however I think given this is such a final outcome, it may be worthwhile as a protective measure. However capability assessments are not always reliable.
- The desire for hastened death is incompatible with our current understanding of mental health.
- I think a psychiatric assessment is probably important for every MAID assessment, but I am not convinced that it needs to be a separate assessment completed only by a psychiatrist. I think general practitioners should be able to include a psychiatric assessment as part of their MAID assessment.
- If concerns raised by attending physician, then yes. I also feel people have the right to refuse psychiatric assessment. The difficulty is that people may decline psychiatric involvement for various reasons (e.g., concern it could influence access to MAID, demoralization, depression, etc).
- There are grey zones in mental illness e.g., personality disorders, early dementia, which cloud the issues.
- I think a thorough mental assessment needs to be done on every patient, but this could potentially be done by another professional with appropriate training, e.g., family physician, psychologist, etc.
- In principle, but in reality, this may be an additional workload burden.
- On the one hand this might help in ruling out depression or other mental factors which might be unduly influencing the person's decision to die, and in establishing capacity in cases where that is questionable; however, it may also unnecessarily delay matters if psychiatrist opinion is not readily available and the situation is more clear-cut. As well, not all psychiatrists will be comfortable performing this function. Perhaps there should be a number of physicians

(psychiatrists and palliative care physicians among them) trained thoroughly in the ethical, medical, mental health and capacity considerations around MAID who could be called upon to participate in each MAID assessment, aiming for broad availability of willing physicians with specialized knowledge and training.



## 5. Should a psychiatric assessment be required when a mental illness is either known or suspected to be comorbid with the primary illness in MAID applications?

YES = 249 (78%)
NO = 30 (9%)
UNSURE = 41 (13%)

### COMMENTS FROM YES RESPONDENTS:

- Again, capacity must be determined. However, having a psychiatric illness as a comorbid condition should not preclude someone from qualifying for MAID, it should (like all other illnesses) be treated as fully as possible before someone chooses MAID.
- Definitely.
- Untreated mental illness and its interference with the capacity to make decisions is clearly relevant.
- The comorbid mental illness if treatable could alter the patient's request for assistance.
- Or at least a second opinion, as in some cases it may not be a relevant contributor.
- But should not exclude eligibility if the person is capable of making treatment decisions.
- I believe this would be prudent and in the patient's best interest.
- Though this may require some clarifications where it may not be required.
- Competency.
- Il est important de connaître l'impact de toute maladie dans la demande de soins et de fins de soins, voire de fin de vie tout court.
- Only if it is considered to be an ACTIVE contributing issue. If the patient has a remote history of mental illness (e.g., depression) that is not felt to be concurrent, then I do not think such a patient should be treated any differently, or require any extra hoops to jump through.
- Nécessaire dans le cas de maladie mentale.
- Preferable in most cases.
- It's part of an appropriately comprehensive assessment.
- Although I feel very concerned that psychiatrists would then become the gatekeeper of MAID. Our role should be to comment on competence and the presence of major mental illness.
- ABSOLUTELY! By appropriate specialty e.g., geriatric psychiatry, child psychiatry, forensics, etc as the case may be.
- As a practising youth forensic psychiatrist I routinely encounter mental illness that affects capacity to stand trial, and see that many docs are uncertain about assessing mental illness.
- Independent assessment (probably psychiatric) should be made in all cases to assess capacity and also as part of a counselling/preparation process for the patient, whether there is a mental illness suspected or not.
- Unquestionably.
- Speaks for itself, especially given my earlier comments.

ANNUAL CONFERENCE SURVEY
YES = 26 (87%)
NO = 4 (13%)

### COMMENTS FROM NO RESPONDENTS:

- This may cause undue delay. Psychiatric assessment should be requested if it is currently affecting decision to request MAID.
- People can make decisions without armies of doctors etc to interact with them.



- Sauf dans le cas d'une maladie mentale sévère et persistante.
- Many physicians are capable of assessing patients who live with mental illness. There are certain circumstances in which a psych consult may be helpful or even very important to have, but that should be at the discretion/need of the assessing physicians.
- I do not support under any conditions.
- Psychiatry should not participate and the CPA should represent the interests of psychiatrists by refusing to participate. By the way, the acronym MAID lends a jovial air to a very serious issue and trivializes intentional killing, another bad thing, just as co-opting the medical profession into participating lends the disgraceful practice an air of respectability. Would society approve of this practice if the medical profession condemned it and refused to participate?

## COMMENTS FROM UNSURE RESPONDENTS:

- Proposée certainement, mais obligatoire??
- There is some nuance in this statement that I feel is not captured in such a brief statement. On the whole, I probably do support this, but with some limitations—otherwise we will get more referrals for assessment when there is no real basis for it.
- This should depend on the presumably mandatory content of such an assessment and should address the issue of assessing a patient who is presumably not psychotic but is seeking to persuade the psychiatrist that they are a suitable candidate for MAID. I don't think that we, as psychiatrists, have experience with this type of assessment, but the politicians and bureaucrats will no doubt happily pass the buck to psychiatrists. It would also be important to know what legal liability attaches to doing such an assessment.
- Likely would be helpful. However resources are a significant issue.
- I am reluctant to suggest a requirement that removes the treating physician's ability to exercise their expert judgement and also to require something that may prove to be a significant barrier to the patient access (given psych access issues).
- Not required, but assessors should be able to get access to a psychiatrist for this type of assessment if requested/needed.
- I would recommend this only if in the opinion of the primary assessor, there is a question. So, I would not necessarily require psychiatric assessment for someone with a history of GAD and remote substance abuse.
- Depends on how bad the mental illness is, and how hopeless the medical condition is, e.g., depressed person refusing treatment for a good prognosis cancer should be assessed.
- It would depend on how the comorbid psychiatric illness will impact the decision. For instance, if someone has end-stage cancer, I think it may not matter that they also have a comorbid psychiatric illness.
- I think that it could be recommended. In general I think that we need to be cautious in building in such broad generalizations. Physicians are always making decisions that may include decisions about those with a mental disorders which are common. What if the person has long-standing addictions or anxiety problems? If someone has a dementia is that considered a comorbid mental disorder? The presence of clinical practice guidelines would be better than a blanket legal requirement.
- You should have a category of "refuse to answer" or "non-pertinent." I am fearful that any answer I give you will be misconstrued given that I disagree with the MAID program itself.
- Case by case.
- I think it depends on the mental illness. If it is mild, and or is unlikely to affect functioning for example, I don't think a psychiatric assessment always needs to be done.
- Yes in case of psychosis, no in case of anxiety disorder.
- There may be times when such an assessment may be needed, but it should not be mandated in all cases.
- I think that each case should be evaluated case by case—if there is some type of guidelines, etc, this generally makes it more difficult to assess the situation case by case.
- Ça dépend du pronostic de la maladie physique.
- The word "required" is my problem here. I think it should be done, but am unsure whether it should be made mandatory.
- Il faudrait élaborer des critères de sévérité.

- I don't know. I think the need for the assessment should be at the discretion of the doctor who does the assessment for MAID. Presumably that doctor will do frequent assessments of patients for MAID, and develop expertise in recognizing when a patient has mental illness that may affect their judgement, and when they do not.
- Again, the purpose of such a mandatory assessment should be specified.
- If the mental illness is suspected to be contributing to the person's desire to die.
- It would make sense for some cases but I'm not convinced it should be a requirement for each case.

\* \* \* \* \*

## 6. Is a chart review and discussion with individuals other than the patient sufficient to inform an adequate psychiatric assessment (either clinical or capacity assessment) for MAID (i.e., no direct face-to-face or telemedicine interaction with the patient)?

YES = 16 (5%)
NO = 273 (85%)
UNSURE = 31 (10%)

### COMMENTS FROM YES RESPONDENTS:

- When patients can no longer communicate their immediate request and they had already stated in the past they would find the condition being reviewed as intolerable.
- If an appropriate assessment has been done, e.g., by a GP, then it is cruel to make a patient repeat this.
- I think so, with the caveat that an experienced psychiatrist can be available to do the assessment.

ANNUAL CONFERENCE SURVEY*
YES = 1 (3%)
NO = 28 (93%)
MAYBE = 1 (3%)

### COMMENTS FROM NO RESPONDENTS:

- Ce n'est pas suffisant mais çela demeure très important pour ceuillir toutes les données pertinentes pour une décision éclairée.
- Cannot be assured of competent and lack of coercion without face-to-face.
- There should be a face-to-face assessment.
- I think you must ask the questions face-to-face and offer followup questions to really establish the person's decision-making capacity.
- The assessment has to be done directly, that is face-to-face. Worse case scenario: via telemedicine.
- Absolutely not. I wouldn't even prescribe an SSRI for a patient without seeing them, much less MAID.
- The opinion of the person that will chose the program is indispensable.
- There may be no need for a full interview in a patient who has preexisting wishes and a psychiatric condition that renders them incapable such as dementia, but the patient would still need to be assessed, at least for functional status, capacity, symptoms.
- Absolutely not.
- I think this is far too grave of a decision to make without consulting the patient themselves.
- Compte tenu de la gravité des conséquences résultant de l'AMAM, l'évaluation de la compétence doit être la plus complète possible : elle doit inclure l'évaluation direct du patient lui-même et la collecte d'information collatérale des proches et du dossier.
- We would not accept that for any other psych consult so why in this circumstance?

\* Percentages may not add to 100 due to rounding



- In my opinion what is suggested above could only constitute a first impression. To regard this is adequate for giving an expert opinion and assessment would be akin to giving psychiatric diagnoses on public figures based on their publicly available statements and information. I thought this had been declared unethical.
- Assessment of the person is always necessary.
- Assessments should be done in person or via telemedicine with the patient.
- The graver the decision, the higher the standard of care it deserves—otherwise administrative euthanasia may devolve.
- Évaluer le patient incluant une évaluation de l'état mental est essentiel.
- If you are requiring a psychiatric assessment, then an appropriate assessment should be conducted either face-to-face or telehealth.
- There is never any excuse for making conclusions without examination.
- A proper assessment should include a face-to-face assessment. The lawyers will interpret the law to suit themselves and blame psychiatrists for inadequate assessments.
- Definitely not.
- Absolutely not.
- One should be required to see the patient, face-to-face as well as doing the chart review and discussing with relatives and other individuals.
- Tout doit être fait avec le patient car il est au centre de la démarche et le premier concerné par l'AMAM, donc toute intervention sert à l'éclairer, à le confirmer ou l'infirmier dans sa demande, tout comme son dossier et l'évaluation psychiatrique devrait être mise à sa disposition. La transparence doit être totale car l'enjeu est majeur.
- Patient always needs to be consulted. If family or representatives need to be involved the patient should be present as long as it doesn't intensify their suffering.
- I am unsure that this is ever sufficient to inform an adequate psychiatric assessment.
- La consultation du dossier et la discussion peuvent établir la pertinence ou non d'une évaluation, mais ne sauraient la remplacer.
- A psychiatric assessment cannot be done without appropriate interaction with the patient.
- Unless there is terminal dementia, psychiatric consultation would be preferable.
- I can't see that a chart review or case conference would be acceptable as a mental health assessment. Notes are often inaccurate/inadequate. Clinicians can present a case any way they want (as I recall from my days as a resident reviewing cases on-call with my attending).
- Assessment needs to be face-to-face.
- And never has been sufficient to make a psychiatric diagnosis. Our special skills require direct interviewing
- NEVER. Must be face-to-face for psychiatric assessment.
- If I understand the question properly, my answer is no. There should always be face-to-face interaction and assessment of the patient by the MAID provider personally.
- I do not support MAID under any conditions.
- There must be some amount of "gut feel" that is important in meeting the person—whether they appear to be of calm and lucid mind, for example—that cannot be obtained from third parties. Furthermore there should be some counselling provided.
- Not sufficient if assessment is for purpose of diagnosis and possible treatment of a psychiatric illness.
- That's a ridiculous proposal.
- The psychiatrist should assess the patient as well.
- What an absurd notion, taking the ridiculous to extraordinary heights.
- I don't believe that provides enough of a safeguard. At least a telemedicine interaction would seem to be a minimal standard for assessment.
- Le psychiatre a une méthode pour éliciter l'information qui est différente de la plupart des autres intervenants et pourrait donc obtenir de l'information différente.

## COMMENTS FROM UNSURE RESPONDENTS:

- Depends on the situation and information provided. Who will pay for the OHIP funded physician for indirect care?
- This would depend on the guideline. In many clinical situations, this kind of indirect consultation is sufficient and there is no reason this could not be an adequate level of involvement in some situations unless a law or guideline declared it to be inadequate.
- Face-to-face preferable when possible but not mandatory.
- If this involves a discussion with another knowledgeable physician (e.g., palliative care, GP) who has had detailed discussions with the patient regarding MAID and their mental health this may be possible.
- This is challenging. The content of charting varies. Without seeing the patient, a psychiatric assessment is limited to more broad statements, e.g., "I would screen for this..," or "I would consider offering a trial of antidepressant treatment if concerns persist." Making definitive statements about capacity, in particular in MAID, without meeting a patient would be difficult. I also feel the burden of the medical assessment would need to be distributed given the importance of the decision. For example having review panels (similar to mental health act), case discussions, etc.
- I could imagine the possibility of such a review being sufficient, but basically I think some direct observation should be part of the psychiatric assessment.
- Chart review and collateral MAY be enough or may require face-to-face assessment.
- Depends on patient's capability.
- I don't understand the question. If a chart review and collateral indicates that the patient may have a mental illness, then I think the person should have a psychiatric assessment and/or MAID should be put on hold. The risk of harm is substantial, and the decision is irreversible.

\* \* \* \* \*

## 7. If the most responsible practitioner treating the patient for their primary illness declines to be involved in a MAID application, should there be a requirement to contact the most responsible practitioner for the purposes of enhancing the understanding of the patient's current clinical situation and relevant background health issues? (The rationale for this is to address concerns arising internationally where itinerant or travelling physicians are doing MAID assessments without long term knowledge of patients.)

YES = 237 (75%)

NO = 29 (9%)

UNSURE = 52 (16%)

### ANNUAL CONFERENCE SURVEY

YES = 20 (83%)

NO = 4 (17%)

## COMMENTS FROM YES RESPONDENTS:

- Provincial bodies would need to fund both participants for this clinical activity.
- As my former mentor used to tell us, "you can never have too much information about a patient." To make a decision of this magnitude without collateral from the MRP is malpractice, in my opinion.
- At very least an attempt should be made to contact the most responsible physician to try and ensure all relevant information has been obtained.
- It will be a miscarriage of justice not providing the person who somebody that the primary practitioner declines doing it.
- Yes. The reason for the refusal is important to assess.
- Involvement in the decision does not mean absenting from the care, and there may be a number of significant contribution that the attending physician could contribute, even if absenting themselves from the decision or other involvement.
- Any decision in such complex circumstances should be subject to judicial review.



- For thoroughness.
- I think that relevant longitudinal history is essential to safely providing this service.
- And he should be free to state his objection to MAID.
- Toute démarche concernant la santé du patient rend les médecins obligés de communiquer entre eux pour la meilleure approche possible et répondre aux besoins du patient, y compris son besoin de mettre un terme à sa santé physique et mentale par la demande de mort.
- In the the practice/application of MAID it is essential for medicine and any physician to respect the Hippocratic oath and not be part or become an executioner or part of an execution plan that is real or perceived or possibly perceived. The medial therapeutic relation is based on trust and the development of trust.
- Yes, I do think it is important to connect with the attending physician. Another challenge is that this adds to the assessment process, and compensation/billing codes would need to be in place.
- Absolutely or there will be physicians abusing the system.
- C'est réglé est en accord avec la bonne pratique medicale.
- If this happened there would need to be enough contact to develop a therapeutic alliance and to ensure that the clinician involved is able to know enough to understand the patient's life and environment context and the patient's lived experience.
- The normal rules of professional conduct should apply. If the MRP does not wish to be involved on ethical or religious grounds that have nothing to do with the medical indications for MAID, and the patient is requesting MAID then the physician should step aside and the patient should decide who to consult. They will need assistance for this and obviously the MRP must be consulted.
- The MRP still has knowledge about the history and treatments attempted which may be hard to tease out from separate charts and may be only in that person's chart for the patient. Some GPs still use paper records (and often have good reason for doing so!)
- I don't know how irremediability of a condition can be determined without information from the treating physician.
- The MRP and the physician doing the assessment should be REQUIRED by law to communicate about this.
- And conversely there should be an obligation put on the MRP to provide such information, despite their moral objections to euthanasia.
- If the most responsible doctor has historical experience with the dying patient this information would be valuable, even critical, in assessing a patient for MAID. The feelings and wishes of spouses and relatives are very important and knowledge of them could help avoid disputes and litigation!
- Since MAID is now available in Canada, there should be less need for patients to go abroad for such services.
- The idea of a patient terminator physician for hire is highly unpalatable; the potential contact with the primary physician would at least lend some professional accountability to the situation. Just because a policy has become law does not make it ethical and does not remove from the fact that I and most of my colleagues took the Hippocratic Oath.
- Seems reasonable and sensible, as long as some thought is given as to what to do if the MRP is either unavailable or unwilling to participate in providing information for this purpose.
- Regardless of our moral beliefs we have a duty to our patient and should not abandon them. I accept that some psychiatric illnesses are malignant and terminal, and psychiatrists need support in dealing with such cases.

## COMMENTS FROM NO RESPONDENTS:

- Must respect responsible physicians choice to not be involved in MAID.
- The most responsible should continue to be the responsible physician, and not be pulled into a process that he does not accept and historically has not been accepted by the medical profession (see Hippocrates).
- If the relevant information is available in the patient's chart, contacting is likely not necessary.
- Definitely not.
- Si le médecin refuse pour des raisons de valeurs personnelles.
- There shouldn't be a requirement, as it may not always be necessary, but it would be advisable to attempt to contact the MRP for enhanced understanding of a patient's history, etc in some, even many, circumstances. Again, this should be

at the discretion of the MAID provider or assessor. Making it a requirement would carry the risk of impeding or delaying MAID assessments and/or MAID procedures if the MRP stalled, delayed, or refused to speak with the provider/assessor. This would not serve the patients well.

- I do not support MAID under any conditions.
- Absolutely not.
- Je ne pense pas que ça devrait être une obligation car le médecin le plus responsable qui est contre l'AMAM pourrait ne pas vouloir collaborer avec le processus. Cependant, il est impérative que le médecin qui fait l'évaluation pour l'AMAM soit tenu de pouvoir démontrer après du Collège des médecins qu'il a fait une évaluation approfondie de la condition du patient, sous peine de sanction disciplinaire (et légale??)

## COMMENTS FROM UNSURE RESPONDENTS:

- The “most responsible” practitioner, if unwilling to do it, must appoint someone in their stead.
- Too complex of a question to answer in this format of questionnaire design.
- This should probably occur but there could be justifiable circumstances where one might not contact the MRP (not sure what those are though).
- I don't understand the question.
- I think it should be a good practice expectation but not a requirement. We need to chart why the MRP was not consulted.
- The question is somewhat unclear, since the first sentence refers to presumably two different “most responsible practitioners.” The situation outlined in the second sentence should be banned.
- There will always be situations where this is not necessary (when a clinical assessment will make it evident that the patient is eligible and supporting information can be obtained from reliable others like family). In completing a consultation and forming an opinion we are expected to obtain relevant collateral. This would typically involve contacting other providers or obtaining their records.
- I think an appropriate assessment is required, and this would seem to ordinarily include getting adequate understanding of the case, which would seem to ordinarily include talking to the care provider who best knows the patient. I am leery about making this a requirement, and even more leery about having it appear in legislation. While the issue of MAID is complex and does seem to require specific legislation (it is a social policy question), I want to keep professional judgment as part of the work of doctors and am hesitant to require this level of detail (i.e., you must contact a specific person for collateral) in guidelines.
- I seriously don't understand this question.
- This likely would require a case-by-case analysis. For example, if the treating doctor is simply ethically opposed to participating, then no contact should be required. There should be a mandate on the treating physician to participate to the extent of clarifying (e.g., on the form) why not participating (e.g., clinical issue of patient, moral objection, other).
- Preferable, but I know from experience that some MRPs refuse to reply to any calls about MAID patients if they oppose it.
- I am unclear about the intent of this question.
- This should ideally be done anyway, but may lead to problems with conscientious objectors.
- I hope Canada does not come to have itinerant/travelling physicians doing MAID assessments. But I also see problems with insisting on contacting the primary MRP—if a doc is going to approve MAID regardless of what the MRP says, it seems a waste to insist on contact.
- The idea of travelling physicians with this niche market is disturbing, but if the most responsibly involved physician refuses to be involved, who exactly is the person who, knowing this, still asks that physician to be involved?
- This may be a best practice responsibility in some cases but not all.
- How can one enforce a Canadian law on an international basis? It doesn't make sense to include this as a requirement if the patient travels outside the country for the suicide. If the assessment is being done in Canada; however, yes the assessing physician should be obligated to contact the MRP for further information.





**8. Should a close family member(s) be contacted to provide input for all MAID assessments, unless a patient specifically objects to such contact? (If the principle of “patient autonomy” is applied in a narrowly interpreted manner then input from family should not be required, but family input may provide valuable information, enhanced confidence regarding MAID decisions, and appropriate respect for the role of family.)**

YES = 234 (74%)
NO = 33 (10%)
UNSURE = 50 (16%)

ANNUAL CONFERENCE SURVEY
YES = 25 (89%)
NO = 2 (7%)
MAYBE = 1 (4%)

**COMMENTS FROM YES RESPONDENTS:**

- Family input is almost always important when making similar decisions.
- It should not be mandatory, just encouraged. Patient should be given option to say no and to specify which family member would be appropriate to contact.
- In case of necessity only, but should be permitted if could help the physician to make the best decision possible.
- Is necessary.
- Family need to be involved in the process wherever possible as MAID will have ongoing ramifications after the person has died.
- Autonomy and selfishness are different matters. Obtaining information from a close relative is not undermining a patient's autonomy. In the end the patient and the physicians involved make the decision, not the close relative. But to cut out the close relative could be very selfish in the sense that the aftermath, the consequences of a death from an illness, a suicide or MAID on the surviving family members can be profound and the patient for his or her own reasons or lack thereof may not be able to appreciate this outcome. Even a specific objection by a patient should be closely examined as to its validity, i.e., what is the reason, what is the harm, what is the benefit.
- But family should only be contacted with patient permission.
- I would argue that collateral information from someone who knows the patient well should be a requirement, in order to have a complete assessment.
- Il faudrait impliquer les familles autant que faire se peut, avec l'accord préalable du patient bien entendu.
- While I think it is useful to involve a family member (or even more than one), there can arise a situation where family member(s) and patient disagree, which can be based on legitimate family member observations of the patient's mental state. This may provide confusion for the assessor but seems legitimate to me.
- Family must live with the consequences of the decision, and will be the people who know the person best. We are all at our most healthy when decisions are collaborative.
- Noting that in some contexts, close friends may be more informative than the closest biological relatives.
- Yes, so long as family members understand they do not have “veto” power over a patient's decision to proceed with MAID.
- I have read of some cases in Belgium where family found out AFTER the person died. This was particularly troubling because the “reason” for the assisted death was 1. bipolar 2. depression.
- Not necessarily a family member, I prefer “a significant other.”
- Yes this would be considered a good practice in psychiatric assessment.
- Will full permission. Not assent, but consent for contact.
- This is not an individual decision and should involve the whole family.
- As in all our work as psychiatrists, relevant collateral is invaluable to a comprehensive, safe and more accurate assessment.
- Of course!
- Contact should be made only with the patient's consent, assuming they are capable of consenting to or refusing this contact.

- I have seen family input much opposed to a patient's stated wish to die in the case of a depression, and they were instrumental in having him receive needed ongoing care in hospital when he wanted to give up and seek medically assisted suicide as an outpatient.
- On ne peut conclure l'évaluation tant qu'on n'a pas l'ensemble du portrait, cela sera donc de la responsabilité du patient de donner son accord ou non mais il devra savoir que sans conclusion d'évaluation, il ne pourra y avoir d'accès à l'ANAM, le dossier restera en suspens. Ceci permet de respecter l'autonomie du patient mais de faire une évaluation scientifique, sociale, affective, etc la plus exhaustive afin de prendre une "bonne décision," car il n'y aura aucun retour possible s'il y a un accord d'ANAM ou un refus (ce qui inciterait les médecins dans le cas d'une nouvelle demande à beaucoup de prudence).
- If the patient and family disagree, it can be distressing for all involved, including the health-care team. I think these are the cases that lead to emotional burnout. I think having family involved is important, but only with the patient's consent. If the patient does not consent to have them involved, then I think this needs to be explicit, that the family is aware that a physician does not have consent to speak with them.
- Generally would not obtain history or information if patient requests so. But for MAID assessments I would consider it mandatory.
- Tout à fait légitime mais pas obligatoire.
- As the family will be affected by the decision there needs to be discussion between patient and family to explore relational factors, options etc/for love to be expressed as they are able/for beliefs and morals to be shared and expressed. This might require very skilled and empathic facilitation.
- Of course, if the patient does not consent to the involvement of family, that should be respected.
- Family should be involved unless the patient formally objects. Then the usual rules under consent and capacity will apply.
- It is hoped that the patient will not be alone in making such a critical decision.
- But only with knowledge of the patient.
- The family are about to lose someone to death earlier than anticipated. They need to feel as if they are heard, but should not be allowed to block a request though.
- I like the points included in the brackets for this question. My question is, what is being done now? One of the differences between suicide and MAID that I've read about, is that family usually support and are present at a planned MAID death, whereas a person dies by suicide alone and impulsively. So I hope that family are involved in the assessment!
- Collateral has always been a vital part of our information gathering diagnostic and treatment process.
- Humans are social creatures and our identity is partially shaped by our family interactions (positively or negatively). The choice to die with medical assistance is one of the most important decision a person can face and impacts society at a greater level—mostly at the level of the family. I would hope that, for the most part, the inclusion of the family could also serve a therapeutic value in helping family face issues surrounding death before the person actually dies. This could also help detect issues, like untreated mental illness, that a person may be hiding.
- Input should be sought unless the patient specifically objects; having a sense of family context could also enhance the counselling that could be provided to the patient.
- Autonomy is preserved if the patient refuses to provide this consent and this is honoured.
- I would require such contact before proceeding, even if the patient does object (analogous to an airline passenger having the right to refuse security clearance but then not being allowed to fly).
- Involving family, where possible, appears indicated. It has been shown to be associated with better patient outcomes. In this kind of situation it is very likely that in most situations involving the family will be associated with better outcomes for those left behind.
- It helps assess the seriousness of the demand and see if it was consistent throughout time.
- I do agree, and if there is a specific objection, that should be examined to see if it points to some overlooked issue which impacts on the decision. When I trained in consult-liaison psychiatry and when I worked in community outreach geropsychiatry, I was repeatedly humbled to find that the collateral history from a close family member often greatly deepened and sometimes changed my impression as to what was going on with the patient. In such an important assessment this would appear to be a wise move. It also might reduce the risk of family feeling excluded and later coming back with complaints against the physician if they disagree with the patient's choice.



- There are long-term consequences for the family of a person choosing MAID and while a blanket recommendation is not always possible, in principle they should be involved.

## COMMENTS FROM NO RESPONDENTS:

- It would be ideal, but if a patient is capable, then the family's wishes really have no bearing.
- Not all assessments but collateral may be indicated in some cases.
- I think that families CAN be involved but ought NOT be involved unless a patient specifically REQUESTS it.
- If patient wants it, yes, but if not, no.
- This may be appropriate in certain situations and it may be helpful to have a family member attend part of the assessment, but I do not feel it is necessary in all situations.
- Not in all cases.
- I would put it instead that it be universally recommended to all patients requesting euthanasia that they allow the assessing physician to solicit input from loved ones of their choosing, and that patients be provided with the reasons why this is a recommended part of the assessment. It would seem odd to judge that a given patient is capable of choosing to end their own life, but that they must be "tricked" or "led" when deciding whether to allow their doctor to speak to their spouse.
- Again, this is something that is certainly desirable, but should not be required. It should be up to the patient and his/her assessor/provider to determine what is needed in order to provide that patient with good medical care and treatment, just as with any other important procedure.
- I do not support MAID under any conditions.
- While standard of practice should involve attempts to get the patient's consent for family member input, it should not be a requirement for competent adults.
- If the patient has the right to refuse this then it should not be a criterion, but instead a recommended part of any good quality assessment where we gather input with permission as part of patient and family-centred care. It is in the physician's interest to try and get this input regardless of criteria.
- As before, no medical profession participation is the optimum.
- Pas une obligation. Dans certains cas, un tel contact sera essentiel à l'évaluation de l'aptitude chez un patient qui n'est pas connu, dans quel cas le psychiatre devra expliquer au patient (et, au besoin, aux instances administratives) pourquoi ce contact est essentiel.

## COMMENTS FROM UNSURE RESPONDENTS:

- As for any procedure, if there is doubt about the patient's competence to make the decision, the person with power of attorney or the closest kin needs to be approached.
- Probably? I have a difficult time when we set terms like "all MAID assessments" rather than saying that one should, as far as possible, contact a close family member.
- It would depend on every particular case.
- I would favour family involvement as they often know a lot about the psychosocial elements that may be impacting the patient's request and may also be completely unaware of the plan by the loved one. Although autonomy is a key principle, given the finality of this process and potential anger and legal repercussions I think family should be contacted.
- Again good practice expectation but not a requirement. Should chart why family not contacted.
- Not in all cases. In one of my MAID assessments the family attended. Ultimately if this remains an OHIP-funded assessment, who will pay for time spent contacting family?
- Obtaining information from others is always valuable. A patient has the right to limit the release of their information and to ask providers to limit the information released to the maximum extent. It is important to delineate asking for information about a person and their function or symptoms ("I've been asked to assess your brother's condition, can you tell me about...") from informing someone else about the nature of your assessment ("I am assessing your brother for medically assisted death...").

- Ensuring there is clarity in recommendations about obtaining relevant information from others is essential or this portion of a guideline could prove to be very obstructive or unduly limiting to a patient who wants their MAID assessment to be private; however are open to having others contacted to give relevant information about their disease and function.
- Usually. There may be special situations.
- Should differs from must.
- Should be encouraged and even likely be seen as standard of care, but I don't support making this required in regulation.
- Should not be mandatory, but recommended.
- Again, these are complex issues. Some patients may be disenfranchised from family in which case contact would be not needed or may be harmful.
- Individual consideration as situations vary.
- Suggest you ask the applicant if such contact is desired.
- Involving family should always be attempted, but only after consulting the patient.
- When close family members are supportive it makes the decision clear and easy. When there is disagreement, conflict and potential litigation may be a risk. The law about patient autonomy should be very clearly defined.



## 9. In addition to legislatively required assessments by physicians, or nurse practitioners, should a multidisciplinary “team” of health care workers be required to provide a formal assessment for all MAID applications?

YES = 96 (31%)*
NO = 144 (46%)
UNSURE = 73 (23%)
NO ANSWER = 1 (0.5%)

### COMMENTS FROM YES RESPONDENTS:

- I think that this should be extensive to psychologists, social work, and other members of the team. We live, after all, in an era of clinical democracy, where hierarchies need to be flattened.
- There are many facets to MAID and all should be explored to the extent possible using the expertise of a multidisciplinary team approach when possible.
- It seems reasonable to me that the assessment opinions should be considered by a “team.” I do not think that it will be necessary for every member of the multidisciplinary team to have individually assessed the patient. The terms of reference for such a team obviously should be made clear. This is a mechanism that would spread the responsibility and also the liability.
- Mais il faudrait que ça se fasse rapidement.
- Including consent and capacity boards that psychiatrists who agree to be involved in assessments can ask for reviews from.
- I think this would be helpful in complicated presentations as allied health care professionals often have valuable observations and collateral (especially with respect to undue influence from others, for example).
- Because it's not just a “medical” issue.
- I feel that her social worker should likely be involved.
- I think a social worker should be involved, at the very least to ensure the patient has been able to access other necessary professionals to make suitable arrangements for death and burial (e.g., spiritual counsel, legal counsel, financial counsel, etc).

ANNUAL CONFERENCE SURVEY*
YES = 15 (56%)
NO = 11 (41%)
MAYBE = 1 (4%)

\* Percentages may not add to 100 due to rounding



- Une équipe multidisciplinaire est nécessaire mais pas limitée à des travailleurs de la santé parce qu'il ne s'agit pas de santé uniquement. Des philosophes, éthiciens, sociologues, anthropologues, etc seraient les bienvenus pour une meilleure compréhension individuelle et systémique.
- Timeliness is also essential.
- Comme dans les autres modèles légaux cette approche est acceptable.
- As it is available. I can imagine remote situations where this might not be possible. All multidisciplinary work should be person-centred and occur with the patient's full knowledge and input.
- I think education should also be an important part of the assessment process and this could be done by other clinicians.
- Ideally there should be more than one person assessing the patient in order to arrive at consensus.
- At least one second opinion by a person with experience in this area should occur.

## COMMENTS FROM NO RESPONDENTS:

- That would be unnecessary bureaucratization.
- Treating physician and psychiatrist/psychologist is enough.
- Do not turn MAID into another health care industry by-product.
- Impractical. Where would this team come from and who would fund them?
- Not sure what they would add to the process. What would they assess?
- Although I'm sure a multidisciplinary team would be helpful, I don't know that this needs to be mandated
- I am reminded of the days when women had to go before a panel of physicians and "prove" she needed an abortion, or the days when a woman needed her husband's consent to have a tubal ligation. If a patient is so ill that they are asking us to help them end their life, then we should make the process as minimally intrusive and invasive as is consistent with good care. And frankly, the understanding of capacity assessments in our institution by non-psychiatrists is in many cases completely wrong, substandard, and inconsistent with current legislation. I'd rather do it myself and know it was done fully, rather than have someone who is not trained in assessing capacity making a mess of things (as happens—I recall one patient staying in hospital for over a year after being declared incapable because the person in charge of arranging placement said the patient had to "agree" to the placement, which of course the patient wouldn't do, as she functions at the level of a five-year-old and wanted to go home).
- It is restricted as it is, going for a multidisciplinary team could make it unnecessarily complicated.
- I think this would be of benefit, but would limit access to some patients. This is an ideal, not a baseline requirement.
- Would make the process too cumbersome and add little or nothing.
- Not required, but highly desirable.
- Multidisciplinary involvement is likely beneficial, but should not be required.
- I believe making this mandatory is not required in all cases. In some cases, a multidisciplinary team involvement would provide the best assessment and care.
- Une évaluation multidisciplinaire serait préférable mais non nécessaire.
- For God's sake, there is a time element here. Pain and suffering will only be prolonged if we add a bureaucracy.
- I don't think that practice should be so closely legislated. There are plenty of situations in which such a team would not be required. Good clinical practice guidelines and the general laws of providing the best care possible should apply.
- If practical, yes, if not, then no.
- Sometimes an OT assessment might help—not always—it should depend on patient needs just as with treatment of other illnesses.
- A big problem when we have tried it.
- Would only render the process overly complicated, to no advantage for the patient.
- Not in all cases. I feel that there are cases where it is relatively straightforward, and that making it more complicated for all is a waste of resources and time.
- Not in every case, but only in complex cases where the course of action or path is not clear one way or the other.
- I do not support MAID under any conditions.

- Too cumbersome.
- No, as before.
- This would be ideal in principle, but given health care resource limitations, I would not see it as feasible.

## COMMENTS FROM UNSURE RESPONDENTS:

- Je crois que cela peut s'appliquer dans certains cas selon la personne, son entourage ou non, son isolement. Cela permettra une évaluation plus complète de la situation.
- Ça semble complexe et lourd.
- Might be nice, similar principle to capacity assessments, but might not be practical.
- There is the risk of a dominant group member influencing the whole group for termination of life.
- Where I practice in NW Ontario, it may not be possible.
- A decision by committee to kill is just as bad as that decision being made by one physician.
- Ideally yes, but the resources required for this would be inordinate, and it is hard to justify such cost when we are struggling to provide adequate and timely care in other domains, including palliative care and pain management.
- Ideally, yes, there should be a multidisciplinary team involved. Practically, I do not know if we have resources in place for smaller centres, or community hospices, etc. Having access to a consultation team for complex cases would be valuable.
- I suppose that depends on 1) who is on the "team" and 2) what role would they play, if they are not adjudicating the request. Certainly it would likely be helpful to the patient and family members to have support from a multidisciplinary team.
- This is usually done, but I am cautious about how structured this should be.
- Experience and practice of a team may make the process easier for the patient and physician/NP. Patients suffer when we struggle to find out how to do something in terms of delays and potential lack of confidence in their carers.
- Who would be on the team? How would that enhance assessments or decisions about allowing MAID? Won't that take even more resources which should go to people on wait lists for treatments to restore quality of life/health/functioning?
- They should not be doing MAID as it is murder plain and simple.
- I like the idea given that MAID is unlikely to be a common procedure for the vast majority of practitioners. A dedicated team can develop expertise that individuals can't.
- For what purpose exactly? And to bring what set of skills that would be of what value exactly in assessing a person's wish to end their life? Worded as is, it just sounds like some attempt at diffusing responsibility by drowning it between many expert professionals whose role in the issues at stake is not clarified.
- Palliative consultation should be required, unless refused by the patient.
- This is a highly disturbing potential clinical practice for which increased numbers of assessors and education cannot remove its innate questionable ethics.
- Depends on what the team can bring to the assessment process





**10. Should capacity assessments be guided by generally accepted principles for assessing capacity contextually applied to MAID with flexibility for assessors to choose from a variety of appropriate assessment tools or formats (as opposed to a prescribed tool)?**

YES = 232 (74%)
NO = 25 (8%)
UNSURE = 56 (18%)

**COMMENTS FROM YES RESPONDENTS:**

- One size rarely fits all.
- Okay.
- This question is so convoluted it is difficult to follow.
- You need to be able to choose from validated assessment tools combined with your own clinical assessment, but some guidance and training in these would be really helpful.
- Guided by good practice is better and more flexible. Avoids a tick box.
- I can't imagine any perfectly formulated "prescribed tool." A variety of appropriate assessment tools would improve the confidence in any such tool with time.
- We are currently working on a guide in Alberta. It will not be required, but is designed to be of assistance to the assessor for capacity, with questions about mental health and vulnerability.
- À ma connaissance, il n'y a pas d'instruments validés spécifiquement pour la capacité de l'AMAM. Je dirais que le MacArthur Capacity Assessment est probablement le meilleur outil à cet effet.
- This statement reflects several of my comments that in many situations MAID is part of normal clinical practice and should not be set apart from the usual practice of medicine.
- Should be guided by generally accepted principles.
- Prescribed "tools" have limited efficacy and accuracy.
- But, nothing is better than a good face-to-face exam. Filling out forms can become rote.
- Tools themselves are usually inadequate. The history and patient assessment are most helpful, but tools may be helpful for specific symptoms like depression or severity of cognitive impairment.
- Again flexibility is key.
- Absolutement.
- I am very nervous about "prescribed tools."
- Assessors should have familiarity with a broad range of evidence-based assessment tools among which they can choose.
- A patient could have the capacity to make the decision regarding MAID, but not have the capacity in other areas.
- Mandating a specific tool would undermine the highest level of judgement, namely that of the most well-trained most responsible health provider, the physician. Tools are just one of many technical factors and enablers that are transcended by expert judgement of the physician (reference Dreyfus model of expertise whereby experts are able to transcend and know when to go beyond simple technical tools). Mandating a tool would only lead to uninformed challenges and power disputes by technicians and bureaucrats who don't understand when the context and judgement goes beyond the limitations or even is different than suggested by a simple tool.
- Sounds reasonable, as long as the guidelines are clear.
- As long as the tools/instruments have been validated, are reliable, etc i.e., I do support that there should be a toolkit of options not one specific prescribed tool but yes a range of "prescribed" tools to choose from not just some random ones choose by whim. The decision must be informed by the best science of the day allowing for future advances.
- This is a diagnostic dilemma at times and a variety of tools and resources should be used. However guidelines would be helpful from those with the expertise in this area.

ANNUAL CONFERENCE SURVEY*
YES = 22 (85%)
NO = 3 (12%)
MAYBE = 1 (4%)

\* Percentages may not add to 100 due to rounding

## COMMENTS FROM NO RESPONDENTS:

- Should be standardized across the country.
- In my experience, capacity assessments are currently done very poorly, i.e., there is a wide range of opinions and beliefs by practitioners that are evident in these assessments if they are done at all, e.g., cognitively-disabled patients with dementia are treated on medical and surgical services with no capacity assessments or very slipshod ones. MAID is a nationally accepted procedure covered by federal legislation. It needs to have national standards and that should include only approved assessment tools for assessment of capacity. If capacity assessments are not done in great detail and recorded properly physicians and others involved in MAID will be open to being sued. Just look at the way in which wills are contested because of presumed lack of capacity.
- Le seuil pour l'aptitude devrait être plus élevé étant donné les conséquences sérieuses découlant d'une décision reliée à l'AMAM.
- Accepted principles, acceptable by whom? Very subjective.
- Un instrument prescrit et soumis à des réévaluations en fonctions des cas étudiés (style théorisation ancrée) m'apparaît nécessaire pour une évaluation équitable pour tous.
- Consistency is important. Not all physicians are capable of assessing capacity, nor of grasping the concepts of capacity. Either there should be physicians with a specialty in such assessments, or there should be a standard tool which assessors get trained to use.
- Seems inordinately complex.
- We need some minimal standard.
- I do not support MAID under any conditions.
- Capacity to refuse treatment is appropriate, but capacity to have a doctor kill you is just bizarre.

## COMMENTS FROM UNSURE RESPONDENTS:

- À mon sens, il n'existe pas d'instruments adaptés à l'AMAM car le risque demeure la mort et le bénéfice recherché est le même, soit la mort.
- A capacity tool specific to this purpose needs to be developed.
- I actually think it should be customized to be specific to MAID as the law specifies differences with the usual health care and consent laws, i.e., current law indicates that consent given at time A is not affected by subsequent incapability. However, the MAID guidelines indicate that if capacity is lost during the time frame between consent and implementation then MAID cannot occur.
- Since this is a new situation and circumstance I am unclear what the "generally accepted principles for assessing capacity" are, as applied to this situation. Nor am I sure what the unspecified "prescribed tool" would be. If this is merely a checklist to ensure completeness of the assessment that may be satisfactory, if it is somebody's specific tool for the assessment, then one needs to be assured of suitable psychometric properties prior to its introduction.
- I probably agree, there is no specific tool developed for this purpose, but neither should "any tool" or an idiosyncratic tool be acceptable. The McArthur CAT tool is probably the best format and should be encouraged.
- I again have no idea what you are talking about.
- I think there should be guidelines as to the necessary components of an assessment, with flexibility as to how the assessment is carried out and/or which specific tools are used. I suspect tools will be developed and altered as experience with MAID progresses.
- I would need more information about the "tools," I am not fully informed on this topic.
- I am unfamiliar with the tools recommended for MAID as I am not providing direct capacity assessments for this. I do think there should be several options, or bedside tests.
- A specific tool should be developed for exceptional circumstances.
- I don't know enough about the tools available. I've been comfortable doing capacity assessments without a prescribed tool. However, I don't know if it would be best to have the assessments be as structured as possible.



- What is more important here to me is to clarify and to make explicit to society at large what is it exactly that the assessor assesses and with what set of skills. It may be that as this is attempted, we will realize that what we can in fact assess as physicians or psychiatrists is in fact quite limited, compared with the unspoken assumption out there that we can confidently and scientifically determine who should be allowed to end their life, and that the use of a prescribed “instrument,” while initially sounding reductionistic, will end up the more honest approach.
- Not sure what this question is trying to ask.
- The question is too convoluted. I am not sure I understand what is being asked.

\* \* \* \* \*

## 11. Do you support allowing mature minors to qualify for MAID?

### COMMENTS FROM YES RESPONDENTS:

- If they are judged to be decisionally competent.
- Provided they meet all the other criteria.
- Kids with chronic/terminal illnesses often have a degree of understanding and maturity well beyond their years, I see no reason why they should not be allowed to make this choice within appropriate guidelines.
- Exception à la règle.
- Only for illnesses that are clearly terminal, with severe suffering. Should be used exceptionally.
- Should hinge on capacity to consent, not age alone, as with other medical decisions.
- Their maturity would have to be part of the assessment just like the mental capacity has to be assessed in any adult.
- I expect that the numbers would be very small, and would be very carefully assessed. This would clearly be in the context of respectful end-of-life care.
- I am a child and adolescent psychiatrist. Why should we condemn only minors to suffering?
- Yes, if MAID is considered a normal part of health care, then the general rules should apply.
- Needs more study and individual consideration.
- Mais ça porte à controverse et c’est beaucoup plus difficile.
- If it’s an irreversible fatal condition.
- In hopeless situations where the parents are capable and securely attached and able to help the child. Always what is in the best interest of the child should be central to the decision making.
- Avant 16 ans, l’avis des parents et leurs appui devraient être requis.
- Truly mature minors have for a long time been allowed to make decisions regarding termination of care, I feel they should be allowed the same rights for MAID.
- Why deny someone who has capacity the ability to make a decision? Age is no guide to capacity. Mature minors who are able to make the decision will have capacity, those who are too young will not.
- For physical illnesses only. It would be very difficult to attest that a mental illness in a minor has truly been demonstrated to be irremediable.
- We all know that minors can suffer from painful and fatal illnesses.

### COMMENTS FROM NO RESPONDENTS:

- I am against MAID under all circumstances.
- Parents should be involved in the decision.

YES = 100 (32%)
NO = 145 (46%)
UNSURE = 68 (22%)

ANNUAL CONFERENCE SURVEY
YES = 5 (19%)
NO = 20 (74%)
MAYBE = 2 (7%)

- If that were allowed, all sorts of new definitions of “mature minor” and assessments to determine maturity would have to be developed. “Mature minor” is more of a concept than a clear entity and so far is interpreted differently in different jurisdictions. It is by no means a solid legal term.
- When you get down to it they are not that mature, ebullient precociousness is often pseudo competence of the overwhelmed.
- I presume this question is relevant where the guardian of such a minor would be in disagreement with the “mature minor” over MAID. I have difficulty defining a “mature minor”—these so often appear to be children and immature youth when placed in contrast to mature adults, in my experience.
- Do not know how you determine that a minor is mature?
- The ethical difference between this and condoning suicide in minors is what?
- Absolutely not. How will we ever agree upon what defines a “mature minor?” As a child and adolescent psychiatrist, one way of identifying a minor as mature is when they can put their present experience into the broader context of their life overall, and take “the long view,” perceiving the future and hold a vision for themselves in it. The majority of minors do not have the capacity to see much beyond their present experience. Without the ability for full perspective taking, the suffering experienced in the present is not evaluated adequately, and often times results in suicidal fantasies or actual attempts as a means to alleviate what is most often temporary suffering.
- Because I would need a better definition “mature minors.” Regardless, these so-called mature minors are very rare breed.
- Not yet able to understand a lot of abstract issues. If, however, there was a substitute decision-maker or family support than yes, assent ok.
- Seuls les majeurs peuvent se qualifier pour l’ANAM, restent le consentement parental ou bien aux juges d’émanciper le mineur. Il est question ici d’une loi pour des situations d’exception dont les conséquences peuvent être irréremédiables et qui change l’essence même de notre humanité.
- We are talking about intolerable suffering and irremediable conditions with no end in sight. That is hard to imagine in most illnesses with minors. I think that the case would have to be made on a case-by-case basis. In psychiatry, I find it hard to imagine that we could ever make the case. Brain plasticity indicates that the brain is never fully mature, and certainly not before the age of 25 or 30. There is considerable suffering in many disorders but the disorders are remediable.
- Only as an extreme last resort.
- What is a mature minor? Sounds like another left-wing loopy concept.
- This is an irrevocable step, frontal lobes only develop in late teens, early 20s.
- Except in cases of irremediable pain associated with terminal illness.
- Not sure what a mature minor is!
- I do not support MAID under any conditions.
- Mature minors is a difficult concept to apply even in regular psychiatric practice as maturity to make decision vary, and in practice this will next to impossible to implement, and might pit those minors against parents/guardians. E.g., transgender interventions are a case in point, where irreversible interventions are usually reserved until they are of legal age.
- It will become too difficult to define and draw the line on the concept “mature.”
- Beyond bizarre.
- Again a dubious classification. This could be tragic, again the much feared slippery slope.

## COMMENTS FROM UNSURE RESPONDENTS:

- Qu’est ce qu’un mineur mûr? Il faudrait définir cette personne avant de procéder.
- In principle, I do support this however I wonder about the value of life experience in assisting the quality of this decision-making process.
- There is no reliable/validated “test” for the maturity of minors.
- It is premature in a process that is as new as it is in Canada.
- I am not sure how you define mature.



- Nécessiterait l'appui de la famille (parents/tuteurs) dans cette situation.
- My gut feeling is no, but to give a yes/no answer, I would have to study this in depth.
- After a capacity assessment.
- I feel these cases need to involve a specialized judge, and medical experts. I would defer to my paediatric colleagues for their expertise in how they might manage this.
- I don't feel I have the knowledge to comment on this question. I'd hope that the government would ensure mature minors have full access to palliative care before considering whether they should be able to request MAID.
- Oui si un tuteur est au dossier.
- With the same reservations I have about it for adults, it is difficult to justify allowing it for adults but not for minors.
- The idea of assisting a mature minor in ending their life is unnerving; at the same time if a mature minor could be allowed to refuse life-saving treatment then it seems difficult to ethically justify not allowing MAID. If the parents strongly object then performing an action that ends a child's life rather than withholding an action that might save it might be experienced as more upsetting and therefore the potential psychological harm to the family may be higher, which might justify disallowing MAID for children if parents refuse to assent.
- If they clearly meet the other criteria and a parent or guardian is involved?
- Probably yes, again in those circumscribed cases of irremediable suffering in the context of anticipated inevitable death, and with family participation (so that a person with hopefully a fully formed frontal lobe is involved in the decision, but the minor has an ability to say yes or no if he/she appears to meet the criteria for capacity).
- Pas pour le moment. C'est peut être injuste envers eux.



## 12. Do you support advanced directives for MAID in anticipation of capacity being lost and with clear criteria for activation of the MAID request?\*

### COMMENTS FROM YES RESPONDENTS:

- Substitute decision-maker would have to agree with the directives as they represent the patient's wish.
- When I develop dementia—and for most of us, that is when, not if—I would like my advanced directives to be followed. They would be my decision made in anticipation, but with a clear mind.
- This is of critical importance for patients with a dementing illness. Without these provisions patients may choose to end their life sooner than they need to.
- This is particularly important for patients with early cognitive decline.
- It's what I would want for myself, so I definitely support this.
- Avec précautions d'avoir plus d'un avis.
- Absolutely.
- I might want this for myself, if I am diagnosed with a dementing illness, for example.
- Dementia offers the best example, it is common and predictable. Personally I would consider asking for MAID for dementia at the point that I no longer recognized my family members.
- Although I fundamentally disagree with MAID, it only makes sense to me that MAID would be supported by advanced wishes of patients. I believe that the majority of the Canadian public is under the impression, albeit false, that the present

YES = 203 (65%)

NO = 70 (22%)

UNSURE = 40 (13%)

### ANNUAL CONFERENCE SURVEY

YES = 17 (65%)

NO = 8 (31%)

MAYBE = 1 (4%)

\* This question was rendered as "Do you support advanced directives for MAID" in the conference survey

legislation allows for MAID to be administered as an advanced directive. When Canadians' opinions were polled, this is the concept of MAID that the majority of our fellow citizens probably held in mind.

- Alzheimer is a perfect example of why this should be allowed.
- Definitely! Current situation is problematic for CNS disease and other situations.
- When meeting strict criteria re notarized signature, prognosis etc.
- But only if it includes a provision for ongoing reassessment for the advance directive.
- Yes, with limitations, and careful discussions about how perception of quality of life might change as capacity does.
- These should follow the same rules as any other advance directive under consent and capacity legislation.
- In line with a living will.
- I see many who lose the capacity to consent or request MAID even though they had clearly expressed this prior to the loss of capacity. The ability to make advance directives when competent should be extended to MAID.
- Otherwise those with, e.g., ALS or dementia may feel forced to die before they "need" to in order to avoid being denied the privilege later on when they reach a point at which they need MAID but no longer have capacity.
- As long as they are not allowed to override other safeguards which would apply.
- With the same reservations I have for capable adults requesting it. One issue that I would anticipate, given the wild and highly prevalent misconceptions about resuscitation and technological care at the end of life, would be the ability of people in our culture to correctly identify "clear criteria for activation."
- Absolutely. The nature of a slow decline condition that effects cognition such as dementia should not exclude one from the spirit of MAID as it currently does, provided that advance directives have some safeguards and clarity which are achievable.
- This is critical for individuals who lose competency through various serious cognitive disorders and yet have an opportunity to make this choice as an advanced care directive should they be suffering from these conditions in the future.
- I think this is reasonable in the case of an anticipated degenerative/progressive illness in which loss of capacity will quite possibly occur before the point of irremediable suffering. Consider specific criteria, as noted, but also the need for a substitute decision-maker in that situation to agree to authorize the assisted death, as per the person's prior capable wishes, after the person becomes incapable. That way someone is giving consent at the time, as with other non-emergency procedures, and using similar substitute consent rules.

## COMMENTS FROM NO RESPONDENTS:

- How can anyone know in advance how they will feel under certain circumstances?
- There are better ways to deal with this.
- It should always be a competent decision in the present.
- La capacité fluctue dans le temps. Il est difficile de prévoir quel sera notre choix par rapport à l'AMAM lorsque nous devenons incapable.
- I do not support anything that makes a physician deliberately complicit in hastening a patient's death.
- Because the person's values and perspective may change between when they sign the advance directives and when the MAID request would be activated. Again, PEOPLE NEED ACCESS TO GOOD PALLIATIVE CARE!!!! They wouldn't need advance directives for palliative care if they were confident they would not be in pain and would be cared for.
- The person must be capable at the time of MAID request.
- I do not support MAID under any conditions.
- If a person provided an advanced directive for MAID but at the time of activation they do not want to die, the experience of MAID could be traumatizing for both the patient and the provider regardless of capacity or consent provided. It may also be traumatizing for the provider to perform this action if the patient does not object but does not understand what is happening to them.
- Absolutely not.
- Dans la pratique, ce n'est jamais si clair que ça. C'est comme les directives anticipées. Le patient refuse l'intubation en théorie, puis il apprend que c'est pour quelques jours pour une condition réversible et alors il accepte.



## COMMENTS FROM UNSURE RESPONDENTS:

- Tricky situation—“maybe” is my answer.
- Seems people can live with situations they imagine they could not. How would it be determined that capacity is lost permanently?
- In theory this seems reasonable and something to be honest that I would like to have available for my own care in future. However it also opens a much greater risk of abuse and error in the application of MAID. I have recently been involved in a case where daughter was trying to move toward strict comfort care only, including stopping insulin in keeping with her father’s previously clearly expressed wishes (he had previous history of depression, had been vehemently against long-term care, etc) but the patient himself, now dementing and facing long-term care, was indicating that he was now quite accepting of his quality of life and had no wish to hasten death.
- Depends on circumstances. Let’s get the basics correct first.
- I think this will be challenging. If the directive is specific to a particular kind of illness such as Alzheimer dementia in someone knowing that this is a high-probability outcome, it would seem to be a stronger argument. On the other hand, some generic advanced directive seems to me very challenging for everyone to know “when to pull the trigger.” I think it might be an invitation for all kinds of moral distress.
- I would support it for myself: not sure I want to extend it beyond that! Afraid of abuses.
- I’m opposed to MAID on principle, but if it became a legal option then anticipatory requests would make sense.
- Would need examples to make a judgement.
- Je n’ai pas lu les directives préalables.
- I would struggle with this as a routine procedure, I would support it being limited to very specific conditions (e.g., ALS, dementias, neurodegenerative disorders). I think resuscitation codes/levels of care may be more relevant.
- In limited circumstances. People are allowed to change their mind and unless their wish was MAID was confirmed fairly close to loss of capacity, how could one be sure they still wished that for themselves? (Patients can find surprising strength in the midst of difficulties that if they had been asked in advance of developing said difficulties, they might have thought it would be unbearable/life not worth living if...).
- It is so very difficult to anticipate the future. I have mixed feelings about this.
- There is a vital importance for advanced directives to be followed even in the case of dementia. However there needs to be a well-established protocol for the establishment of how these directives are obtained. This is where physicians should have a role as well as other health-care providers to ensure there is no coercion or abuse occurring. There is a need for clarity around end of life management, what constitutes heroic measures to keep people alive and a rational approach to the distribution of health care resources. This is very complex and my concern is that MAID has been introducing rather than engaging in a fulsome dialogue.



### 13. Do you support a tracking process for MAID applications so that, in the event of multiple and diverging opinions as to the nature of the illness or decisional capacity, all opinions are considered?

YES = 266 (85%)
NO = 21 (7%)
UNSURE = 26 (8%)

#### COMMENTS FROM YES RESPONDENTS:

- With caveat that the person’s wishes carry most weight.
- In something irreversible, all the available information should be considered. You’d want all the path reports before amputating someone’s leg, so of course all of the opinions should be available.
- This will increase provider confidence in our assessments for requesting patients and may mitigate legal risk.

ANNUAL CONFERENCE SURVEY
YES = 29 (100%)
NO = 0 (0%)

- Every application should be scrutinized and its like research—it should all be transparent, not just the recommendation you like.
- Protection against potential abuses of power is important.
- Absolutely.
- Restera la question des experts et des critères d’expertise qui posent, comme on le sait, bien des problèmes.
- Ça. À de soi.
- Yes, yes, yes.
- It will be important to perform quality measures to ensure that all jurisdictions are providing the same level of access and that decisions are consistent. This will protect everyone (physicians, care providers, families and patients).
- Who does the tracking and how are opinions weighted if differing from that of the patient?
- However, I am concerned about how cumbersome this might become. Someone has to be in a position to make the call.
- Evidence, data and transparency and reporting helps ensure good oversight and good science.

#### COMMENTS FROM NO RESPONDENTS:

- Seems to be too unwieldy/bureaucratic and may permit less than legitimate stakeholders to have input—herbalists and naturopaths claiming that the disease is in fact treatable with their particular potions.
- This is too cumbersome to be practical. Currently legislation does not call for this type of process. What we do need is an annual federal report on MAID in Canada (model—state of Oregon).
- Abstention dans ces cas et revision plus tard 2 à 6 mois.
- I believe this would change the nature of capacity (which can fluctuate and is contextual) and the way we address this in health care overall. This kind of oversight or tracking should not be MAID specific if the group recommends it is utilized. There are broad reaching implications in creating this kind of system.
- Only an advanced directive or a direct request by patient should be considered.
- I don’t support MAID, let alone a tracking process. Your questions remind me of the question that required only a yes or no answer: “HAVE YOU STOPPED BEATING YOUR WIFE?”
- No, the normal medical decision-making rules need to apply.
- Too complicating again.
- I do not support MAID under any conditions.
- Going from worse to worse.

#### COMMENTS FROM UNSURE RESPONDENTS:

- Not sure what the question means.
- It is complicating the process even further.
- How would this affect patient autonomy?
- I don’t know.
- Probably, but I’m not sure.
- This might be too complex.
- My concern is that physicians would become targets for family/advocate discontent. I do think accountability of the process is important as well. If multiple opinions, then I could see it triggering a larger review panel process.
- This sounds good and useful in theory, but I have grave concerns about how it would work in practice.
- Not quite sure what you mean by this?
- Je ne suis pas trop certaine ce que la question veut dire. Si les opinions sont divergentes, je pense que l’AMAM ne devrait pas avoir lieu jusqu’à ce que la situation soit clarifiée.





#### 14. Please provide further comments you feel are relevant.

- My answers reflect my view that physicians should have no role in assisting dying.
- Question très nouvelle et qui nécessite beaucoup d'expérience humaine et professionnelle, du jugement clinique et un grand respect...doit être traitée avec grande finesse et délicatesse.
- I think that MAID is essentially a good thing to have available—the difficult part is to figure out how to prevent it from being abused. I am particularly concerned about the “wealth transfer” that is taking place in Canada with our elderly demographic—the baby boomers, or their offspring might get greedy and not want to see what they perceive as their rightful inheritance being used up by the costs of nursing care.
- Je trouve très dangereux que l'AMAM puisse être considérée pour les mineurs, les patients avec démence et simplement pour souffrance psychologique; les patients psychiatriques sont vulnérables, et plus sujets à coercition par des proches/ autres mal intentionnés à leur suggérer l'AMAM. L'AMAM n'est pas le traitement de pathologies psychiatriques difficiles à traiter.
- None that I can think of now.
- I hope the CPA will take a position against MAID or at least communicate the serious potential risks of any process that enables MAID. These risks include clinical errors (in assessment and implementation), “slippery slope,” changing the role of physicians and serious “boundary violation” issues, etc. One of the risks rarely (if ever) addressed is the potential increase in ALL suicides as a result of a culturally permissive attitude toward suicide as a method for relief of suffering.
- There needs to be a much better tracking system for MAID in Canada. Currently each province is doing its own thing. Knowledge is critical to make this process a better one.
- This is a very difficult area. If it is put in place, it should perhaps be done on a trial basis in a limited geographic area.
- It is clear that the Carter decision does include psychiatric patients as per the EF decision from the court of appeal in Alberta. To deny psychiatric patients access to MAID is an infringement on their Charter rights and increases stigma.
- I was dismayed by the exclusion of advanced directives and psychiatric patients from the legislation. I would like the CPA to develop guidelines and principles for MAID in psychiatric patients and patients with progressive dementias. It is usually older, well-educated professionals who choose MAID—most likely ourselves!
- The expense of this system will be considerable. Is it a good use of funds? Making this a medical procedure means it will likely be funded from that budget.
- God is the author of life and death. Remember the Hippocratic oath words “I will give no deadly poison though it be asked of me.”
- In general I do not support MAID for patients with the primary condition being mental illness (i.e., chronic depression). The wish for death colludes with the underlying illness itself. Potential for abuse including family members advocating for death can be a complex issue as well which would be very hard to disentangle.
- Il n'y a pas de place pour les états d'âme du docteur c'est le bien être du patient qui doit primer en tout temps.
- I have been very distressed by the number of cases of MAID being requested, and in a majority of these cases ultimately provided, in my elderly patients for what seems no other reason than “existential suffering” and the various insults of aging. Examples include: not wanting to go to long-term care so preferring death; having chronic pain that was demonstrably well controlled with medication and minimal side effects but patient just didn't want to have to take medications anymore and so was suffering pain—she was given MAID; a man with two violent suicide attempts but no evidence of depression who then wanted MAID and precipitant was clearly shaming and abusive behaviour as well as refusal to allow appropriate supports for his medical problems into the home by his wife. I was in principle supportive of MAID but have become extremely leery of being involved given these experiences.
- I am profoundly concerned that there will not be enough safeguards to protect the vulnerable, pressured to request it or worse, with the push to expand to substitute decision-makers and advance directives a lot of people will have their right to live their natural lives overshadowed by a few who have to live longer than they wish in agony. We abolished the death penalty in part because of the imperfections of the legal system no falsely convicted innocent person should have to die so why are we now seeing that again on the horizon.
- I have done two assessments over OTN. The Ontario fee code for psychiatrists has not paid me adequately. Time with patient is limited but I spend time speaking to primary physician, possibly family-based on this and reviewing/preparing documentation is time consuming.

- The ethical analysis of this question to date has been very narrow. It is crucial that the CPA take a clear stance against mental disorders being primary qualifying conditions and keep MAID to terminal illnesses alone.
- This survey has all questions “required” and I was not able to skip or refuse to answer a question. This is very irritating and will reduce the response rate, especially from those who have well formed opinions however cannot fit them into your questions or someone who does not want to answer one specific questions for a number of reasons. For a feedback process, this is disappointing and forces opinions into limited boxes.
- What about an accelerated application process for non-questionable terminal illness. For example metastasized brain cancer in young male patient now non-ambulatory and declining rapidly. This is an example of an actual patient that passed in the middle of applying where the application was delayed due to physician scheduling issues and whose wife I saw since diagnosis.
- Still uncertain about MAID.
- There should be a free choice if one wishes to opt out of MAID requests as per personal preference and values, and there should be no obligation or requirement to find an alternate physician as that goes against the original preference or value.
- Thank you for the opportunity to contribute.
- This is an important topic and needs to be approached with the treating physician, family and community involvement being in alignment.
- Complètement contre.
- I went into medicine to cure occasionally, to relieve discomfort, to comfort always, but not to kill, even those who were going through a phase of wanting to end it all.
- Thank you for the stimulating and important questions.
- I have worked with some of the most refractory depressed patients in our region quite by coincidence by being involved with surgical treatments for depression. I have never been able to predict which patients would improve and stay well with the interventions we provide (whether biological or environmental). I don't think psychiatry is currently in the position to prognosticate irremediability. When we understand and become more competent and treating the clinical conditions we help our patients face, hopefully we will become more expert at prognosticating. Until then medically assisted death for psychiatric patients is unethical (in my opinion).
- As a member of the British Columbia Psychiatric Association executive, we are also working on recommendations to help guide our colleagues in this complex area. We would be happy to continue and liaise with the national CPA.
- It's not a medical issue, it's a social and moral issue—why are doctors involved? Of the fifteen people who attended the Wannsee conference that decided on the extermination of European Jews as a Final Solution, eight held academic doctorates. Intelligence is no guarantee for good moral decision-making.
- This is a thorny problem and for those practitioners interested in being involved, I would recommend training accompanied by a certificate of competence to be renewed every two years.
- Some of these questions are very black and white and I hope do not reflect hidden agendas of those actively involved from the CPA. Some of the issues may come down to clear policy, while others should be guiding principles (e.g., contacting family would be desirable or even necessary in some situations and not others).
- We will mature over time as a society using this legislation. We should not be afraid to allow it to run its course and revise as needed.
- I am currently involved in MAID and find it challenging but very rewarding. Inclusion of patients with mental illness as the primary reason for MAID is controversial and would have to be extremely clear and well thought out before I would support it.
- Thanks for asking and your careful consideration. I have done several MAID assessments and am impressed by their diversity but also some similarities.
- Although (after 58 years in practice of psychiatry), I am generally not in favour of assisting medical death for individuals with psychiatric illness, I did have one patient with a schizophrenic illness, with painful hallucinations commanding him to kill himself, who, even after additional consultation with an esteemed colleague, killed himself.
- Je crois que l'offre d'une aide médicale à mourir pour des cas ayant uniquement une maladie mentale enverrait un message paradoxal et contradictoire quant au rôle du psychiatre et notamment quant à notre travail pour diminuer le suicide. Je suis tout à fait opposée à l'extension de l'aide médicale à mourir à des patients ayant uniquement une maladie



mentale, considérant de plus que la psychiatrie est encore une discipline complexe avec des pronostics très variés pour des mêmes diagnostics.

- As a psychiatrist at a community general hospital, I've been asked to represent "mental health" in MAID previewing and debriefing of cases. Our hospital has had five cases so far and I've attended three meetings in the last month. So far, my mental health expertise had not been required and staff involved in the provision of MAID have not required my services.
- Looking forward to further guidance.
- I feel that one should be able to use some means of assuring that in the event of dementia one's desire to end life should be allowed. In essence some form of "living will" type of direction.
- We have a duty to protect those who for reasons of mental illness cannot protect themselves. Given that suicidal ideation is a common symptom of a variety of mental disorders, the possibility of "rational suicide" in a person with a mental disorder would be an extremely rare occurrence if it happens at all. Having broad legislation to open the door for assisted suicide in the case of mental illness would bring about much more harm than good for our patients and for society in general. These patients need our compassion and efforts to help them live, not help them die.
- Data collection and annual external review of completed MAIDs should be part of the program.
- Je crains que l'on demande encore aux psychiatres de jouer un rôle sociétal pour lequel ils n'ont pas été formé (plan humain, juridico-légal, sociologique et ultimement philosophique—la raison d'être).
- In the community, I see physicians spending a great deal of their time counselling patients/families regarding MAID. It can be emotional and time-consuming. I would like to see more support for physicians/health care staff in addition to patients/families. I would support patients administering MAID, not physicians directly, to limit escalating rates of MAID. I would see MAID for severe mental illness as a rare exception, akin to "case law," that would need to be dealt with each case individually and not allow MAID for severe mental illness otherwise.
- I believe MAID should only be allowed when death is imminent in order to alleviate suffering associated with final moments of life.
- La loi fédérale est un peu trop large. La loi du Québec me semble plus susceptible d'éviter la pente glissante.
- This is a highly contentious and divisive issue and cannot be forced. I agree with the limited approach taken by the present legislation. In my view it should be very restrictive. Maybe after a couple of decades experience with this we would be able to take a balanced view towards further fine tuning or loosening of the criteria but not now.
- A MAID decision must always be in the service of the patient and his/her pressing need.
- Considering MAID is a mark of a civilized and compassionate country that is prepared to take on the responsibility of tackling challenging ethical decisions rather than relying on dogma to avoid the intellectual and emotional challenges involved. It will require clear guidelines with regard to eligibility and the assessment process if we are to do it in a safe and consistent way that protects both the patient and those involved in the decision.
- If we are able to mobilize resources so quickly to "solve" the problems posed by MAID/ensure rapid access to MAID, think what we could do if we applied such energy and resources to the original cause of the suffering instead? How about rapid access to pain treatment (as appropriate), depression, etc.
- Je crois que l'aide médicale à mourir est nécessaire.
- I must again lobby for the CPA to advocate strongly for palliative care (including palliative psychiatric care) for all Canadians. I think the CPA also needs to be more blunt that MAID is suicide. Planned, socially acceptable, an understandable choice, but suicide just the same.
- MAID is an immoral and illegal law and is against the natural law. The mentally ill will be victimized by this law as well as vulnerable others. The CPA should be defending our patients from the onslaught of their dignity and freedoms instead of trying to cooperate to apply this law. This is the time for the CPA to be courageous and take a stand for us psychiatrists who spend our life preventing self-destruction by "just saying no."
- I do not support MAID. Some of the questions I answered with "no" when it could mean "not applicable." However, I believe in relieving pain and suffering even if pain medication results in death. I do not support keeping patients alive by "artificial" means such as ventilators, feeding tubes, intravenous therapy when patients are suffering physically and or mentally. Thank you.
- Psychiatrists can play a valuable role but our time is limited and our involvement shouldn't become an unnecessary barrier to MAID.

- Very murky area. Need a proper registry of all MAID cases, scientific study, access to data in a transparent manner, knowledge transfer tools, conferences, and ethical/spiritual/legal guidance as we learn more. Canada MUST be a world leader in MAID knowledge, skills and attitudes. We can make it better every day.
- I am thankful that I don't expect to be involved in such proceedings.
- I appreciate efforts from committee members and the CPA at large, but I think there needs to be more critical thinking done around the role expected of psychiatrists, what constitutes our skills and expertise, and whether the latter two match the former. Admittedly, such critical reflection on our part may run counter to soft consensus in force since the SCC decision and the subsequent legislative process, but I would not equate critical reflection with opposition to euthanasia. The moral anguish about ending one's life in our culture was not extinguished by the recent judicial process, and the use of technical sounding but poorly defined words such as "irremediability" and "assessment" simply buries that anguish, for the general public I think, in the comfortable assumption that "experts" will sort it out. Somehow, I feel that this may lead to a misunderstanding between us and the public, and that this could backfire down the road.
- It is very important not to see a patient's choice of MAID as a failure of psychiatric care.
- I do not support MAID under any conditions. I took a oath to heal, not to harm or kill!
- I believe that intractable mental illness is as painful as terminal cancer. Patients should be able to say enough is enough.
- Excellent questions.
- We need better palliative care; it would diminish the demand for MAID. After 32 years of "fighting" hard to encourage very ill, suicidal patients to never give up, I doubt I will ever feel comfortable with any of my patients requesting assisted dying. I will never approve it but will consider transferring the patient to a colleague. At any rate, I am retiring in 18 months.
- Thank you for asking!
- Congrats to CPA for taking this on!
- What else is there to say?
- Thanks for your consideration of psychiatrist input on this important issue. I generally agree with Dr. Sonu Gaind's previously expressed concerns. While I do not wish to impose undue suffering on people waiting for a decision on the use of MAID in mental illness, I believe it is very important that we get this right, as the stakes are high. It will also be important to closely track requests for MAID for mental illness, if it becomes authorized, in order to learn more about the situations that can arise and continue to refine the guidelines and legislation if needed.
- The court of last resort has spoken and we should respect that. However, the SCC has essentially created a medical procedure by their definitions. Physicians are under no obligation to be involved. Regulatory bodies obviously should have a process and tracking for MAID. I am concerned about the impact on physician well-being. This should be an opt-in not an opt-out. There should not be mandatory training in MAID for learners such as residents and medical students. This is a revolutionary change in medicine. I believe that we can have respectful disagreement. If there must be MAID then the process, including agents used, should come from a government body (since it is responsible to respond to the SCC). The agents should be produced by government so that no company or shareholder issues arise. A learned group of physicians should get together and ensure that the means cover all possibilities. Stores of the agents could be located around the country. The rights of institutions and sponsoring bodies to not participate as well as those of physicians, nurses, pharmacists, etc should be upheld. No regulatory body should insist that any physician must assist the patient to get to the MAID process. By definition the SCC said this is solely for competent patients. Such persons should be able to contact the MAID resources. Government could make available readily accessible information on the process. This should all be the task and responsibility of government, not the medical profession. Government makes the laws, in this case the one the SCC overturned. The medical profession has no obligation to be involved.
- Many thanks to the CPA for putting such important work into this issue.







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**Presentation to Senate Committee on Legal and Constitutional Affairs  
Re: Bill C-14 (Medical Assistance in Dying)  
K. Sonu Gaind, President, Canadian Psychiatric Association  
May 11, 2016**

The Canadian Psychiatric Association (CPA) is pleased to have this opportunity to present to the Senate on the issue of Medical Assistance in Dying (MAID). My name is Karandeep Sonu Gaind and I am the President of the CPA. The CPA is the national voice for Canada's 4,700 psychiatrists and more than 900 psychiatric residents. Founded in 1951, the association is dedicated to promoting an environment that fosters excellence in clinical care, education and research.

The CPA supports Bill C-14's proposal to further study the issue of MAID when mental illness is the sole underlying medical condition, without prejudgement of the outcome.

There are unique issues when mental illness is present that were not considered in the Supreme Court Canada v Carter ruling. By affecting the brain, mental illness affects how a person thinks and feels, including how they feel about themselves and their place in the world. The very symptoms of mental illness may thus make individuals particularly vulnerable to be induced to end their life at a time of weakness.

Symptoms of mental illness can affect a person's emotional resilience, making even normal life stresses seem unbearable, and can lead to cognitive distortions, including negative views of oneself and the future. Thus symptoms of mental illness not only lead to suffering, they may independently affect the person's decision making process regarding their will to live or die.

Remediability is another key issue that has different implications for mental illness compared to other medical illnesses. In mental illness, remediability cannot be looked at only in biomedical terms of symptom improvement. Psychosocial factors such as isolation and loneliness, poverty, housing, and underemployment or role in society are all things that impact suffering from mental illness and need to be considered as part of attempted remediation. The concept of when a mental illness should be considered irremediable is very different and not something the profession has previously needed to define. As the CPA has pointed out to Minister Wilson-Raybould and Minister Philpott, there is no established standard of care in Canada, or as far as CPA is aware of in the world, for defining the threshold when typical psychiatric conditions should be considered irremediable.

Combined with challenges of lack of access, this lack of standards alone would have troubling implications if MAID for the sole criteria of mental illness were allowed for in the pending June 2016 framework. Recent review of data from the Netherlands supports these concerns, as it showed the majority of cases of Physician Assisted Death for mental illness did have unresolved psychosocial suffering such as social isolation.

Consistent with the further study called for in draft Bill C-14, the CPA has struck a time-limited Task Force to better understand these issues.

There are other issues important in ensuring consistent national standards, including the appropriate mix of providers doing sequential assessments, and length of waiting period when mental illness is involved, but I will close by addressing some common misconceptions regarding mental illness in MAID discussions.

First, the term "treatment resistant depression" or TRD should not be misunderstood as meaning "irremediable". TRD is a research and clinical concept meant to guide potential treatment options when biomedical symptoms have not been adequately reduced following two attempted biomedical treatment courses. It would be improper, even dangerous, to misapply the concept of TRD as meaning irremediable for MAID discussions.

Second, while CPA and others have advocated for years to eliminate stigma and discrimination against those with mental illness, it is important to realize it is not discriminatory to consider the particular nuances of mental illness in MAID discussions. "Equity" does not mean everything is "the same", it means treating things fairly and impartially. Failure to consider the particular circumstances of mental illness as it could impact MAID processes would itself be stigmatizing, as it would fail to acknowledge the realities of mental illness on people and their lives.

I want to thank the Committee once again for your thoughtful consideration of these issues, and am happy to answer any questions you may have.

Respectfully submitted,

K. Sonu Gaiind, MD, FRCPC, FCPA  
President, Canadian Psychiatric Association



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## **Verbal Remarks to Special Joint Commons-Senate Committee on Physician-Assisted Death**

**K. Sonu Gaiind, MD, FRCPC, FCPA**  
**President, Canadian Psychiatric Association**  
**January 27, 2016**

The Canadian Psychiatric Association (CPA) is pleased to have this opportunity to present to the committee on this important issue. My name is Karandeep Sonu Gaiind and I am the President of the CPA. The CPA is the national voice for Canada's 4,700 psychiatrists and more than 900 psychiatric residents. Founded in 1951, the association is dedicated to promoting an environment that fosters excellence in clinical care, education and research.

My remarks today will focus on specific issues related to mental illness that must be considered in any physician-assisted death (PAD) framework. The CPA is actively engaged in developing a full position with a range of specific recommendations, my comments today are meant to raise key points for the Committee to consider in its deliberations, but should not be construed as CPA's final position on this issue, that fulsome position is still being developed.

I'll start with key issues that need to be taken into consideration when discussing terms like irremediable, intolerable and enduring suffering, and capacity in the context of mental illness.

### ***Intolerable and Enduring***

The evaluation of what is intolerable and enduring suffering due to illness symptoms is affected both by the severity of those symptoms and impairment, and by the individual's perception of their experience. The subjective assessment of "intolerable" and predictive assessment of "enduring" can both be affected by mental illness in particular ways.

Mental illnesses can affect cognition and impair insight and judgement. Symptoms of cognitive distortions common with clinical depression include negative expectations of the future, loss of hope and loss of expectation for improvement (even when there may be realistic hope for positive improvement), loss of cognitive flexibility, loss of future-oriented thought, and selective ruminations focused on the negative and minimizing or ignoring the positive. There are commonly distortions of a person's own sense of identity and role in the world, including feelings of excessive guilt and worthlessness, or feeling like a burden to others. When clinically depressed, people also have lower emotional resilience and are less capable of dealing with normal life stressors, and can experience even moderate level stresses as being intolerable or overwhelming. While we are not at the point of being able to apply this clinically, increasingly research findings are suggesting there are areas of the brain with altered functioning during times of severe depression that correlate with some of these cognitive changes.

### ***Irremediable***

In terms of what is irremediable, careful consideration needs to be given about what this means in the context of mental illness. Irremediable of course cannot simply mean incurable, as many conditions in psychiatry and medicine are considered chronic and not curable, but things may be done to remediate or improve the situation. Multiple treatment options typically exist for even the most severe instances of mental illness where symptoms and suffering may be treated and reduced, even if not cured. And as importantly,

it is essential to remember the person is more than just their illness. Psychosocial factors play a big role in a person's illness experience, particularly so in many mental illnesses. For example, if you take an overly narrow view of assessing "irremediable" only in the context of potential symptom improvement through biomedical treatments in severe depression, you ignore potentially remediating or improving the person's experience by addressing key factors like social isolation or poverty.

### **Capacity**

Moving on to capacity, in medicine we consider four broad components in assessing capacity:

- The ability to make a choice.
- The ability to understand relevant information.
- The ability to appreciate the situation and the consequences of decisions.
- The ability to manipulate information rationally.

Even when persons with mental illness can express a choice and understand and recall information, their appreciation of the situation, of present and future expectations, and ability to manipulate information rationally can be affected by the cognitive distortions previously discussed.

I want to emphasize none of this is to suggest that simply the presence of any mental illness alone impairs people's judgement and cognition. But by definition in the PAD discussion we are talking about the most severe situations, and in severe cases of mental illness the risk of such cognitive distortions is of course higher. And we think with our brains, not with our hearts or limbs.

All these issues speak directly to the Court's concern about ensuring the person is not induced to take their life at a time of weakness. Apart from the actual suffering caused by symptoms, if cognitive distortions are present these risk undermining the person's decision-making process—in the Court's consideration of factors of coercion or duress, it would be as if the mental illness is undermining the person's autonomy to make a decision free from the influence of cognitive distortions. It is this recursive nature of symptoms on the evaluative process, where the very symptoms of mental illness may interfere with the person's evaluation of their mental illness and its present and future impact, that poses the challenge.

Finally, one other point bears consideration. In the context of the Court's finding of loss of liberty if the person chooses to end their life prematurely because they fear eventually becoming unable to take their life in the face of progressive physical incapacity and suffering, mental illnesses very rarely if ever lead on their own to such progressive severe physical incapacity.

With that as general background, and again emphasizing that the full CPA position is still being developed, there are a few guiding principles we can offer at this time:

- When psychiatric illness is present, to ensure nuanced issues that could affect decision-making are properly assessed, and allow for time for potential remediation of symptoms and/or psychosocial factors, multiple assessors with suitable skill sets should do sequential assessments over a period of time. Our final position will reflect more specifics, and there may be varied mechanisms depending on jurisdictional needs, but spreading the assessment over multiple suitable assessors, who are aware of the potential impact of mental illnesses on cognition, capacity, etc, and sequential assessments, are needed safeguards.
- The concepts of irremediable, and intolerable and enduring suffering, should not be exclusively focused on the biomedical condition, but must be considered in the full context of the person's condition, including considering the potential impact of possible psychosocial interventions on suffering and symptoms.

- Psychiatrists may choose to not be involved in the PAD process. In such situations, patients requesting PAD should have access to information regarding available PAD resources and the referral process, including psychiatric resources as required.
- Finally, it is important to recognize that the term treatment-resistant depression, or treatment-resistant mental illness in general, does not define that an illness is irremediable. Rather this term is typically used to help guide the course of further treatment options using an evidence-based approach. This should be explicitly articulated in any PAD framework to avoid risking conflation of the terms “treatment-resistant” and “irremediable”.

I want to thank the Committee once again for its thoughtful consideration of these issues, and am happy to answer any questions you may have.





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## **Preliminary Remarks on Physician-Assisted Death**

**Presented to the  
External Panel on Options for a Legislative  
Response to *Carter v. Canada***

November 5, 2015

Dear Members of the External Panel,

The Canadian Psychiatric Association (CPA) thanks you for the opportunity to discuss issues relevant to the Physician Assisted Death (PAD) issue in response to the Supreme Court of Canada *Carter v. Canada* decision. The CPA is the national voice for Canada's 4,700 psychiatrists and more than 900 psychiatric residents. Founded in 1951, the association is dedicated to promoting an environment that fosters excellence in the provision of clinical care, education and research.

For each of the four issues the panel has requested feedback on, we are providing Points for Consideration and, if applicable, Recommendations. The focus of our submission is on issues specifically relevant to mental illness and the role of psychiatrists.

**Issue 1: Different forms of physician-assisted dying: (1) assisted suicide, where a doctor prescribes a lethal dose of medication that patients take themselves, and (2) voluntary euthanasia, where a doctor injects a lethal dose of medication to terminate a patient's life on the patient's consent**

#### Points for Consideration

In terms of either of the above issues related to prescribing or administering a lethal dose of medication to terminate a patient's life, this falls outside the scope of clinical practice and expertise of psychiatry.

#### Recommendation

1. The CPA does not anticipate or recommend that psychiatrists be involved in the actual procedure of prescribing or administering lethal doses of medication.

**Issue 2: Eligibility criteria and definition of key terms**

#### Points for Consideration

In its ruling in *Carter v. Canada*, the Supreme Court discusses physician-assisted death in the context of "a competent adult person who clearly consents to the termination of life" and "has a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition." Clarity of key terms and criteria is essential to ensure unwanted risks are mitigated (issue 3) and appropriate safeguards in place (issue 4).

We should first acknowledge it is appropriate to continue using the term Physician Assisted Death (PAD) rather than the term Physician Assisted Suicide, as has sometimes been used in the past. "Suicide" has connotations and clinical relevance in the context of symptoms of mental illness which should not be conflated with the issue of Physician Assisted Death.

When discussing issues of mental illness in the context of PAD, there are two main scenarios that must be considered. The first scenario is whether patients with other medical illnesses for which they are seeking PAD concurrently have a mental illness; the second scenario could be patients seeking PAD on the basis of their mental illness. We will address both these situations below.

#### *Patients seeking PAD for other medical illnesses who concurrently have a mental illness*

In the scenario where a person has intolerable and enduring suffering from an irremediable medical illness and concurrently has a psychiatric illness, the primary role of a psychiatrist would be to

assess whether the patient's mental illness is impairing their capacity to make an informed decision regarding PAD. The psychiatrist's role would not be to assess whether the person's medical illness fulfills the required definitions of irremediable, intolerable or enduring, as that determination would need to be made by medical professionals with expertise in the relevant medical illness.

### Recommendations

2. In situations where patients have a mental illness, including if they are seeking PAD for other medical illness(es), psychiatrists should be involved in assessing whether the patient's mental illness is impairing their capacity to make a decision regarding PAD.
3. Psychiatrists may be consulted for an opinion but do not need to routinely be involved in all capacity assessments if there is no evidence of a mental illness.

The issue of capacity is discussed further below.

### *Patients seeking PAD for mental illness*

In the event a person seeks PAD on the basis of a mental illness, the terms "irremediable", "intolerable and enduring suffering" and "capacity" need to be considered carefully in the context of mental illness.

### **Irremediable**

If "irremediable" is considered to mean incurable, this could apply to many diagnoses in psychiatry and medicine. Schizophrenia is typically considered a chronic illness and not curable, major mood disorders such as clinical depression or bipolar disorder can be chronic or recurring; likewise in medicine chronic illnesses such as diabetes or arthritis are not curable.

If "irremediable" is considered untreatable, then very few situations in psychiatry would be considered irremediable. Multiple treatment options typically exist for even the most severe instances of mental illness where symptoms and suffering may be treated and reduced, but not cured. There may be times when a patient does not wish to have certain treatments, this is discussed further under capacity below. Also, as discussed further below, the course of mental illnesses is determined not only by biomedical treatments, but also by psychosocial interventions aimed at reducing suffering. Rarely if ever should it be considered 'irremediable' regarding interventions aimed at addressing psychosocial stressors for a person with mental illness.

If "irremediable" is considered terminal, then once again mental illnesses themselves are typically not terminal, although in some severe mental illnesses patients can be at high risk of behaviour that leads to death. The distinction is important since mental illness on its own does not typically lead to a person's death, but the impact of cognitive distortions and impairments in insight and judgement caused by symptoms of mental illness may lead to behaviour that results in death. For example, suicide in cases of clinical depression or other mental illness, or starvation in the context of a severe eating disorder, are behaviours influenced by the patient's mental illness that may result in the patient's death. This risk of death from these behaviours is reduced or eliminated if the symptoms of the underlying mental illness are effectively treated.

Finally, a key point needs to be made regarding the term "Treatment Resistant Depression" (TRD). In media reporting on the PAD issue, TRD has sometimes erroneously been assumed to refer to conditions that are irremediable or untreatable. In reality TRD simply refers to situations where a person's clinical depression has not responded effectively to two different antidepressant trials. TRD does not mean the patient's depression is untreatable, in fact the concept of TRD is used clinically to help guide next steps in management, not to imply there are no more options. Lack of clarity about this could lead to significant confusion about clinical depression and issues of PAD.

## Recommendations

4. In the context of mental illness, irremediable should not be considered to mean incurable as this would set the threshold for identifying a condition as irremediable too low (i.e. all chronic mental illness could then be considered irremediable).
5. The concept of irremediable should not be considered as simply identifying the diagnostic condition, but must be considered in the entire context of the expected illness course including considering the potential impact of possible treatment options on suffering and symptoms.
6. Treatment Resistant Depression should not be confused with the term irremediable, and this should be explicitly articulated in any PAD framework.

## **Intolerable and Enduring Suffering**

The subjective assessment of “intolerable” and predictive assessment of “enduring” can both be affected by mental illness.

Mental illnesses can affect cognition and impair insight and judgement. Symptoms of cognitive distortions common with clinical depression include negative expectations of the future, loss of hope and loss of expectation for improvement (even when there may be hope for positive improvement), loss of cognitive flexibility, loss of future oriented thought, and selective ruminations focused on the negative and minimizing or ignoring the positive. There are commonly distortions of a person’s own sense of identity and role in the world, including feelings of excessive guilt and worthlessness, or feeling a burden to others or the world. Additionally, when clinically depressed, people have lower emotional resilience and are less capable of dealing with life stressors.

In mental illnesses with psychotic symptoms, which include schizophrenia but also other illnesses such as in severe clinical depression or bipolar disorder, reality testing is impaired and the person may suffer from frankly delusional beliefs. In anxiety disorders, there is a tendency to focus on negative expected outcomes.

Finally, in understanding and assessing the impact of suffering in the context of mental illness, psychosocial, cultural and environmental factors play a significant role. Helping relieve suffering in these situations cannot rely solely upon biomedical treatments but must include addressing these psychosocial factors. For example, stressors including unstable housing, financial instability, isolation, and others increase suffering of patients with clinical depression, it would be inappropriate if the societal response in such situations was to facilitate these people dying by deeming that person’s suffering enduring and intolerable.

All these issues lead to challenges in identifying when the definitions of “intolerable” and “enduring” are met in the context of mental illness. With active symptoms as above, the symptoms themselves impact the person’s evaluative processes in ways that increase the likelihood they believe their suffering is intolerable and/or enduring. If not for the cognitive distortions described above, that same person, faced with the exact same situation and degree of suffering, is less likely to feel their situation is intolerable and/or enduring.

## **Capacity**

For health care decisions in medicine, the term “capacity” is typically used instead of the term “competent”. When a person has capacity to make a decision, they are deemed capable of making that decision. Capacity involves four broad components:

- The ability to make a choice.
- The ability to understand relevant information.
- The ability to appreciate the situation and the consequences of decisions.
- The ability to manipulate information rationally.

Even when patients with mental illness can express a choice and understand and recall information, their appreciation of the situation (present and future expectations) and ability to manipulate information rationally can be affected by the cognitive distortions cited above. It is this recursive nature of symptoms on the evaluative process, where the very symptoms of mental illness interfere with the person's evaluation of their mental illness and its impact, that poses challenges.

It is also important to recognize that capacity is not universal, it is specific to each decision being made. A person may have capacity to decide to take or not take a medication, for example, but lack capacity to make a rational decision about housing or finances. Similarly, a person may have capacity to accept or refuse a particular treatment, but lack capacity to make a rational decision about dying. Combined with the cognitive distortions described above, this may raise situations where a person is capable of refusing suggested treatments, because for example they are legitimately concerned about potential side-effects, but would not be deemed capable of deciding to pursue PAD.

Medical decision-making often weighs the balance of autonomy, or the person's right to make a decision, and beneficence, or the medical team's belief of what is best for the patient. If autonomy is considered to be the person's right to make an independent decision without external control or influence, with mental illnesses the cognitive symptoms of the illness itself may challenge the patient's autonomy; the symptoms may lead to decision-making and behaviour that the patient would not follow if they were not subject to cognitive distortions of the illness.

These issues are particularly important to highlight given the serious and irreversible nature of the PAD decision. Thus with mental illnesses and PAD decisions, the principle of beneficence may need to play a more prominent role in the decision-making process. This is not to challenge the patient's autonomy, rather it is necessary since the patient's autonomy may be undermined by symptoms of the mental illness itself. Further, even when it may appear that a person with mental illness is capable of making a PAD decision, it may be exceedingly difficult if not impossible to rule out if their decision to pursue PAD is influenced by illness-based cognitive distortions.

It is also worth pointing out that in its ruling the Supreme Court cited the trial judge's ruling in Ms. Taylor's case that "Ms. Taylor's right to life was engaged insofar as the prohibition (on PAD) might force her to take her life earlier than she otherwise would if she had access to PAD" ("the prohibition on PAD had the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable"). While this may be true of progressive or degenerative medical conditions that lead to increasing physical incapacity, this is rarely if ever the case with mental illnesses.

### Recommendation

7. When mental illness is present, especially if the PAD decision is being based on intolerable and enduring suffering from a mental illness, if there is lack of clarity about the degree of impact of cognitive distortions on the patient's decision-making process, a patient may not be able to be deemed capable for making a PAD decision. In such cases, the principle of beneficence may need to play a greater role.

### **Issue 3: Risks to individuals and society with PAD**

#### Points for Consideration

In the context of mental illness many of the risks have been discussed above. Specifically, mental illness symptoms pose a risk to a patient's capacity to make a PAD decision by virtue of the symptom's impact on the patient's decision-making process.

The impact of mental illness on cognitive processes also poses a potential risk to the certainty of clinical capacity assessments. This is not to suggest that someone with mental illness cannot be capable to make a PAD decision, rather it raises the question of whether clinically we are able to properly assess their capacity (i.e., do we know whether, absent the effects of the mental illness on their cognitive patterns, insight and judgement, they would still want to die?).

Additionally, those with serious mental illness are already amongst the most vulnerable group in society. Particularly vulnerable populations include those with intellectual and developmental disabilities, the elderly with dementia, and children and adolescents with various psychiatric conditions. Caregiver burden levels can be high in many of these situations, and there may be financial implications related to the patient's caregiving needs or estate inheritance, all of which can influence decision-making. In situations where they lack the capacity to make decisions for themselves, it is essential that any PAD framework contain robust safeguards and oversight of any substitute decision-making process to ensure appropriate decisions are made in the best interest of the patient.

The safeguards outlined below would help mitigate these risks.

### **Issue 4: Safeguards to address risks and procedures for assessing requests for assistance in dying, and the protection of physicians' freedom of conscience**

#### Points for Consideration

In cases where mental illness is present, given the impact of illness symptoms on the decision-making process and the serious and irreversible nature of the PAD process, it is essential there be multiple safeguards over a period of time.

Spreading the evaluative process into different components, each done by those expert in that particular domain, would serve as one safeguard. Determining whether an illness is irremediable and the patient likely to suffer from intolerable and enduring suffering is an assessment of the impact and projected course of the patient's illness; determining their capacity to make a PAD decision is a related but separate issue. Rather than conflating these issues in one assessment, these assessments could be carried out by different experts.

Spreading the evaluative process over time provides another safeguard, as it reduces the risk the patient makes a PAD decision purely in the context of a transient period of increased suffering or weakness. For mental illnesses, where the symptoms of illness may impact cognition, insight and judgement, this is particularly important. In this regard, when mental illness is present, it is important any PAD framework account for timeframes often required prior to response to treatment is seen. In cases of clinical depression, four to six weeks often need to pass before success or failure of treatment can be assessed.

As discussed above, capacity is specific to each decision, and a person may have capacity to accept or refuse a treatment but lack capacity to make a PAD decision. In such cases it is possible that a patient continues to suffer from higher levels of symptoms and distress than they otherwise might if they had certain treatments, and that this results in ongoing cognitive distortions and impairment of insight and judgement in the context of PAD decisions. For example,



electroconvulsive therapy (ECT) remains a highly effective treatment for many cases of clinical depression. However, there may also be side-effects of memory loss during the time of treatment, or other reasons patients may not wish to have this treatment. Similarly, other treatments that remain in the research stage, or may be considered invasive in that they involve surgery, have been shown to offer potential promise to some patients with very severe symptoms. The Supreme Court indicated that “irremediable....does not require the patient to undertake treatments that are not acceptable to the individual.” This raises the challenging question of what treatments a patient with mental illness would need to have prior to concluding their mental illness is irremediable and leading to intolerable and enduring suffering, especially if the symptoms of their mental illness are impacting their cognition, insight and judgement, and/or decision-making process regarding acceptability of other treatments.

Finally, provincial mental health legislation includes mechanisms for review boards or similar to adjudicate on cases where patient capacity is at issue. Similarly PAD panels could be operationalized so the final decision does not rest with individuals directly involved in administering clinical care to the patient.

### Recommendations

8. PAD decisions should not be based on a single assessment, but rather on multiple assessments by different experts. The appropriate expert for each piece of the PAD decision (i.e., illness impact and course versus patient capacity to decide on PAD) should be used. These expert opinions could inform a PAD panel.
9. In cases where mental illness is present and PAD being sought, especially if the mental illness is forming the basis of the PAD request, a minimum of six weeks needs to elapse between sequential assessments, and reasonable treatment options should be pursued during this time.
10. The CPA supports psychiatrists ‘opting out’ of the PAD process on grounds of freedom of conscience. In such circumstances, the patient should have access to another psychiatrist being involved in the PAD process if required.

Thank you again for seeking the input of the CPA on this important issue, we look forward to further discussions with you.

Respectfully submitted,

Sonu Gaiind, MD, FRCPC, FCPA  
President

Canadian Society of Palliative Care Physicians

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Canadian Society of Palliative Care Physicians (CSPCP) represents nearly 500 palliative care physicians. We have a long experience with patient requests to hasten their deaths -- prior to and following MAiD legislation.

Three major areas of concern exist in considering expanded eligibility requirements for MAiD:

- 1- viable alternatives to MAiD are lacking
- 2- infrastructure to measure, monitor and report data on MAiD is inconsistent and mechanisms to support complex, informed assessments are lacking
- 3- the current advance care planning situation has large limitations that will not support safe decision making in MAiD

The lack of consistent access to high quality palliative care [1], including pediatric palliative care [2], mental health care [3] and dementia support for patients and care givers [4] is well documented. Without these alternatives, a choice for MAiD by advance request, by mature minors and by persons with mental health illness is not a true choice -- hence potentially not voluntary.

The current infrastructure for MAiD is also inconsistent both regionally and provincially. Members of the public cannot easily access high quality information about the process and about referrals -- and equally importantly, alternatives [5]. Many current MAiD providers and assessors are over-burdened [6]. Adding increasingly complex requests would be a problem, particularly where capacity assessments are essential. Additionally, we have not created a system to monitor the current MAiD situation -- how many requests are received, what is the outcome, what forms of intolerable suffering are behind a request and could this suffering exist because access to alternatives is absent.

Current practice regarding advance requests is variable across Canada, across institutions and across providers and has significant limitations [7]. Best practice in advance care planning recommends clearly articulating values and then linking values to treatment options [8]. A person who values reducing suffering at the end of life may request MAiD in an advance request simply because they are not aware of other options, including palliative care. We know that patients often have inadequate knowledge of all end of life treatments including CPR and palliative care [9]. This makes "informed consent" for a procedure such as MAiD scrupulous for competent people and a magnitude more challenging in advance directives for MAiD. Anticipating how as individuals we will adjust to illness or disability is not easy. Many healthy people state that they would not want to live in a state of dependence, yet people may change their perception about this once they accommodate a new normal [10]. In addition, patients with disabilities consistently rank their quality of life as higher than care providers do [11]. To be able to accurately predict when in the future one's quality of life may be intolerable is challenging-- even for patients.

It is hard to imagine how an advance request could accommodate people who change their minds. In the Netherlands, up to 50% of patients when newly diagnosed with ALS consider physician administered hastened death (euthanasia equivalent to MAiD), yet only 20 % of ALS patients die of euthanasia [12]. In the US states where patient-administered hastened death (physician assisted suicide) is legal, 40% of people who receive a prescription to end their lives do not use the medication [13]. Only about 20% of patients who make initial inquiries about



accessing “Death with Dignity” or physician assisted suicide actually end their lives with medications [14]. Patients may make the request as a “hypothetical exit plan” and not follow through. Some patients wish to hasten their deaths as an expression of emotional distress that may respond to interventions to reduce suffering [15]. Even in the last two weeks of life in a palliative care unit, patients may change their minds [16].

We ask a lot from substitute decision makers. Substitute decision makers may struggle to respect a patient’s expressed wishes [17] and experience negative consequences when involved in decisions that may influence or shorten the patient’s life [18]. Communication and documentation with health care professionals is poor [19]. Currently we do not have a proper process to ensure that substitute decision makers understand, support and respect an advanced request for a specific treatment. Furthermore, we have no objective means of confirming whether an incapable person’s suffering is “intolerable” to the point that he or she would want MAiD. This discernment may also be compromised if the substitute decision maker is depleted financially, emotionally and/or physically (i.e. experiencing caregiver burnout).

Consider three distinct situations that may arise -- with quite different expectations and challenges of substitute decision makers:

1. A person has requested MAiD, completed the two assessments, agreed upon a date and then loses capacity, so is unable to consent on the agreed date. This may be a situation where a substitute decision maker has a high degree of confidence about the patient’s wishes.
2. A person is diagnosed with a grievous and irremediable illness, disease or disability. The individual is currently not in a state of suffering, related to the grievous and irremediable condition. The individual includes a request for medical assistance in dying in an advance or personal directive. In this situation the substitute decision maker may not achieve a high level of confidence about when or if the patient experiences intolerable suffering.
3. A person requests medical assistance in dying, within an advance or personal directive, in advance of a diagnosis of a grievous and irremediable illness, disease or disability. This is a very challenging situation with very little guidance for a substitute decision maker and they may not have enough information to be confident they can make an informed choice.

Even in a situation where the substitute decision maker is confident in how to represent the patient’s well informed wishes, there is a lack of concordance between a patient’s previously stated wishes and decisions that are made on their behalf when ill and not competent to decide [20]. Importantly, we do not have processes in place to monitor whether patient wishes are being respected. If a substitute decision maker requests MAiD for a loved one, how do we know that MAiD is in fact what they requested?

To summarize, the CSPCP has three major areas of concern as expanded eligibility requirements for MAiD are being considered:

- 1- Viable alternatives to MAiD are lacking and are required for voluntary choice. In addition, public and professional education around death and dying is required so that advance requests are well informed.
- 2- Infrastructure to support MAiD is inconsistent and unsustainable. Health care providers must be well supported to take on additional, more complex work of completing well informed assessments if eligibility requirements are expanded.
- 3- The current advance care planning situation will not support safe decision making in MAiD by advance request. We need to develop a robust advance care planning system that supports excellent communication, support to substitute decision makers and acknowledges the uncertainty in anticipating future suffering.

Crafting adequate safeguards and ensuring they are in place will be necessary as consideration is given to expanding eligibility. This may not be possible within a five year time frame.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

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## CARP

### **1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

CARP welcomes this opportunity to provide the CCA Expert Panel on Medical Assistance in Dying in Canada with our views on advance requests for medical assistance in dying.

#### About CARP

CARP is a national not-for-profit, non-partisan association with 300,000 members across Canada. Most of our members are retired and enjoy above average education and income.

#### CARP's position

CARP believes the criteria under which patients can request and receive assistance in dying from a physician should be expanded. A 2016 poll of 6,109 CARP members indicates eight-out-of-ten members support advance consent for medical assistance in dying for an individual diagnosed with a grievous and irremediable medical condition, such as dementia.

#### Problems with Current Legislation

The current assisted dying legislation, while a huge improvement over the previous law, does not allow individuals to ensure their wishes will be followed should they lose the ability to make competent decisions. It fails to provide Canadians with acceptable options. When individuals are competent to make decisions, they are not near enough to death. When they are near enough to death, they may no longer be competent.

#### Need for Advance Requests

According to a 2010 study commissioned by the Alzheimer's Society of Canada (The Rising Tide), "Canada is facing a dementia epidemic and needs to take action now. Approximately 500,000 Canadians have Alzheimer's disease or related dementia today. It is the most significant cause of disability among Canadians (65+) ..."

The study also forecasts that dementia worldwide will increase two-fold over the next twenty years. Where today 35 million people in the world have dementia, by 2050 that number is expected to increase to 115 million. In Canada, over a million people will likely suffer from dementia by 2050, so the concern among CARP members is very real.

Granting people the right to make an advance request for an assisted death is a critical part of allowing individuals to make their own healthcare decisions. It would provide peace of mind to those who fear a prolonged life with dementia more than death.

At the moment many older Canadians feel no security in this regard. Instances like the Margot Bentley case (as reported in the Vancouver Sun, "the former nurse signed a living will several years before she got Alzheimer's disease, requesting euthanasia in the event she developed an incurable disease, but her wishes have never been honoured") have made many CARP members aware of the limitations of our current laws.

Patients' wishes outlined in advance care directives must be obeyed under the law. Individuals can stipulate a range of circumstances under which they refuse treatment. Refusing to accept an advance request for medical aid in dying (under specific circumstances) is inconsistent with the essence of patient-centred healthcare: that treatment is the patient's decision. It only makes

sense to allow Canadians to make advance requests for medical aid in dying as well, in circumstances where they will no longer be able to make their wishes known.

CARP members have consistently supported medical assistance in dying. The clarification sought by CCA's expert panel is important to CARP members who, in making advance directives for their medical care, seek certainty that their personal health choices will be upheld later in their lives, should they no longer be able to make their own personal healthcare decisions, such as in cases of dementia.

We are pleased CCA is gathering information on this issue and hope that the findings will result in changes to the Canadian medical assistance in dying legislation to ensure Canadians' right to make their own healthcare decisions. CARP would be pleased to answer any questions related to this submission, and to provide any further input that might be of use to the expert panel.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

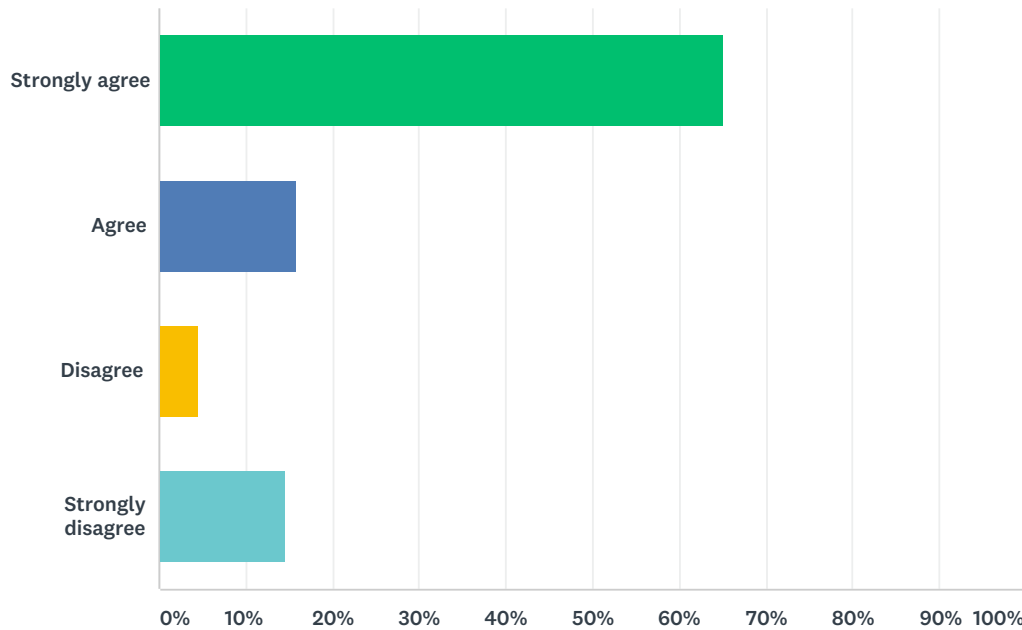
*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see the 2016 CARP MAID Survey Results, attached, particularly the responses to Question 11, in which CARP members were asked whether they agree or disagree (on a spectrum) that an individual who has been diagnosed with a grievous and irremediable condition may make an advance request for medical assistance in dying.

Also attached is the 2010 study commissioned by the Alzheimer's Society of Canada, entitled *Rising Tide: The Impact of Dementia on Canadian Society*, referenced in this submission which forecasts a significant increase in the number of people suffering from dementia in the future.

**Q1 The special joint committee recommended that "individuals with a grievous and irremediable medical condition that causes enduring suffering be able to have assistance to die".Do you agree with this recommendation?**

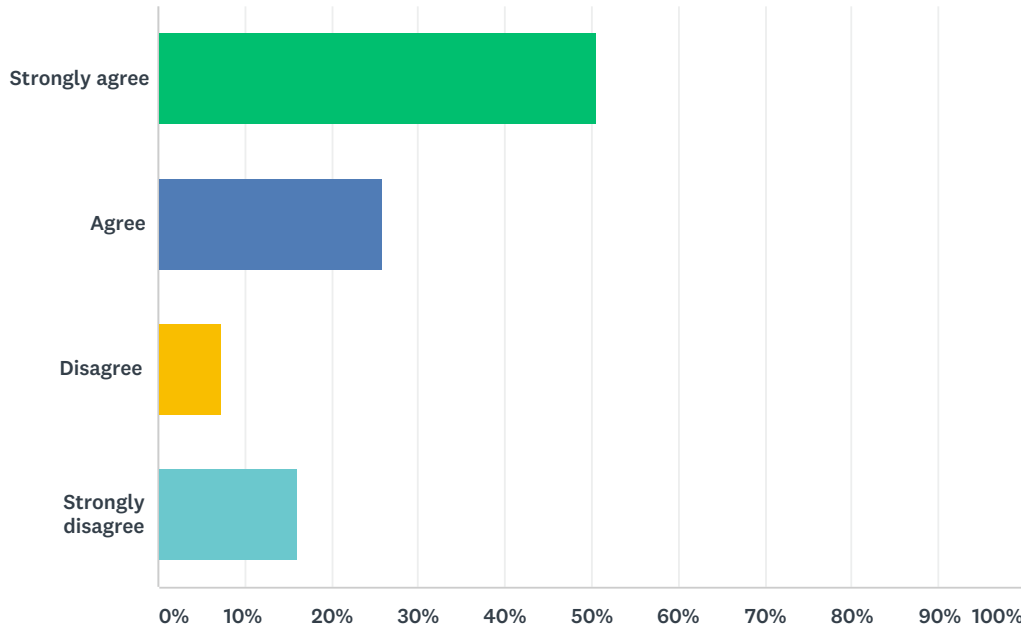
Answered: 6,184 Skipped: 59



ANSWER CHOICES	RESPONSES	
Strongly agree	65.01%	4,020
Agree	15.82%	978
Disagree	4.56%	282
Strongly disagree	14.62%	904
TOTAL		6,184

**Q2 Do you agree or disagree with the committee's recommendation that "physicians, nurse practitioners and registered nurses working under the direction of a physician all be allowed to provide medical assistance to die"?**

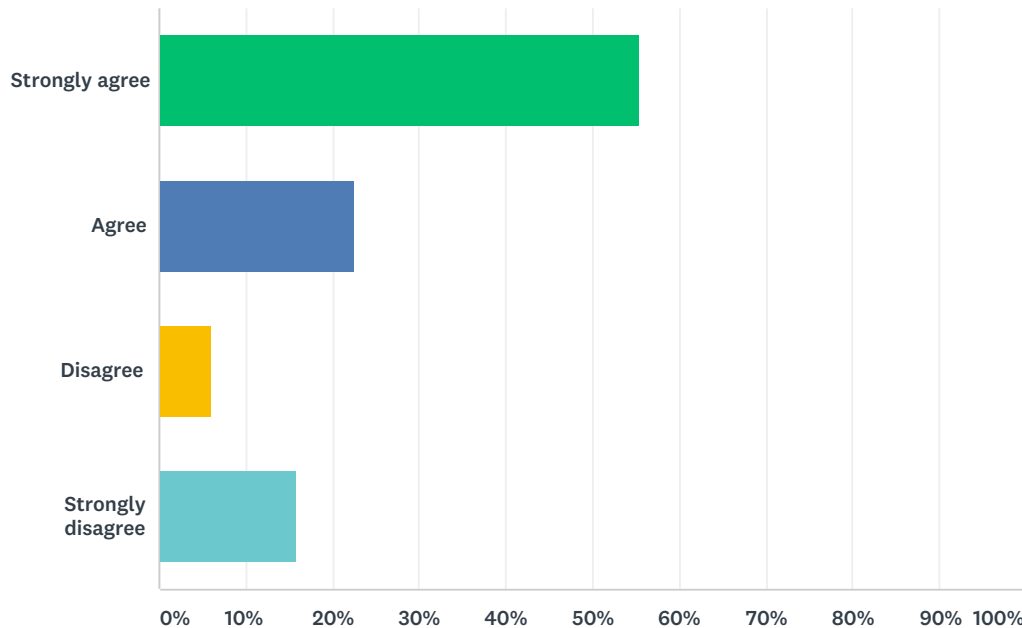
Answered: 6,182 Skipped: 61



ANSWER CHOICES	RESPONSES	
Strongly agree	50.68%	3,133
Agree	25.95%	1,604
Disagree	7.30%	451
Strongly disagree	16.08%	994
TOTAL		6,182

**Q3 Do you agree or disagree with the committee's recommendation that medical assistance to die be provided in all publicly funded healthcare institutions. (Publicly funded institutions would include hospitals, hospices and long-term care homes.)**

Answered: 6,187 Skipped: 56

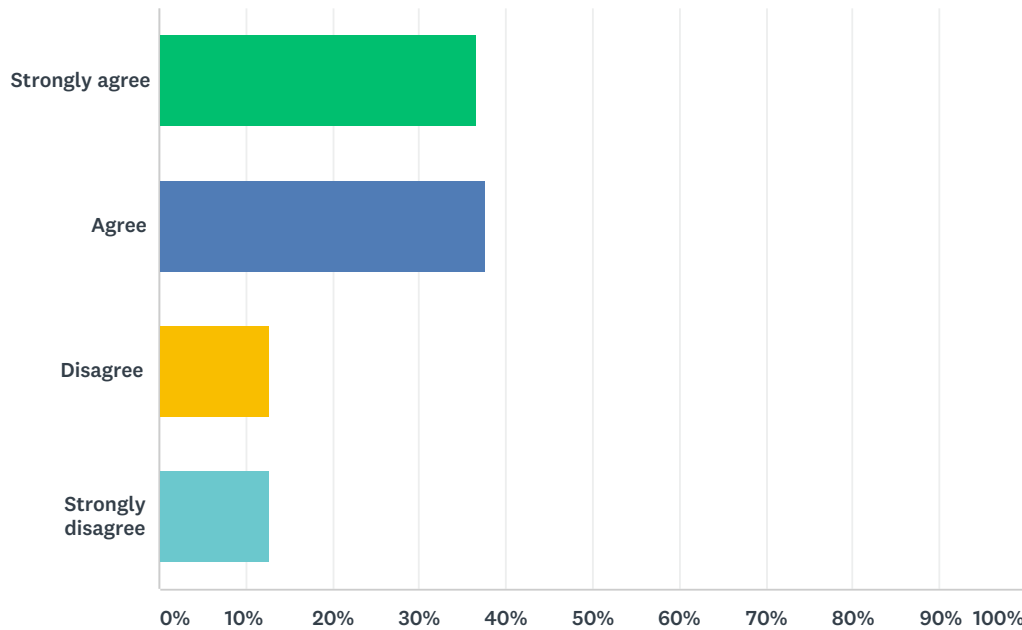


ANSWER CHOICES	RESPONSES	
Strongly agree	55.54%	3,436
Agree	22.50%	1,392
Disagree	6.01%	372
Strongly disagree	15.95%	987
TOTAL		6,187



# Q4 Do you agree or disagree with the committee's recommendation that a request for medical assistance in dying can only be carried out if two independent physicians have determined that the patient meets all the eligibility criteria?

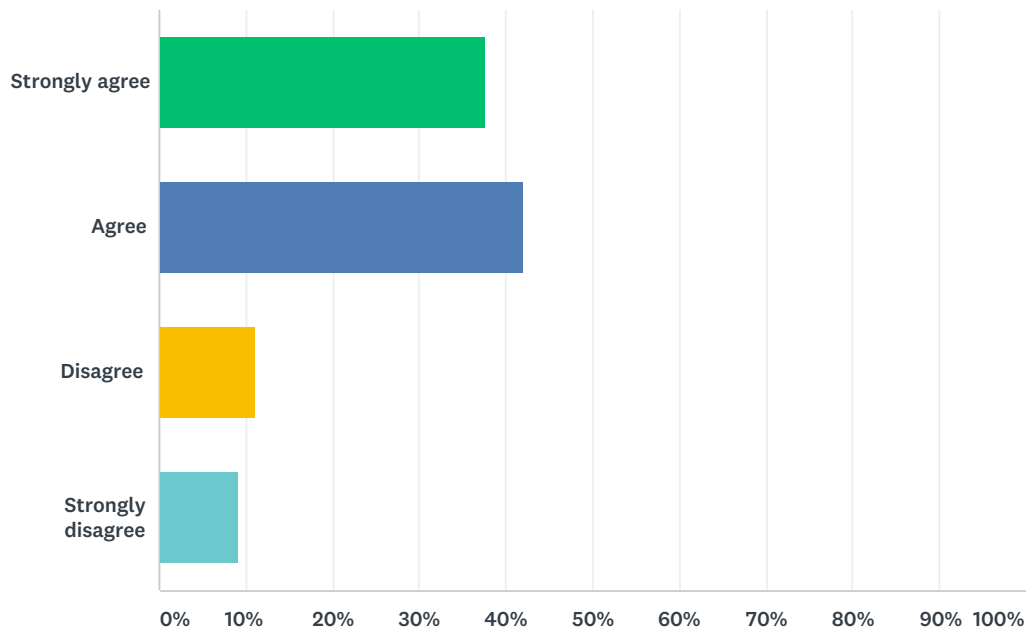
Answered: 6,071 Skipped: 172



ANSWER CHOICES	RESPONSES	
Strongly agree	36.63%	2,224
Agree	37.74%	2,291
Disagree	12.78%	776
Strongly disagree	12.85%	780
TOTAL		6,071

## Q5 Do you agree or disagree with the committee's recommendation that where possible, the request should be made in writing and witnessed by two people who have no conflict of interest?

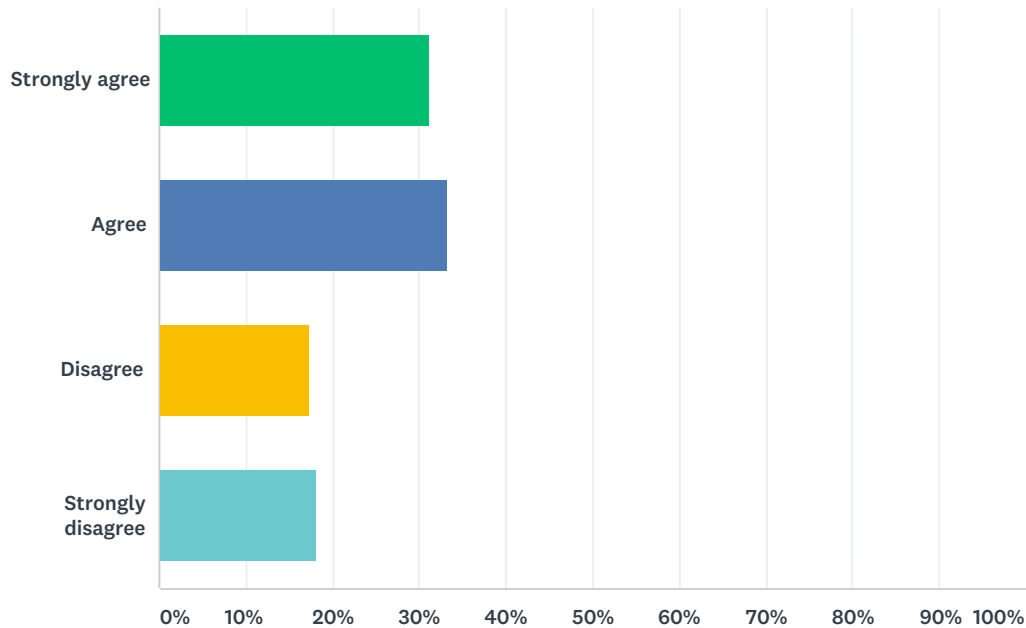
Answered: 6,065 Skipped: 178



ANSWER CHOICES	RESPONSES	
Strongly agree	37.64%	2,283
Agree	42.11%	2,554
Disagree	11.11%	674
Strongly disagree	9.13%	554
TOTAL		6,065

## Q6 Do you Agree or Disagree with the committee's recommendation that medical assistance to die should not include a prior review and approval process?

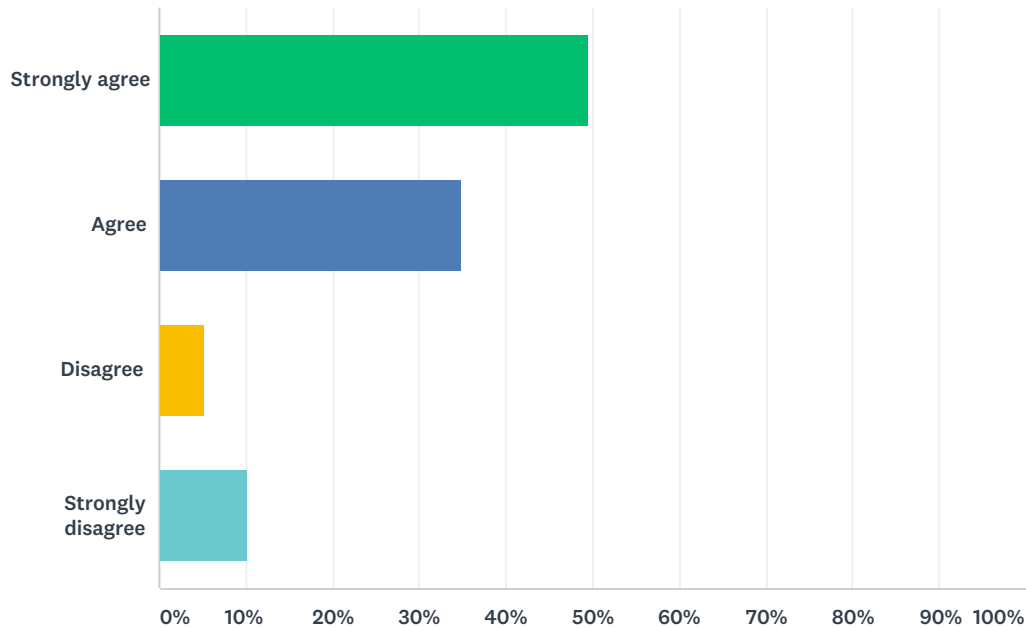
Answered: 5,996 Skipped: 247



ANSWER CHOICES	RESPONSES	
Strongly agree	31.10%	1,865
Agree	33.31%	1,997
Disagree	17.31%	1,038
Strongly disagree	18.28%	1,096
TOTAL		5,996

# Q7 Do you agree or disagree with the committee's recommendation that any period of reflection contained in legislation be flexible and take into account the nature of the patient's medical condition?

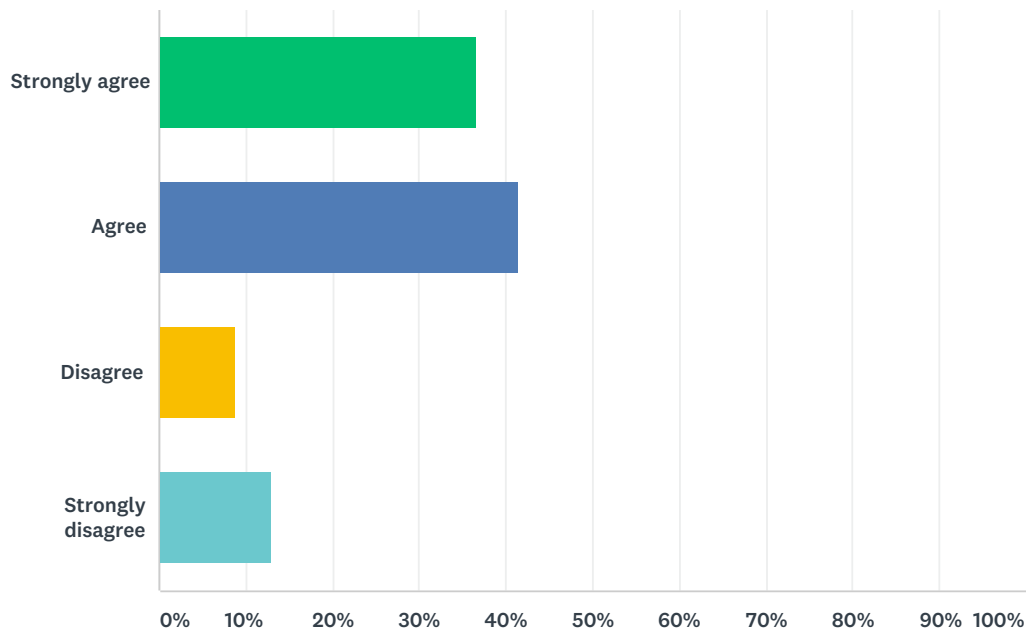
Answered: 6,047 Skipped: 196



ANSWER CHOICES	RESPONSES	
Strongly agree	49.63%	3,001
Agree	34.93%	2,112
Disagree	5.24%	317
Strongly disagree	10.20%	617
TOTAL		6,047

**Q8 Do you agree or disagree with the committee's recommendation that informed consent be determined by established medical practices? (Thus a psychiatric evaluation would be required only when one or both of the physicians assessing the patients eligibility believed a psychiatric assessment to be necessary).**

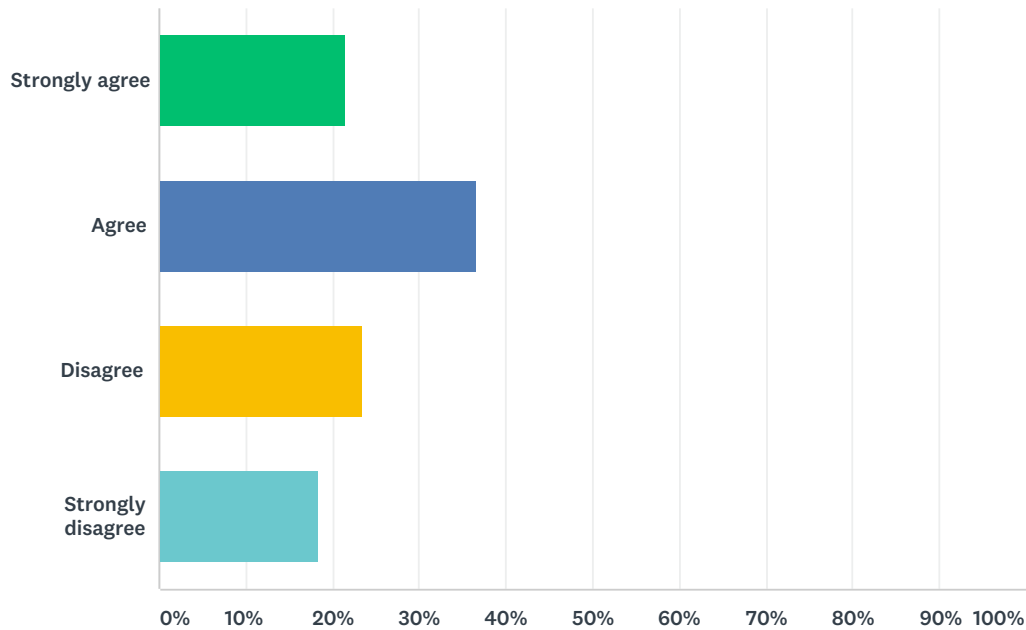
Answered: 6,033 Skipped: 210



ANSWER CHOICES	RESPONSES	
Strongly agree	36.71%	2,215
Agree	41.52%	2,505
Disagree	8.74%	527
Strongly disagree	13.03%	786
TOTAL		6,033

**Q9 Do you agree or disagree with the committee's recommendation that Individuals whose suffering comes from a psychological rather than a physical illness should be eligible to receive medical assistance to die provided all other criteria are met?**

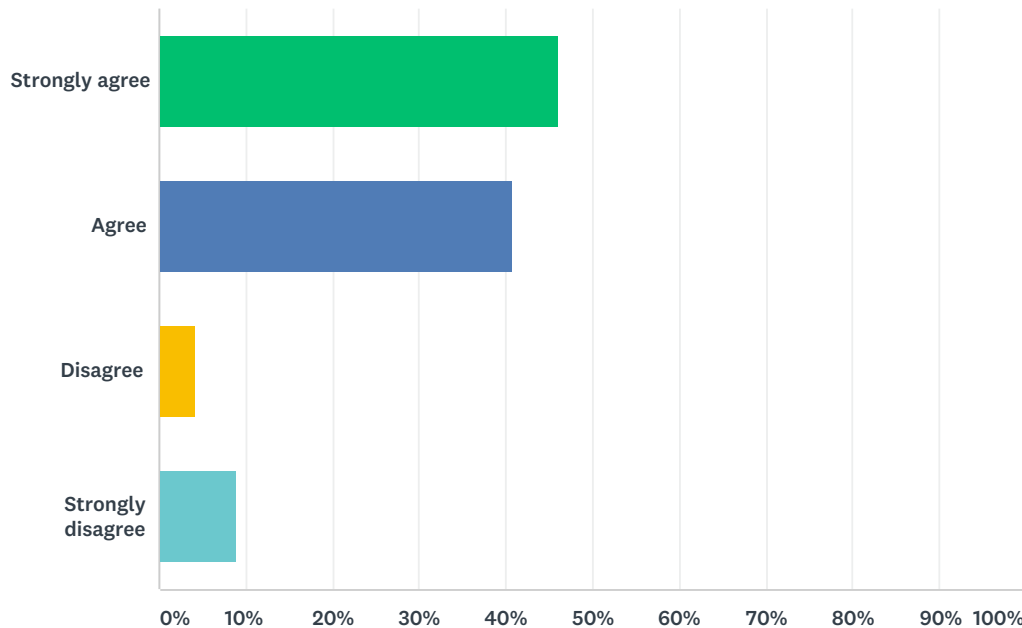
Answered: 6,036 Skipped: 207



ANSWER CHOICES	RESPONSES	
Strongly agree	21.60%	1,304
Agree	36.68%	2,214
Disagree	23.41%	1,413
Strongly disagree	18.31%	1,105
TOTAL		6,036

**Q10 Do you agree or disagree with the committee's recommendation that the process for providing medical assistance in dying must respect a health practitioner's freedom of conscience; while at the same time respecting the needs of a patient who seeks medical assistance in dying? (At a minimum, the committee recommended that the objecting practitioner must provide an effective referral for the patient).**

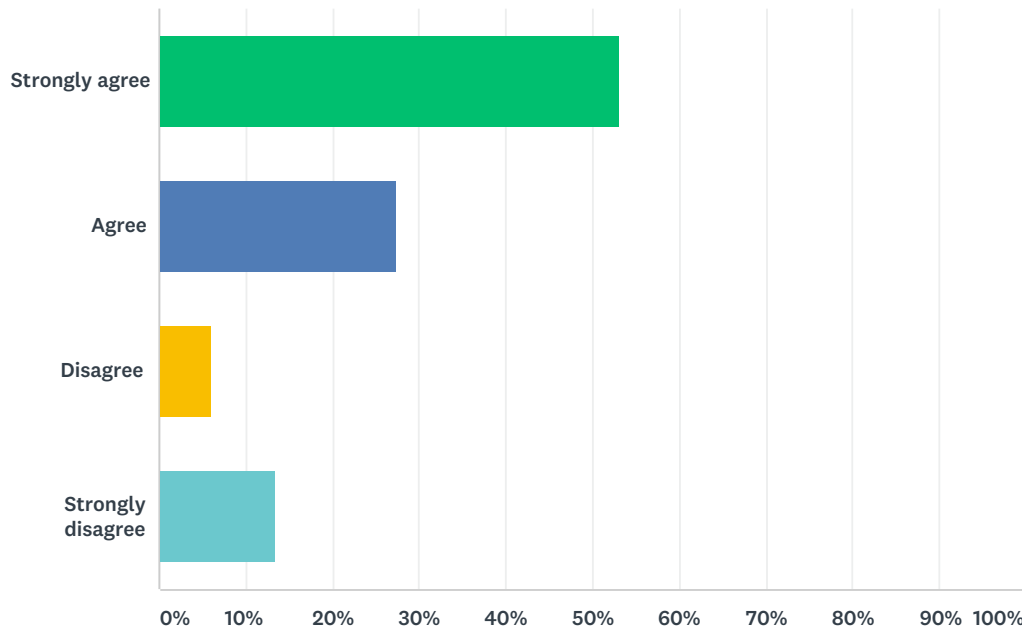
Answered: 6,054 Skipped: 189



ANSWER CHOICES	RESPONSES	
Strongly agree	46.02%	2,786
Agree	40.80%	2,470
Disagree	4.21%	255
Strongly disagree	8.97%	543
TOTAL		6,054

**Q11 Do you agree or disagree with the committee's recommendation that an individual who has been diagnosed with a grievous and irremediable medical condition may make an advance request for medical assistance in dying? (For example an individual who is diagnosed with dementia may request an assisted death for a future time when they are no longer competent).**

Answered: 6,109 Skipped: 134



ANSWER CHOICES	RESPONSES	
Strongly agree	53.18%	3,249
Agree	27.35%	1,671
Disagree	6.07%	371
Strongly disagree	13.39%	818
TOTAL		6,109

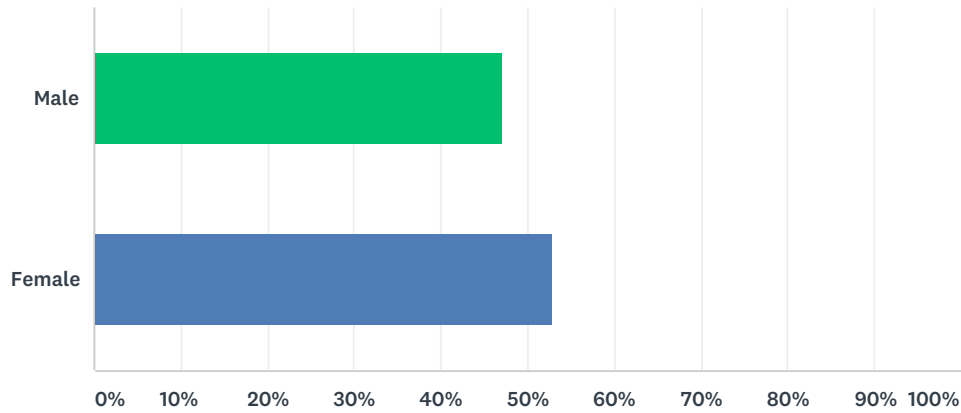


## Q12 Additional comments.

Answered: 1,740   Skipped: 4,503

## Q13 What is your gender?

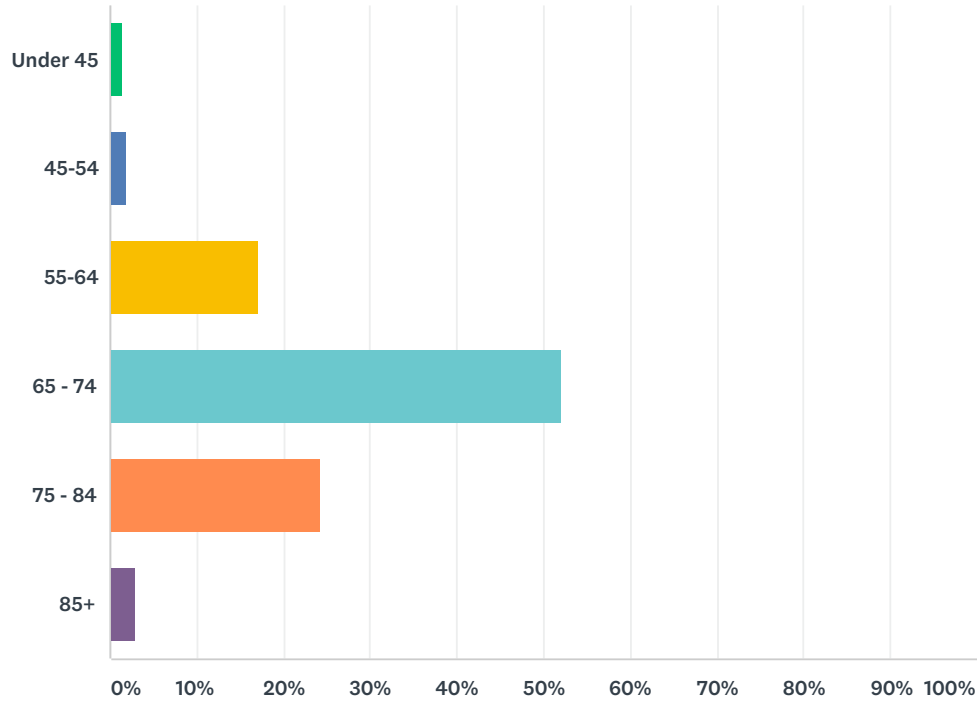
Answered: 6,137 Skipped: 106



ANSWER CHOICES		RESPONSES	
Male		47.14%	2,893
Female		52.86%	3,244
TOTAL			6,137

## Q14 What is your age range?

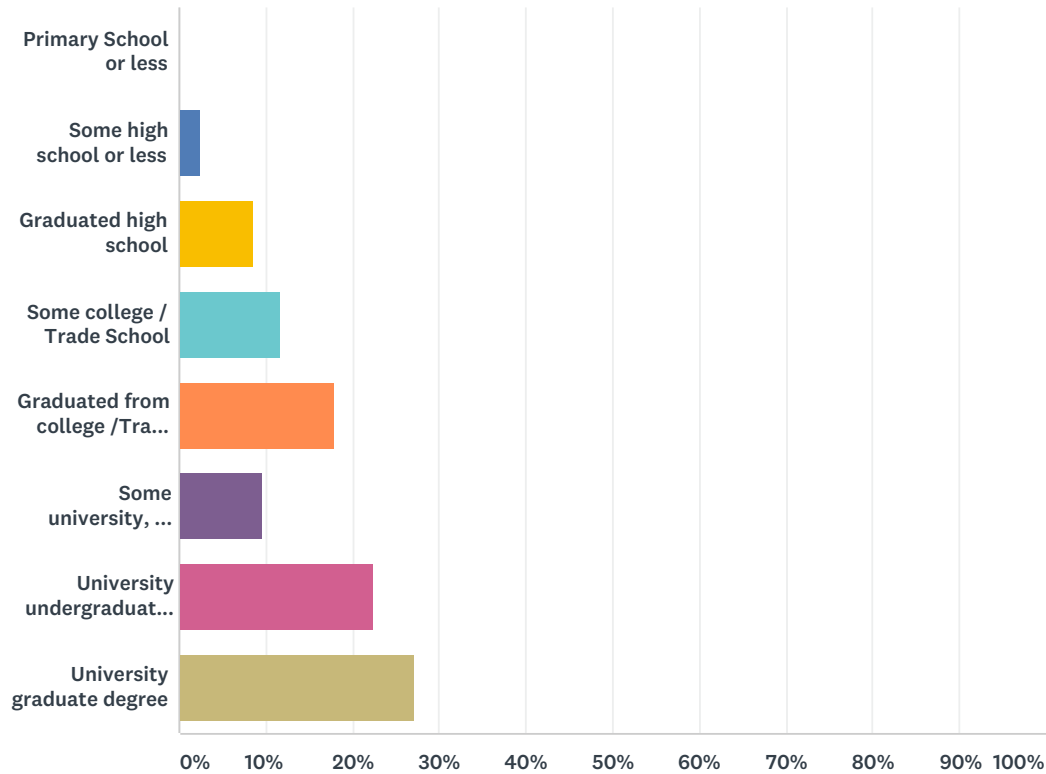
Answered: 6,174 Skipped: 69



ANSWER CHOICES	RESPONSES	
Under 45	1.54%	95
45-54	1.93%	119
55-64	17.15%	1,059
65 - 74	52.02%	3,212
75 - 84	24.36%	1,504
85+	3.00%	185
TOTAL		6,174

## Q15 What is your level of education?

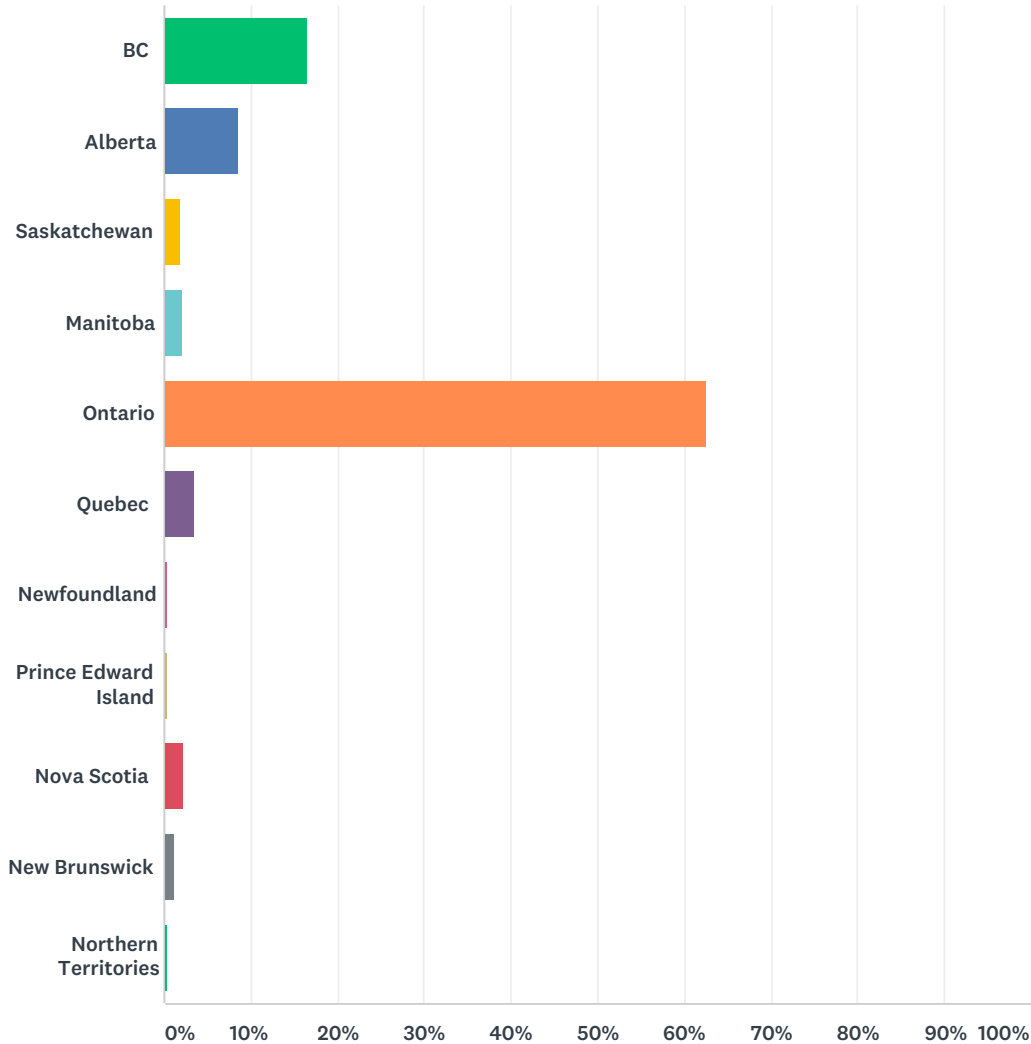
Answered: 6,169 Skipped: 74



ANSWER CHOICES	RESPONSES	
Primary School or less	0.00%	0
Some high school or less	2.48%	153
Graduated high school	8.64%	533
Some college / Trade School	11.67%	720
Graduated from college /Trade School	17.94%	1,107
Some university, but did not finish	9.58%	591
University undergraduate degree	22.43%	1,384
University graduate degree	27.25%	1,681
TOTAL		6,169

## Q16 Where do you live?

Answered: 6,165 Skipped: 78



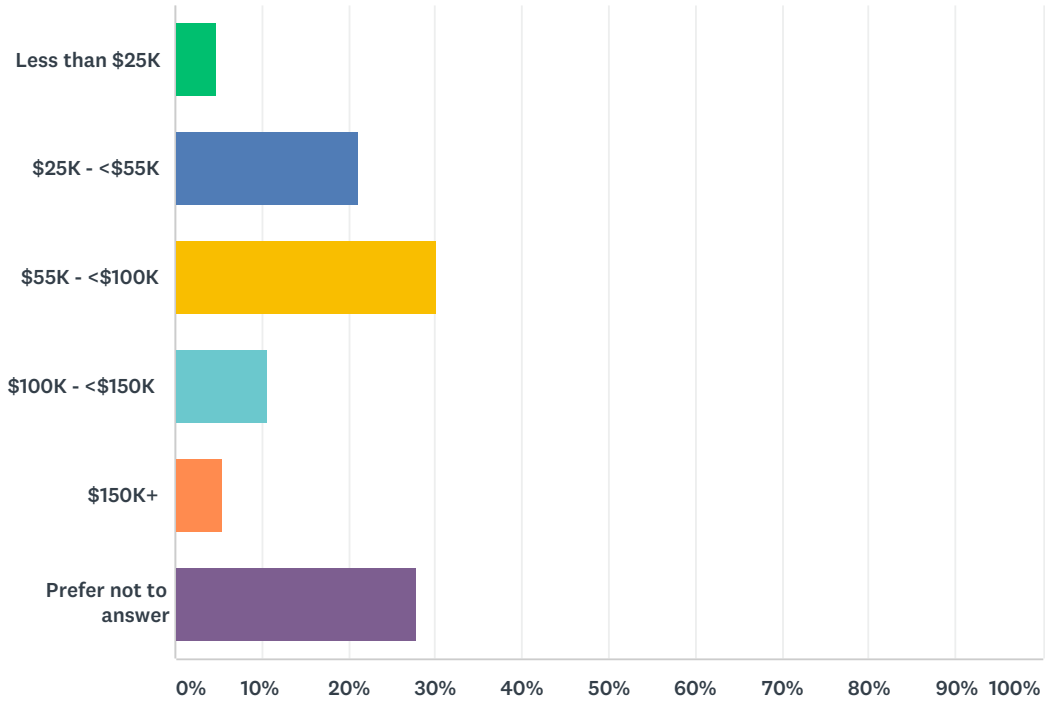
ANSWER CHOICES	RESPONSES	
BC	16.46%	1,015
Alberta	8.63%	532
Saskatchewan	1.95%	120
Manitoba	2.09%	129
Ontario	62.51%	3,854
Quebec	3.50%	216
Newfoundland	0.52%	32
Prince Edward Island	0.41%	25
Nova Scotia	2.35%	145
New Brunswick	1.23%	76

## 2016-03-01 CARP Assisted Dying Survey

Northern Territories	0.34%	21
TOTAL		6,165

## Q17 What is your annual income?

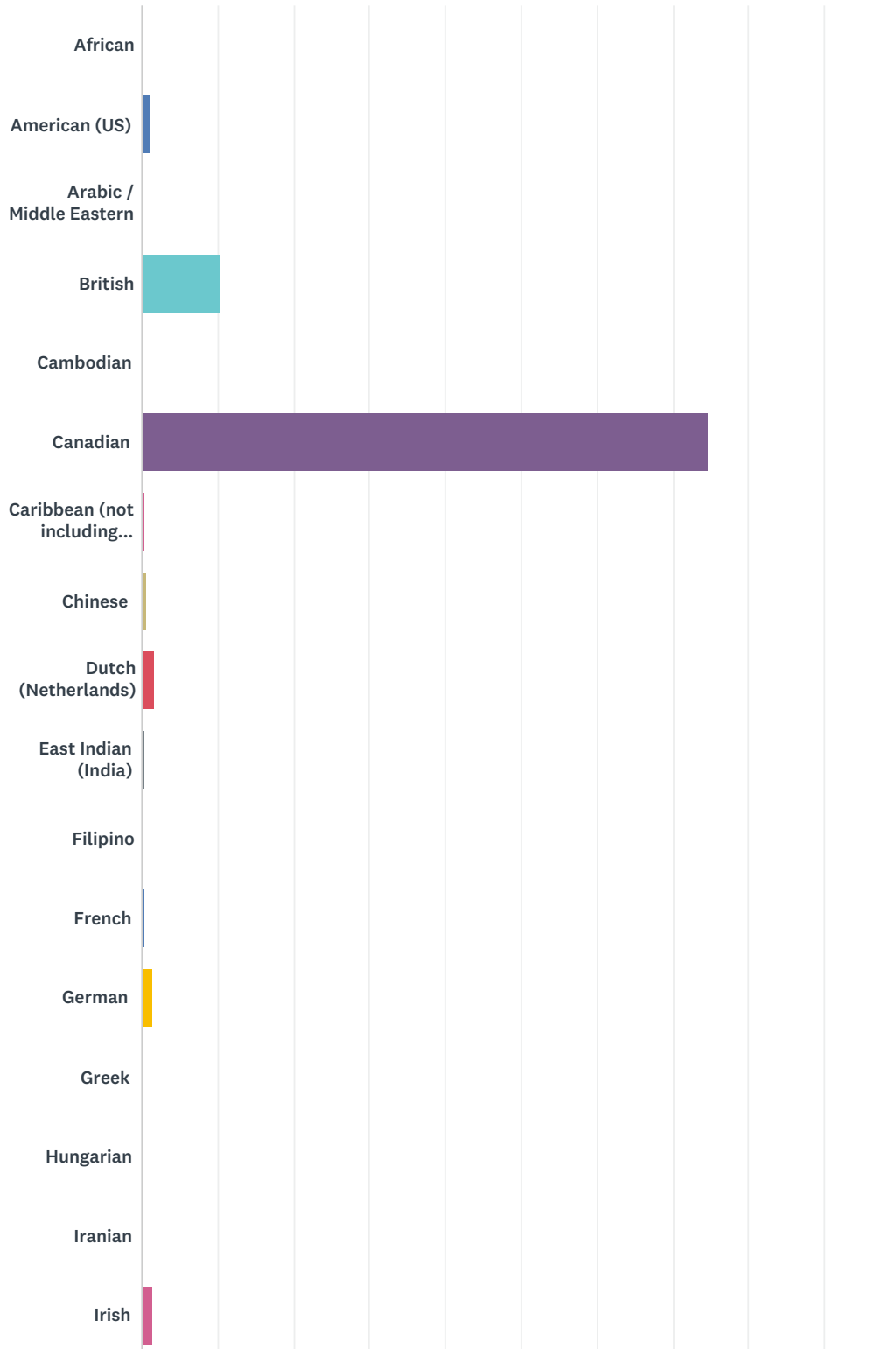
Answered: 6,116 Skipped: 127



ANSWER CHOICES	RESPONSES	
Less than \$25K	4.71%	288
\$25K - <\$55K	21.22%	1,298
\$55K - <\$100K	30.04%	1,837
\$100K - <\$150K	10.74%	657
\$150K+	5.44%	333
Prefer not to answer	27.84%	1,703
TOTAL		6,116

**Q18 Sometimes people identify themselves with a specific ethnicity or cultural background which is different from their citizenship or nationality. Thinking about your own identity in ethnic or cultural terms, please select which group you most identify yourself with?**

Answered: 5,210 Skipped: 1,033





## 2016-03-01 CARP Assisted Dying Survey



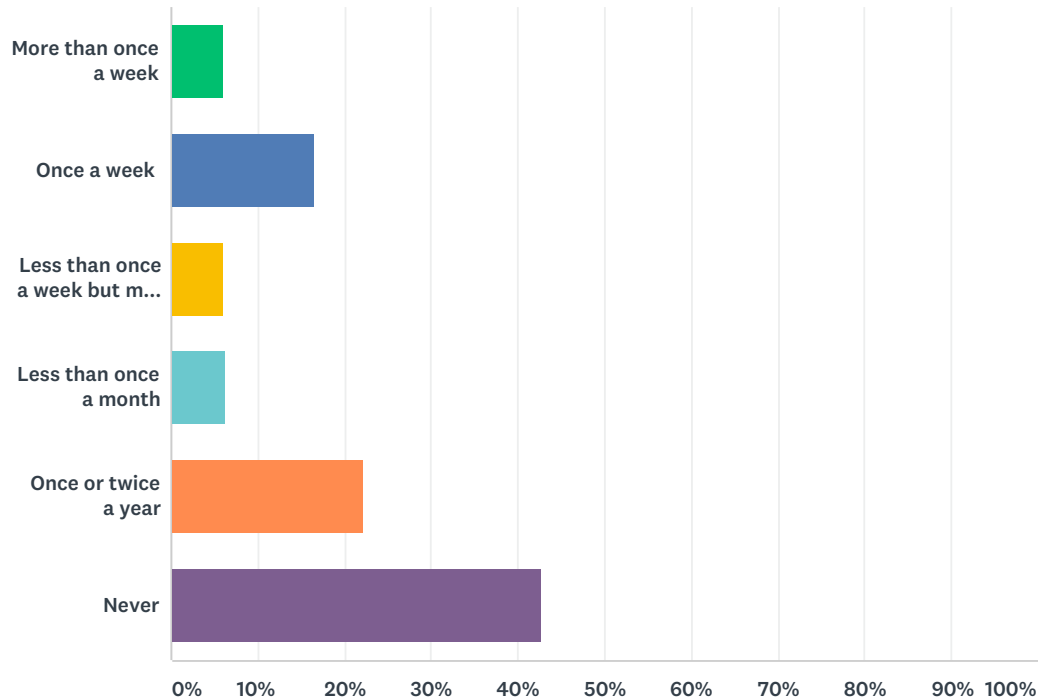
ANSWER CHOICES	RESPONSES	
African	0.15%	8
American (US)	1.00%	52

# 2016-03-01 CARP Assisted Dying Survey

Arabic / Middle Eastern	0.08%	4
British	10.50%	547
Cambodian	0.06%	3
Canadian	74.63%	3,888
Caribbean (not including Jamaican)	0.48%	25
Chinese	0.54%	28
Dutch (Netherlands)	1.61%	84
East Indian (India)	0.40%	21
Filipino	0.12%	6
French	0.50%	26
German	1.44%	75
Greek	0.04%	2
Hungarian	0.23%	12
Iranian	0.04%	2
Irish	1.52%	79
Italian	0.63%	33
Jamaican / Caribbean	0.15%	8
Japanese	0.02%	1
Korean	0.04%	2
Latin American (other than Mexican)	0.06%	3
Mexican	0.02%	1
Pakistani	0.04%	2
Polish	0.44%	23
Portuguese	0.13%	7
Russian	0.13%	7
Spanish	0.04%	2
Ukrainian	0.52%	27
Vietnamese	0.00%	0
Other Central / Eastern European (Romanian, Slovak, etc.)	0.44%	23
Other Western European (Belgium, Norway, etc.)	0.71%	37
Other South Asian / South East Asian (Bangladeshi, Indonesian, etc.)	0.06%	3
Other	1.07%	56
Prefer not to say	2.17%	113
TOTAL		5,210

## Q19 How often do you attend church, temple, mosque, synagogue services at your place of worship?

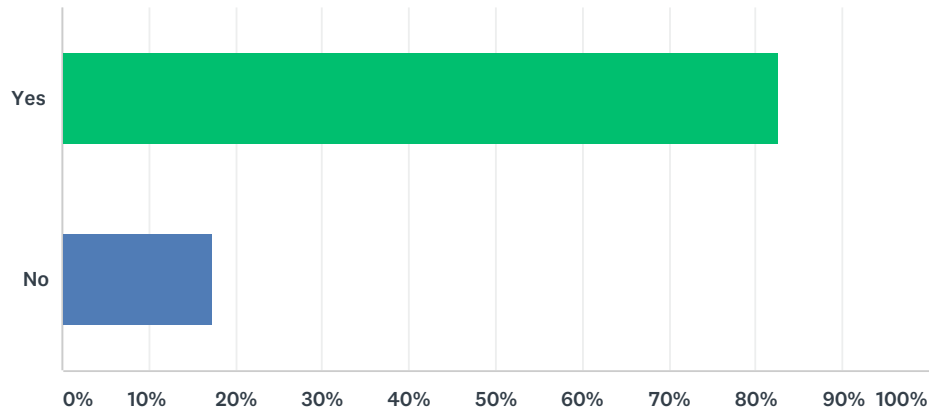
Answered: 6,059 Skipped: 184



ANSWER CHOICES	RESPONSES	
More than once a week	6.16%	373
Once a week	16.60%	1,006
Less than once a week but more than once a month	6.11%	370
Less than once a month	6.19%	375
Once or twice a year	22.23%	1,347
Never	42.71%	2,588
TOTAL		6,059

## Q20 Do you have children?

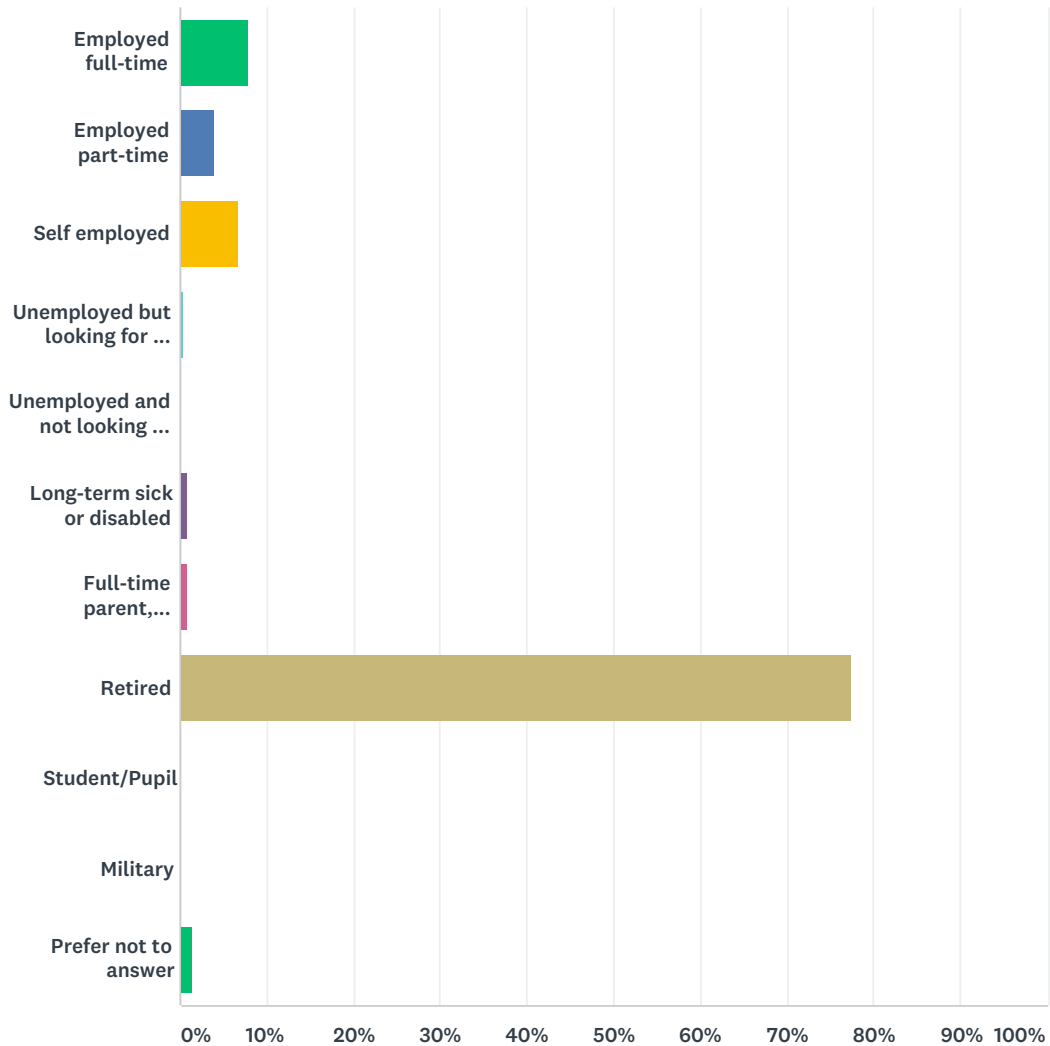
Answered: 6,123 Skipped: 120



ANSWER CHOICES	RESPONSES	
Yes	82.54%	5,054
No	17.46%	1,069
TOTAL		6,123

## Q21 What is your employment status?

Answered: 6,162 Skipped: 81



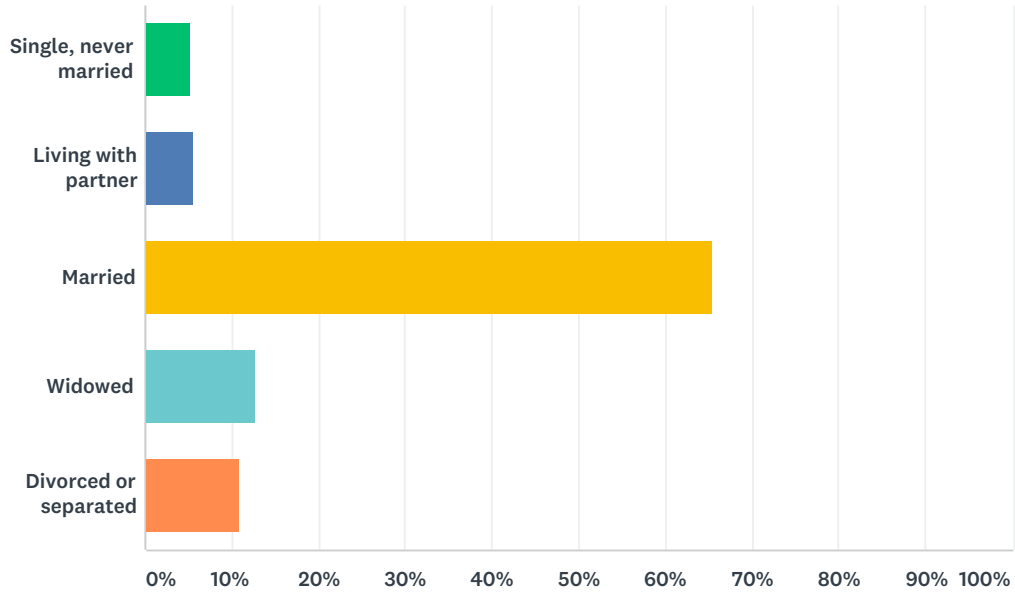
ANSWER CHOICES	RESPONSES	
Employed full-time	8.05%	496
Employed part-time	4.01%	247
Self employed	6.67%	411
Unemployed but looking for a job	0.42%	26
Unemployed and not looking for a job	0.18%	11
Long-term sick or disabled	0.84%	52
Full-time parent, homemaker or caregiver	0.76%	47
Retired	77.31%	4,764
Student/Pupil	0.18%	11
Military	0.18%	11

## 2016-03-01 CARP Assisted Dying Survey

Prefer not to answer	1.40%	86
TOTAL		6,162

## Q22 What is your marital status

Answered: 6,149 Skipped: 94



ANSWER CHOICES	RESPONSES	
Single, never married	5.27%	324
Living with partner	5.59%	344
Married	65.54%	4,030
Widowed	12.82%	788
Divorced or separated	10.78%	663
TOTAL		6,149

# Rising Tide: The Impact of Dementia on Canadian Society

A study commissioned by  
the Alzheimer Society

Now  
Within a Generation

500,000

1,100,000

Canadians with Alzheimer's disease or a related dementia

Now  
Within a Generation

\$15 billion

\$153 billion

Cost to Canadians for dementia care

Now  
Within a Generation

231 million hours

756 million hours

The time Canadians will be providing in informal care

Alzheimer Society



# Alzheimer *Society*

The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada. The Society is a principal funder of Alzheimer research and training, provides enhanced care and support to people with the disease, their families and their caregivers, and is a prominent voice within all levels of government.

*Rising Tide: The Impact of Dementia on Canadian Society*

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# Rising Tide:

## The Impact of Dementia on Canadian Society

### Table of Contents

Acknowledgements	5
Subject Matter Experts	5
<b>Canada's Dementia Epidemic – A Call To Action</b>	<b>8</b>
The Need for Current Information	8
Rising to the Challenge	9
A Brief Introduction To Dementia	10
What Is Dementia?	10
Alzheimer's Disease	10
Vascular Dementia	11
Related Dementias	11
Risk Factors For Dementia	11
Non-Modifiable Risk Factors	11
Modifiable Risk Factors	11
Risk Reduction	12
Care And Treatment	13
<b>Why Canada Must Act</b>	<b>15</b>
The Dementia Base Case – The Growth Of Dementia	16
Incidence: Number Of New Cases Of Dementia Per Year	16
Prevalence: Number Of People With Dementia	17
Health Care Utilization	19
A Shift Towards Home/Community-Based	19
Growth in Caregiving Hours	21
Economic Burden of Dementia	22
Total Economic Burden	22
Annual Total Economic Burden	22
Cumulative Economic Burden	23
Direct Health Costs	23
Opportunity Cost of Informal Caregivers	24
Indirect Costs	25

## Table of Contents (cont'd)

Dementia Base Case Conclusions	26
<b>What Can Be Done?</b>	<b>27</b>
Scenario Analysis	28
Intervention Simulations	28
Intervention 1: Prevention – Increase In Physical Activity	28
Intervention 2: Prevention – A Program To Delay Dementia Onset	30
Intervention 3: Support – Caregiver Development And Support Program	31
Intervention 4: Support – System Navigator/Case Management	33
Intervention Value Comparisons	35
Scenario Analysis Conclusions	36
A Valuable Tool for Policymakers	37
<b>What Has Been Done</b>	<b>38</b>
Policy Analysis	39
What Has Been Done In Other Countries?	39
A Survey of Dementia Priority Policies	40
The Current Situation In Canada	42
At the Federal Level	42
At the Provincial Level	42
General Agreement On Key Elements	45
Leading Concepts And Models	45
Integrated Models Of Care	46
SIPA – An Example of Integrative Care for the Elderly	46
Chronic Disease Prevention And Management	47
Dementia and the Chronic Care Model	47
<b>How We Can Make A Difference</b>	<b>48</b>
Improved Care At Every Stage Of The Dementia Care Continuum	49
Recommendations For Moving Forward	51
#1 Increase the Investment in Dementia Research	52
#2 Provide Support for Informal Caregivers	53
#3 Emphasize Prevention & Early Intervention	53
#4 Build an Integrated System Of Care	54
#5 Strengthen and Supplement The Dementia Workforce	55
<b>Conclusion</b>	<b>56</b>
Appendix A: Adapting Life At Risk® For Rising Tide	57
Appendix B: Sources	58
Appendix C: Key Life At Risk® Data And Assumptions	62
Appendix D: Dementia Continuum Map	64

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Unless otherwise noted, facts referred to in this document on dementia, its prevalence and the economic burden associated with it are from Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., and Ahmad, S. *Rising Tide: The Impact of Dementia in Canada 2008 to 2038*, available at [www.alzheimer.ca](http://www.alzheimer.ca).

Except where noted, facts about dementia, its risk factors and associated care are taken from the Alzheimer Society of Canada, as discussed by its Scientific Director, Dr. Jack Diamond, in the report *Alzheimer's Disease and Current Research*. This information can also be found at [www.alzheimer.ca](http://www.alzheimer.ca).

### Subject Matter Experts

The Alzheimer Society would like to acknowledge the generous support, ideas and advice from the following subject matter experts who assisted at various stages of the project:

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# Canada's Dementia Epidemic – A Call to Action

Canada is facing a dementia epidemic and needs to take action now. Approximately 500,000 Canadians have Alzheimer's disease or a related dementia today. It is the most significant cause of disability among Canadians (65+) and it already costs Canadian society many billions of dollars each year.

For the past decade, dementia and its potential impacts on national economies have been the subject of growing interest around the globe. Forecasts show that within 20 years, worldwide prevalence will increase two-fold. There are more than 35 million people with dementia in the world at this time. It is estimated that by 2050, this number will increase to 115 million people<sup>1</sup>. Canada, too, can expect a several-fold increase in dementia in the coming decades.

The governments of Australia, Norway, the Netherlands, Scotland, England, France, and the European Parliament have all taken steps to study dementia and its consequences. Many have chosen to make dementia a national priority. Canada has yet to take these steps.

## The Need for Current Information

The Canadian government, dementia researchers and the Alzheimer Society have been using the 1991 *Canadian Study on Health and Aging* (and the longitudinal follow-up of 1996) as the most recent basis for understanding the prevalence, incidence and economic consequences of dementia. The costs for health care, medications, diagnostic imaging and labour have all increased well beyond what was forecasted in 1991, and newer studies from other countries have shown that the true costs of dementia are markedly higher than previously projected.

Canada requires a national plan grounded in an up-to-date and comprehensive understanding of the dementia burden in Canada, in order to quantify, prepare for, and mitigate the impact of dementia. The Alzheimer Society has begun work towards such a plan.

The *Rising Tide* study was launched in 2008 in order to gain understanding of the demographic and epidemiological profile of dementia in Canada, to develop a future picture of the health and economic burden of dementia on Canadian Society, and to introduce a discussion of what can be done to reduce the impact. RiskAnalytica, a science-based risk management firm with expertise in population health analysis, was engaged by the Alzheimer Society of Canada for this research project. Specifically, the study was commissioned to generate:

- the projected prevalence of dementia in Canada by sex and age-group for a 30-year period;
- the projected economic burden of dementia in Canada for the next 30 years;
- a platform for evaluating and comparing proposed intervention strategies to mitigate the impact of dementia on Canadian society. Four intervention scenarios were generated using the platform, to illustrate its potential as an on-going evaluation tool for policy analysis and decision-making;
- a scan of the comparative health policy context to ensure that Canada's approach to dementia can capitalize on and work within the current health system.

RiskAnalytica's Life at Risk® evaluation framework is a sophisticated platform for evaluating the relative impact of strategies that may inform future policy, economic and investment decisions. It was used to generate the Dementia Base Case – an estimate of the health and economic impacts of dementia in Canada over the next 30 years, assuming no change in current policy, treatment or health interventions.

In addition, the Alzheimer Society, RiskAnalytica and a network of leading dementia subject matter experts framed and evaluated a variety of "what-if" scenarios to simulate potential interventions and the health and economic outcomes that would result from each.

---

<sup>1</sup> *World Alzheimer Report*. Alzheimer's Disease International. September 21, 2009. <http://www.alz.co.uk/research/worldreport/>

# Canada's Dementia Epidemic – A Call to Action

## Rising to the Challenge

The goal of *Rising Tide* is to generate a solid, evidence-based foundation (the Dementia Base Case) upon which policymakers can build a comprehensive national plan to prepare for and mitigate the burden of dementia on Canadian society. It is also to direct health expenditures towards activities that have the greatest potential to maximize quality of life, to support individuals and families, to leverage our scarce health human resources, and at the same time to manage growth in the rate of institutionalization and overall health costs.

Finally, *Rising Tide* demonstrates that Canadians must call on their federal, provincial and territorial governments to take action now – to rise to the challenge of the dementia epidemic by acting on the recommendations contained in this report.



# A Brief Introduction to Dementia

## What is Dementia?

Dementia refers to a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged. Dementias are generally categorized as reversible (dementias secondary to some primary illness such as thyroid disease or kidney disease, which can be successfully treated) or irreversible. This report focuses on irreversible dementias associated with progressive neurodegenerative diseases: Alzheimer's disease, Vascular Dementia, and other dementias (specifically frontotemporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease).

Symptoms commonly include loss of memory, judgment and reasoning, and also changes in mood, behaviour and the ability to communicate. These symptoms may affect a person's ability to function at work, in social relationships, or in the usual activities of daily living.

People with dementia are not the only ones affected by the disease. Dementia places a long-term progressive burden on those who care for them. Dementia usually implies not only a long period of profound disability and suffering for the person, but also severe strain and financial burden on family and caregivers<sup>2</sup>, health providers, the health care system, the business community, and society in general.

## Alzheimer's Disease

Alzheimer's disease, the most common form of dementia<sup>3</sup>, is a progressive, degenerative and fatal brain disease, in which cell to cell connections in the brain are lost and brain cells eventually die. It is *not* a normal part of aging.

While some debate remains, the majority of researchers believe that Alzheimer's disease occurs when the effects of many negative influences on the brain cross a certain threshold, overwhelming the brain's self-repair mechanisms. These mechanisms maintain the crucial balance between the production and elimination of the naturally occurring products of metabolism. These products are beneficial at normal levels, but become toxic at abnormally high levels. Therefore, this balance is essential to maintaining the brain's nerve cells in a healthy state.

A situation known as "oxidative stress" alters this balance and causes toxic effects on cells everywhere in the body including the brain. Many diseases, some drugs and the "internal" stress generated when a person's health and well-being are threatened can lead to 'oxidative stress.' It is believed that this, in turn, leads to the formation of plaques and tangles in the brain, which interfere with brain functions and are a characteristic of Alzheimer's disease. Therefore, oxidative stress is a key target for Alzheimer treatments, and a reason why healthy lifestyles are included in risk reduction strategies.

The vast majority of Alzheimer's disease cases are of the sporadic form (also referred to as "late onset") of the disease. However, about 5 to 7 per cent of the Alzheimer population is in the category called Familial Alzheimer's disease (FAD), in which onset typically occurs at an earlier age. The rate of decline in Alzheimer's disease is extremely variable and changes from person to person. In many instances, it may be preceded by a few years of Mild Cognitive Impairment (MCI), a condition in which true dementia is absent, but nevertheless memory and cognitive functions are detectably reduced.

Alzheimer's disease is ultimately fatal, and death usually occurs within seven to 10 years after diagnosis. The body is weakened by inactivity and muscle wasting, and a lowering of the body's immune functions makes bacterial and viral infections very common. This leads to the usual cause of death – pneumonia, hastened by the decreased ability of the affected person to cough and generally to move about normally.

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<sup>2</sup> *Dementia – Etiology and Epidemiology, A Systematic Review*. The Swedish Council on Technology Assessment in Health Care. Vol. 1, June 2008.

<sup>3</sup> Alzheimer's disease currently represents approximately 63% of all dementias included in *Rising Tide* (and will increase to 69% within 30 years).

## Vascular Dementia

Vascular Dementia is the second most common form of dementia (after Alzheimer's disease)<sup>4</sup>. It is caused by problems in the supply of blood to the brain. There are a number of conditions that can cause or increase damage to the vascular system. These include high blood pressure, heart problems, high cholesterol and diabetes. The two main types of Vascular Dementia are stroke-related dementia and small vessel disease-related dementia. Many individuals with Alzheimer's disease also have Vascular Dementia.

## Related Dementias

Other dementias include Frontotemporal Dementia (FTD, which includes Pick's Disease), dementia with Lewy bodies and Creutzfeldt-Jakob Disease (CJD). These dementias occur in combination with various chronic non-dementia conditions such as Parkinson's disease and Huntington's disease.

## Risk Factors for Dementia

Risk factors contribute to the likelihood of getting a disease. They include the characteristics of a person, their lifestyle and their environment. Some risk factors can be controlled and are therefore of great interest in disease prevention and management. Other risk factors cannot be controlled. Many of the risk factors for Alzheimer's disease, such as high cholesterol levels or high blood pressure, are risk factors for many other diseases, especially cardiac diseases. Although agreement on most risk factors is well established, there are some that remain controversial.

The risk factor section below is specific to Alzheimer's disease, although some risks may also apply to other dementias

### Non-Modifiable Risk Factors

- *Aging* - Aging is the most important risk factor. Despite the presence of other risk factors, the disease never sets in until some minimum adult age is reached.<sup>5</sup>
- *Genetic risk factors* – Aside from the mutated genes, which are heavily implicated in Familial Alzheimer's disease (FAD), genetic risk factors also play a role in the common sporadic form of Alzheimer's disease. The apoE4 gene<sup>6</sup> is the most important gene identified to date for the common form of the disease. However, since having a parent or sibling with Alzheimer's disease increases one's risk by two to three times<sup>7</sup>, other genes, not yet identified, likely also predispose individuals to Alzheimer's disease.

### Modifiable Risk factors

- Type 2 (adult onset) Diabetes
- Head injury
- Strokes and 'Ministrokes' (very small haemorrhages in the brain that may only be revealed through later brain imaging)
- High cholesterol levels<sup>8,9</sup>

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<sup>4</sup> Vascular dementia accounts for approximately 20% of all dementias included in *Rising Tide*.

<sup>5</sup> The occurrence of dementia increases with age particularly in the elderly, over the ages of 75 and 80. Fratiglioni, L. et al. "Incidence of Dementia and Major Subtypes in Europe: A Collaborative Study of Population-Based Cohorts." *Neurology*. 54:11 (2000): 10-15.

<sup>6</sup> If a person's pair of apoE genes includes one of the apo4 variety (inherited from one parent), they have three times the normal risk of developing Alzheimer's disease. If they carry two apoE4 genes (one from each parent), the risk increases to ten times. However, individuals with no apoE4 genes can still get Alzheimer's disease, just as individuals with two apoE4 genes can escape it.

<sup>7</sup> Breitner, John C.S. "Clinical genetics and genetic counseling in Alzheimer disease" *Annals of Internal Medicine*, 1991.

<sup>8</sup> High levels of low-density lipoprotein (LDL) appear to significantly increase a person's risk of developing vascular dementia. "Dementia: Hope through Research." National Institute of Neurological Disorders and Stroke. 7 Aug 2009. [http://www.ninds.nih.gov/disorders/dementias/detail\\_dementia.htm#1367219213](http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm#1367219213)

<sup>9</sup> Longitudinal studies have established that midlife elevation of the total serum cholesterol level is associated with an increased risk of subsequent Alzheimer's disease. Patterson, Christopher et al. "General Risk Factors for Dementia: A Systematic Evidence Review." *Alzheimer's & Dementia: the Journal of the Alzheimer's Association*. 3.4 (2007): 341-347

- High blood pressure<sup>10</sup>
- Mild Cognitive Impairment (MCI)
- Chronic inflammatory conditions (such as certain forms of arthritis)
- A history of clinical depression<sup>11</sup>
- Inadequate intellectual stimulation
- Obesity

Further risk factors which have been identified, but not substantiated as well, include lack of formal education (which may be related to inadequate mental stimulation), low socio-economic status, smoking, and excessive drinking.

For a more detailed discussion of risk factors, please see *A Report on Alzheimer's Disease and Current Research* by Dr. Jack Diamond, Scientific Director, Alzheimer Society of Canada, available at [www.alzheimer.ca](http://www.alzheimer.ca).

## Risk Reduction

In risk reduction, two things matter: how many risk factors a person is exposed to, and how efficiently their brain's self-healing process works. The brain's ability to withstand risk factors and to preserve and even enhance its healing capacity can be significantly helped by the adoption of a healthy lifestyle.

Healthy lifestyles enhance the production of 'growth factors' in the brain, which help brain cells maintain and make new connections. Recent discoveries suggest that healthy lifestyles may even help in the creation of new nerve cells.

Healthy lifestyles are also often effective in reducing the Alzheimer risk indirectly, by reducing specific risk factors such as stress and obesity. Appropriate treatment of medical conditions such as diabetes, high cholesterol and high blood pressure levels are also of obvious benefit. [Notably, in studies of identical twins, it was found that about 60 per cent of the overall risk factors for Alzheimer's disease comes entirely from lifestyle and not genetic susceptibility].

Strategies identified for reducing the risk of Alzheimer's disease and related dementias, or to slow the progression of these diseases once it has begun (protective factors) include:

- **Healthy diet** - A Mediterranean-style diet is associated with decreased risk of Alzheimer's disease.<sup>12</sup> Also important is eating anti-oxidant rich foods such as blueberries and raspberries, and dark green leafy vegetables such as spinach and collard greens. The anti-oxidants selenium and folic acid are also recommended by some. Folic acid, also known as folate, is reputed to help ward off heart disease. Moderate consumption of wine (250–500 ml/day versus a smaller or larger amount) is associated with a reduced risk of subsequent dementia, including Alzheimer's disease.<sup>13</sup> Similarly, certain spices used in curries, especially curcumin (found in turmeric), have been implicated in the lower than average incidence of Alzheimer's disease in curry-eating populations. Finally, there is interest in increasing the intake of omega-3 fatty acids (found especially in cold water fish, flax and walnuts) based on findings that these fatty acids were low in individuals with Alzheimer's disease, and that in some (but not all) studies, supplementing diets with them improved cognitive functioning.

<sup>10</sup> Patterson, Christopher et al. "Diagnosis and Treatment of Dementia: 1. Risk Assessment and Primary Prevention of Alzheimer Disease" *Canadian Medical Association Journal*. 178.5 (2008): 548-556.

<sup>11</sup> A systematic evidence review concluded that depression is associated with Alzheimer's disease, however further research is required on the topic. Jorm, Anthony F. "History of Depression as a Risk Factor for Dementia: an Updated Review." *Australian and New Zealand Journal of Psychiatry*. 35.6: 776-781.

<sup>12</sup> Scarmeas, N. et al. "Mediterranean Diet and Risk for Alzheimer's Disease." *Annals of Neurology*. 59.6 (2006): 912-921

<sup>13</sup> Larrieu, S. et al. "Nutritional Factors and Risk of Incident Dementia in the PAQUID Longitudinal Cohort." *Journal of Nutrition Health and Aging*. Vol. 8 (2004): 150-154.

- **Aerobic exercise** - Increased levels of physical activity have been linked to a reduced risk of subsequent dementia<sup>14</sup>. Even modest levels of exercise are beneficial, such as a few daily walks up and down stairs. Exercise stimulates the production in the brain of growth factors, especially one known as brain-derived neurotrophic factor (BDNF), which both promote connectivity between nerve cells and help preserve their health. Exercising also helps maintain a good blood supply and therefore oxygen supply to the brain. This is particularly important because reduced oxygen supply (hypoxia) of the brain promotes the production of the protein beta amyloid, which is associated with Alzheimer's disease.
- **An active social life** – This includes interactive and especially organized social leisure activities, for example playing cards or group theatre-going. Loneliness in individuals age 65+ has been linked to a higher risk for dementia, and clearly increased socialization is key, including things like spending time with family.
- **Intellectual activity** – This is the 'use it or lose it' principle behind such activities as doing crossword puzzles, reading or playing chess. Interestingly, in a Swedish twins study, greater participation in intellectual activities was associated with lower risk for Alzheimer's disease for women, but not for men. As with an active social life, it appears that intellectual activity establishes cognitive reserve, defined as "the brain's ability to operate effectively even when some function is disrupted or the amount of damage that the brain can sustain before changes in cognition are evident"<sup>15</sup>.
- **Protecting your head** – Although the link between head injury and the later development of dementia is still being debated, there is clear evidence that the use of head protection (especially recreational/sporting safety helmets) reduces the risk of traumatic head injury<sup>16</sup>.

The accepted view today is that promoting brain health through lifestyle choices is the most effective way of reducing the chances of developing Alzheimer's disease or a related dementia or slowing down the progression of these diseases in people who already have them. Adopting a lifestyle that ignores risk factors does not mean, however, that one will develop the disease, but it does increase the odds.

## Care and Treatment

Appropriate care and treatment for people with dementia<sup>17</sup> varies greatly and is dependent on the stage of the disease, as well as how it affects each individual at any given point in time. The following illustrates a range of health interventions and other activities that are provided today at different stages.

Healthy individuals and individuals for whom a diagnosis has not been made	<ul style="list-style-type: none"> <li>• The Alzheimer Society provides information on the nature of dementia, how to recognize the disease (warning signs and symptoms) and how to find help if these are present. The Society also educates the general public on risk reduction and prevention strategies.</li> </ul>
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<sup>14</sup> Patterson, Christopher et al. "Diagnosis and Treatment of Dementia: 1. Risk Assessment and Primary Prevention of Alzheimer Disease. *Canadian Medical Association Journal*. 178.5 (2008): 548-556.

<sup>15</sup> *Can Alzheimer's Disease Be Prevented?* U.S. Department of Health and Human Services, 2009.

<sup>16</sup> Plassman, B.L., Havlik, R.J., Stephens, D.C., et al. "Documented Head Injury in Early Adulthood and Risk of Alzheimer's Disease and Other Dementias." *Neurology*. 55.8 (2000): 1158-1166.

<sup>17</sup> This report generally refers to people with dementia as *people with dementia*, unless they are being described in a clinical setting, in which case they may be referred to as *patients*. This report may also refer to *patients* when referring to a source in which that term is used. People living in care facilities are generally referred to as *residents*.

Diagnosis	<ul style="list-style-type: none"> <li>• Access to diagnosis is limited by stigma and by the availability of diagnostic expertise. The Alzheimer Society works to offset the stigma associated with dementia so that individuals who need help seek it with guidance and support.</li> <li>• Diagnosis is typically made by the family physician or by a geriatrician, neurologist or psychiatrist, and usually includes clinical history and neuropsychological testing, with perhaps diagnostic imaging.</li> </ul>
Disease Management	<ul style="list-style-type: none"> <li>• Once a diagnosis is made, the physician may prescribe a cholinesterase inhibitor to mitigate the symptoms associated with the decline in memory, language and thinking abilities. There are, as of yet, no therapies that have been proven to slow down, stop or reverse the decline.</li> <li>• Other drugs may be introduced to manage co-morbid conditions or to manage the behavioural and psychological symptoms of dementia.</li> <li>• Individuals who have just been diagnosed with dementia may be referred to the Alzheimer Society to initiate educational and support services for the individual with dementia and their family/caregiver.</li> <li>• Individuals with dementia may benefit from a variety of community-based services that may be available where they live – respite care, adult day programs, early stage support groups, home help, etc.</li> <li>• Family caregivers may have counselling, education and support groups.</li> </ul>
Long-Term Care	There is a variety of residential care services across the country ranging from nursing homes to dementia-specific housing. Individuals typically move into care facilities when it becomes unsafe to continue residing in their own homes and family caregivers become exhausted.
End-of-Life Care	The final stages of the disease require palliation – managing pain and providing comfort are key treatment goals. There are very few clinicians with dementia-specific palliative care experience.

While there is a broad spectrum of services appropriate to people with dementia and their caregivers at various stages of the disease, these services are maldistributed, uncoordinated and, where available, delivered with little standardization and continuity. The services are provided by too few specialized providers or by inadequately prepared generalist providers. Training of health, long-term care and continuing care providers is limited in dementia prevention, identification, diagnosis, and treatment.

The predicted surge in dementia prevalence threatens to overwhelm Canada's health care system unless specific and targeted actions are undertaken. **Canada must act.**



# Why Canada Must Act

By 2038:

- 1,125,200 will have Dementia in Canada – 2.8% of the Canadian population
- The cumulative economic burden will be \$872 billion
- Demand for long-term care will increase 10-fold



Alzheimer *Society*

# Why Canada Must Act

## The Dementia Base Case – The Growth of Dementia

*Rising Tide* presents comprehensive forecasts of the impact of dementia for each of the next 30 years. This impact was quantified using RiskAnalytica's Life at Risk® simulation platform, customized based on the latest dementia research. Subject matter experts worked closely with the Alzheimer Society and RiskAnalytica teams to validate data sources, the modeling strategy and results<sup>18</sup>.

The Dementia Base Case, a forecast of the population health and economic impact of dementia on Canadian society for each of the next 30 years was generated using validated data inputs. The Base Case assumes no change in policy, no significant new scientific discovery and no intervention. The resultant profile includes measures of the population health and economic burden attributable to dementia.

By factoring in the expected population changes and evidence-based assumptions about dementia over the next three decades, a forecast of the number of new dementia cases (Incidence), deaths (Mortality), and the number of Canadians living with dementia (Prevalence) is established for each of the next 30 years.

The study then categorized those living with dementia by type and location of care that research suggests they will receive, and determined expected constraints in long-term care capacity. On this basis, a profile of care delivery was developed, i.e. a picture of how and where care will be provided to Canadians living with dementia (Health Care Utilization).

Finally, by applying assumptions for direct, indirect and opportunity costs, the total cost associated with dementia (Economic Burden) was calculated both on an annual basis in future dollars (adjusted for inflation) for 10, 20 and 30 years into the future, and on a cumulative basis for 10, 20 and 30 years (2008 present values). Together, these illustrate the Base Case Economic Burden of dementia in Canada.

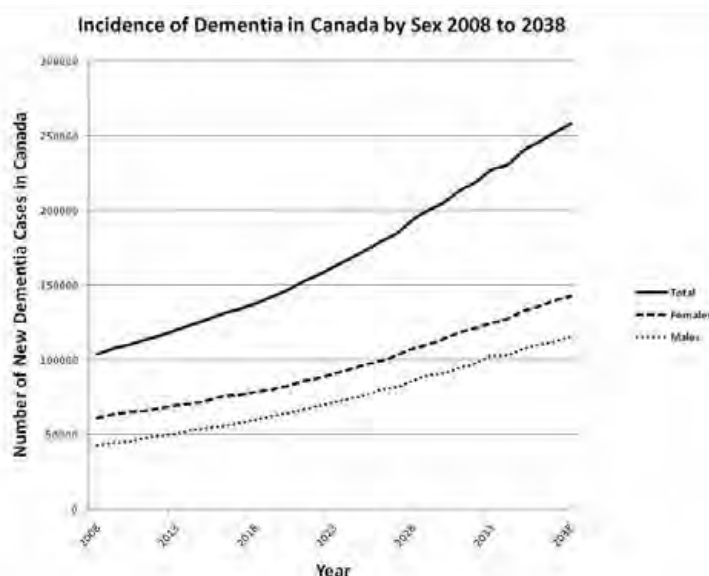
Highlights of the Base Case follow. Supporting details plus breakdowns at the provincial level are available in the document *Rising Tide: The Impact of Dementia in Canada 2008 to 2038*, which is available at [www.alzheimer.ca](http://www.alzheimer.ca).

## Incidence: Number of New Cases of Dementia per Year

As illustrated in Exhibit 1, the number of new cases of dementia in 2038 among Canadians (65+) will be 2.5 times that of 2008.

Projected incidence:      2008 - 103,728 new dementia cases per year  
   2038 - 257,811 new dementia cases per year

### Exhibit 1: Current and Future Dementia Incidence in Canada, Ages 65+: 2008-2038



<sup>18</sup> See Appendix A for a more detailed explanation of the evidence-based customization process.

Alzheimer's disease accounts for roughly 50% of new dementia diagnoses each year for Canadians (65+) throughout the simulation period.

Incidence 2008-2038:

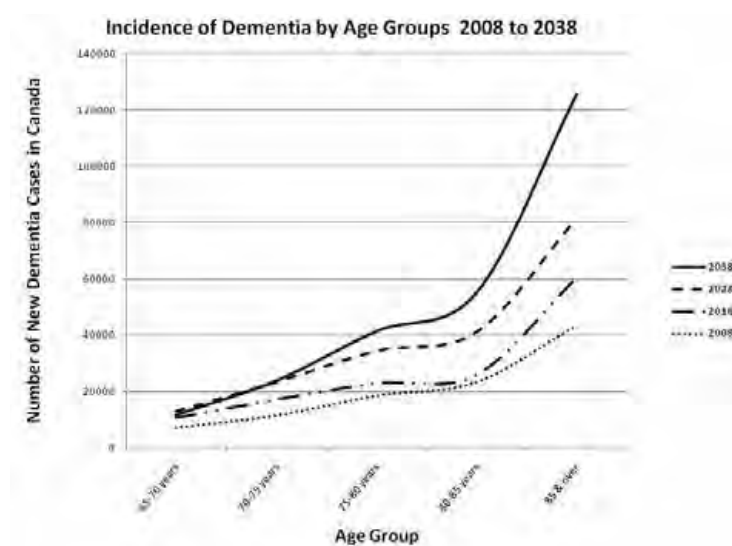
- Alzheimer's disease 50-52%
- Vascular Dementia 20-21%
- Related dementias 28-29%

As illustrated in Exhibit 2, newly diagnosed cases will skew toward the older age groups over time. This increase in dementia incidence for older Canadians results primarily from general aging of the Canadian population.

Of this aging population:

- The proportion of men diagnosed with dementia who are over the age of 85 will increase from 33% in 2008 → 43% by 2038.
- The proportion of women diagnosed with dementia who are over the age of 85 will increase from 46% in 2008 → 52% by 2038.

## Exhibit 2: Current and Future Dementia Incidence in Canada, Select Years, by Age Groups, 65+: 2008-2038



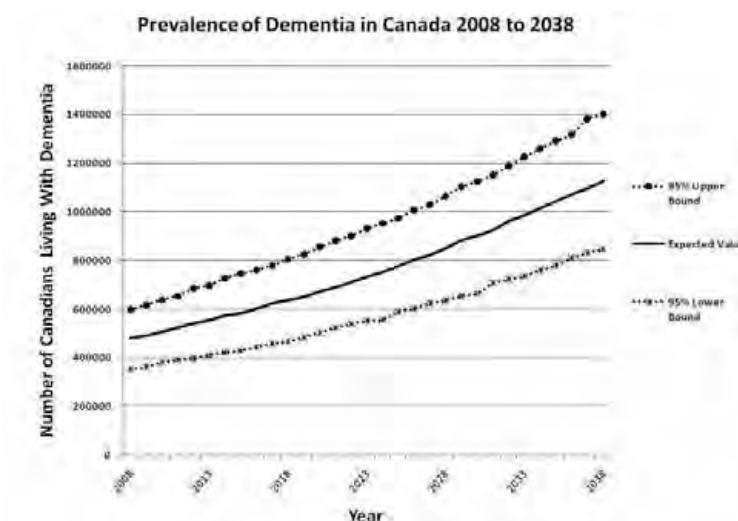
## Prevalence: Number of People Living with Dementia

As illustrated in Exhibit 3, by 2038 the number of Canadians (of all ages) with dementia will increase to 2.3 times the 2008 level, i.e. to 1.1 million people, representing 2.8% of the Canadian population.

Projected prevalence: 2008 – 480,618 people, or 1.5% of the Canadian population  
 2038 – 1,125,184 people, or 2.8% of the Canadian population



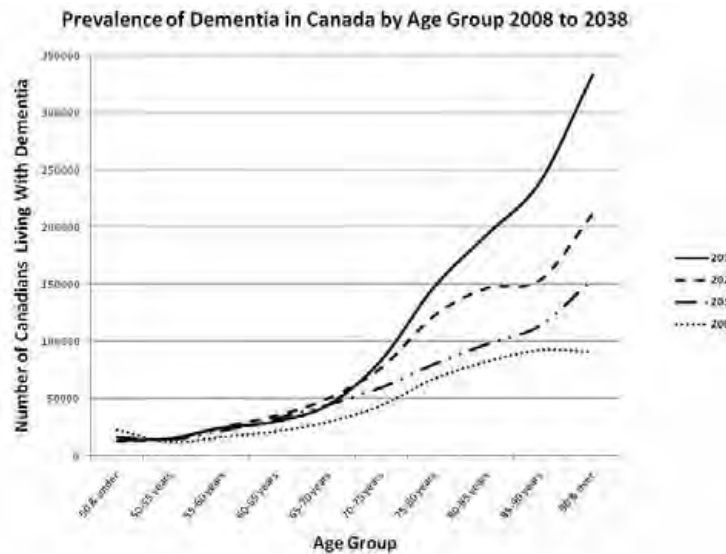
### Exhibit 3 Current and Future Dementia Prevalence in Canada, All Age Groups: 2008-2038



Note: This chart shows the expected value and the confidence intervals for prevalence estimates in select years: 2008-2038

- Canadians with Alzheimer's disease or Vascular Dementia will account for the vast majority of dementia cases in Canada (approximately 83%).
  - 2008 303,878 cases (63%) Alzheimer's disease / 94,183 (19.5%) Vascular Dementia
  - 2038 770,811 cases (68.5%) Alzheimer's disease / 221,220 (19.7%) Vascular Dementia
- The prevalence of dementia is higher in females than males, with a ratio of approximately 1.36 throughout the simulation period.
  - The average female to male ratio of Alzheimer's disease prevalence is approximately 2.29
  - The average female to male ratio of Vascular Dementia prevalence is approximately 0.85
- The proportion of the Canadian population with dementia increases with age. % of Canadians with dementia:
  - 7% in 2008 → 9% in 2038 of Canadians over age 60 will have dementia;
  - 49% in 2008 → 50% in 2038 of Canadians over age 90 will have dementia.
- Furthermore, as illustrated in Exhibit 4, prevalence of dementia in Canada will skew toward the older age groups due to general aging of the Canadian population.
  - % of individuals with dementia who are over the age of 80: 2008 → 2038
    - In total: 55% → 68%
    - Alzheimer's disease: 71% → 78%
    - Vascular Dementia: 51% → 61%

## Exhibit 4 Current and Future Dementia Prevalence in Canada, Males and Females, All Age Groups: 2008- 2038



## Health Care Utilization

To obtain a picture of how and where care will be provided to Canadians living with dementia, prevalence is classified into three care types:

- individuals receiving care in long-term care facilities such as nursing homes;
- individuals living at home and receiving community care;
- individuals living at home and receiving no formal care.

## A Shift Towards Home/Community-Based Care

The model forecasts the demand for long-term care beds based on the projected prevalence and severity of dementia. However, availability of long-term care beds is constrained. Based on historical growth trends, the model assumes that the total number of long-term care beds in Canada will grow from approximately 280,000 beds in 2008 to 690,000 in 2038. This leaves a projected shortfall of more than 157,000 beds in 2038. The model assigns this shortfall to community care.

Exhibit 5 presents the prevalence of dementia for Canadians (65+) according to care type. Dementia prevalence increases across all care types over the 30-year simulation period. However, there is a significant shift from institutional care towards home/community-based care.

- In 2008, 55% of Canadians (65+) with dementia were living in their own homes, most with the support of some kind of community care.
- By 2038, 62% of Canadians (65+) with dementia will be living in their own homes. This represents an increase of 510,000 individuals and would substantially increase community care and caregiver burden.

## Exhibit 5 Dementia Prevalence by Care Type (Ages 65+) :2008-2038

Year	Prevalence of Dementia by Care Type in Canada (Ages 65+)					
	Long-Term Care		Community Care		No Formal Care	
	Prevalence of Dementia	Percent with Dementia	Prevalence of Dementia	Percent with Dementia	Prevalence of Dementia	Percent with Dementia
2008	183,268	45.4%	134,416	33.3%	85,938	21.3%
2018	249,268	41.8%	221,970	37.3%	124,553	20.9%
2028	335,882	39.4%	337,682	39.6%	178,747	21.0%
2038	442,682	37.6%	503,661	42.7%	232,146	19.7%

Exhibit 6 quantifies the long-term care bed shortfall:

- The long-term care bed shortfall will increase from approximately 15,400 in 2008 to 157,500 in 2038.

## Exhibit 6 Supply of Long-Term Care Beds & Number of Beds Occupied by Individuals Living with Dementia (Ages 65+):2008-2038

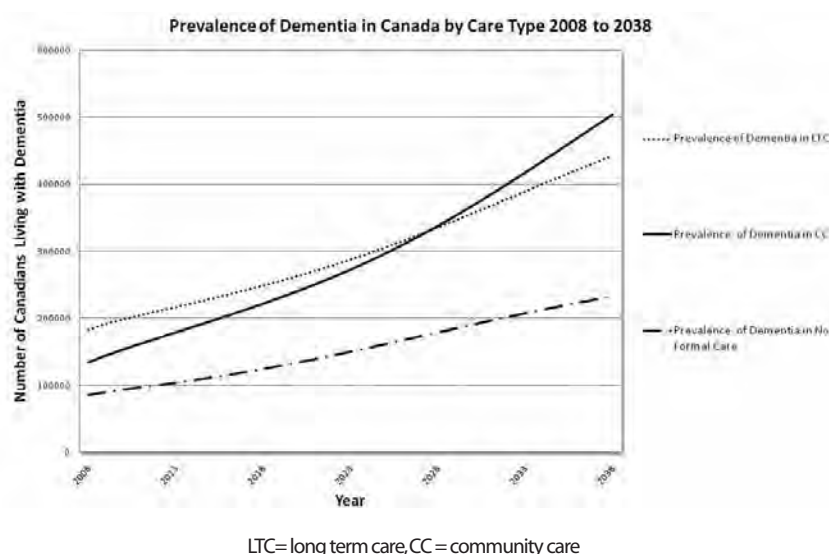
Year	Supply and Demand (by Persons with Dementia) of Long-Term Care (LTC) Beds in Canada, Ages 65+			
	Number of LTC Beds	Number of LTC Beds Occupied by People with Dementia	Prevalence of Dementia That Would Have Been in LTC	Excess Demand for LTC
2008	285,178	183,268	198,659	15,392
2018	387,880	249,268	296,473	47,204
2028	522,657	335,882	422,351	86,469
2038	688,846	442,682	600,142	157,461

Exhibit 7 illustrates the trend in the type of care utilized by Canadians (65+) living with dementia. The number of people receiving community-based care will increase at a slightly faster rate than those in long-term care due to the long-term care capacity constraints.

There is a marked shift from long-term care to community care for Canadians (65+) living with dementia:

- in community care setting receiving community care services: 33.3% in 2008 → 42.7% by 2038 (or an additional 370,000 people);
- in long-term care setting: 45.4% in 2008 → 37.6 % by 2038 (or an additional 260,000 people);
- in community setting (at home) receiving no formal care: 20-21% throughout the simulation period (or an additional 140,000 individuals).

## Exhibit 7 Prevalence of Dementia by Care Type, (Ages 65+): 2008-2038



## Growth in Caregiving Hours

The task of caregiving changes throughout the progression of dementia. Initially, when the person with dementia is still living at home, the focus for the informal caregiver<sup>19</sup> may be on helping with transportation, household finance, meals and day-to-day living activities. By the time the individual is receiving care from community service providers, the scope of the caregiving role broadens to include supervision to ensure safety. Once the individual is in a long-term care facility, the needs change again. While support for activities of daily living is provided by the care facility, the informal/family caregiver continues to be engaged as a member of the care team to provide supportive care, including social engagement and affection.

Informal Care Hours: Exhibit 8 summarizes the number of hours of work provided by unpaid caregivers for people with dementia in each of the three care types:

- By year 2038, the total number of hours of informal care will more than triple, increasing from approximately 231 million hours in 2008, to 756 million hours.
- Informal caregivers within community care settings account for the largest proportion of informal care, increasing from 60% to 69% over the 30-year simulation period.

## Exhibit 8 Hours of Informal Care per Year, By Care Type: 2008-2038

Year	Hours of Informal Care Per Year By Care Type			
	Hours in Long-Term Care	Hours in Community Care	Hours in No Formal Care	Total Hours of Informal Care
2008	44,593,849	139,289,343	46,955,109	230,838,301
2018	60,653,577	230,017,730	68,053,794	358,725,101
2028	81,728,906	349,924,438	97,664,641	529,317,984
2038	107,716,208	521,920,684	126,841,507	756,478,399

<sup>19</sup> The term 'informal care' is used in health services research to connote a difference between unpaid caregivers, usually family or friends, and caregiving provided by individuals who are paid for this service. The term makes no distinction beyond this.

# Economic Burden of Dementia

## Total Economic Burden

The Life at Risk® economic framework calculates the Total Economic Burden of dementia as the sum of direct health costs, opportunity costs (foregone wages) of unpaid informal caregivers and indirect costs. The Monetary Economic Burden reflects only actual monetary outlays and hence ignores opportunity costs.

$$\text{Total Economic Burden} = \text{Direct Health Costs} + \text{Opportunity Costs of Informal Caregivers} + \text{Indirect Costs}$$

$$\text{Monetary Economic Burden} = \text{Direct Health Costs} + \text{Indirect Costs}$$

Direct health costs are costs incurred while treating a particular disease and can accrue within or outside the formal health care system. Direct health costs pertaining to dementia within the formal health system include the cost of prescription medication, long-term care staff costs, support staff costs, long-term care administrative costs, and physician and hospital costs. Direct health costs outside the formal health care system include the cost of over-the-counter medication, long-term care accommodation and out-of-pocket expenses.

Opportunity costs of informal caregivers are the wages informal caregivers could have earned had they been able to participate in the labour force.

Indirect costs are costs that have no direct connection to dementia, but are a consequence of it. They include the loss in wages (e.g. days off or sick time) and in corporate profits that result from the reduction in labour productivity for both the individual with dementia and the provider of informal care.

Exhibit 9 presents the simulation results of the **annual Total Economic Burden** of dementia in future values. Exhibit 10 presents the **cumulative Total Economic Burden** in 2008 present values.

A breakdown of the cost components follows in Exhibits 11 – 17.

## Annual Total Economic Burden

The annual Total Economic Burden, expressed in future dollars, increases substantially from approximately \$15 billion in 2008 to \$153 billion by year 2038.

- The Monetary Burden of dementia (direct plus indirect costs) will reach approximately \$97 billion by year 2038.
- Opportunity costs of informal caregivers will add a further \$56 billion to the annual Economic Burden by 2038.

## Exhibit 9 Total Annual Economic Burden Attributed to Dementia, Future Values: 2008-2038

Year	Total Economic Burden of Dementia, Future Values				
	Total Direct Costs a	Total Unpaid Caregivers Opportunity Cost b	Total Indirect Costs c	Monetary Economic Burden a+c	Total Economic Burden a+b+c
2008	\$8,063,733,967	\$4,995,340,836	\$1,864,955,665	\$9,928,689,632	\$14,924,030,467
2018	\$19,573,547,540	\$12,303,233,856	\$4,845,163,396	\$24,418,710,937	\$36,721,944,792
2028	\$43,842,755,134	\$26,921,613,083	\$4,380,174,051	\$48,222,929,184	\$75,144,542,267
2038	\$92,832,808,780	\$55,708,854,294	\$4,097,831,931	\$96,930,640,711	\$152,639,495,005

## Cumulative Economic Burden

The cumulative Economic Burden, expressed in 2008 dollars, will reach approximately \$872 billion over the 30-year simulation period.

- Monetary Burden (direct and indirect costs) accounts for approximately \$570 billion.
- The cumulative opportunity cost of informal caregivers, accounting for a further \$302 billion, represents a substantial additional societal burden.

### Exhibit 10 Cumulative Total Economic Burden Attributed to Dementia, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Total Economic Burden of Dementia, 2008 Present Values				
	Total Direct Costs	Total Informal Caregiver Opportunity Cost	Total Indirect Costs	Monetary Economic Burden	Total Economic Burden
2008	\$8,063,733,967	\$4,995,340,836	\$1,864,955,665	\$9,928,689,632	\$14,924,030,467
2018	\$119,911,702,031	\$75,072,662,869	\$43,703,002,416	\$163,614,704,446	\$238,687,367,315
2028	\$270,811,509,553	\$168,884,202,340	\$66,957,982,212	\$337,769,491,765	\$506,653,694,104
2038	\$489,972,224,214	\$301,629,828,371	\$80,615,884,427	\$570,588,108,641	\$872,217,937,012

The next three sections present a more in-depth look at the components of Economic Burden.

## Direct Health Costs

Direct Health Costs are forecasted on the basis of (1) care type, and (2) within care type, whether care is being provided for dementia alone, or for dementia on top of a co-occurring or co-morbid health condition. In order to isolate the costs of care attributable to dementia alone, total costs of care are reported for those with a diagnosis of dementia alone upon admission, whereas only incremental costs are reported for those with dementia as a co-morbid condition.

In addition to the direct costs of Canadians living with dementia, Direct Health Costs also include the costs informal caregivers incur to treat their own negative health outcomes that often result from the stressful nature of providing support to individuals with dementia. These are referred to as Excess Health Costs.

Exhibit 11 presents the annual Direct Health Costs (expressed in future dollars) for Canadians with dementia and informal caregivers:

- Direct Health Costs for both primary dementia cases and co-morbid dementia cases will more than double every 10 years for the next 30 years across all care types.
- Excess Health Costs will increase substantially over time, to account for nearly \$1 billion of Direct Health Costs by 2038.

### Exhibit 11 Total and Incremental Direct Health Costs of Dementia by Care Type, Future Values: 2008-2038

Year	Direct Health Costs For Long-Term Care (LTC), Community Care (CC), No Care, and Excess Health Costs, Future Values							
	Direct Cost LTC Due to Dementia	Incremental Direct Cost LTC Due to Co- morbid Dementia	Direct Cost CC Due to Dementia	Incremental Direct Cost CC Due to Co- morbid Dementia	Direct Cost No Care Due to Dementia	Incremental Direct Cost No Care Due to Co- morbid Dementia	Excess Health Costs Associated with Caregivers	Total Direct Cost – All Methods of Care and Caregivers
2008	\$3,488,976,859	\$899,673,278	\$899,663,518	\$2,171,161,676	\$148,158,636	\$357,551,846	\$98,548,155	\$8,063,733,967
2018	\$7,814,993,328	\$2,015,186,959	\$2,446,654,228	\$5,904,520,732	\$340,327,241	\$821,313,134	\$230,551,918	\$19,573,547,540
2028	\$16,589,338,377	\$4,277,753,921	\$5,863,632,470	\$14,150,728,409	\$724,283,584	\$1,747,916,558	\$489,101,815	\$43,842,755,134
2038	\$33,243,745,344	\$8,572,286,535	\$13,297,576,167	\$32,091,095,371	\$1,361,996,359	\$3,286,911,426	\$979,197,580	\$92,832,808,780

Exhibit 12 presents cumulative Direct Health Costs:

- Cumulative Direct Health Costs through to 2038 approaches \$500 billion (in 2008 dollars).

### Exhibit 12 Cumulative Total and Incremental Direct Health Costs of Dementia by Care Type, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Direct Health Costs For Long-Term Care (LTC) ,Community Care (CC), No Care, and Excess Health Costs, 2008 Present Values							
	Direct Cost LTC Due to Dementia	Incremental Direct Cost LTC Due to Co-morbid Dementia	Direct Cost CC Due to Dementia	Incremental Direct Cost CC Due to Co-morbid Dementia	Direct Cost No Care Due to Dementia	Incremental Direct Cost No Care Due to Co-morbid Dementia	Excess Health Costs Associated with Caregivers	Total Direct Cost – All Methods of Care and Caregivers
2008	\$3,488,976,859	\$899,673,278	\$899,663,518	\$2,171,161,676	\$148,158,636	\$357,551,846	\$98,548,155	\$8,063,733,967
2018	\$49,483,790,230	\$12,759,971,066	\$14,355,120,812	\$34,643,272,222	\$2,119,405,842	\$5,114,770,853	\$1,435,371,005	\$119,911,702,031
2028	\$107,898,793,861	\$27,822,959,423	\$33,963,531,583	\$81,964,330,756	\$4,687,316,392	\$11,311,919,968	\$3,162,657,570	\$270,811,509,553
2038	\$188,201,526,525	\$48,529,953,381	\$64,495,526,295	\$155,647,319,436	\$8,077,102,509	\$19,492,504,775	\$5,528,291,293	\$489,972,224,214

### Opportunity Cost of Informal Caregivers

The simulated Opportunity Cost of informal caregivers (expressed in future dollars) is presented in Exhibit 13. This cost represents the lost wages that result from an individual's restriction from participating in the labour force because of informal care responsibilities.

- The annual Opportunity Cost of unpaid caregivers is projected to increase from approximately \$5 billion dollars in 2008 to over \$55 billion by the year 2038.
- Opportunity Costs associated with community care are considerably greater than those for long-term care and those associated with no formal care. The higher costs reflect both the larger role that informal caregivers play when providing care to family members with dementia in the community and the growing proportion of patients receiving community care.

### Exhibit 13 Total and Incremental Informal Care Opportunity Costs of Dementia at Average Wages by Care Type, Future Values: 2008-2038

Year	Care Opportunity Costs of Dementia at Average Wages, Long-Term Care (LTC), Community Care (CC), and No Formal Care, Future Values						
	Cost of Informal Caregivers, LTC Due to Dementia	Incremental Cost of Informal Caregivers, LTC Due to Co-morbid Dementia	Costs of Informal Caregivers, CC Due to Dementia	Incremental Cost of Informal Caregivers, CC Due to Co-morbid Dementia	Cost of Informal Caregivers, No Care Due to Dementia	Incremental Cost of Informal Caregivers No Care Due to Co-morbid Dementia	Total Informal Caregivers Opportunity Cost
2008	\$336,476,524	\$628,534,364	\$1,050,987,865	\$1,963,233,516	\$354,293,079	\$661,815,489	\$4,995,340,836
2018	\$725,331,408	\$1,354,910,916	\$2,750,688,306	\$5,138,254,833	\$813,827,595	\$1,520,220,798	\$12,303,233,856
2028	\$1,449,381,353	\$2,707,428,073	\$6,205,563,971	\$11,591,923,737	\$1,731,985,851	\$3,235,330,099	\$26,921,613,083
2038	\$2,765,867,093	\$5,166,608,637	\$13,401,541,610	\$25,033,929,072	\$3,256,954,147	\$6,083,953,734	\$55,708,854,294



Exhibit 14 presents the 30-year cumulative Opportunity Cost of informal caregivers to Canadians with dementia.

- Cumulative Opportunity Costs through to 2038 exceeds \$300 billion (in 2008 dollars).

#### Exhibit 14 Cumulative Total and Incremental Informal Care Opportunity Costs of Dementia By Care Type at Average Wages, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Opportunity Costs of Informal Caregivers, Long-Term Care (LTC), Community Care (CC), and No Care, At Average Wages, 2008 Present Values						
	Cost of Informal Caregivers, LTC Due to Dementia	Incremental Cost of Informal Caregivers, LTC Due to Co- morbid Dementia	Cost of Informal Caregivers, CC Due to Dementia	Incremental Cost of Informal Caregivers, CC Due to Co- morbid Dementia	Cost of Informal Caregivers, No Care Due to Dementia	Incremental Cost of Informal Caregivers, No Care Due to Co- morbid Dementia	Total Informal Caregiver Opportunity Cost
2008	\$336,476,524	\$628,534,364	\$1,050,987,865	\$1,963,233,516	\$354,293,079	\$661,815,489	\$4,995,340,836
2018	\$4,678,537,056	\$8,739,454,625	\$16,429,374,630	\$30,689,887,115	\$5,068,154,260	\$9,467,255,183	\$75,072,662,869
2028	\$9,925,658,275	\$18,541,018,076	\$37,751,455,816	\$70,519,295,072	\$11,208,821,864	\$20,937,953,236	\$168,884,202,340
2038	\$16,739,291,093	\$31,268,807,583	\$69,117,064,165	\$129,109,898,864	\$19,314,847,907	\$36,079,918,758	\$301,629,828,371

#### Indirect Costs

The Life at Risk® economic simulation module evaluates the indirect impact of a health condition by examining its effect on production. Dementia negatively impacts production in two ways:

- a lower productivity level for Canadians living with dementia than for otherwise healthy individuals. This reduced productivity translates into a reduction in output;
- reduced productivity faced by employed informal caregivers due to the fatigue and stress<sup>20</sup> associated with providing care. This reduced productivity is also measured in terms of lost production.

Lost production is translated into lost wages and reduction in corporate profits. The sum of lost wages and reduction in corporate profits yields the Indirect Cost of disability associated with dementia and the provision of informal care<sup>21</sup>.

Exhibit 15 presents the **lost production** attributable to dementia over the 30-year simulation period in annual future values.

- Lost production attributed to dementia was approximately \$3 billion in 2008.
- Lost production attributed to dementia is estimated to rise to \$6.8 billion per year by 2038.

#### Exhibit 15 Annual Lost Production Attributed to the Disability Due to Dementia and Informal Care, Future Values: 2008-2038

Year	Annual Lost Production from Dementia, Future Values
2008	\$2,909,240,693
2018	\$7,821,560,906
2028	\$7,186,325,477
2038	\$6,765,521,872

<sup>20</sup> The 2009 *World Alzheimer Report* reference studies that estimate that 40 to 75 per cent of caregivers display very high levels of psychological morbidity as a result of their caregiving, and 15 to 32 per cent major depressive disorder. *World Alzheimer Report*. Alzheimer Disease International, 2009. <http://www.alz.co.uk/research/worldreport/>

<sup>21</sup> Also associated with losses in wages and in corporate profits is a reduction in consumption (or demand) and in government taxation revenues. However, these costs represent derivative indirect cost and, to avoid double-counting, are not included in the final determination of the Economic Burden of dementia.



Exhibit 16 shows the cumulative value of lost production expressed in 2008 dollars.

- Cumulative lost production due to dementia and informal caregiving will be approximately \$130 billion over the 30-year simulation period.

#### Exhibit 16 Cumulative Lost Production Attributed to the Disability Due to Dementia and Informal Care, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Lost Production from Dementia, 2008 Present Values
2008	\$2,909,240,693
2018	\$69,463,141,959
2028	\$107,348,702,524
2038	\$129,846,366,889

Exhibit 17 shows the cumulative value of lost wages and lost corporate profits, which together equal total Indirect Costs expressed in present values (2008 dollars).

#### Exhibit 17 Cumulative Indirect Costs of Disability Due to Dementia, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Wage Impact of Dementia	Cumulative Corporate Profits Impact of Dementia	Cumulative Indirect Costs of Dementia
2008	\$1,487,257,049	\$377,698,616	\$1,864,955,665
2018	\$35,282,225,387	\$8,420,777,029	\$43,703,002,416
2028	\$54,287,882,025	\$12,670,100,186	\$66,957,982,212
2038	\$65,484,620,435	\$15,131,263,992	\$80,615,884,427

## Dementia Base Case Conclusions

Since age is a primary and unchangeable risk factor for dementia, the growth of the dementia problem in Canada will gather speed as the population ages. The first of the baby boomers will enter their senior years (65+) in 2011, at which time the aging of the Canadian population and the dementia burden on Canadian society will begin to accelerate.

The Dementia Base Case shows that without intervention:

- by 2038, the rate of dementia incidence will increase to 250,000 new cases per year, 2.5 times the current level (2008). By 2038, 1.1 million Canadians will have dementia, approximately 2.8% of all Canadians and 9% of Canadians over 60;
- over the next 30 years, the excess demand for long-term care required by dementia patients will increase over 10 times the current demand (2008 values). This excess demand will cause more individuals, with higher dementia severity levels requiring more complex care, to rely on community-based care and informal care support;
- over the next 30 years, dementia will cost society over \$872 billion dollars in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with the provision of informal care.

The Dementia Base Case makes clear that dementia will place a tremendous strain on Canada's capacity to provide essential healthcare services and community care, as well as patient and caregiver support services, potentially overwhelming the country's health care system.

# What Can Be Done

- Prevention – Increase in Physical Activity
- Prevention – A Program to Delay Dementia Onset
- Support – Caregiver Development and Support Program
- Support – System Navigator



# What Can Be Done?

## Scenario Analysis

The first phase of *Rising Tide* established the Dementia Base Case: what will happen if the dementia epidemic is not addressed by any major policy change. The alarming result is intended to evoke a call-to-action, but also to provide a useful standard by which choices can be evaluated. The Scenario Analysis phase of the project shows how the Dementia Base Case can be used to identify meaningful actions – that is, *how it can be used to make a difference on Canadian society*.

Four intervention scenarios, selected by the Alzheimer Society and a panel of subject matter experts, were generated:

- Intervention 1: Prevention – Increase in Physical Activity
- Intervention 2: Prevention – A Program to Delay Dementia Onset
- Intervention 3: Support – Caregiver Development and Support Program
- Intervention 4: Support – System Navigator/Case Management

The scenarios were selected for their anticipated health and economic value, but also because evidence-based data are available to support them. **They are not meant to be the final word on what must be done, but do illustrate how policy options can be evaluated and compared in a very practical way.**

For each scenario, subject matter experts identified the relevant data and worked closely with the RiskAnalytica team to customize the Life at Risk® simulation model. As with the Dementia Base Case, subject matter experts also reviewed the simulation results for relevance and practicality. The results are expressed in “value” terms, that is in terms of how each intervention would change the health and economic burden of dementia in Canada compared to the Base Case.

## Intervention Simulations

### Intervention 1: Prevention – Increase in Physical Activity

The first prevention scenario examines the impact of an intervention which broadly applies evidence that increased physical activity can reduce dementia incidence. The intervention focuses on increasing physical activity by 50% for all Canadians (65+) without dementia, who are already moderately to highly active.

Prevalence data are based on the current self-reported physical activity levels from the Statistics Canada CANSIM database, and the odds ratios related to physical activity from the Canadian Study of Health and Aging (Laurin et al. 2001).

Exhibit 18 provides a summary of the value of the intervention over the next 30 years.

- A 50% increase in physical activity level for Canadians (65+) without dementia who already rate themselves as moderately to highly active was shown to significantly reduce the number of individuals diagnosed with dementia in the short and long-term. The follow-on effects of this reduction result in fewer individuals living with dementia and a reduction in the pressure on long-term care, community care and informal care. In turn, this was shown to produce significant savings in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with dementia, and the provision of care by informal caregivers throughout the simulation timeframe.

## Exhibit 18 Intervention 1: Prevention – Increase in Physical Activity, Impact on Dementia Burden: 2008-2038

Intervention 1: Prevention – Increase in Physical Activity Impact on Dementia Burden Intervention Scenario vs. Base Case					
Year	Health Impact				
	Incidence		Prevalence		
2018	-5,978		-32,454		
2028	-8,243		-64,189		
2038	-10,758		-96,412		
Year	Health Care Utilization (Ages 65+)				
	Prevalence of Dementia in Long-Term Care	Prevalence of Dementia in Community Care		Prevalence of Dementia in No Formal Care	
2018	-13,578	-11,698		-7,178	
2028	-25,296	-25,454		-13,439	
2038	-36,216	-41,556		-18,641	
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$3,385,855,647	-\$2,127,624,745	-\$122,283,860	-\$29,645,387	-\$5,665,409,639
2028	-\$13,686,500,180	-\$8,529,091,994	-\$532,274,656	-\$124,825,659	-\$22,872,692,489
2038	-\$31,180,831,406	-\$19,120,537,780	-\$1,232,947,001	-\$285,207,023	-\$51,819,523,210

### Short-Term Impact

In the short-term (10 years), a prevention program to increase levels of physical activity by 50% for Canadians (65+) without dementia who are already moderately to highly active, would result in:

- a reduction in the number of new cases of dementia of more than 5,970 (4.3% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 32,450 (-5.1%);
- over 13,570 fewer Canadians (65+) living with dementia in long-term care (-7.4%);
- over 11,690 fewer Canadians (65+) living with dementia in community care (-5.3%);
- a reduction in the cumulative Total Economic Burden of more than \$5.6 billion (in 2008 dollars), (-2.4% reduction from the Base Case).

### Long-Term Impact

In the long-term (30 years), a prevention program to increase levels of physical activity by 50% for Canadians (65+) without dementia who are already moderately to highly active, would result in:

- a reduction in the number of new cases of dementia of more than 10,750 (4.2% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 96,410 (-8.6%);
- over 36,210 fewer Canadians (65+) living with dementia in long-term care (-8.2%);
- over 41,550 fewer Canadians (65+) living with dementia in community care (-8.3%);
- a reduction in the cumulative Total Economic Burden of more than \$51.8 billion (in 2008 dollars) (-5.9% reduction from the Base Case).

## Intervention 2: Prevention – A Program to Delay Dementia Onset

The second intervention scenario examines the impact of a hypothetical prevention program which would delay the onset of dementia by approximately two years. The prevention program targets the entire dementia-free 65+ Canadian population and would combine a variety of promising, evidence-based strategies such as following a healthy diet and lifestyle.

A comprehensive study by Brookmeyer *et al.* (2007) estimates that the relative (expected) effect of such a prevention program would reduce the risk of developing dementia by 23%. This scenario assumes that the relative risk factor is equally applicable across all dementia disease types, both genders and all age groups (65+).

Exhibit 19 provides a summary of the value of the intervention over the next 30 years.

- Relative to the Base Case, delaying the onset of dementia by two years resulted in fewer individuals living with dementia and significantly reduced the constraints placed on health care resources and the health care system.
- This intervention was shown to produce significant savings in health costs, informal caregiver opportunity costs and indirect costs associated with dementia and informal care throughout the simulated timeframe.

### Exhibit 19 Intervention 2: Prevention – Hypothetical Program to Delay Dementia Onset: 2008-2038

Intervention 2: Prevention –Hypothetical Program to Delay Dementia Onset Impact on Dementia Burden: Intervention Scenario vs. Dementia Base Case					
Year	Health Impact				
	Incidence			Prevalence	
2018	-25,951			-137,502	
2028	-36,353			-269,736	
2038	-48,409			-409,647	
Year	Health Care Utilization (Ages 65+)				
	Prevalence of Dementia in Long Term Care		Prevalence of Dementia in Community Care		Prevalence of Dementia in No Formal Care
2018	-57,529		-49,748		-30,226
2028	-106,298		-106,942		-56,495
2038	-153,878		-175,868		-79,901
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$14,442,029,463	-\$9,074,731,356	-\$556,647,414	-\$135,013,264	-\$24,208,421,497
2028	-\$57,808,986,147	-\$36,024,947,299	-\$2,329,458,341	-\$546,597,397	-\$96,709,989,184
2038	-\$131,676,392,947	-\$80,750,710,864	-\$5,037,965,302	-\$1,166,583,594	-\$218,631,652,707

### Short-term Impact

In the short-term (10 years), a program to delay dementia onset by two years would result in:

- a reduction in the number of new cases of dementia of more than 25,950 (18.9% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 137,500 (-21.6%);
- over 57,520 fewer Canadians (65+) living with dementia in long-term care (-31.4%);



- over 49,740 fewer Canadians (65+) living with dementia in community care (-22.4%);
- a cumulative reduction in the Total Economic Burden of more than \$24.2 billion (in 2008 dollars) (-10.1% reduction from the Base Case).

### Long-Term Impact

In the long-term (30 years), a program to delay dementia onset by two years would result in:

- a reduction in the number of new cases of dementia of more than 48,400 (-18.9% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 409,640 (-36.4%);
- over 153,870 fewer Canadians (65+) living with dementia in long-term care (-34.8%);
- over 175,860 fewer Canadians (65+) living with dementia in community care (-34.9%);
- a cumulative reduction in the Total Economic Burden of more than \$218.6 billion (in 2008 dollars) (-25.1% reduction from the Base Case).

### Intervention 3: Support – Caregiver Development and Support Program<sup>22</sup>

The third intervention examines an informal caregiver skill-building and support program that reduces the amount of caregiving time and hence the health and economic burden placed on informal caregivers. The caregiver support program also aims to delay admission for the person with dementia into long-term care. The intervention is applied to all informal caregivers and individuals with dementia receiving care.

The reduction in caregiving time from such a program is based on a study by Graff *et al.* (2008). The study showed that informal caregiver hours could be reduced by an average of 212.3 hours over a three month timeframe by providing a program of occupational therapy to individuals living with dementia and their informal caregivers targeting improvement in:

- informal caregiver competence, skills and communications strategies for supervision of activities of daily living;
- coping strategies for patient behaviours and the overall burden of care.

An informal caregiver support program has also been shown to impact admissions into long-term care by delaying the time to admission. These effects are modeled based on a study by Mittleman *et al.* (2006). The study showed that admission of individuals living with dementia in long-term care facilities could be delayed by a median of 557 days by providing a counselling and support intervention program for spousal caregivers. Based on these findings, this scenario assumes that Canadians who would have been admitted to long-term care under the Dementia Base Case scenario (no intervention) will do so after a 557 day delay. It further assumes that the impact on all types of informal caregivers parallels that of the spouses in the study.

Exhibit 20 and Exhibit 21 provide a summary of the two sources of value which can be expected from this intervention over the next 30 years. Exhibit 20 focuses on the benefits of delaying institutionalization, and Exhibit 21 on the reduction in caregiving time.

- A caregiver support program that delays admission into long-term care is expected to lessen the pressures placed on long-term care resources producing significant savings in health costs. With fewer people admitted into long-term care, there will be more people residing within the community receiving community-based care and informal care. While this would shift costs to caregivers by increasing unpaid caregiver opportunity costs and indirect costs associated with dementia and informal care, the savings in direct health costs more than compensates, thus producing a significantly lower Total Economic Burden, as compared to the Base Case.
- The caregiver support program is expected to reduce economic burden for informal caregivers. As compared to the Base Case, this is expected to produce significant savings in unpaid caregiver opportunity costs as well as in indirect costs associated with informal care provision.

<sup>22</sup> Note that Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

## Exhibit 20 Intervention 3: Support – Caregiver Development & Support Program, Impact on Dementia Burden: 2008-2038

Benefit 1: Impact of Delaying Admission into Long-Term Care

Intervention 3: Support –Caregiver Development & Support Program Impact on Dementia Burden: Benefit 1: Impact of Delaying Admission to Long-Term Care (LTC) Intervention Scenario vs. Base Case					
Year	Health Care Utilization (Ages 65+)				
	Prevalence of Dementia in Long-term Care				
2018	-8,813				
2028	-13,355				
2038	-14,270				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$4,720,740,315	\$2,241,144,070	\$14,345,869	\$3,533,610	-\$2,461,716,766
2028	-\$12,363,624,312	\$5,709,864,958	\$54,358,941	\$12,846,813	-\$6,586,553,600
2038	-\$22,534,463,075	\$10,072,095,845	\$135,646,031	\$31,457,453	-\$12,295,263,746

## Exhibit 21 Intervention 3: Support – Caregiver Development & Support Program, Impact on Dementia Burden: 2008-2038

Benefit 2: Impact of Reducing Informal Caregiving Burden

Intervention 3: Support –Caregiver Development & Support Program Impact on Dementia Burden: Benefit 2: Impact of Reducing Informal Caregiving Burden Intervention Scenario vs. Base Case				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)			
	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$10,231,165,526	-\$39,164,418	-\$9,507,720	-\$10,279,837,664
2028	-\$26,715,147,944	-\$144,407,047	-\$33,937,116	-\$26,893,492,107
2038	-\$50,173,500,166	-\$305,146,802	-\$70,732,866	-\$50,549,379,834

### Short-term Impact

In the short-term (10 years), helping caregivers develop coping skills and build competencies in their caregiving roles would result in:

- over 8,810 fewer Canadians (65+) living with dementia in long-term care (a 4.8% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than \$12.7 billion (in 2008 dollars);  
(a 5.3% reduction from the Base Case);
  - more than \$ 2.4 billion (-1.0%) due to delaying institutionalization;
  - more than \$10.2 billion (-4.3%) due to reducing informal caregiver burden.

## Long-Term Impact

In the long-term (30 years), helping caregivers develop coping skills and build competencies in their caregiving roles would result in:

- Over 14,270 fewer Canadians (65+) living with dementia in facility-based care (a 3.2% reduction from the Base Case);
- A reduction in the cumulative Total Economic Burden of more than \$62.8 billion (in 2008 dollars) (a 7.2% reduction from the Base Case);
  - More than \$12.2 billion (-1.4%) due to delaying institutionalization;
  - More than \$50.5 billion (-5.8%) due to reducing informal caregiver burden.

## Intervention 4: Support – System Navigator/Case Management<sup>22</sup>

The fourth scenario examines the impact of assigning a system navigator (case manager) to each newly diagnosed person with dementia in order to provide care coordination to individuals with dementia and support to informal caregivers. The intervention is applied to all individuals with dementia and their informal caregivers.

The effects of a system navigator are estimated and modeled based on the Lewisham Case Management Scheme from a study by Challis *et al* (2002). This study showed that individuals with dementia, and their caregivers, who had received an intensive care management service that brought together secondary health care in the community and intensive care management, remained in the community longer, led to a reduced informal caregiver burden and reduced overall costs compared to individuals receiving usual care. The study concluded that a system navigator would delay long-term care admission by two years and would reduce informal caregiving hours.

Exhibits 22 and 23 provide a summary of the value of the intervention over the next 30 years. Exhibit 22 focuses on the benefits of delaying institutionalization, and Exhibit 23 on the reduction in caregiving time.

- It is anticipated that providing system navigation support would delay admission into long-term care, lessen the pressure placed on those resources, and produce significant savings in health costs. As in Intervention 3, this would result in more individuals with dementia relying on community-based care and informal care resources, and an increase in unpaid caregiver opportunity costs and indirect costs. However, as in the previous scenario, the savings in direct health costs would more than compensate, producing a significantly lower Total Economic Burden compared to the Base Case.
- It is anticipated that providing system navigation support would reduce the financial burden on informal caregivers. As compared to the Base Case, this would produce significant savings in informal caregiver opportunity costs, as well as the indirect costs associated with informal care provision throughout the simulated timeframe.



## Exhibit 22 Intervention 4:Support - System Navigator,Impact on Dementia Burden: 2008-2038

### Benefit 1:Impact of Delaying Admission into Long-Term Care

Intervention 4: Support –System Navigator:Impact on Dementia Burden Benefit 1:Impact of Delaying Admission into Long-Term Care Intervention Scenario vs. Base Case					
Year	Health Care Utilization (Ages 65+)				
	Prevalence of Dementia in Long-Term Care				
2018	-11,691				
2028	-17,708				
2038	-19,093				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$6,154,810,083	\$2,921,162,482	\$16,229,642	\$3,991,095	-\$3,213,426,864
2028	-\$16,275,405,812	\$7,514,362,369	\$67,633,929	\$15,953,949	-\$8,677,455,565
2038	-\$29,827,007,373	\$13,326,371,848	\$174,806,333	\$40,490,895	-\$16,285,338,297

## Exhibit 23 Intervention 4:Support - System Navigator,Impact on Dementia Burden: 2008-2038

### Benefit 2:Impact of Reducing Informal Caregiving Burden

Intervention 4: Support –System Navigator:Impact on Dementia Burden Benefit 2:Impact of Reducing Informal Caregiving Burden Intervention Scenario vs. Base Case				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)			
	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-\$19,767,575,038	-\$62,551,207	-\$15,186,335	-\$19,845,312,580
2028	-\$51,616,180,998	-\$226,717,455	-\$53,295,581	-\$51,896,194,034
2038	-\$96,939,926,041	-\$464,702,999	-\$107,775,061	-\$97,512,404,101

## Short-term Impact

In the short-term (10 years), providing system navigation support for individuals with dementia and their caregivers would result in:

- over 11,690 fewer Canadians (65+) living with dementia in long-term care (a 6.4% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than \$23.0 billion (in 2008 dollars) (a 9.7% reduction from the Base Case);
  - more than \$ 3.2 billion (-1.4%) due to delaying institutionalization;
  - more than \$19.8 billion (-8.3%) due to reducing informal caregiver burden.

## Long-Term Impact

In the long-term (30 years), providing system navigation support for individuals with dementia and their caregivers would result in:

- over 19,090 fewer Canadians (65+) living with dementia in long-term care (a 4.3% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than \$113.7 billion (in 2008 dollars) (a 13.0% reduction from the Base Case);
  - more than \$16.2 billion (-1.9%) due to delaying institutionalization;
  - more than \$97.5 billion (-11.2%) due to reducing informal caregiver burden.

## Intervention Value Comparisons

**Exhibit 24 Impact of Interventions on Dementia Prevalence**

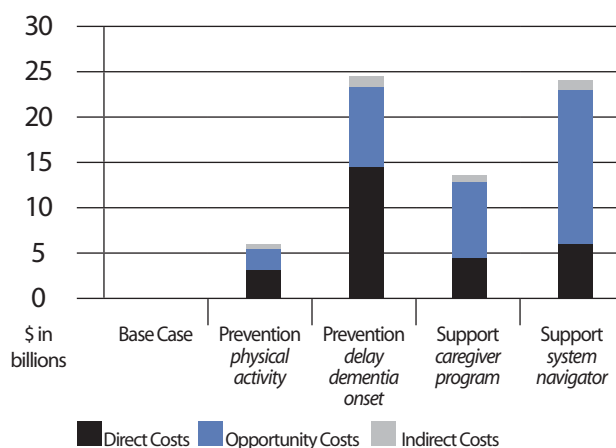
Years 2008 through	Intervention 1 Prevention: Increased Physical Activity		Intervention 2 Prevention: Hypothetical Program to Delay Dementia Onset	
	Simulated Value	% of Base Case	Simulated Value	% of Base Case
2018	-32,454	-5.1%	-137,502	-21.6%
2028	-64,189	-7.6%	-269,736	-31.8%
2038	-96,412	-8.6%	-409,647	-36.4%

**Exhibit 25 Cumulative Impact of Interventions on Total Economic Burden (2008 dollars)**

Years 2008 through	Intervention 1		Intervention 2 Prevention: Hypothetical Program to Delay Dementia Onset		Intervention 3 Support: Caregiver Development and Support Program		Intervention 4 Support: System Navigator	
	Simulated Value	% of Base Case	Simulated Value	% of Base Case	Simulated Value	% of Base Case	Simulated Value	% of Base Case
2018	-\$ 5,665,409,639	-2.4%	-\$ 24,208,421,497	-10.1%	-\$12,741,554,430	-5.3%	-\$ 23,058,739,444	-9.7%
2028	-\$22,872,692,489	-4.5%	-\$ 96,709,989,184	-19.1%	-\$33,480,045,707	-6.6%	-\$ 60,573,649,599	-12.0%
2038	-\$51,819,523,210	-5.9%	-\$218,631,652,707	-25.1%	-\$62,844,643,580	-7.2%	-\$113,797,742,398	-13.0%

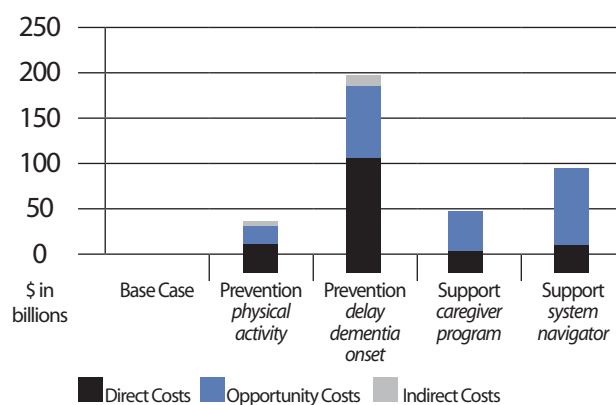
Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

## Exhibit 26 Cumulative 10-year Impact of Interventions on Total Economic Burden (2008 dollars)



Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

## Exhibit 27 Cumulative 30-year Impact of Interventions on Total Economic Burden (2008 dollars)



Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

## Scenario Analysis Conclusions

*Rising Tide* has looked at how dementia policy and program interventions could help to address the dementia challenge through prevention and support strategies to individuals living with dementia and their informal caregivers. The value potential of each scenario has highlighted how dementia prevention and management could reduce the health and economic burden of dementia.

The intervention scenarios demonstrate that:

- increasing by 50% the activity level of Canadians (65+) who are already active would yield a 30-year reduction in Direct Health Costs of \$31 billion and a reduction in Total Economic Burden of \$52 billion;
- delaying onset of dementia by two years would yield a 30-year reduction of \$219 billion in Total Economic Burden, along with a reduction in prevalence of 410,000 individuals – a 36% reduction from the Base Case;
- helping caregivers develop coping skills and build competencies in their caregiving roles would yield a 30-year value of \$63 billion<sup>22</sup>;
- providing system navigation support to individuals with dementia and their caregivers would yield a 30-year value of \$114 billion<sup>22</sup>;

- the Life at Risk® platform provides a useful assessment and comparison tool for conducting evidence-based strategic options and policy analysis.

Each of the scenarios delivers considerable value, clearly indicating that an effort to devise an intervention or set of interventions warrants attention.

The two prevention strategies presented were shown to produce significant benefits from a population health perspective. These scenarios were estimated to significantly reduce the number of individuals living with dementia by 2038. With fewer Canadians living with dementia, the burden placed on health care resources across all types of care would be reduced, producing substantial savings for Canadian governments and society.

The two support interventions focused on providing help to individuals living with dementia and their informal caregivers were also shown to provide significant economic relief. The scenarios presented show substantial savings by delaying admission to long-term care facilities for individuals with dementia. Beyond the reduction in demand for long-term care resources, there are additional emotional and quality of life benefits due to the decrease in informal caregiver burden.

## **A Valuable Tool for Policymakers**

The Dementia Base Case makes the magnitude of the population health and economic burden of dementia undeniable and reinforces the urgent need for a national dementia strategy to guide, manage and mitigate the health, economic and social impacts of dementia. These intervention scenarios clearly illustrate how the Dementia Base Case can also be used to assess and compare the relative value of alternative options.

There is a great deal of work to be done; this is only a starting point, but a crucial one. The Dementia Base Case provides policymakers and health care decision-makers with a vitally important model for gauging the impact of a comprehensive Canadian dementia strategy.

# What Has Been Done

- What has been done elsewhere
- Current Approaches in Canada
- Leading Concepts and Models



# What Has Been Done

## Policy Analysis

The final phase of *Rising Tide* involved looking at existing and emerging policy responses to the dementia epidemic in other countries and in different parts of Canada. A rich range of options have already been applied, which helps to broaden the understanding of what can be done. In addition, *Rising Tide* takes a brief look at two of the leading concepts and models on which many of these options are based.

The analysis concludes with recommendations for consideration. These recommendations, if adopted by policymakers and decision makers in Canada, will reduce the disease's impact on Canadian society.

## What Has Been Done in Other Countries?

There are more than 35 million people living with dementia in the world at this time<sup>23</sup>. It is estimated that by 2050, this number will increase to 115 million people. Owing to a number of factors – ageism, stigma associated with mental disorders, the recency of treatment options – policy responses have been dismal in most countries, with however a few notable exceptions.

Australia, Norway, the Netherlands, France, and the United Kingdom have each developed specific plans or frameworks for dealing with dementia, largely directed at greater integration of health and social policies; establishing more home-based programs; adapting care facilities to better meet the needs of residents with dementia; providing education for people with dementia, their families, health professionals and the public; and investing in research. In 2008, the Council of the European Union passed a number of resolutions committing the European Parliament to support European action to combat neurodegenerative diseases, particularly Alzheimer's disease.

In March 2009, the Ontario Ministry of Health and Long-Term Care prepared a literature review looking for relevant government policies addressing neurological conditions, including Alzheimer's disease and other dementias. Of the eleven countries examined, only one – the United Kingdom (UK) with its National Service Framework (NSF) for Long-Term Conditions – has adopted an explicitly integrated framework to address all long-term neurological conditions. The report identified that “dementia is a relatively new area of policy focus and few countries have specific policies to address the disorder<sup>24</sup>.”

A comparative analysis of dementia care in OECD countries was conducted in 2004<sup>25</sup>. The following common elements of their national dementia policies were identified:

- delaying institutionalization, enabling individuals to remain at home as long as possible;
- supporting caregivers in order to delay the move of individuals living with dementia to long-term care;
- giving individuals living with dementia as much control over their care as possible, while recognizing limitations due to cognitive impairment (e.g., in relation to having the capacity to make informed choices);
- equating service provision with need;
- promoting early diagnosis;
- co-ordinating services at the local level where possible;
- making long-term care, when required, as home-like as possible.

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<sup>23</sup> 2010 figures. *World Alzheimer Report*. Alzheimer's Disease International. September: 2009.

<sup>24</sup> *A Rapid Literature Review of Government Policies for Addressing Neurological Diseases*. Ministry of Health and Long Term Care. Toronto, ON: 2009.

<sup>25</sup> Moise, P., Schwarzing, M., Um, M., and the Dementia Experts' Group. “Dementia Care in Nine OECD Countries: A Comparative Analysis.” *OECD Health Working Papers*. OECD (Organization of Economic Development and Co-ordination), 2004.

## A Survey of Dementia Priority Policies

The dementia-specific policies of six countries that have made dementia a health priority were reviewed by the Alzheimer Society and are summarized below. Each offers valuable lessons when considering Canada's needs.

Country	Research	Improved Care	Caregiver Support	Workforce
Australia (2006-2010)	<ul style="list-style-type: none"> <li>• Collaborative research centres</li> <li>• Additional research funding</li> <li>• Prevention focus</li> </ul>	<ul style="list-style-type: none"> <li>• Primary care guidelines</li> <li>• Expanded psycho-geriatric consults</li> <li>• Early intervention</li> <li>• Helpline</li> <li>• Memory community centres</li> </ul>	<ul style="list-style-type: none"> <li>• Training</li> <li>• Home care support for behaviour problems</li> </ul>	<ul style="list-style-type: none"> <li>• Training</li> </ul>
The Netherlands (2008-2011)		<ul style="list-style-type: none"> <li>• Case management</li> <li>• Transportation to care settings</li> <li>• Peer support (Alzheimer café)</li> <li>• Helpline</li> <li>• Care hotels</li> <li>• Cluster housing with home automation</li> <li>• Client/person-centred policy development</li> </ul>	<ul style="list-style-type: none"> <li>• Respite care programs, temporary stays, holidays</li> </ul>	
Norway (2006- 2015)	<ul style="list-style-type: none"> <li>• Research in quality development</li> </ul>	<ul style="list-style-type: none"> <li>• Day programs</li> <li>• Adapted living facilities</li> </ul>	<ul style="list-style-type: none"> <li>• Partnerships with providers, families and communities</li> </ul>	<ul style="list-style-type: none"> <li>• Raising skills and knowledge</li> <li>• Improving collaboration among professionals</li> <li>• National standards to improve medical services in nursing homes</li> </ul>
France (2008-2012)	<ul style="list-style-type: none"> <li>• Partnerships/ network establishment</li> <li>• Additional funding</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated access points</li> <li>• 1,000 new case managers</li> <li>• In-home specialist teams</li> <li>• Helpline</li> </ul>	<ul style="list-style-type: none"> <li>• Respite care programs</li> <li>• Strengthening of caregiver rights, education, support for return to work</li> <li>• Improving health monitoring of caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Developing skill sets in all care professionals</li> <li>• Developing new competencies – case managers, gerontology assistants</li> </ul>



Scotland (2008-2011)	<ul style="list-style-type: none"> <li>• Increased funding for research</li> <li>• Network establishment</li> </ul>	<ul style="list-style-type: none"> <li>• Early diagnosis, intervention</li> <li>• Post-diagnostic support</li> <li>• Integration of palliative care</li> </ul>	<ul style="list-style-type: none"> <li>• Information</li> </ul>	<ul style="list-style-type: none"> <li>• Developing skill sets in all care professionals</li> <li>• Developing new competencies – case managers, gerontology assistants</li> </ul>
United Kingdom (2009-2014)	<ul style="list-style-type: none"> <li>• Increased funding for dementia care research</li> </ul>	<ul style="list-style-type: none"> <li>• Early diagnosis and intervention</li> <li>• Public information to promote help-seeking</li> <li>• Easy access to care</li> <li>• Peer support</li> <li>• Specialist home care services</li> <li>• Improved care for individuals with dementia in general hospitals</li> <li>• Housing support</li> <li>• Helpline (Telecare)</li> <li>• Improved end-of-life care</li> <li>• Development of a comprehensive model of care</li> </ul>	<ul style="list-style-type: none"> <li>• Information</li> <li>• Carer needs assessment</li> <li>• Carer strategy</li> </ul>	<ul style="list-style-type: none"> <li>• Training, continuing professional development in dementia for care professionals</li> </ul>

There are several common elements in the policies of these countries. All of these strategies are recent. Most acknowledge the importance of investing in research, supporting caregivers in their role and improving the skills of professionals who provide care to individuals with dementia. Strategies to improve the delivery of care to individuals with dementia include focusing on early diagnosis and intervention, using case management, increasing specialized home care, and making information about the disease widely available through channels such as health helplines.

A comparison of national dementia strategies also reveals some unique features such as:

- the call for a national priority in the United Kingdom with cross-government strategy development;
- the concept of Alzheimer holidays, hotels, farms in the Netherlands;
- the Dutch concept of building the national strategy on the foundation of problems identified, experienced and prioritized by individuals with dementia and their caregivers;
- the French concept of mobilizing society for the fight against dementia;
- the French goal of making dementia a European priority.



# The Current Situation in Canada

## At the Federal Level

The role of the Government of Canada in the provision of health services is limited to specified populations, namely: First Nations and Inuit, members of the Canadian Armed Forces, veterans, federal public servants working abroad and inmates of federal correctional facilities. Veterans Affairs Canada has received accolades from the health policy community for its Veterans Independence Program (VIP).

From a \$2.9 billion annual budget of Veterans Affairs Canada, \$303 million goes to the Veterans Independence Program to provide home care and support to 102,154 of Canada's 197,460 war service veterans. The average age of these veterans is 84; only 4,190 occupy long-term care beds. The Veterans Independence Program helps to keep them living independently in their own homes by paying for such services as housekeeping and grounds maintenance. The average cost per person for VIP home care is about \$2,680 a year, compared with \$43,000 a year for a room in an Ontario care facility or up to \$1,000 a day in hospital<sup>26</sup>.

The federal government also provides financial aid of up to \$4,095 per year to caregivers who are caring for elderly parents or grandparents, or adult dependents that are dependent due to mental or physical impairment. Caregivers may also claim medical expenses of up to \$10,000 per year, including respite care and attendant care.

The federal government's most significant role in dementia is the funding of dementia research, primarily through the Institute of Aging of the Canadian Institutes of Health Research (CIHR). Over the past decade, CIHR has significantly increased annual funding for dementia research from approximately \$4.5 million to \$20 million.

As in many countries, progress in policy development is impeded by lack of clarity as to which department is to take responsibility for dementia policy. Should it be the department responsible for seniors' issues, for chronic diseases or for mental health? As a consequence, policy for the management of dementia has been disjointed.

## At the Provincial Level

Likewise, no provincial government has a department that deals strictly with dementia. Each jurisdiction has found its own way to deal with the management of dementia, whether through mental health policy, through their seniors' department, long-term care or chronic disease management.

Most provinces and territories have policies with respect to long-term care facilities, respite care and other publicly funded or administered services used by individuals living with dementia. The few dementia-specific strategies/policies that have been implemented in Canada are described below. So far, in the context of provincial dementia strategies, only Ontario has attached significant funding in support of strengthening dementia care.

## British Columbia

The province of British Columbia worked with key stakeholders in 2007 to develop the *BC Dementia Service Framework*<sup>27</sup> to guide service delivery improvements with a view to system change. Recommendations were developed for action by the public, health service providers and decision-makers, as well as policymakers. An analysis of the current system of dementia care in BC identified seven critical gaps, including:

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<sup>26</sup> Steed, Judy. "Small Mercies." Toronto Star. 8 Nov 2008. <http://www.thestar.com/atkinson2008/article/532165>.

<sup>27</sup> B.C. Dementia Services Framework. British Columbia Ministry of Health (2007). [http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework\\_PDF.aspx](http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework_PDF.aspx)

- in the health care system's capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers;
- in the number of health care providers with expertise in elder and dementia care for people with dementia and their families/caregivers;
- in the knowledge of health care providers about dementia as a chronic condition and about best practices in dementia care;
- in the policy that mitigates the impact of dementia on the people with dementia and their families/caregivers, and on the communities they live in;
- in the recognition of the role of families and caregivers as partners on the care team;
- in the capacity and ability of the acute care setting to meet the needs of people with dementia;
- in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.

Policy solutions recommended include:

- developing a research agenda on dementia and best practices on dementia care and services;
- developing a policy lens for the review of all policy to ensure that new policies are beneficial to individuals with dementia, including incorporating the view of dementia as a chronic condition for which chronic disease prevention and management is an appropriate framework;
- reducing stigma associated with dementia;
- improving the knowledge of health care providers about dementia;
- fostering innovation in models of service delivery.

## Manitoba

In October 2002, Manitoba Health released *A Strategy for Alzheimer Disease and Related Dementias*<sup>28</sup> in Manitoba. The strategy was developed through an extensive consultation process co-chaired by Manitoba Health and the Alzheimer Society of Manitoba. The consultation was interdisciplinary and included representation from all Regional Health Authorities, and a variety of senior serving organizations. The goal was to provide the best possible care and support to Manitobans affected by Alzheimer's disease and related dementias and their caregivers, through the continuum of the disease. The strategy focused on the following nine areas of change:

- education for professionals, paraprofessionals, families, individuals, communities and the general public;
- guidelines for diagnosis;
- standards across all programs and services;
- family and individual support;
- comprehensive programs and services for individuals in community facilities;
- case management and interdisciplinary collaboration;
- equitable access to programs and services across Manitoba;
- human resources issues including recruitment, retention and remuneration; and
- ongoing, rigorous research and evaluation.

## Saskatchewan

In 2005, the Minister of Health of Saskatchewan released *A Strategy for Alzheimer Disease and Related Dementias* in Saskatchewan, which was developed jointly with the Alzheimer Society of Saskatchewan and contains 60 recommendations focused on seven goals.

<sup>28</sup> Mattus, Hope and Wendy Schettler et al. *A Strategy for Alzheimer Disease in Manitoba*. October, 2002: <http://www.gov.mb.ca/health/documents/alzheimer.pdf>.

1. Public awareness and education.
2. Diagnosis and treatment.
3. Support for individuals and caregivers.
4. Supportive environments.
5. Programs and services.
6. Education and training.
7. Research.

## **Ontario**

Canada's first comprehensive strategy on Alzheimer's disease and related dementias (ADRD) was initiated in Ontario in 1999, with \$68.4 million invested in the strategy over the next five years<sup>29</sup>. The Strategy, under the auspices of the Ministry of Health and Long-Term Care and the Ontario Seniors' Secretariat, had the following goals:

- to support and improve the quality of life of individuals with ADRD and their caregivers;
- to improve treatment, care and environmental conditions of individuals with ADRD;
- to increase public awareness of dementia and the services available; and
- to develop linkages between the initiatives within the strategy.

### ***Ten initiatives support these goals:***

1. Staff education and training.
2. Physician training.
3. Increasing public awareness, information and education.
4. Planning for appropriate, safe and secure environments.
5. Respite services for caregivers.
6. Research on caregiver needs.
7. Advance directives<sup>30</sup> on care choices.
8. Psycho-geriatric consulting services.
9. Dementia networks, a research coalition, and specialized geriatric services.
10. Intergenerational volunteer initiative.

Since the implementation of the strategy, the Ontario government has funded the establishment of the Alzheimer Knowledge Exchange (AKE), a clearinghouse for current ADRD knowledge along with a resource for e-learning and web-based support for knowledge exchange. As well, services to individuals with dementia are being improved through the province's Aging at Home Strategy.

## **Quebec**

The Quebec government announced that it will implement recommendations that Alzheimer's disease and related dementias be regarded as chronic conditions<sup>31</sup> and integrated into the ministerial action plan for 2010–2015, which identifies chronic conditions as a priority. The report also asserts that the Ministry must work with academia to develop guidelines and practice tools for the management of dementia through collaboration with the planned National Institute for Excellence in Health and Social Services (INESSS).

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<sup>29</sup> Ontario's Strategy for Alzheimer Disease and Related Dementias. The Queen's Printer for Ontario, 2005.  
<http://www.culture.gov.on.ca/seniors/english/programs/alzheimer/initiatives.shtml>

<sup>30</sup> Advanced care directives are specific instructions, prepared in advance, intended to direct a person's medical care in the event that he/she is unable to do so in the future.

<sup>31</sup> Bergman, Howard. Relever le défi de la maladie d'Alzheimer et des maladies apparentées : Une vision centrée sur la personne, l'humanisme et l'excellence.

The recommendations have been made in the context of significant health system reform in Quebec, including the creation of integrated services delivered through health and social service centres (CSSS), along with family medicine groups (GMF) and clinical networks.

The plan defines seven Priority Actions and a further 24 recommendations related to dementia.

1. Raise awareness, inform and mobilize.
2. Ensure the availability of locally-responsive, personalized and coordinated services and evidence-based treatment for individuals with dementia and their caregivers.
3. In advanced stages of the disease, promote quality of life, provide access to home support.
4. Promote quality end-of-life care, in accordance with the wishes of the client and family, and characterized by dignity and comfort.
5. Provide services to family caregivers, considered partners in support.
6. Develop and support professional practice.
7. Mobilize an unprecedented research effort.

### **Newfoundland & Labrador**

In 2001, the province of Newfoundland and Labrador, working with the Alzheimer Society of Newfoundland and Labrador, developed a *Provincial Strategy for Alzheimer Disease and other Dementias*, with four goals.

1. A coordinated system of care.
2. Access to current information on Alzheimer's disease and other dementias.
3. Support for individuals with Alzheimer's disease and other dementias, and their families/caregivers.
4. Education and skill development.

### **General Agreement on Key Elements**

A review of dementia strategies from several countries and several Canadian provinces reveals general agreement on key elements to be factored into any comprehensive dementia strategy:

- the public needs better access to information to increase awareness, to overcome stigma, and to seek help such that early interventions can be initiated;
- people who provide care to individuals with dementia need knowledge support to ensure that dementia is recognized and that the professionals know what treatments and care strategies are appropriate for different stages in the disease;
- caregivers need help to cope, including, reducing the financial disincentives to fulfill caregiving roles and ensuring that caregivers are supported with respite and training are critical features;
- case management and system navigation are becoming important features of dementia strategies;
- organizing services along the lines of the chronic disease prevention and management model is congruent with current policy direction in several provinces;
- continued investment in research is a common feature.

### **Leading Concepts and Models**

Before looking at individual strategies that Canada should consider in dealing with the dementia epidemic, it is helpful to understand the leading concepts and models that are already accepted or are currently being implemented. A national policy response should work in concert with these leading concepts and models.

## Integrated Models of Care

The goal of integrated models of care is to improve coordination of care for individuals who are reliant on a complex array of specialized medical, community and social services. One of the most significant concerns voiced by patients and caregivers who are frequent users of health services, is that care is uncoordinated and it can be difficult to tell who, if anyone, is in charge. In short, the system is difficult to navigate.<sup>32</sup>

Integrated models of care are a response to a disjointed maze of health care services. In an integrated model, health care service delivery systems are redesigned to formally align primary care and acute care with a network of community support services for improved efficiency and effectiveness.

There is a considerable body of literature on the subject of integrated models of care to draw upon. Researchers have used the experience of 250 provincial policymakers involved in redesigning health care service delivery systems to identify best practices<sup>33</sup>, and others have created a framework<sup>34</sup> describing the philosophical and policy prerequisites, clinical best practices and linkage mechanisms necessary for successful care coordination across all settings.

In brief, the models of care found to be most effective at improving outcomes, client satisfaction and/or cost effectiveness tend to have the following features:<sup>35</sup>

- umbrella organizational structures that guide, support, maintain, and are accountable for integration, service delivery and quality and cost outcomes;
- multidisciplinary case management, a single entry point into the health care system, and packaging and coordinating services;
- organized provider networks joined together by standardized procedures, service agreements, joint training, shared information systems and even common ownership of resources;
- financial incentives to promote prevention, rehabilitation and the downward substitution of services, as well as to enable service integration and efficiency.

## SIPA – An Example of Integrative Care for the Elderly

An example of an effective Canadian program of integrated care for elderly clients with disabilities is SIPA (French language acronym for Integrated System of Care for Older Persons) in Montreal. When compared against usual care, researchers found that SIPA increased accessibility for health and social home care, reduced hospital alternate level of care beds<sup>36</sup> by 50%, and increased caregiver satisfaction, while increasing community costs about the same amount as institutional costs were reduced. The researchers concluded that this model has the potential to reduce long-term care facility and hospital utilization without increasing cost.<sup>37</sup>

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<sup>32</sup> Who is the Puzzle Maker? *Patient/Caregiver Perspective on Navigating Health Services in Ontario*. The Change Foundation, June 2008. [http://www.changefoundation.ca/docs/ChgFdn\\_Puzzle\\_Web.pdf](http://www.changefoundation.ca/docs/ChgFdn_Puzzle_Web.pdf).

<sup>33</sup> MacAdam, Margaret. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks, 2008. [http://www.cprn.org/documents/49813\\_EN.pdf](http://www.cprn.org/documents/49813_EN.pdf).

<sup>34</sup> Hollander, Marcus J. and Michael J. Prince. "Organizing Healthcare Delivery Systems for Persons with Ongoing Care Needs and Their Families: A Best Practices Framework." *Healthcare Quarterly*, 11.1 (2008): 45-54.

<sup>35</sup> MacAdam, Margaret. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks, 2008. [http://www.cprn.org/documents/49813\\_EN.pdf](http://www.cprn.org/documents/49813_EN.pdf).

<sup>36</sup> The concept of "alternate level of care" (ALC) is a key hospital utilization and health system performance indicator. An ALC bed represents a bed occupied by a patient whose acute care is complete, but the patient has not been transferred to a more appropriate level of care, whether at home (with or without home care) or in a long-term care facility.

<sup>37</sup> Beland, Francois, Howard Bergman and Paule Lebel, et al. "A System of Integrated Care for Older Persons with Disabilities in Canada: Results from a Randomized Controlled Trial." *Journal of Gerontology*, 61A.4 (2006): 367-373.

## Chronic Disease Prevention and Management

The basic tenet of the chronic disease prevention and management concept is productive interactions between informed active patients and prepared, proactive practice teams. It is patient-centred and designed specifically to improve care for individuals with chronic conditions.

Conventional health care systems were designed to manage short episodes of acute care and simply do not respond well to the challenges of chronic care. In coping with chronic conditions, the acute care model is expensive, fails to get at root causes of illness or disease, lacks continuity and is frustrating and expensive for patients. Therefore, as many jurisdictions struggle to deal with rising incidence of chronic conditions, they are turning to the chronic care model.

Since its development in the early 1990's, the Chronic Care Model<sup>38</sup> (also known as the "chronic disease model" or "Wagner model") has become a policy cornerstone in several countries and is a key policy feature in British Columbia, Alberta, and Ontario.

The Chronic Care Model emphasizes case management, defined roles for all team members, and coordination of care across multiple health providers and health settings. It includes planned visits with health care team members so that patients remain engaged in learning and managing their health/disease. As an integrated model of care, it requires a redesign of care delivery systems for seamless information sharing and case management.

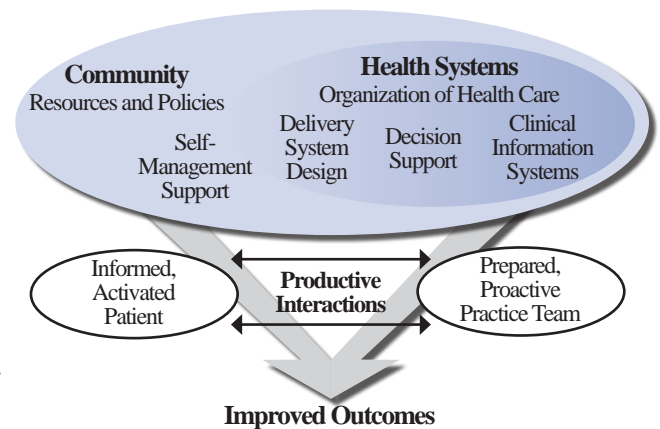
The Chronic Care Model makes better use of our already scarce health human resources as the use of allied health professionals, such as dietitians, nurses, etc., and redistributes resources to the most appropriate and cost-effective providers. As well, the length and number of emergency or acute care occurrences are reduced.

### Dementia and the Chronic Care Model

Dementia appears to be highly suitable to the core principles of chronic disease management. With earlier diagnoses, individuals with dementia and their families are in a good position to take on the task of self-management – learning about the disease, risk mitigation opportunities, intervention choices, and coping mechanisms.

In addition to the concept of self-management, roles are identified for family physicians, specialized experts (psychiatrists, geriatricians, neurologists, neuropsychologists), community resources providers (Alzheimer Society staff and volunteers) and family/informal caregivers – each plays an interdependent role, but all are working together. Since the Chronic Care Model uses the patient's unique situation as the starting point and marshals the resources needed to create and implement a care plan, co-morbid conditions would also be identified and incorporated into the team care approach.

### The Chronic Care Model



<sup>38</sup> Developed by Ed Wagner at the MacColl Institute for Health Care Improvement.



# How We Can Make a Difference

- Recommendations for a National Dementia Strategy



## How We Can Make a Difference

Canadians need a pan-Canadian response to the dementia epidemic that improves care at every stage. Other countries have risen to the challenge. Canada must do the same. To date, the record of tackling this challenge in Canada has been uneven: some provinces are without any dementia-specific policies, others have policies that have not been implemented. The few provinces that have made earnest efforts are still largely unprepared for the impending societal impact of dementia.

Clearly, something must be done.

There were more than 480,000 Canadians with dementia in 2008. This number will grow by 32% to 635,000 within 10 years, and by 77% to about 850,000 in a mere 20 years. Canadians are supporting their family members who have dementia through 230,000,000 hours of unpaid caregiving. By 2038, those caregiving hours will balloon to 756,000,000.

The current Economic Burden of \$15 billion per year will grow to \$153 billion per year (in future values) by 2038, if nothing is done to change the trajectory.

If dementia were stopped now, and all the money that would have been spent on it was put aside, including the income that caregivers forego to look after their family members, by 2038 it would equal \$872 billion (in 2008 dollars).

**We must take action now.** A pan-Canadian response is imperative if we are to meet this critical societal challenge.

Despite the lack of a national plan, Canada has valuable experience on which to build. A pan-Canadian response can and should leverage the experience of provinces that have put measures in place (Ontario), provinces with imaginative new ideas (Quebec), as well as the experience from other jurisdictions facing similar challenges. Canada's national dementia strategy must be developed in partnership with the Alzheimer Society, Canada's research community and federal/provincial/territorial governments.

## Improved Care at Every Stage of the Dementia Care Continuum

Before we look at the recommendations, it should be noted that improved care at every stage of dementia is an achievable goal. From risk reduction for healthy individuals to end-of-life care, promising options exist. The chart highlights these options by stage<sup>39</sup> – a useful consideration when aiming for a comprehensive dementia strategy. The options can be assessed in detail using research evidence and the Life at Risk® platform to compare their health and economic impacts, relative to cost of implementation.

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<sup>39</sup> Early in the project, a broad cross-section of experts was asked for advice in defining the dementia experience from beginning to end. The Dementia Care Continuum, used for this discussion and mapped in Appendix D is the product of this discussion



Care Continuum	Policy Option
Healthy individuals & individuals for whom a diagnosis has not been made	<ul style="list-style-type: none"> <li>• Promote brain health and encourage healthy lifestyle choices for risk reduction;</li> <li>• Make individuals aware of the impact of lifestyle choices on their cognition: healthy individuals as well as individuals with dementia;</li> <li>• Target research into prevention;</li> <li>• Ensure that health professionals are aware of risk factors and protective factors and can use this knowledge as the basis of advice to their patients.</li> </ul>
Referral	<ul style="list-style-type: none"> <li>• Governments need to work with universities and professional associations and colleges to ensure an adequate supply of geriatricians, geriatric psychiatrists, neurologists, neuropsychologists and other professionals necessary for the diagnosis, treatment and care of people with dementia;</li> <li>• Governments must work with universities and professional associations and colleges to ensure minimum competence in the diagnosis and treatment of dementia among primary care professionals.</li> </ul>
Diagnosis	<ul style="list-style-type: none"> <li>• Reduce stigma, so worried individuals will seek help;</li> <li>• Create opportunities for cognitive screening for MCI and dementia diagnosis for all at-risk Canadians (65+);</li> <li>• Ensure Canadians have access to quick, convenient, dignified diagnosis;</li> <li>• Support diagnostic education for primary care providers;</li> <li>• Improve access to specialized geriatric and neurological expertise to primary care providers through collaborative practices;</li> <li>• Ensure that diagnosis is conveyed in a sensitive, helpful way and that it is followed by treatment, care and access to information;</li> <li>• Provide support programs so all individuals newly diagnosed have proactive access to reliable services, including support and education;</li> <li>• Support research investigating the role of biomarkers and advanced imaging in the diagnosis of dementia.</li> </ul>
Co-morbid Conditions	<ul style="list-style-type: none"> <li>• Promote chronic disease management approaches such as multidisciplinary teams, use of registries, protocols, and guidelines for patient/caregiver self-management, so that dementia is identified and treated in the context of the many chronic conditions to which Canadians (65+) are prone;</li> <li>• Promote screening for depression in patients who have dementia, and for their caregivers;</li> <li>• Target research into the interplay between cognitive and other chronic conditions.</li> </ul>
Disease Management	<ul style="list-style-type: none"> <li>• Promote early detection and intervention;</li> <li>• Promote models of care that integrate primary care, hospital services, long-term care services and facilities, and community care;</li> <li>• Support case management, system navigation;</li> <li>• Ensure equitable access to appropriate medication;</li> <li>• Support research into new approaches to treatment and care.</li> </ul>

Caregiver Support	<ul style="list-style-type: none"> <li>• Monitor the health of caregivers;</li> <li>• Provide training and education for caregivers through the Alzheimer Society and/or regional health authorities;</li> <li>• Reduce the financial hardship associated with caregiving;</li> <li>• Create opportunities for respite, peer support.</li> </ul>
Long-Term Care	<ul style="list-style-type: none"> <li>• Ensure that long-term care is funded at a level that permits the availability of staff trained in understanding dementia, skilled in the management of the psychiatric and behavioural symptoms of dementia, and deployed to ensure that residents have days filled with social interaction, physical activity and nutritious meals;</li> <li>• Create national person-centred standards for care facilities;</li> <li>• Research the role of built space in enhancing the lives of residents with dementia.</li> </ul>
End-of-Life Care	<ul style="list-style-type: none"> <li>• Ensure that staff of hospitals, long-term care facilities, and home care and community agencies have access to palliative care support, including the management of pain in verbally non-communicative patients;</li> <li>• Promote advance directives.</li> </ul>

## Recommendations for Moving Forward

A Canadian dementia strategy must be comprehensive in scope and designed to reduce the impact of dementia on Canadian families, businesses, communities and governments. Jurisdictional dovetailing is key as each element in a program is dependent on the other elements.

While not wanting to limit the potential scope of a national strategy, the following is offered as a starting point of discussion as key features of a Pan-Canadian Response to the Dementia Epidemic.

1. Increasing the investment in dementia research.
2. Providing support for informal caregivers.
3. Emphasizing prevention and early intervention.
4. Building an integrated system of care.
5. Strengthening and supplementing the dementia workforce.

## #1 Increase the Investment in Dementia Research

A comprehensive strategy must include an accelerated investment in dementia research. Most of what we know about dementia care and treatment has been learned as a result of recent research investments. Research is paramount to managing the impending dementia epidemic.

### Canadian Expertise

Canada has some of the best dementia researchers at work in the world today. The accomplishments of these scientists and others are all the more notable when considering the modest investment made in dementia research. Canadian Institutes for Health Research (CIHR) is currently spending about \$21 million per year on dementia research (80% biomedical, 15% clinical) and the Alzheimer Society spends an additional \$3 million (approximately half for biomedical and half for “quality of life”). Canada’s strengths in Alzheimer’s disease research, described by CIHR’s CEO Alain Beaudet, includes “genetics, the biological basis of neurodegenerative processes, brain imaging, animal model development, early diagnostic tools, publicly and privately funded clinical trials, and long-term/end-of-life care<sup>40</sup>.” It is imperative that we leverage Canada’s dementia expertise to the fullest.

### International Partnerships

CIHR has recently developed a dementia focus – the International Collaborative Research Strategy for Alzheimer’s Disease (ICRSAD), which is becoming a productive international partnership. This should be encouraged and supported with new investment. International partnerships are particularly beneficial for prevention research because partnerships can pool larger study populations. To adequately understand the complex interplay of risk and protective factors, and to understand the role that prevention strategies may play in delaying onset of dementia or in preventing it outright, large cohort studies are essential.

### Prevention

Current efforts to find a cure are focused on individuals who have been identified as having dementia. Individuals with sufficient symptoms of dementia to warrant a diagnosis are already experiencing significant brain cell death. Real progress towards conquering dementia will be made when individuals most at risk can be identified and prevention interventions are initiated before symptoms show up. This will entail significant investment in research into biomarkers, advanced diagnostic imaging, as well as the cohort and prevention studies mentioned above.

### Psychosocial Research – Improving Quality of Life

Important research is also being done in the psychosocial field, emphasizing the importance of the quality of life for a person with dementia as well as their family caregivers. Quality of life research spans a wide array of topics ranging from: enhancing memory, cognitive abilities, language, and daily living activities; examining the impact of family caregivers; and supporting and enabling individuals with dementia. Further research is focused on quality of life at different stages of the disease and care levels, such as: meeting care needs at the community level, improving quality of care at the institutional level, and shifting to a person-centred care model in long-term care facilities.

In order to maintain Canada’s leadership role in dementia research, to reap the commercial benefits of discovery and improve the quality of life of Canadians, Canada needs to dramatically increase funding it makes available to its dementia scientists.

**In response to the dementia epidemic Canada must, as a minimum, triple dementia research spending.**

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<sup>40</sup> Alain Beaudet, in *Global Research in Alzheimer’s Disease*, Canadian Institutes of Health Research, 2009

## #2 Provide Support for Informal Caregivers

Support for caregivers, and clear recognition of the important role they play as care partners, is an essential component of any comprehensive strategy to deal with dementia. Compared with other chronic conditions, the demands of dementia on caregivers are particularly severe. An Ontario Home Care study reported that those providing informal care to persons with dementia are likely to spend 75% more time caregiving than those providing care to individuals with other conditions.<sup>41</sup>

However, caregivers report that they find the work rewarding and that, given the choice, they would want to continue doing it for as long as possible. Caregiving by family members helps keep families intact. As well, family caregivers are better able to recognize changes in symptoms and escalate attention as required.

Nevertheless, the task of caregiving can be unrelenting. When the role becomes unbearable, there are two frequent consequences: (1) the person with dementia moves to a long-term care facility; and (2) the caregiver's health is diminished and the individual requires health services themselves.<sup>42</sup> The job is hard – physically, emotionally, and financially. Caregiver stress has been shown to be a significant predictor of early institutionalization for the person with dementia.<sup>43</sup>

There is also growing international recognition that informal caregivers will be in short supply in the near future.<sup>44</sup> The shift in population growth to the very elderly means that spouses will be less able to perform caregiving duties. Younger family members will be less available as women's participation in the workforce continues to grow, and families are both smaller and more likely to live geographically apart. Finally, changing family norms are resulting in reluctance among younger people to look after frail elderly family members.

As a consequence, it is incumbent on governments to demonstrate that the work of caregivers is valued and that society makes it easier to continue providing care – through caregiver information and training, meaningful respite care and other programs that can support them in their roles as care partners, including financial support.

**The pan-Canadian response to the dementia epidemic must provide meaningful support to caregivers.**

## #3 Emphasize Prevention & Early Intervention

The scenario analysis demonstrates that a central feature of a pan-Canadian response to the dementia epidemic needs to be a focus on maintenance of brain health, prevention of dementia, delay of onset and early intervention. This is an area of exciting promise as there is new research evidence into the role of risk factors and protective factors. Epidemiological studies and animal models have demonstrated a link between a number of factors and reduced risk for dementia.

*Rising Tide* examined the impact of two prevention strategies in the Scenario Analysis: one that increased physical exercise of healthy Canadians (65+); the other a hypothetical prevention program that delayed dementia onset by 2 years. Both were shown to have significant impacts.

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<sup>41</sup> A profile of Ontario's Home Care clients with Alzheimer's Disease or Other Dementias. University of Waterloo, Ideas for Health, and the Alzheimer Society of Ontario.. 29 Sept 2008. <http://alzheimerontario.org/local/files/Web%20site/Public%20Policy/Profile-of-Home-Care-Clients-April-2007.pdf>

<sup>42</sup> World Alzheimer Report, Alzheimer Disease International, 2009.

<sup>43</sup> Fisher, L and M.A. Lieberman. "A Longitudinal Study of Predictors of Nursing Home Placement for Patients with Dementia: The Contribution of Family Characteristics." *Gerontologist*. 39.6 (1999): 677-686.

<sup>44</sup> Moise, P., Schwarzing, M., Um, M., and the Dementia Experts' Group. "Dementia Care in Nine OECD Countries: A Comparative Analysis." *OECD Health Working Papers*. OECD, 2004.

It isn't known whether the 2-year delay in onset would come from regular use of statins, anti-inflammatory agents, exercise or improvements in diet. What is clear is that the case for doing further research and applying the risk reduction knowledge already available is beyond a doubt.

In addition, greater emphasis on early intervention is needed. Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties.<sup>45</sup> Early detection also offers opportunities for early treatment, more self-management, greater education and support, all of which can improve quality of life for those directly involved while reducing the heavy societal costs associated with institutionalization.

**A pan-Canadian response to the dementia epidemic must focus on maintenance of brain health, prevention of dementia, delay of onset and early intervention.**

#### **#4 Build an Integrated System of Care**

As a leading health policy concept specifically suited to the impending dementia epidemic, Canada's National Dementia Strategy must establish integrated models of care as a priority across all jurisdictions. Only then will there be real improvement in care for Canadians who need complex arrays of specialized medical, community and social services, including individuals with dementia.

Health care service delivery systems must be redesigned to formally align primary care and acute care with a network of community support services. Integrative models of care, as a focus of our national strategy, would facilitate the use of research to reduce or delay incidence, to help caregivers perform their role, and to organize services in the community in order to reduce long-term care facility utilization.

Governments across Canada should seed innovation in integrated systems of community care, such as the SIPA initiative mentioned earlier. Hallmarks of a national integrated system of care strategy would include:

- consistency with the care coordination best practices described by Hollander and Prince (2001; 2008);
- clearly defined community-specific relationships among home care, community services including the Alzheimer Society, hospital services, primary care, residential care, hospice and specialized geriatric services, with well-defined roles for each, yet with common philosophies of care, protocols, and guidelines;
- case management to ensure that the various integrated pieces are well-coordinated from the individual's perspective;
- a focus on prevention;
- facilitating early intervention;
- building a chronic disease prevention and management framework;
- mandating dementia-friendly residential care.

**The pan-Canadian dementia strategy must foster greater integration of care and increased use of accepted frameworks or "best practices" in chronic disease prevention and management, community support and community care coordination.**

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<sup>45</sup> Sternberg, S.A., Wolfson, C., & Baumgarten, M. "Undetected Dementia in Community-Dwelling Older Individuals: The Canadian Study of Health and Aging". *Journal of the American Geriatrics Society*. Vol. 48 (2000): 1430-1434.

## #5 Strengthen and Supplement the Dementia Workforce

Canada must ensure basic dementia skills among primary care providers, emergency department staff, care facility nurses, assisted living personal support workers, and all others employed in care settings that are likely to serve individuals with dementia. Individuals concerned about their brain health are sometimes hesitant to seek help. When they do, it is imperative that health professionals can recognize the warning signs, make a diagnosis and provide treatment and support.

These care providers need to be supported with the expertise of geriatricians, neurologists, psychiatrists, nurses, and other professionals with specialized knowledge of dementia and its treatment. Government will need to work with universities and the professional colleges that regulate these professionals to improve the supply of these scarce skills.

In the meantime, strategies that will make the best use of our limited specialized resources through a collaborative team approach need to be employed. Nurses, pharmacists and other health professionals are both expanding their scopes of practice and developing interdisciplinary team skills. The voluntary sector is already providing useful knowledge and supports to Canadians living with dementia and their caregivers. These initiatives should be fostered.

Standardized evidence-driven care plans and protocols for dementia prevention, diagnosis, disease management and end-of-life care, as a common basis for training entire care teams, are needed – from primary care to specialized care, from patient self-management to caregiver support, for the formal health system to the voluntary sector, and across all health disciplines.

**Canada needs to ensure that the dementia epidemic is met with an appropriate supply of dementia specialists and well-trained generalists working collaboratively. These scarce resources must be supplemented by a well-resourced voluntary sector, with a nationally available support program as a priority.**

## Conclusion

*Rising Tide*, through the analysis of available data, has provided Canada with important information about the impact of dementia on Canadian society and what can be done to change the trajectory of this impact – whether measured in individuals acquiring the disease, the hours spent by their caregivers, the cost of providing health services or the economic impact of interrupting a career to look after somebody at home.

It is the fervent hope of the Alzheimer Society that these ideas will foster further discussion and analysis, and find their way into policies that create real change. This study and report can also serve as a prototype for how other neurological conditions and chronic conditions might be addressed.

The Government of Canada has demonstrated sensitivity to the issues raised in this report by (1) funding in part the study that serves as the foundation for this report; and (2) committing in June 2009, \$15 million over four years to fund a population study to help Canada better understand neurological conditions and their impact on Canada. The latter is a unique partnership between the government and Neurological Health Charities of Canada (NHCC), including the Alzheimer Society, which will help us learn about the relationships among the neurological conditions. It is a step forward.

However, it is clear from this current analysis that Canada must take immediate steps to both prevent or delay onset of dementia, and better serve Canadians who develop one kind of dementia or another. Accordingly, Canadians are urged to prevail on the federal government and their respective provincial or territorial governments to develop a pan-Canadian response to the dementia epidemic, the hallmark of the response to include:

1. An accelerated investment into all areas of dementia research including Biomedical, Clinical, Quality of Life, Health Services and Knowledge Translation;
2. A clear recognition of the important role played by informal caregivers – by providing information and education, support in their roles as care partners including financial support;
3. An increased recognition of the importance of prevention and early intervention for these diseases, for both health care professionals as well as the general public;
4. Greater integration of care and increased use of accepted frameworks or “best practices” in chronic disease prevention and management, community support and community care coordination;
5. A strengthening of Canada’s dementia workforce by:
  - a. increasing the availability of specialists including geriatricians, neurologists, psychiatrists and advanced practice nurses with specialized knowledge of dementia;
  - b. improving the diagnostic and treatment capabilities of all frontline professionals;
  - c. making the best use of general and specialized resources through inter-professional collaboration;
  - d. supporting patient self-management and caregiver participation in care coordination; and
  - e. leveraging the capabilities of the voluntary sector through investment and training.

Now that we have a clear sense of the scale and impact of the dementia epidemic in Canada, inaction is not an option. Our economy, our health care system, the lives of millions of Canadians will be affected.

We must put our minds to it and implement the recommendations described above. Canada *can* meet the challenge of the dementia epidemic. **The time to act is now.**



## Appendix A: Adapting *Life at Risk*<sup>®</sup> for Rising Tide

*Rising Tide* used RiskAnalytica's Life at Risk<sup>®</sup> simulation platform to model the impact of dementia on the Canadian population for the next 30 years: 2008-2038. The platform is customizable to suit the needs of the particular problem at hand, in this case, forecasting the health and economic impacts of dementia, using data imported from primary and/or secondary sources.

Within the Life at Risk<sup>®</sup> platform, the possible future health states of a population along with the associated economic burden are simulated by incorporating the relationships between different populations, the natural history of the disease, socio-economic risk factors, epidemiology, and economic impacts.

- Within the model, individuals are divided into independent population groups called cells, based on their individual characteristics (age, gender, health state, etc.). Individuals move from one cell to another according to specified rules based upon epidemiological research findings. The model generates **incidence** (new dementia cases in a year) and **prevalence** (number of individuals living with dementia) data over time as individuals move from cell to cell.
- The population's movement is further modeled through various disease states, providing a profile of **health care utilization** over time by individuals with dementia. Individuals with dementia are grouped according to the type of care they receive, whether as residents in care facilities (**Long Term Care** or LTC), at home receiving **Community Care** (CC) or at home but receiving **no formal care**.
- The economic model considers the costs associated with each disease state and care type. It also considers the effects of dementia with respect to workplace productivity both for employed individuals with dementia and for their unpaid informal caregivers<sup>46</sup>.

The decrease in labour hours and the resultant decrease in production are translated and added into the **Total Economic Burden**.

The quality of demographic, epidemiological and treatment/care data are critical drivers of quality in the model's results, and appropriate selection of data and rules at the outset is paramount. Accordingly, a literature review and data scan was completed to identify the state of research and knowledge in the fields of dementia epidemiology, prevention, treatment, and care management. Data was collected across a wide spectrum of indicators: incidence, prevalence, mortality, survival, life expectancy, risk factors, direct and indirect health costs, and hospital and care facility utilization. A list of sources is summarized in Appendix B.

Subject matter experts in Dementia, Epidemiology and Health Economics were consulted widely to review the data collected in the environmental scan. Several teleconferences were held with subject experts from the Universities of Toronto, Ottawa, McMaster, McGill, and Waterloo to review preliminary findings, to identify alternative data sources, and to comment on the epidemiological implications of various (national and international) data sources within the Canadian context. Advice gained through these consultations led to the identification of evidence-based empirical models and data for use by the platform that was acceptable to subject experts. A summary of Key Life at Risk<sup>®</sup> data and assumptions are included in Appendix C.

A panel of 30 of Canada's leading dementia experts – epidemiologists, neurologists, geriatric psychiatrists, geriatricians, psychologists, nurses and social workers, Alzheimer Society professional staff, long term care leaders, and other leading experts – came together to develop a **Dementia Continuum Map**, included in Appendix D, which depicts the range of dementia experiences, including the identification of risk factors, screening, early detection, treatment, disease management, counselling, care and caregiver support. The Map was developed in order to (1) clarify the paths of individuals through the dementia disease process, (2) identify the drivers of health and economic burden and thus to aid in defining data requirements for the Model, and (3) identify leverage points in the dementia disease management process which may become foci for improvement and hence candidates for policy and intervention development.

Using the map, the panel identified a number of key intervention opportunities to inform *Rising Tide's* subsequent selection of intervention scenarios for simulation. A list of subject matter experts consulted for Data & Model Validation and Dementia Continuum Mapping can be found at the beginning of this paper.

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<sup>46</sup> The term 'informal caregiver' is used in this report to refer to those (usually family members) who support individuals with dementia, but who are not providing care in the formal capacity of health professionals.



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## Appendix C: Key Life at Risk<sup>®</sup> Data and Assumptions<sup>47</sup>

### Demographic Data

- All population demographics were obtained from Statistics Canada's CANSIM database.

### Epidemiological Data

- Health states of the population were generated using the demographic model by assuming static historical incidence, mortality rates and prevalence proportions.
- Dementia prevalence and the prevalence of major subtypes (Alzheimer's disease and Vascular Dementia) was estimated from a combination of data from the 1991 Canadian Study of Health and Aging (CSHA) and European data from the EURODEM studies provided in Berr et al. (2005).
- Dementia incidence rates and the rates of major subtypes (Alzheimer's disease and Vascular Dementia) were estimated from the 1996 CSHA follow-up study.
- Mortality was estimated using data from the CSHA (Wolfson et al. 2001)

### Health Care Utilization and Costs

- The proportions of individuals residing in long-term care, as well as those residing in their home and receiving care in their communities, in Ontario, are reported in Tranmer *et al.* (2003). The historical proportion of those residing in long-term care and community care with dementia was assumed to apply to the future dementia prevalence simulations.
- A further division of dementia patients into those with co-morbid conditions, as well as those suffering from dementia alone, was adopted from Wodchis *et al.* (2008). The study indicated that in Ontario, for the year 2007/08, nearly 18% of residents admitted to long-term care directly following an acute care hospitalization had Alzheimer's disease or a related dementia as the principle diagnosis on their acute care discharge record. In this context, the model assumed that 18% of all dementia patients residing in long-term care were admitted into long-term care with dementia as their primary diagnosis. Wodchis *et al.* (2008) further estimated that the cost per resident per day for individuals living with dementia is approximately 1.06 times the average cost of long-term care. The same assumption used for prevalence in long-term care due to dementia (18%) is assumed for Community Care and No Formal Care.
- Statistics Canada Table 107-5509119 provides the number of long-term care beds, of which 64.3% were occupied by individuals with dementia in 2000.
- Long-term care bed utilization is constrained by the supply of beds.
- The supply of beds is determined from a log function of dementia prevalence and long-term care beds as determined from history (1991 to 2006).
- The demand for beds is determined by holding constant the proportions of individuals with dementia in long-term care by age and gender from Tranmer *et al.* (2003).
- The actual number of individuals with dementia occupying a bed is determined by holding the dementia occupancy rate of 64.3% for long-term care beds constant.
- As of 2000, there has been a difference between the demand for beds and the supply of beds for individuals with dementia.
- It is assumed that individuals with dementia in long-term care in Ontario are representative of the dementia population in Canada.

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<sup>47</sup> Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., and Ahmad, S. Rising Tide: the Impact of Dementia in Canada 2008 to 2038, available at [www.alzheimer.ca](http://www.alzheimer.ca) <<http://www.alzheimer.ca>>

## Economic Model Assumptions

- Disability (in the economic model) is assumed to correspond to one's reduction in productivity in the workplace. The reduction is computed with respect to the production capacity of a healthy (no disability due to any disease) individual within the workplace.
- The disability associated with dementia is computed among the employed population only.
- The disability associated with dementia is computed from Statistics Canada Labour Force Survey and the Statistics Canada Participation and Activity Limitation Survey (PALS 2001) disability study.
- Unpaid caregivers exhibit the same employment rates as the general Canadian population.
- The number of hours which an employed unpaid caregiver devotes for the provision of care to an individual with dementia is directly proportional to the amount of time lost within their workplace.
- The amount of time lost at work is proportional to the loss of productivity. As a result, the amount of time which is spent on caregiving is indistinguishable from an economic disability.
- Costs are calculated within the economic model in future dollars. However, for analysis and comparison purposes, cumulative costs are presented as present values adjusted to 2008 dollars at ten year intervals.

## Direct Health Costs Due to Dementia

- It is assumed that the costs of long-term care for individuals with dementia is 1.06 times the average cost of long-term care per Wodchis *et al.* (2008).
- It is assumed that there are no direct health care costs for individuals living with dementia that are not using formal care services.
- These costs were simulated, adjusting for inflation over time.

## Direct Health Costs Due to Co-Morbid Dementia

- The incremental long-term care direct health care costs due to dementia as a co-morbid condition is 6%.
- The incremental community care direct health care costs due to dementia as a co-morbid condition is of 52.9% as taken from Shapiro and Tate (1997), and using incremental average costs of home care for dementia.
- It is assumed that there are no direct health care costs for individuals living with dementia that are not using formal care services.

## Out-of-Pocket Expenses for Individuals with Dementia Not Receiving Formal Care

Not receiving formal care for dementia

- It is assumed that this is equal to out-of-pocket expenses when in community care due to dementia.

Not receiving formal care for co-morbid dementia

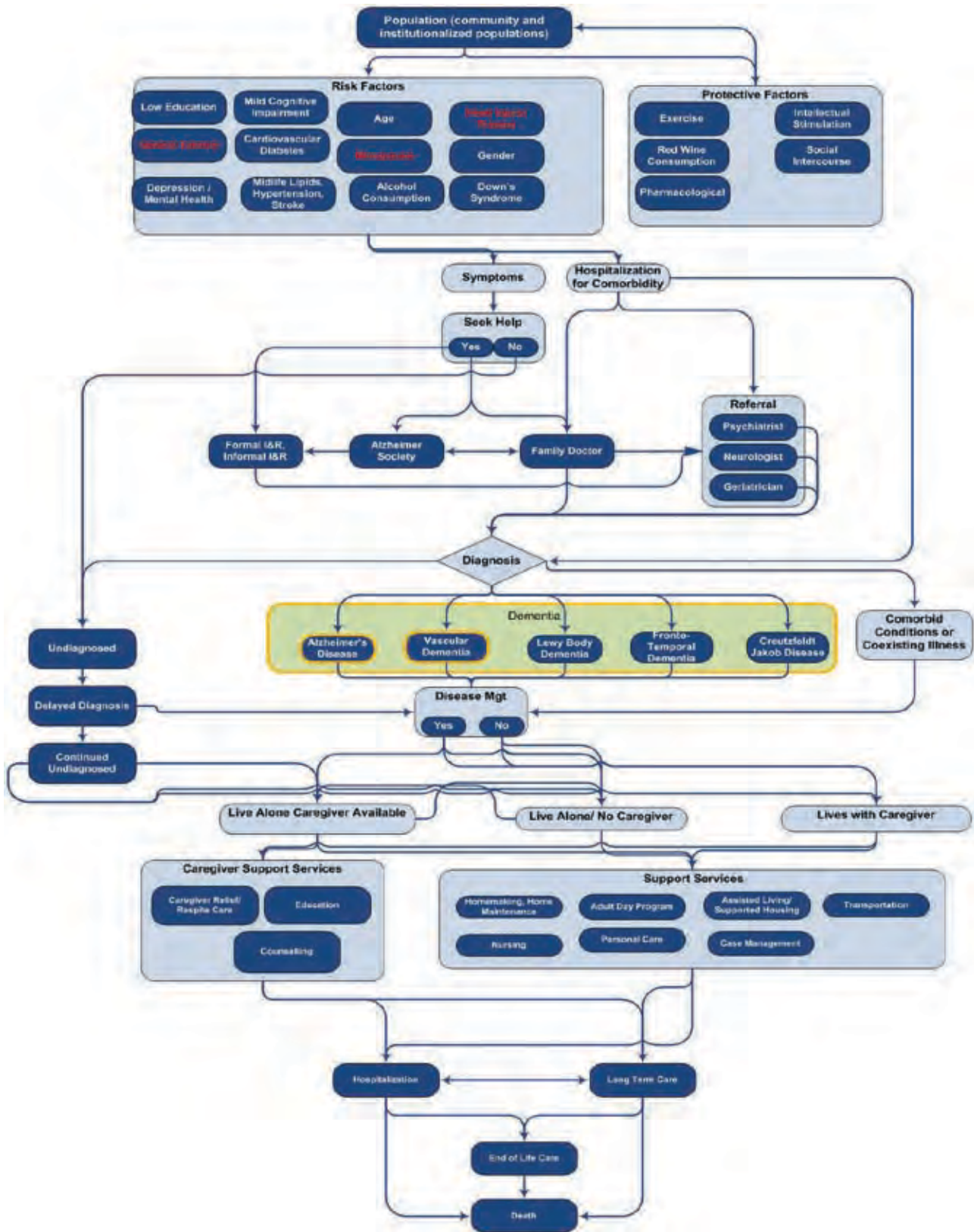
- It is assumed that this is equal to out-of-pocket expenses when in community care due to co-morbid dementia.

## Informal Caregivers

Informal caregiver hours and costs across each care type/setting were calculated as costs directly due to dementia and costs due to dementia as a co-morbid condition.



## Appendix D: Dementia Continuum Map









**Alzheimer** *Society*

Alzheimer Society of Canada

20 Eglinton Avenue West, Suite 1600, Toronto, Ontario, M4R 1K8

Tel: (416) 488-8772 1-800-616-8816 Fax: (416) 322-6656 E-mail: [info@alzheimer.ca](mailto:info@alzheimer.ca)

Web site: [www.alzheimer.ca](http://www.alzheimer.ca)

Charitable registration number: 11878 4925 RR0001

Catholic Civil Rights League

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attachment.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attachment.

**What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition? [1000 word maximum]**

The Catholic Civil Rights League (CCRL) reiterates our original and ongoing opposition to assisted suicide and euthanasia.

The CCRL was an intervener in the *Carter* decision at the Supreme Court of Canada (SCC). We made subsequent submissions to two expert panels, and to the Parliament of Canada in respect of Bill C-14, such that our opposition to possible expansion of assisted suicide and euthanasia remains as vigorous now as it has been throughout this debate.

As a Catholic organization, we wish to promote a worldview that includes an understanding of respect for human life from conception until natural death. Our submission is rooted in faith and in reason. Our opposition to assisted suicide and euthanasia and its expansion is also informed by the fact that it is fundamentally wrong for Canada from a clinical, legal, cultural, ethical, and historical context.

**Palliative Care Remains Limited**

The CCRL argued that the regime of assisted suicide and euthanasia inspired by the Supreme Court of Canada (SCC) and enshrined in law by the Liberal government had failed to address or take into account at all, the inadequacy of palliative care as a treatment option in Canada.

Only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services – depending on where they live in Canada, according to the Canadian Institute for Health Information, Health Care Use at the End of Life in Western Canada (Ottawa: CIHI, 2007).

In 2011, The Parliamentary Committee on Palliative and Compassionate Care (PCPCC) sought means of addressing the nation's shortfalls. The PCPCC's report "Not to be Forgotten: Care of Vulnerable Canadians" focussed specifically on three areas: palliative care, suicide prevention and elder abuse.

**Previous Parliamentary Debates Ignored**

The February 2015 decision to overturn *Carter* and the legislative response by the federal government turned the work of the Parliamentary Committee on its head as the nation has gone from suicide prevention to promoting suicide as a societal good. The CCRL refers to this as suicide relativism.

Nine different motions or legislative attempts had been raised in Parliament between 1993 and 2012, with six separate votes on the issue, all of which *rejected* efforts to change the law, recognizing the risks to the most highly vulnerable. In fact, in 2011 and in 2012 Parliament gave its near unanimous support for a national anti-suicide prevention policy.

It was only in May of 2014 that the House of Commons passed NDP MP Charlie Angus's motion for a federal government to cooperate with the provinces and territories to ensure access to "high-quality, home-based and hospice palliative care," provide more support to caregivers, and encourage Canadians to "discuss and plan for end-of-life care." Mr. Angus and other MPs specifically stated that PAD and euthanasia had no place in that national dialogue. The SCC's decision and the assisted suicide and euthanasia law has completely undermined this dialogue.

From a clinical standpoint, how can expansion of assisted suicide and euthanasia to minors, and to all through advance directive, not also necessitate a further decline in the provision of palliative care? How can it be ethical to expand the intentional killing of a patient when it is clear that alternatives already lacking will continue to decline?

### **Canada is Already Experiencing High Rates of Physician Killing Beyond Expectations**

The correlation between the propagation of assisted suicide and euthanasia with the decline in other medical options has been noted in other jurisdictions that have had legalized regimes for over 10 years. In fact, with just over one year of the current regime, various studies have identified that assisted suicide has already reached a comparative level in Canada that took Belgium and the Netherlands many years to achieve.

Dutch ethicist named Professor Theo Boer, who once supported euthanasia laws in the Netherlands changed his opinion of the practice. In an article published on July 17, 2014 in the Calgary Herald, Dr. Boer admitted that he was “wrong – terribly wrong” to have supported it. “. . . With 12 years of experience, I take a very different view,” he told the British Parliament in 2014 when they were considering legalizing assisted suicide. “Euthanasia is now becoming so prevalent in the Netherlands, that it is on the way to becoming a default mode of dying for cancer patients. Assisted deaths have increased by about 15 per cent every year since 2008 and the number could hit a record 6,000 this year. Campaigns for doctor-administered death to be made ever easier will not rest until a lethal pill is made available to anyone over 70 who wishes to die.” He concluded, “Some slopes truly are slippery.”

### **Safeguards Are Illusory**

From a legal context, the removal of assisted suicide and euthanasia from the Criminal Code was allowed by the Supreme Court and the original trial judge in *Carter* on the promise of safeguards for vulnerable people. Such safeguards are illusory. The CCRL submits that minors and those who suffer from mental illness are always highly vulnerable.

A more recent decision of the High Court of Ireland came to the opposite conclusion:

“The Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and *has drawn exactly the opposite conclusions*” (emphasis added).<sup>1</sup>

That Irish court’s review, upheld on appeal, based on the available evidence from the medical literature and reported findings, found serious examples of abuse, disturbing practices, and several cases of deaths without explicit request. The Court’s concerns were based on risks of impropriety that remained “strikingly high” in countries which have legalized assisted suicide.

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<sup>1</sup> *Fleming v. Ireland & Ors*, [2013] I.E.H.C. 2 (H.C.), summarizing paras. 88-105 of the judgment. Judgment of the High Court of Ireland, upheld unanimously on appeal to the Supreme Court of Ireland, *Fleming v. Ireland & Ors*, [2013] I.E.S.C. 19 (Ireland S.C.)

Ireland is not alone in this context. In 2014, a U.K. Supreme Court decision deferred to Parliament the issue of assisted suicide in *Nicklinson*. British MPs then voted in September 2015 against adopting an assisted suicide bill, 330 to 118.

The CCRL has consistently warned, as we do so now, that the pursuit of safeguards for vulnerable people have been ignored over time in other mature western jurisdictions when it comes to assisted suicide.

The risks to the highly vulnerable, namely the aged, children and those with mental health issues have increased, while the availability of palliative care options has not changed significantly.

To broaden the scope of assisted suicide and euthanasia to make it accessible to minors, those with mental health issues and to all via advanced directive, will serve only to precipitate deaths in these populations without providing other options to live without suffering.

Expansion ought to be rejected.

If rates in the first half of 2017 persist without escalation, Quebec euthanasia rates will reach levels after two years that correspond to Belgian rates after seven to eight years (i.e., per 100,000 population and as a percentage of deaths from all causes). (October 3, 2017)

<http://consciencelaws.org/background/procedures/assist017.aspx>

Lemmens, Trudo, The Conflict between Open-Ended Access to Physician-Assisted Dying and the Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime for the Canadian Post-Carter Era (February 18, 2016). in Catherine Regis, Lara Khoury & Robert Kouri, eds., *Les Grands Conflits en Droit de la Santé [Key Conflicts in Health Law]* (Cowensville: Yvon Blais, 2016) 261-317.. Available at SSRN: <https://ssrn.com/abstract=2734543>

#### COMMENTARY

Scott Y.H. Kim and Trudo Lemmens

**Should assisted dying for psychiatric disorders be legalized in Canada?** CMAJ cmaj.160365; published ahead of print June 21, 2016, doi:10.1503/cmaj.160365

**Full Text (PDF)**

#### **Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders**

Louis C Charland, PhD Professor, Departments of Philosophy and Psychiatry, School of Health Studies, and Rotman Institute of Philosophy Western University London, Ontario, Canada

Trudo Lemmens LicJur, LLM (Bioethics), DCL Professor, Scholl Chair in Health Law and Policy University of Toronto Toronto, Ontario, Canada

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[http://www.jemh.ca/issues/open/documents/JEMH\\_Open-Volume\\_Benchmark\\_Decision\\_Making\\_to\\_Consent\\_to\\_Medical\\_Assistance\\_in\\_Dying-May2016-rev.pdf](http://www.jemh.ca/issues/open/documents/JEMH_Open-Volume_Benchmark_Decision_Making_to_Consent_to_Medical_Assistance_in_Dying-May2016-rev.pdf)

APA Position on Medical Euthanasia, February 25, 2017 by **Mark S. Komrad, MD**

<http://www.psychiatrictimes.com/suicide/apa-position-medical-euthanasia>

Catholic Health Alliance of Canada

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Thank you for the opportunity to respond to your questions regarding "three particularly complex types of requests for MAID... requests by mature minors, advance requests, and requests where mental illness is the sole underlying medical condition."

**Background and Context:**

In October 2016, the CHAC, (an Alliance comprised of 12 organizations sponsoring more than 100 Catholic hospitals, community health centres, nursing homes, and long-term care facilities across Canada) submitted a brief to the Provincial-Territorial Advisory Group on Physician-Assisted Dying. In this submission, the CHAC noted that "We are opposed to assisted death, both physician-assisted suicide and physician performed euthanasia."

Further, the CHAC submitted that Catholic health organizations would not participate in physician-assisted death and that protection of conscience must not put the person receiving care at risk of harm or abandonment.

The CHAC also made a commitment to providing high quality palliative and hospice care that encompasses support for the physical, spiritual, emotional and psychological needs of patients. We also remain committed to ensuring that patients receive all necessary information in order to make informed choices and to staying engaged with people in our care. In particular, we continue to ensure that all exploratory discussions around end of life options continue.

These positions and commitments remain the same following the approval of Bill C14.

Alliance organizations across the country have been increasingly involved with people in our care requesting eligibility assessments for MAID carried out by various provincial care coordination entities or other third parties. We have noted collectively, a trend that most people who are requesting MAID are already very close to death with the majority of requests arising from palliative and hospice care and other end of life settings.

As stated in its 2016 submission, the CHAC remains committed to advocating for actions which attempt to minimize the harms and challenges physician-assisted death create for the protection of life and compassionate care particularly as it relates to those who are most vulnerable and disabled. We remain in agreement with the Supreme Court of Canada's comments that "stringent limits" must be put in place to protect vulnerable patients.

However, we believe that the "safeguards" which have been put in place to this point for patients who are currently eligible for MAID remain inadequate and do not constitute "stringent limits". They do not go far enough to protect the vulnerable individuals referred to in the SCC decision. Therefore, with regard to expanding access for MAID to mature minors, advance requests, and where mental illness is the sole underlying medical condition, our position is that rather than expanding the eligibility criteria, further consideration ought to be given to assessing how well the current "safeguards" meet the "stringent criteria" called for by the SCC. The speed with which MAID is developing in Canada is unparalleled in the rest of the world and we would urge you to consider the negative impact a precipitous expansion of the eligibility criteria to extremely vulnerable persons might have on our culture and our beliefs about human dignity.

It is within this background and context of reaffirming our opposition to MAID and continuing to advocate for limiting current harms that we oppose any expansion of patient eligibility. However in light of our collective experience stated above, we offer the following questions which are relevant to mature minors, advance directives and situations where mental illness is the sole underlying medical condition. We do this not as a way of posing solutions in order to expand the eligibility criteria but as examples of struggles that clinicians currently face in providing care and treatment and which would no doubt be exacerbated if the eligibility criteria were expanded.

## Mental Illness

In the absence of any other underlying medical condition, how would one ensure that all options which might offer clinical benefit are pursued before a decision is made to pursue MAID? This is particularly important in light of the potential for healing within the therapeutic relationship between psychiatrists and patients with mental health illnesses.

How could positions currently taken in many institutions which are committed to suicide prevention be reconciled with MAID? This would be particularly difficult in institutions which are entirely devoted to treating only patients with mental health issues.

Some patients with persistent psychotic illness may lack the capacity for mental health treatment but often do have capacity for physical health treatments. Where would the capacity for MAID fall into this situation?

How would the requirement for protection of patients at imminent risk of harm to themselves or others and the ensuing Form 1 be reconciled with a written request for MAID? What would the role of psychiatry be in these instances?

## Advance Requests

Given that many advance directives are drawn up well in advance of a life altering illness, how would one ensure that the conversation between a skilled palliative care provider occurs in order that issues regarding pain and symptom control are adequately addressed?

Would the lack of a fully informed conversation in advance of loss of capacity lead a disproportionate number of people to believe that MAID is the only option at the end of life?

How would this work practically? This is particularly so given the current "safeguard" which does not allow potential beneficiaries to be witnesses to written requests. How could this be vetted/safeguarded?

How might one determine that an incapable person might be experiencing intolerable and intractable suffering? If that is no longer the litmus test under the present criteria then how do those criteria fit this new population of incapable patients?

Would there be a different set of "safeguards" for incapable patients who through an advance directive might be able to ask for euthanasia but not assisted suicide?

## Mature Minors

Would any amount of safeguards be sufficient to protect this particularly vulnerable group?



How would one ensure that a mature minor fully understands and appreciates all other options before making a decision for MAID?

How would one be able to manage the risk that even one mature minor was not fully informed? Given that the impact of such a situation on families would likely not be felt until after the fact, is this a risk that society is willing to take by expanding the eligibility criteria?

How would one deal with the emotional, political and social justice issues particularly in light of the epidemic of youth suicide in some First Nations communities?

How would the issue of assent vs consent be addressed if the criteria were expanded? What would the role of the parent be in terms of being informed - before the fact - after the fact etc?

From a research perspective, vulnerable groups, like mature minors, need greater protection and assistance in participating/choosing something that groups that are not vulnerable do not require. Given that this is so in research, would this mean that we would have a greater obligation to ensure their access to MAID - likely not, but how would question be addressed?

These are simply a few questions for discussion relative to the questions posed. They are neither exhaustive or intended to imply that the CHAC supports MAID in its current form or in its expanded form.

Thank you for the opportunity to respond.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attachment.



**Catholic Health Alliance of Canada**  
**Alliance catholique canadienne de la santé**

**Alliance Submission to CCA**  
**August 2017**

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**Background and Context:**

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Alliance organizations across the country have been increasingly involved with people in our care requesting eligibility assessments for MAID carried out by various provincial care coordination entities or other third parties. We have noted collectively, a trend that most people who are requesting MAID are already very close to death with the majority of requests arising from palliative and hospice care and other end of life settings.

As stated in its 2016 submission, the CHAC remains committed to advocating for actions which attempt to minimize the harms and challenges which physician-assisted death create for the protection of life and

compassionate care particularly as it relates to those who are most vulnerable and disabled. We remain in agreement with the Supreme Court of Canada's comments that "stringent limits" must be put in place to protect vulnerable patients.

However, we believe that the "safeguards" which have been put in place to this point for patients who are currently eligible for MAID remain inadequate and do not constitute "stringent limits". They do not go far enough to protect the vulnerable individuals referred to in the SCC decision. Therefore, with regard to expanding access for MAID to mature minors, advance requests, and where mental illness is the sole underlying medical condition, our position is that rather than expanding the eligibility criteria, further consideration ought to be given to assessing how well the current "safeguards" meet the "stringent criteria" called for by the SCC. The speed with which MAID is developing in Canada is unparalleled in the rest of the world and we would urge you to consider the negative impact a precipitous expansion of the eligibility criteria to extremely vulnerable persons might have on our culture and our beliefs about human dignity.

It is within this background and context of reaffirming our opposition to MAID and continuing to advocate for limiting current harms that we oppose any expansion of patient eligibility. However in light of our collective experience stated above, we offer the following questions which are relevant to mature minors, advance directives and situations where mental illness is the sole underlying medical condition. We do this not as a way of posing solutions in order to expand the eligibility criteria but as examples of struggles that clinicians currently face in providing care and treatment and which would no doubt be exacerbated if the eligibility criteria were expanded.

### Mental Illness

In the absence of any other underlying medical condition, how would one ensure that all options which might offer clinical benefit are pursued before a decision is made to pursue MAID? This is particularly important in light of the potential for healing within the therapeutic relationship between psychiatrists and patients with mental health illnesses.

How could positions currently taken in many institutions which are committed to suicide prevention be reconciled with MAID? This would be particularly difficult in institutions which are entirely devoted to treating only patients with mental health issues.

Some patients with persistent psychotic illness may lack the capacity for mental health treatment but often do have capacity for physical health treatments. Where would the capacity for MAID fall into this situation?

How would the requirement for protection of patients at imminent risk of harm to themselves or others and the ensuing Form 1 be reconciled with a written request for MAID? What would the role of psychiatry be in these instances?

### Advance Requests

Given that many advance directives are drawn up well in advance of a life altering illness, how could one ensure that the conversation between a skilled palliative care provider occurs in order that issues regarding pain and symptom control are adequately addressed?

Would the lack of a fully informed conversation in advance of loss of capacity lead a disproportionate number of people to believe that MAID is the only option at the end of life?

How would this work practically? This is particularly so given the current "safeguard" which does not allow potential beneficiaries to be witnesses to written requests. How could this be vetted/safeguarded?

How might one determine that an incapable person might be experiencing intolerable and intractable suffering? If that is no longer the litmus test under the present criteria then how do those criteria fit this new population of incapable patients?

Would there be a different set of "safeguards" for incapable patients who through an advance directive might be able to ask for euthanasia but not assisted suicide?

#### Mature Minors

Would any amount of safeguards be sufficient to protect this particularly vulnerable group?

How would one ensure that a mature minor fully understands and appreciates all other options before making a decision for MAID?

How would one be able to manage the risk that even one mature minor was not fully informed? Given that the impact of such a situation on families would likely not be felt until after the fact, is this a risk that society is willing to take by expanding the eligibility criteria?

How would one deal with the emotional, political and social justice issues particularly in light of the epidemic of youth suicide in some First Nations communities?

How would the issue of assent vs consent be addressed if the criteria were expanded? What would the role of the parent be in terms of being informed - before the fact - after the fact etc?

From a research perspective, vulnerable groups, like mature minors, need greater protection and assistance in participating/choosing something that groups that are not vulnerable do not require. Given that this is so in research, would this mean that we would have a greater obligation to ensure their access to MAID - likely not, but how would question be addressed?

These are simply a few questions for discussion relative to the questions posed. They are neither exhaustive or intended to imply that the CHAC supports MAID in its current form or in its expanded form.

Thank you for the opportunity to respond.

## **CAMH**

### **1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

CAMH's main issue concerning requests for MAiD where mental illness is the sole underlying medical condition is the lack of evidence that mental illness is an irremediable medical condition in individual cases.

#### **Mental illness and irremediableness**

Individuals eligible for MAiD under current legislation must have a grievous and irremediable medical condition and be close to natural death. Since the government is considering amending MAiD legislation so that people with mental illness do not have to meet the criteria of natural death, we must determine if mental illness fits a broader definition of a grievous and irremediable medical condition.

Grievousness of an illness is subjective and mental illness can cause individuals to endure psychological and sometimes physical suffering. Irremediableness of an illness, however, is an objective determination which should be based on the best medical evidence available. And currently, there is no established standard of care that sets a threshold for when a mental illness should be considered irremediable.

On one hand, mental illness is not terminal. Death by suicide can be a tragic consequence of mental illness. We do have knowledge of risk factors and evidence-informed interventions that can reduce the likelihood that person will die by suicide. However, it is impossible for experts to predict a specific suicide event and conclude that a person's illness is inevitable due to their mental illness.

On the other hand, mental illness is typically chronic and recurrent - its symptoms do not always fully abate (similar to many physical illnesses). These illnesses are not curable per se, but are possible to treat and manage. Many Canadians live well with chronic and recurrent illnesses. For this reason, such a broad definition of irremediable should not be used within the context of MAiD.

Importantly, mental illness is treatable. Clinical treatment can usually improve the symptoms of mental illness and many people are able to find a successful treatment regimen after a brief period of time. Others can take several years and various treatment protocols, but eventually most people with mental illness are able to find ways to manage their symptoms.

Recovery-based care can help all people with mental illness achieve and maintain wellness. Recovery not only embraces personalized treatment and management of symptoms, but focuses on the whole person. Clinicians and care teams provide ongoing support to patients as they develop skills to manage their mental illness, its symptoms and associated stigma. Recovery-based outcomes focus less on the presence or absence of symptoms, but on the ability to live as one chooses. While some individuals continue to experience symptoms of their illness, they can live meaningful lives.

The difficulty is that we cannot predict the trajectory of any individual's mental illness. At any point in time it may appear that an individual is not responding to current interventions – that their illness is currently irremediable – but it is not possible to determine with any certainty the

course of this individual's illness. There is simply not enough evidence in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness.

The lack of evidence that mental illness is an irremediable medical condition in individual cases, as well as the gravity of the outcome of MAiD, leads CAMH to recommend that no amendment be made to MAiD legislation for people with mental illness as their sole underlying medical condition at this time. People with mental illness should access MAiD the same way those with physical illnesses do – by meeting all of the criteria outlined in current the legislation.

#### Other considerations

CAMH also recommends that decision-makers consider several other factors when determining whether or not to make an amendment to MAiD legislation for people with mental illness as their only medical condition:

- Access to mental health care: Many individuals with mental illness, particularly those living in poverty, are unable to access evidence-informed mental health care and supports. Should Canada provide access to MAiD when 1/3-1/2 of Canadians with mental illness cannot get their needs met in the current healthcare system?
- Social determinants of health: The social determinants of health have a significant impact on a person's suffering and ability to cope with a grievous illness. People with mental illness disproportionately experience poor social determinants of health. It is often these psychosocial dimensions of suffering that motivate individuals to request MAiD. Safeguards may be needed to make sure this is not the case.
- Recovery: For some, the recovery principles of autonomy and choice mean having access to a full range of health-care options, including MAiD. Clinicians understand that there is always a degree of risk when providing recovery-based care and that they may not always agree with a person's decisions. For many, however, empowering their patients to access MAiD would push that risk beyond the limits of their duty of care.
- Consent and capacity: Many individuals with mental illness can experience severely disordered insights or impairments in reasoning. This may be easy to recognize when they are experiencing an acute episode of their illness, but can be difficult to identify when symptoms are better controlled. Therefore, concluding that an individual truly has capacity to consent to MAiD may be a challenge. Developing more robust capacity assessment tools, increasing training for health professionals, and setting a benchmark for informed consent have been recommended.
- International experiences: Data from Belgium and the Netherlands indicate that euthanasia and/or assisted suicide (EAS) for mental illness is uncommon, but raises some concerns. Findings from two case studies show that doctors are not always consistent in applying EAS criteria and some patients who receive EAS are not competent, some have a treatable illness that could be improved with treatment and some change their minds about EAS even if they continue to experience suffering.
- Inclusive consultation: People with lived experience of mental illness must be fully engaged in the decision-making process. Their voices must be included when making decisions that affect them. Family members, racialized groups, ethnic communities and Indigenous peoples must also help inform this decision.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\*Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*





## **Policy Advice on Medical Assistance in Dying and Mental Illness October 2017**

Medical Assistance in Dying (MAiD) is now legally available in Canada for adults with grievous and irremediable medical conditions who meet certain criteria and are capable of making that decision. The new law does not explicitly exclude people with mental illness as their only medical condition from accessing MAiD, however it is unlikely that most of these individuals will meet all of the eligibility criteria - in particular, the criteria that their 'natural death has become reasonably foreseeable'<sup>1</sup>.

When MAiD legislation was passed, it included a requirement that the government initiate an independent review to explore the issue of requests where mental illness is the sole underlying medical condition, as well situations involving mature minors and people who have made advance requests<sup>2</sup>. The review on mental illness will focus specifically on situations where individuals suffering from mental illness are not nearing natural death\*<sup>3</sup>. The Canadian Council of Academies (CCA) has been tasked with conducting this review and providing the government with their findings. The CCA has until December 2018 to submit its findings to the government.

The issue of whether people with mental illness as their sole underlying medical condition should be able to access MAiD in situations where they are not nearing a natural death is a difficult one. MAiD is not simply another healthcare treatment. Ending a life – even when it is requested by someone who is suffering – raises moral and ethical questions for all involved. This struggle is reflected in the Supreme Court and government's cautious approach to MAiD for people with mental illness to date. Canadians themselves are divided on the issue of MAiD, and most do not support making it available to those with only mental illness<sup>4</sup>. Public discourse has seen lawyers, ethicists, physicians, reporters and advocates passionately defend one side or the other of this complex and nuanced debate. At the Centre for Addiction and Mental Health (CAMH), this debate is exceptionally challenging. The government's ultimate decision – whatever it may be - will deeply impact the lives of our patients, their families, our physicians and staff.

Since September 2015, a group of CAMH staff with expertise in clinical, legal, ethics, public policy and lived experience have been deliberating over the issue of MAiD and mental illness. We have raised questions and concerns in deputations to Government and Senate Committees. We have consulted with our colleagues both within and external to CAMH. We have hosted an evening of catalytic

\* 'Natural death' is understood to mean that death is a likely consequence of the progressive illness for which MAiD was requested. It does not simply refer to an individual's proximity to death, such as advanced age.

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<sup>1</sup> Bill C-14, section 241.2(2)(d).

<sup>2</sup> Bill C-14, section 9.1(1).

<sup>3</sup> Downie & Chandler, 2017

<sup>4</sup> External Panel, 2015

conversation with clinical experts and heard from mental health service users at an event that we co-hosted with the CAMH Empowerment Council (an organization that is composed of, and represents, people with current or past mental health and addictions problems). We have received a wealth of informed and impassioned input, but there remain no easy answers.

It is difficult to develop good policy in such a morally and ethically charged environment, particularly when little medical evidence exists. It is this lack of evidence that ultimately leads CAMH to advise that there be *no amendment to MAiD legislation for people with mental illness as their sole underlying medical condition at this time*. This paper outlines our rationale for this conclusion. It also summarizes several other considerations that decision-makers should reflect on when determining if MAiD should be available to people with mental illness who are not nearing natural death.

### **Legal background and context**

Mental illness has been a part of the MAiD debate since the Supreme Court of Canada's ruling in February 2015. In that decision, the Court struck down the law prohibiting physicians from assisting patients to die under certain circumstances. The Court gave the federal government one year to develop a law that would allow for physician assisted dying (as it was named at the time) for competent adults who are suffering from a 'grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition' (para 127). The Court did not further define 'grievous and irremediable' or name specific medical conditions that would apply.

Since the Court did not explicitly exclude mental illness in its definition of a grievous and irremediable medical condition, some individuals and groups have argued that people with mental illness as their sole underlying condition should be able to access MAiD<sup>5</sup>. Others note that during the trial process the Court commented that international cases related to MAiD for mental illness were not relevant to the current case (para 111)<sup>6</sup> implying that mental illness is not within the scope of the Court's decision<sup>7</sup>, or at least making the Court's intentions on the matter unclear<sup>8</sup>.

When the federal government passed its MAiD legislation in June 2016, it restricted the 'grievous and irremediable' definition to mean a 'serious and incurable illness, disease or disability' where a person is 'in an advanced state of irreversible decline in capability', is experiencing 'enduring physical or psychological suffering intolerable to them which cannot be relieved under conditions they consider acceptable' and whose 'natural death has become reasonably foreseeable'. Similar to the Supreme Court's decision, the legislation does not specifically exclude individuals with stand-alone mental illness from accessing MAiD. However, it was acknowledged in the preamble to the legislation that it would be difficult for most people with mental illness as their only medical condition to qualify for MAiD under the law given that natural death is not typically a foreseeable outcome of mental illness (advanced eating disorders being the main exception).

Recognizing that the current law would limit most of those with only mental illness from accessing MAiD, and acknowledging the complexity of the issue, the government provided a commitment to explore 'requests where mental illness is the sole underlying medical condition'. Clarification from the

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<sup>5</sup> Joint Centre for Bioethics, 2015; Special Joint Committee, 2016

<sup>6</sup> Carter v Canada, 2015

<sup>7</sup> Lemmens, 2017

<sup>8</sup> Walker Renshaw & Finley, 2015

Minister of Justice and Attorney General of Canada notes that this review will look at situations where people with mental illness are not in an advanced state of irreversible decline or nearing a natural death<sup>9</sup>. Essentially, the government is considering amending MAiD legislation so that people with mental illness as their only medical condition do not have to meet the criteria of irreversible decline and reasonable foreseeability of natural death.

### **Is mental illness a grievous and irremediable medical condition?**

If the government were to decide that irreversible decline and reasonable foreseeability of natural death were no longer required criteria for MAiD, this would return us to a very broad definition of 'grievous and irremediable'. The question we are attempting to grapple with is whether mental illness even fits within a broader definition. Is mental illness a grievous and irremediable medical condition?

The grievousness of an illness is subjective and there is no doubt that mental illness can be grievous to individuals. CAMH patients and others with lived experience of mental illness talk openly about how their symptoms can cause enduring psychological and sometimes physical suffering. The irremediableness of an illness, on the other hand, is an objective determination which should be based on the best medical evidence available. And currently, there is no established standard of care that sets a threshold for when a mental illness should be considered irremediable<sup>10</sup>.

### ***Mental illness can be incurable***

MAiD legislation equates irremediable with incurable. One interpretation of incurable is that the medical condition is terminal, irreversible or inevitable. Death by suicide can be a tragic consequence of mental illness. Fortunately, clinicians and care teams have good knowledge about the risk factors that heighten the risk of suicide and can use evidence informed interventions to reduce the likelihood that a person will die by suicide. Precautions such as acute hospitalization can also be taken if a psychiatric assessment indicates that a person is at a heightened risk of suicide. However, it is impossible for experts to predict a specific suicide event and conclude that an individual's death is proximal or inevitable due to their mental illness<sup>11</sup>.

Incurable can also mean that it is impossible for a medical condition to fully abate. In this respect, many forms of mental illness could be considered incurable. Mental illness, like countless physical illnesses, is typically chronic and recurrent. These illnesses are not curable *per se*, but they are possible to treat and manage (e.g. with medications, rehabilitation, other lifestyle changes, etc.). Every day vast numbers of Canadians find ways to live well with chronic and recurrent illnesses. For this reason, the Canadian Psychiatric Association argues that this interpretation of irremediable is too broad to use in the current context because it would allow those with very treatable illnesses to access MAiD<sup>12</sup>. Others argue that MAiD should be available to the full array of individuals with chronic and recurrent illnesses<sup>13</sup>.

### ***Mental illness is treatable***

Mental illness is usually manageable in that symptoms can improve with clinical treatment. There are currently a range of effective treatments for people with mental illness and research has provided some

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<sup>9</sup> Downie & Chandler, 2017

<sup>10</sup> Gaind, 2016

<sup>11</sup> Large et al, 2016

<sup>12</sup> Gaind, 2015

<sup>13</sup> Downie 2017; Gokool, 2017

knowledge about personalizing these treatments<sup>14</sup>. The challenge is that each person responds differently to treatment and at this time it is difficult to determine which treatment will work for a particular individual<sup>15</sup>. Many people with mental illness and their care teams are able to find a treatment regimen that works for them after a brief period of time. For other people, this can take several years and various treatment protocols, but eventually most people are able to find ways to manage their symptoms.

For all people with mental illness, a recovery-based approach to mental health care can be beneficial for achieving and maintaining wellness. Recovery not only embraces personalized treatment and management of symptoms, but focuses on the development of the whole person, including autonomy and citizenship. Recovery-based care is central to the work of CAMH. Our clinicians and care teams provide ongoing support to patients as they develop skills to manage their mental illness, its symptoms and associated stigma. Recovery-based outcomes focus less on the presence or absence of symptoms, but on the ability to live as one chooses. While some individuals continue to experience symptoms of their illness, they can live meaningful lives.

The difficulty is that to date we are not able to predict the trajectory of any one individual's mental illness. Some people will recover (including from illnesses such as schizophrenia), some will have persistent symptoms and others will have worsening symptoms. At any point in time it may appear that an individual is not responding to any interventions – that their illness is currently irremediable - but it is not possible to determine with any certainty the course of this individual's illness. There is simply not enough evidence available in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness.

The law states that in order to access MAiD an individual must have an irremediable medical condition. Right now, there is not enough medical evidence to say whether someone's mental illness is irremediable or not. Given this lack of evidence and the gravity of the outcome of MAiD, it would be extremely risky at this time to amend legislation to provide access to MAiD for people whose only medical condition is mental illness and who are not in an advanced state of irreversible decline and nearing natural death. People with mental illness should have access to MAiD under the same circumstances as those with physical illnesses do - by meeting all of the criteria outlined in the current legislation.

**Recommendation one: The federal government should not make an amendment to MAiD legislation for people with mental illness as their sole underlying medical condition at this time due to a lack of evidence that mental illness is an irremediable medical condition in individual cases.**

#### **Other Considerations**

The core of CAMH's policy advice is informed by the lack of evidence that mental illness is an irremediable medical condition. However, there are also several other factors that decision-makers should take into consideration when determining if there should be an amendment to MAiD legislation for people with mental illness as their only medical condition.

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<sup>14</sup> Ozomaro et al, 2013

<sup>15</sup> Simon & Perlis, 2010

### ***Access to mental health care***

In any given year, 1 in 5 Canadians experience a mental health or substance use problem<sup>16</sup>. Mental illness is the leading cause of disability in the country<sup>17</sup> and in Ontario the burden of mental illness is greater than the burden of cancer or infectious diseases<sup>18</sup>. Despite the prevalence and impact of mental illness, Canada has historically underfunded mental health care<sup>19</sup>. This means that many Canadians with mental illness are not able to access evidence-informed mental health care and supports.

Access to mental health care is problematic across the system. People with mental illness are less likely to have a primary care physician than those without mental illness<sup>20</sup> and those that do find it difficult to get proper screening, diagnosis and treatment for their mental illness in these settings<sup>21</sup>. Community-based mental health services have lengthy wait times, particularly for children and youth who can wait over a year and half for counselling or therapy<sup>22</sup>. In our own hospital, patients in CAMH's Emergency Department now wait 40% longer for an inpatient bed than they did five years ago<sup>23</sup>. Wait times to receive a range of vital services at CAMH and Ontario's other specialty psychiatric hospitals have also increased significantly in the past five years<sup>24</sup>.

Individuals who live in poverty can have even more difficulty accessing mental health care. Limited resources and supports can make it difficult for them to navigate the complexities of the mental health system. Public drug plans frequently limit access to innovative medications<sup>25</sup>. Structured psychotherapy – a well-recognized, non-pharmaceutical treatment for mental illness - is not widely covered by provincial health insurance plans. People who live in poverty simply cannot access this highly effective treatment.

Federal and provincial investments in mental health care have increased recently, but there is still a long way to go before all Canadians have equitable access to evidence-informed mental health care and supports. This is a concern for many when it comes to MAiD. Should Canada provide access to MAiD for mental illness as a sole underlying condition when 1/3 to 1/2 of Canadians with mental illness are not getting their needs met in the current healthcare system<sup>26</sup>? Mental health service users talked about this at the CAMH and Empowerment Council event. They voiced concerns about lack of access to mental health care and talked about the need to improve access to a range of mental health treatments - not just medications. Some thought it was 'frightening' to think about providing MAiD for mental illness in the current health care climate. Others thought that it was unfair to restrict access to MAiD and force people who are suffering to wait for improvements in the mental health care system that could take years to materialize.

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<sup>16</sup> Smetanin et al, 2011

<sup>17</sup> MHCC, 2014

<sup>18</sup> Ratnasingham et al, 2013

<sup>19</sup> WHO, 2011

<sup>20</sup> Bradford et al, 2008

<sup>21</sup> CAMH, 2016

<sup>22</sup> CMHO, 2016

<sup>23</sup> OAGO, 2016

<sup>24</sup> Ibid

<sup>25</sup> CEADM, 2017

<sup>26</sup> Pearson et al, 2013; Patten et al, 2016

### ***Social determinants of health***

The social determinants of health have a significant impact on physical and mental health<sup>27</sup>. For people living with a grievous illness, poor social determinants of health can impact suffering and the ability to cope. This is particularly relevant when determining whether MAiD legislation should be amended to expressly allow access to MAiD for people with mental illness as their only medical condition, as people with mental illness disproportionately experience poor social determinants of health.

People with mental illness are vulnerable to isolation and a lack of social support<sup>28</sup>. They have lower incomes, are less likely to participate in the labour force and are less likely to have adequate housing than people with other types of disabilities and people without disabilities<sup>29</sup>. Affordable and supportive housing in particular is known to be a key component of recovery for people with mental illness<sup>30</sup>, yet many are homeless or living in substandard accommodations<sup>31</sup>. This is concerning given that it is often the psychosocial dimensions of suffering that motivate individuals to request euthanasia or assisted suicide<sup>32</sup>. To address this, some disability advocates have recommended adding safeguards to the MAiD assessment process to ensure that poor social determinants of health are not motivating peoples' requests<sup>33</sup>. At the CAMH and Empowerment Council's event with mental health service users, several individuals stressed that isolation, lack of social support and quality of life must be part of the conversation on MAiD and mental illness.

### ***Recovery***

Many mental health care providers, including CAMH, are committed to the recovery philosophy. In the mental health field, recovery is seen as a life long journey that focuses on autonomy, empowerment, choice, personal growth and meaningful social inclusion<sup>34</sup>. Providers of recovery-based care support people by delivering self-directed, individualized and strengths-based mental health care<sup>35</sup>. At the core of recovery-based care is the hope and the belief that people can and will overcome obstacles<sup>36</sup>.

When considering MAiD and mental illness through a recovery lens differing viewpoints emerge. For some, the focus on autonomy means that people with mental illness should be able to choose from a full range of health care options, and some see MAiD as one of these options. They express concern that denying people who are suffering from mental illness the same options as those suffering from physical illnesses could reinforce stigma<sup>37</sup>, as well as discrimination and institutional paternalism towards those with mental illness. Some mental health service users at the CAMH and Empowerment Council discussion said that if they knew they might have the option of MAiD it would lessen their pain and suffering. They talked about how having the option to die on their own terms would make it easier to live. While these individuals did not think that they would actually access MAiD themselves, there are

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<sup>27</sup> CMA, 2013; ESDC, 2016

<sup>28</sup> Granerud & Severnson, 2006; Boardman, 2011; Linz & Strum, 2013

<sup>29</sup> As cited by the OHRC, 2015.

<sup>30</sup> MHCC, 2012

<sup>31</sup> Ibid

<sup>32</sup> As cited in CACL, 2016

<sup>33</sup> CACL, 2016

<sup>34</sup> Department of Health, 2011

<sup>35</sup> APA, 2012

<sup>36</sup> Ibid

<sup>37</sup> Walker-Renshaw, 2015

others who, given the option, would go ahead with MAiD<sup>38</sup>. While some individuals would see this outcome as evidence of autonomy and empowerment, others would see it as a failure of recovery-based care.

When a person is suffering from a grievous mental illness, it is the role of recovery-based care providers to offer support, teach coping strategies and remind the individual that their life is valuable. Mental health care providers recognize that there is always a degree of risk when providing recovery-based care. Adhering to a philosophy of autonomy and empowerment means that there may be times when a mental health care provider does not agree with a person's capable decisions. But these providers do need to intervene if someone is at risk arising from decisions that are made while they do not have decision-making capacity. Mental health care providers must find a balance between supporting positive risk taking and ensuring safety<sup>39</sup>, especially as a person's judgment becomes more impaired by illness. For many mental health care providers, empowering their patients to access MAiD would push that risk taking beyond the limits of their duty of care and compromise their other responsibilities to promote life and (to the extent possible) prevent suicide.

### ***Consent and capacity***

Capacity has been central to the debate on MAiD and mental illness. Criteria in both the Supreme Court's decision and government legislation require individuals to be capable of making their own healthcare decisions. Overall, there seems to be consensus with this criteria.

Under the *Health Care Consent Act* (HCCA), a person is considered capable if they are able to understand information about the treatment being offered to them and appreciate the consequences of accepting or not accepting this treatment. It requires that the person be able to apply this information to their own situation<sup>40</sup>. It is also recognized that a person's capacity to make a particular decision about treatment can fluctuate over time and in relation to different treatment plans (that is, a person may be capable of making a decision about one kind of treatment, but not another)<sup>41</sup>.

All people, including those with mental illness, are presumed capable unless proven otherwise<sup>42</sup>. A mental illness does not preclude capacity to make healthcare decisions. That being said, in cases where a person with a mental illness requests MAiD (where mental illness is the sole underlying condition or in cases of a co-occurring physical condition) determining whether or not an individual has capacity to make this request for MAiD is not an easy task. The concern is that many individuals with mental illness experience disordered insight or impairments in reasoning capacity that make it difficult for them to connect their symptoms with their illness, fully understand the risks and benefits of treatment, and/or make treatment decisions based on personal goals and values<sup>43</sup>.

When a person experiences an acute episode of their mental illness (such as a major depressive episode or an acute psychotic episode), it is not uncommon for them to have severely distorted beliefs about themselves, the world, and their future. This can include the belief that death is a desirable option. But sometimes this sense of helplessness, worthlessness and hopelessness continues even when the

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<sup>38</sup> Kim et al, 2016

<sup>39</sup> Department of Health, 2011

<sup>40</sup> Section 4(1) of the HCCA

<sup>41</sup> Neilson & Chaimowitz, 2015

<sup>42</sup> Ibid

<sup>43</sup> William & Fulford, 1998

symptoms of the mental illness are better controlled<sup>44</sup>. This distorted insight raises questions about the individual's capacity to make a MAiD request during both the acute and less acute phases of their illness. Determining whether or not a request for MAiD is driven by disordered insight is imperative given that MAiD is not simply another healthcare decision.

There have been recommendations that capacity to consent to MAiD should be assessed using existing tools and practices<sup>45</sup>. The difficulty is that there is currently no specific tool that physicians are required to use to assess capacity in those with mental illness<sup>46</sup>. While the McArthur Competence Assessment Tool is seen by many authorities as the most comprehensive, neither this tool nor any others were developed specifically to assess capacity to consent to MAiD (though Trillium Health Partners have recently created their own MAiD Capacity Assessment Form)<sup>47</sup>. Some health care providers have recognized the complexity of assessing capacity in people with mental illness. They have argued for the development of better, more robust capacity assessment tools as well as education for health care professionals to improve their competency in assessing capacity in people with mental illness<sup>48</sup>. Others have called for a national standard to protect all vulnerable people who request MAiD by embedding safeguards in the criminal code that would set a benchmark for informed consent as well as requirements for a vulnerability assessment in response to all MAiD requests and prior independent review of all requests by a judge or review board<sup>49</sup>.

### ***International Experiences***

Any decision to amend Canada's MAiD legislation to provide access to MAiD for people with mental illness as their only medical condition should be informed by the experiences in other jurisdictions where it has previously been legalized. MAiD – known internationally as euthanasia and/or assisted suicide (EAS) – is legal in Belgium, Columbia, Germany, Japan, Luxembourg, the Netherlands, Switzerland and several US states (California, Colorado, Montana, Oregon, Vermont, Washington and the District of Columbia). EAS for mental illness as a sole underlying condition is available only in Belgium, Luxembourg, the Netherlands and Sweden. The little data that exists comes primarily from Belgium and the Netherlands.

EAS for mental illness is uncommon in both Belgium and the Netherlands. In 2015, 15% of all Belgian EAS cases were individuals with non-terminal illness<sup>50</sup> including roughly 3% who had a mental illness<sup>51</sup>. That same year, 1% of all EAS cases in the Netherlands were individuals with mental illness as their main condition (this number increased from .01% of all EAS cases in 2008)<sup>52</sup>. Two recent case reviews provide some insights about individuals who request and follow-through with EAS for mental illness in these two countries<sup>53</sup>.

In Belgium, a review of 100 consecutive cases of requests for EAS by individuals with mental illness as their main condition found that most were women with depression and/or a personality disorder. Their

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<sup>44</sup> Grant & Beck, 2009

<sup>45</sup> Special Joint Committee, 2015

<sup>46</sup> Dembo, 2017

<sup>47</sup> Ibid

<sup>48</sup> Expert Advisory Group, 2015

<sup>49</sup> CACL, 2016

<sup>50</sup> As cited by Kim, 2017

<sup>51</sup> As cited by Aviv, 2015

<sup>52</sup> As cited by Kim, 2017

<sup>53</sup> Thienpont et al, 2015; Kim, 2016



average age was 47. Of the 100 requests, 35 went ahead with EAS. Of the 65 who did not proceed with EAS, 38 withdrew their request before a decision was made and 11 withdrew their request after approval. Eight (8) individuals continued to pursue their requests, 6 died by suicide and 2 died of natural causes. At follow-up a year later, 48 of the 57 people who were still living had put their requests on hold because they were ‘managing with regular, occasional or no therapy’<sup>54</sup>.

In the Netherlands, a review of 66 cases of completed EAS for mental illness also found that most were women with depression. The majority were older than 50. Most patients had extensive treatment histories, but 56% had refused at least some treatment due to low motivation. Only 39% of patients had received ECT at some point in their treatment trajectories. In 24% of cases there were disagreements amongst physicians on whether the individual met all of the EAS criteria. Most physician disagreement was around the futility of the person’s illness (81%) and/or the patient’s competence (50%). Researchers also noted that social isolation and loneliness were key themes in patients’ histories<sup>55</sup>.

While the number of EAS cases is low and interpretation of case histories is potentially subjective, these two studies raise some concerns about the practice of EAS in situations where mental illness is the main condition. Specifically, doctors are not always consistent in applying EAS criteria, which are vague and rely on clinical judgments in situations where there is little evidence. This can be exacerbated in the absence of practice guidelines<sup>56</sup>. The findings of both of these studies raise concerns about the possibility that some patients receiving EAS for mental illness will not be capable, will have a treatable condition that would have improved, and will have changed their minds about EAS even if they had continued to experience suffering<sup>57</sup>.

### ***Inclusive consultation***

Public discourse on MAiD has mainly been dominated by professionals, many of whom are white and belong to mainstream culture. CAMH has engaged with people with lived experience in the development of our policy advice, but we recognize that we have still only heard from a limited number of individuals. It was clear at the event that we hosted with the Empowerment Council that many people were only beginning to hear about the possibility of a change to MAiD legislation for people with mental illness as a sole underlying condition. There was a sense that they had not had enough time to process the complexity of the issue, the implications of such a legislative change, and the arising dilemmas. Questions of community responsibility, discrimination, accountability and care have yet to be explored and appraised. CAMH recognizes that the CCA must gather, summarize and submit its findings to the government by December 2018. It is imperative, however, that decision-makers ensure that people with lived experience of mental illness are fully engaged in this process throughout. The voices of family members, racialized groups, ethnic communities and Indigenous peoples should also be sought to help inform this decision.

The decision of whether to amend MAiD legislation should be grounded primarily in the lack of medical evidence that mental illness is an irremediable medical condition. Other considerations, however, should also help inform the decision.

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<sup>54</sup> Thienpont et al, 2015

<sup>55</sup> Kim, 2016

<sup>56</sup> Dierickx et al, 2017

<sup>57</sup> Kim, 2017

**Recommendation two: Decision-makers should consider the following when determining whether or not to amend MAiD legislation for people with mental illness as a sole underlying medical condition: access to mental health care; the social determinants of health; recovery and recovery-based care; consent and capacity; international experiences; and inclusive consultation.**

In summary, MAiD is a complex moral and ethical issue. Determining whether to amend MAiD legislation so that people with mental illness as their only medical condition do not have to meet the criteria of irreversible decline and reasonable foreseeability of natural death adds further emotion and opinion to the debate. While there are various factors that decision-makers should consider – including the ones we have outlined in this paper – good public policy should be evidence-informed. And in this case, the lack of evidence that mental illness is an irremediable medical condition in individual cases should ultimately guide decision-makers to conclude that an amendment to MAiD legislation for people with mental illness as their sole underlying medical condition should not be made at this time.

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Christian Legal Fellowship

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached submission, which is an executive summary of CLF's position paper (attached).

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached submission and CLF's position paper (attached).



**EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE IN THE CASE OF MATURE MINORS,  
ADVANCE REQUESTS, AND MENTAL ILLNESS:**

**LEGAL, ETHICAL, CULTURAL, AND CLINICAL CONSIDERATIONS**

SUBMISSION OF THE  
**CHRISTIAN LEGAL FELLOWSHIP/ALLIANCE DES CHRÉTIENS EN DROIT**  
TO THE  
**COUNCIL OF CANADIAN ACADEMIES**  
**EXPERT PANEL ON MEDICAL ASSISTANCE IN DYING IN CANADA**

OCTOBER 6, 2017

[WWW.CHRISTIANLEGALFELLOWSHIP.ORG](http://WWW.CHRISTIANLEGALFELLOWSHIP.ORG)



*\*\*Note – given the word limit for stakeholder submissions, Christian Legal Fellowship (CLF) has prepared a [Background Paper](#) expanding on the submission below.\*\**

**Q1. What are your organization’s main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Christian Legal Fellowship’s overarching concern relates to the adverse impact that expanding euthanasia and assisted suicide (“EAS”) will have on vulnerable populations, such as:

- Patients who do not wish to receive/be pressured to receive EAS;
- Persons whose sense of dignity and access to “equal concern, respect and consideration” are susceptible to socially constructed conceptions;<sup>1</sup>
- Patients whose sole or primary underlying condition is a mental illness;<sup>2</sup>
- Minors;<sup>3</sup> and
- Patients who are incapable of providing contemporaneous consent.<sup>4</sup>

No court has conducted a *Charter* analysis of the rights of such persons in the EAS context; the only persons whose *Charter* rights have ever been considered in this regard are those of “Ms. Taylor and of persons in her position”.<sup>5</sup>

No right or freedom is absolute, and this Council<sup>6</sup> must consider the rights and interests of those who will be adversely affected by expanding eligibility, as well as the broader societal impact and the implications of determining that some lives are not worth living. As discussed further in CLF’s [Background Paper](#), it is CLF’s position that if eligibility for EAS were to be expanded, any so-called “protections” or “safeguards” for such persons would be insufficient to protect their s. 7 and s. 15 *Charter* rights.

***Mature minors***

Canadian courts have consistently recognized that children (“mature minors”) are a “[highly vulnerable](#)” group in need of protection.<sup>7</sup> The law regularly draws distinctions based on age to protect minors, and in the criminal law context, young people are treated differently from adults because of “reduced maturity and moral capacity”.<sup>8</sup>

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<sup>1</sup> [Eldridge v British Columbia \(Attorney General\)](#), [1997] 3 SCR 624 at para 56; see also Lydia S Dugdale & Daniel Callahan, “[Assisted Death and the Public Good](#)” (2017) 110 Southern Medical Journal 559.

<sup>2</sup> [Carter v Canada](#), 2015 SCC 5 at para 111 [“*Carter* (SCC)”].

<sup>3</sup> [Ibid](#) at para 111.

<sup>4</sup> [Ibid](#) at para 147.

<sup>5</sup> [Ibid](#) at para 56.

<sup>6</sup> The Council has specifically asked for submissions on: (1) “*What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for the three topic areas?*” and (2) “*What are the potential impacts on society of permitting or prohibiting requests for MAID for the three topic areas?*”

<sup>7</sup> [AC v Manitoba](#), 2009 SCC 30 at paras 104, 143 [“AC”].

<sup>8</sup> [R v DB](#), 2008 SCC 25 at para 47.

While children are sometimes permitted to make health care decisions, they are not guaranteed an unqualified right to do so; courts have consistently intervened to *protect* minors from decisions that imperil their health and create unnecessary risk of death. All minors need protection from making “life-threatening mistakes”<sup>9</sup> and “the more serious the nature of the decision and the more severe its potential impact on the life or health of the child, the greater the degree of scrutiny will be required”.<sup>10</sup>

Extending assisted suicide to minors also undermines Canada’s [international commitments](#)<sup>11</sup> to protect and nurture children to full development. It would result in state-imposed stress and anxiety on children by fostering uncertainty as to their inherent value and dignity; children would be viewed as a category of people the state can be authorized to kill.

### ***Mental illness***

Expanding assisted suicide to non-terminally ill patients “with psychiatric conditions will put many vulnerable and stigmatized people at risk.”<sup>12</sup> Many patients struggling with mental illness are unable to find effective coping techniques for “long periods of their lives” and presenting assisted suicide as a “viable option” reinforces a loss of hope and “demoralization” for struggling patients.<sup>13</sup> EAS also undermines a core clinical imperative of “helping patients even through sustained periods of suffering during which people often lose the will to live and despair about whether things will get better.”<sup>14</sup> An alarming percentage (close to 48%) of mentally ill patients change their minds regarding assisted suicide requests.<sup>15</sup>

### ***Advance directives***

*Carter* explicitly states that assisted suicide should only be made available where a person “clearly consents to the termination of life.”<sup>16</sup> Consent for irreversible decisions such as to terminate one’s life can only be meaningful where it is truly independent and informed, which is virtually impossible in the context of dementia.<sup>17</sup>

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<sup>9</sup> [AC](#), *supra* note 7 at para 130.

<sup>10</sup> [Ibid](#) at paras 21-22.

<sup>11</sup> Such as the [UN Convention on the Rights of the Child](#), signed by Canada May 28, 1990.

<sup>12</sup> Kim, Scott & Trudo Lemmens, “[Should Assisted Dying for Psychiatric Disorders Be Legalized in Canada?](#)” CMAJ 1016 at 5.

<sup>13</sup> [Ibid](#); Ron Berghmans, Guy Widdershoven, and Ineke Widdershoven-Heerding, “[Physician-assisted suicide in psychiatry and loss of hope](#),” (2013) 36 International Journal of Law and Psychiatry at 437.

<sup>14</sup> [Kim, Scott & Trudo Lemmens](#), *supra* note 12 at 3.

<sup>15</sup> Canadian Mental Health Association, [Position Paper on Medical Assistance in Dying](#) at 4.

<sup>16</sup> [Carter](#) (SCC), *supra* note 2 paras 127, 147.

<sup>17</sup> Rebecca Dresser, “[On Legalizing Physician-Assisted Death for Dementia](#)” (2017) 47 Hastings Center Report 5 at 5-6: “To be capable of independent choice, an individual must be able to understand the important information relevant to that choice. The memory and other cognitive impairments associated with dementia reduce a person’s ability to evaluate the choice for PAD. As a result, many, perhaps most, individuals diagnosed with dementia are incapable of making that choice”.

Many assumptions about advance directives and dementia patients are unfounded.<sup>18</sup> Patients with “moderate to severe dementia can reliably rate their own quality of life”<sup>19</sup>, and studies reveal that such patients “rate their quality of life higher than do their family members who are influenced by their own distress”.<sup>20</sup>

Finally, the lack of access to palliative care exacerbates the concerns discussed above. It is troubling that so much emphasis has been placed on expanding access to medical assistance in **dying**, when many Canadians do not even have meaningful access to medical assistance in **living**.<sup>21</sup>

**Q2. Please identify or provide relevant knowledge that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

#### CHRISTIAN LEGAL FELLOWSHIP: RELEVANT KNOWLEDGE

- **October 2017:** [Background Paper](#) regarding the legal and social impact of expanding MAID to mature minors, where mental illness is the sole underlying medical condition and by advance directive.
- **April 2017:** [Factum](#) filed jointly with the Evangelical Fellowship of Canada and the Assembly of Catholic Bishops in the case of *Christian Medical and Dental Society et al v. College of Physicians and Surgeons of Ontario*. The case involves a *Charter* challenge to (1) a Human Rights policy mandating effective referrals and obligatory emergency care even if it conflicts with conscience or religious beliefs; and (2) a Medical Assistance in Dying policy that specifically requires effective referrals for assisted suicide.
- **March 2017:** [Oral](#) and [written](#) submissions before Ontario’s Standing Committee on Finance and Economics re the Medical Aid in Dying bill (Bill 84).
- **August 2016:** [Written submissions](#) urging the Government of Manitoba to introduce legislation protecting freedom of conscience for health care professionals and explaining why forcing health care providers to participate in facilitating the death of a patient would violate the *Canadian Charter of Rights and Freedoms*. The government subsequently introduced Bill C-34, *The Medical Assistance in Dying (Protection for Health Professionals and Others) Act*, which specifically protects the rights of those who refuse to aid in the provision of medical assistance in dying on the basis of his or her personal convictions.

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<sup>18</sup> M de Boer et al, “[Suffering from dementia – the patient's perspective: A review of the literature](#).” 19 *International Psychogeriatrics* at 1027-8.

<sup>19</sup> Christopher Beer et al, “[Factors Associated with Self and Informant Ratings of the Quality of Life of People with Dementia Living in Care Facilities: A Cross Sectional Study](#)” (2010) 5 *PLoS ONE* 1 at 1.

<sup>20</sup> Romyne Gallagher, “[Medical assistance in dying: Living with dignity until life naturally ends](#)” (2017) 59 *BCMJ* 50 at 51.

<sup>21</sup> In *Carter v Canada*, 2012 BCSC 886 at para 192 Justice Smith observed that “high quality palliative care is far from universally available in Canada” and cited expert evidence that “only 16-30% of Canadians receive palliative care as part of their life-threatening illness” and that “there are many places in Canada, particularly in rural or remote areas, where there is little or no access to palliative care specialist nurses or physicians.”

- May 2016: Written [submission](#) filed with the Senate Standing Committee on Legal and Constitutional Affairs concerning Bill C-14.
- May 2016: Oral [submissions](#) before the federal House of Commons Standing Committee on Justice and Human Rights concerning Bill C-14.
- May 2016: Written [submission](#) filed with the federal House of Commons Standing Committee on Justice and Human Rights concerning the government's proposed assisted-dying legislation, Bill C-14.
- March 2016: Written [submission](#) filed with Alberta's Minister of Health, Minister of Seniors, Justice Minister, Solicitor General and Minister of Aboriginal Relations of Alberta in response to the provincial government's consultation concerning physician-assisted dying and end-of-life decisions.
- March 2016: [Open letter](#) to Jody Wilson-Raybould, Minister of Justice of Canada and the Auditor General of Canada, to "express concern about and to rectify certain misunderstandings reflected in the Special Joint Committee's Report regarding the scope of the *Carter* ruling and its implications for Parliament's legislative response."
- February 2016: Written [submission](#) filed with the federal Special Joint Parliamentary Committee on Physician-Assisted Dying.
- January 2016: Written [submission](#) to Ontario's Attorney General and Minister of Health in response to the provincial government's consultation concerning physician-assisted dying and end-of-life decisions.
- January 2016: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Ontario, urging freedom of conscience for health care professionals.
- January 2016: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of New Brunswick, urging freedom of conscience for health care professionals.
- December 2015: [Factum](#) filed with the Supreme Court of Canada in "*Carter II*", urging the Court to extend time for Parliament to pass a euthanasia law and to maintain a national prohibition on euthanasia in the interim.
- November 2015: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Manitoba, urging freedom of conscience for health care professionals.
- November 2015: Written [submission](#) in response to invitation, with the federal External Panel on Options for a Legislative Response to *Carter v. Canada*
- October 2015: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Saskatchewan, urging freedom of conscience for health care professionals.
- September 2015: [Recommendations](#) concerning the Supreme Court's decision in *Carter* to the provincial/territorial Expert Advisory Group on Physician-Assisted Dying.
- August 2014: [Factum](#) filed with the Supreme Court of Canada in the second appeal for *Carter v Canada*.

- December 2012: [Factum](#) filed with the British Columbia Court of Appeal in the first appeal for *Carter v Canada*.
- December 2012: [Factum](#) filed with Superior Court for the District of Trois-Rivières in *Leblanc v Canada* (Quebec).
- July 2012: CLF [granted](#) the right to intervene, make written and oral submissions and cross-examine witnesses in *Leblanc v Canada (Attorney General) & Québec (Attorney General)*.
- December 2011: [Factum](#) filed with the Supreme Court of British Columbia in *Carter Et Al v Canada*.



**EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE IN THE CASE OF MATURE MINORS,  
ADVANCE REQUESTS, AND MENTAL ILLNESS:**

**LEGAL, ETHICAL, CULTURAL, AND CLINICAL CONSIDERATIONS**

BACKGROUND PAPER OF THE  
**CHRISTIAN LEGAL FELLOWSHIP/ALLIANCE DES CHRÉTIENS EN DROIT**

OCTOBER 6, 2017

[WWW.CHRISTIANLEGALFELLOWSHIP.ORG](http://WWW.CHRISTIANLEGALFELLOWSHIP.ORG)

***“Killing a person — in order to relieve the suffering produced by a medically manageable physical or mental condition — is not a proportionate response to the harm represented by the non-life-threatening suffering resulting from that condition.”***

-Supreme Court of Canada, 2001<sup>1</sup>

## **Overview**

Christian Legal Fellowship (“CLF”) is Canada’s national association of Christian legal professionals. Its membership consists of over 700 lawyers, law students, professors, and retired judges nationwide, representing over 30 denominations and virtually every area of legal practice.

CLF has consistently engaged with the development of Canadian euthanasia and assisted suicide (“EAS”) policies since 2011, when the *Carter* litigation first commenced (see Appendix “A” for additional information).

While some commenters have suggested that the Supreme Court’s decision in *Carter* must extend EAS to include advance directives, mental illness and mature minors, this reading of *Carter* fundamentally misinterprets the factual context and parameters of the Court’s reasoning.<sup>2</sup>

In addition to correcting this misinterpretation, one of CLF’s overarching concerns is the adverse impact that expanding EAS will have on vulnerable populations, such as seniors, mature minors, persons with disabilities, and those who suffer from mental illness. This concern regarding adverse impact raises two key considerations for the Council of Canadian Academies: (1) no right or freedom is absolute; and (2) sections 7 and 15 *Charter* rights of vulnerable communities and individuals are increasingly engaged and violated as EAS eligibility is expanded, particularly where access to meaningful medical care aimed at alleviating suffering is lacking.

## **No right or freedom is absolute**

Any interpretation of sections 7 and 15 of the *Charter*, and the principles of “liberty” and “autonomy” must take into account not only the interests of those patients seeking EAS, but also how the exercise of those interests impacts on the rights of others. Conduct that would potentially cause harm to or interference with the rights of others is not necessarily protected by the *Charter*.<sup>3</sup> Justice Smith of the British Columbia Supreme Court recognized this in her *Carter* judgment noting that the existence of arguments for expansion of circumstances permitting physician-assisted suicide “does not mean that those arguments will succeed.”<sup>4</sup>

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<sup>1</sup> *R v Latimer*, 2001 SCC 1 at para 41.

<sup>2</sup> See discussion below; see also John Sikkema & Derek Ross, “[Misreading Carter](#)” (January 8, 2016) *Convivium*.

<sup>3</sup> *Syndicat Northcrest v Amselem*, 2004 SCC 47 at paras 61-62.

<sup>4</sup> *Carter v Canada*, 2012 BCSC 886 at para 315 [“*Carter* (BCSC)”].

Therefore, this Council<sup>5</sup> must consider the rights and interests of those who will be adversely affected by expanding EAS, including the broader societal impact and the implications of determining that certain lives are not worth living.

### **Charter rights of vulnerable communities and individuals**

The only category of persons whose *Charter* rights have ever been considered by a Canadian court in the EAS context are those of “Ms. Taylor and of persons in her position”.<sup>6</sup> No court has conducted a *Charter* analysis in the EAS context of the rights of:

- Patients who do not wish to receive EAS or to be pressured, directly or indirectly, to receive EAS;
- Persons with illnesses and/or disabilities whose sense of self-worth, hope, and dignity, and access to “equal concern, respect and consideration”, are susceptible to socially constructed conceptions regarding the value of their lives/existence;<sup>7</sup>
- Patients whose sole or primary underlying condition is a mental illness (“persons with psychiatric disorders” are specifically precluded from *Carter’s* parameters);<sup>8</sup>
- Patients who are not adults, i.e. children (“minors” are specifically precluded from *Carter’s* parameters);<sup>9</sup> and
- Patients who are incapacitated/suffering from dementia/incapable of providing contemporaneous consent (only “competent adults” are included in *Carter’s* parameters).<sup>10</sup>

For reasons discussed below, it is CLF’s position that if eligibility for EAS were to be expanded beyond that currently provided for under Bill C-14, any so-called “protections” or “safeguards” would be insufficient to protect certain persons’ *Charter* rights to life, liberty and security and/or their right to the equal protection of the law without discrimination based on age or mental or physical disability, in a manner that is demonstrably justified in a free and democratic society.

Given the specific scope of study undertaken by the Council, this paper will address only mature minors, mental illness and advance directives.

### **Section 7**

Section 7 of the *Charter* states that “everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”<sup>11</sup>

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<sup>5</sup> The Council has specifically asked for submissions on: (1) “What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for the three topic areas?” and (2) “What are the potential impacts on society of permitting or prohibiting requests for MAID for the three topic areas?”.

<sup>6</sup> *Carter v Canada*, 2015 SCC 5, para 56 [“*Carter* (SCC)”].

<sup>7</sup> *Eldridge v British Columbia (Attorney General)*, [1997] 3 SCR 624, para 56; see also note 54 and discussion.

<sup>8</sup> *Carter* (SCC), *supra* note 6 at para 111.

<sup>9</sup> *Carter* (SCC), *supra* note 6 at para 111.

<sup>10</sup> *Carter* (SCC), *supra* note 6 at para 147.



In broad terms, the right to life is engaged “where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly.”<sup>12</sup> Liberty is defined as “the right to make fundamental personal choices free from state interference”<sup>13</sup> and security of the person points to “a notion of personal autonomy involving ... control over one’s bodily integrity free from state interference.”<sup>14</sup> Security of the person protects “both the physical and the psychological integrity of the individual”<sup>15</sup> and is infringed when state actions impose suffering on an individual,<sup>16</sup> and where state action has a “serious and profound effect on a person’s psychological integrity” that is “greater than ordinary stress or anxiety.”<sup>17</sup>

As with all *Charter* rights there are reasonable limits<sup>18</sup> and justifiable infringements, considering the nature of the law itself as well as competing moral claims and broad societal implications.<sup>19</sup> However, expanding EAS to mature minors is not one of those reasonable limits or justifiable infringements, for the reasons outlined below.

### ***Mature minors***

Canadian courts have consistently recognized that children (“mature minors”) are a “[highly vulnerable](#)” group in need of protection.<sup>20</sup> On this ground, the law regularly draws distinctions based on age to protect minors, and in the criminal law context, it is a principle of fundamental justice that young people are treated differently from adults because of “reduced maturity and moral capacity”.<sup>21</sup>

While children are sometimes permitted to make their own health care decisions, minors with capacity are not guaranteed an unqualified right to do so, and courts have consistently intervened to **protect** minors from decisions that imperil their health and create unnecessary risk of death. All minors need protection from making “life-threatening mistakes”<sup>22</sup> and even where they are able to exercise some measure of mature, independent judgment, “the more serious the nature of the decision and the more

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<sup>11</sup> [Canadian Charter of Rights and Freedoms](#), s 7, Part I of the *Constitution Act*, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11 [*Charter*].

<sup>12</sup> [Carter \(SCC\)](#), *supra* note 6 at para 62.

<sup>13</sup> [Blencoe v British Columbia \(Human Rights Commission\)](#), 2000 SCC 44 at para 54.

<sup>14</sup> [Rodriguez v British Columbia \(Attorney General\)](#), [1993] 3 SCR 519 at 587-88.

<sup>15</sup> [New Brunswick \(Minister of Health and Community Services\) v G\(J\)](#), [1999] 3 SCR 46 at para 58.

<sup>16</sup> [Rodriguez](#), *supra* note 14 at 589.

<sup>17</sup> [New Brunswick](#), *supra* note 15 at paras 77-78.

<sup>18</sup> Most *Charter* rights are subject to the limitation clause in section 1, whereby infringements are permitted provided they can be “demonstrably justified in a free and democratic society”. Section 7 has an internal limitation, namely that infringements are permitted to the extent that they accord with the principles of fundamental justice. As per [Carter \(SCC\)](#), *supra* note 6 at para 95, it is “difficult” to justify section 7 infringements because these rights are “fundamental, and ‘not easily overridden by competing social interests,’” evidenced by the fact the Supreme Court has not yet upheld a section 7 violation under section 1.

<sup>19</sup> [Carter \(SCC\)](#), *supra* note 6 at para 79.

<sup>20</sup> [AC v Manitoba](#), 2009 SCC 30, paras 104, 143 [“AC”].

<sup>21</sup> [R v DB](#), 2008 SCC 25, para 47.

<sup>22</sup> [AC](#), *supra* note 20 at para 130.

severe its potential impact on the life or health of the child, the greater the degree of scrutiny will be required”.<sup>23</sup>

The Supreme Court has been guided by the best interests of the child in determining whether an intervention in opposition to a minor’s wishes is necessary and desirable. The Supreme Court has upheld the constitutionality of child welfare legislation that allows a child’s wishes to be overridden, even where those wishes engage a *Charter* right (i.e. freedom of religion).<sup>24</sup> In *AC v Manitoba*, the majority noted “it is dangerous to speculate on whether a judge would ever...decline to order medical treatment for a child under the age of 16 where the result would be probable death.”<sup>25</sup>

Canada’s [international commitments](#)<sup>26</sup> further entrench its obligation to protect children, help ensure their *full* development, recognize the right of the child to enjoy the highest attainable standard of health, and take appropriate measure to diminish infant and child mortality.

The United Nations’ Human Right Committee (UNHRC), in its definitive interpretation of Article 6 of the *International Covenant of Civil and Political Rights* (which Canada has acceded to), emphasizes that “the expression ‘inherent right to life’ cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures”, including “all possible measures to reduce infant mortality and to increase life expectancy.”<sup>27</sup> The UNHRC has also recognized that individuals planning or attempting to commit suicide are often undergoing a momentary crisis which may affect their ability to make irreversible decisions such as to terminate their life. Therefore, the UNHRC’s draft General Comment on Article 6 urges participating states to take adequate measures “to prevent suicides, especially among individuals in particularly vulnerable situations.”<sup>28</sup>

Extending assisted suicide to minors eviscerates Canada’s obligation to protect and nurture children to full development and utterly fails children in their state of vulnerability. Any such extension would result in state-imposed stress and anxiety on children by fostering uncertainty as to their inherent value, worth and dignity as human beings; children would be viewed as a category of people the state can be authorized to kill. Minors are particularly susceptible to external expectations and pressures and would be at a greater risk of accepting EAS in the face of such pressures, subtle and undetectable as they may be. Expanding access to minors would therefore impose “an increased risk of death on [them], either directly or indirectly”<sup>29</sup>, and would be contrary to the *Charter* rights to life, liberty and security of children.

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<sup>23</sup> [Ibid](#) at paras 21-22.

<sup>24</sup> [AC](#), *supra* note 20.

<sup>25</sup> [Ibid](#) at para 133.

<sup>26</sup> Such as the [UN Convention on the Rights of the Child](#), signed by Canada May 28, 1990.

<sup>27</sup> UN Human Rights Committee, “[CCPR General Comment No 6: Article 6 \(Right to Life\)](#)”, (1982) at para 5.

<sup>28</sup> Human Rights Committee, “[General Comment No. 36 on Article 6 of the International Covenant on Civil and Political Rights, on the Right to Life](#)” at para 10.

<sup>29</sup> [Carter \(SCC\)](#), *supra* note 6 at para 62.

### **Broader Social Impact of Normalizing Suicide**

As noted in the preamble to Bill C-14, suicide is a significant public health issue that has lasting and harmful effects on individuals, families and communities. There is therefore a societal interest in suicide prevention, supporting communities that are disproportionately impacted by suicide, maintaining respect for the inviolability of life, and preventing the normalization of suicide as a “solution” to suffering.

Expanding eligibility for assisted suicide undermines these important societal aims, as demonstrated by experience in other jurisdictions where there is a correlation between legalizing assisted death and increasing suicide rates.<sup>30</sup> Part of this increase is due to “continuing attitudinal and cultural shifts” where the “values of autonomy and self-determination have become more prominent” and “acceptance of euthanasia continues to increase in the population at large.”<sup>31</sup>

#### ***Mental illness***

The impact of these attitudinal shifts is likely to be disproportionately borne by those living with mental illness. Expanding assisted suicide to non-terminally ill patients “with psychiatric conditions will put many vulnerable and stigmatized people at risk.”<sup>32</sup> In Belgium & Netherlands, psychiatric assisted suicide has increased by 15% a year since 2006, and 1/25 deaths in Netherlands is result of psychiatric assisted suicide.<sup>33</sup>

Many patients struggling with mental illness don’t find effective coping techniques for “long periods of their lives” and presenting assisted suicide as a “viable option” reinforces a loss of hope and “demoralization” for struggling patients.<sup>34</sup> Not only does EAS remove “a central therapeutic element in the doctor-patient relationship”<sup>35</sup> - that element being hope - it sets aside a “core clinical imperative in psychiatric treatment: compassionately and skillfully helping patients even through sustained periods of suffering during which people often lose the will to live and despair about whether things will get better.”<sup>36</sup> Furthermore, an astonishing percentage (close to 48%) of mentally ill patients change their minds regarding assisted suicide requests;<sup>37</sup> establishing further grounds to reject EAS as a “solution” to mental illness.

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<sup>30</sup> Lydia S Dugdale & Daniel Callahan, “[Assisted Death and the Public Good](#)” (2017) 110 Southern Medical Journal 559 at 559-560.

<sup>31</sup> Canadian Mental Health Association, [Position Paper on Medical Assistance in Dying](#) at 4 [CMHA].

<sup>32</sup> Kim, Scott & Trudo Lemmens, “[Should Assisted Dying for Psychiatric Disorders Be Legalized in Canada?](#)” CMAJ 1016 at 5.

<sup>33</sup> [CMHA](#), *supra* note 31 at 4.

<sup>34</sup> [Kim, Scott & Lemmens](#), *supra* note 32; Ron Berghmans, Guy Widdershoven & Ineke Widdershoven-Heerding, “[Physician-assisted suicide in psychiatry and loss of hope](#),” (2013) 36 International Journal of Law and Psychiatry at 437.

<sup>35</sup> [Kim, Scott & Lemmens](#), *supra* note 32 at 6.

<sup>36</sup> *Ibid* at 3.

<sup>37</sup> Citing a Belgian case study, see [CMHA](#), *supra* note 31 at 4.

Instead, those living with mental illnesses should be assisted by their physicians and health-care professionals “to live and thrive”.<sup>38</sup> These patients should not face a situation in which the doctor-patient relationship is “compromised by conferring on physicians the power to adjudicate whose life is worth living.”<sup>39</sup>

### **Implications of Determining that Some Lives are Not Worth Living**

Inherent in expanding access to EAS is the necessary social conclusion that some lives are not worth living. The essence of crafting criteria for access is to conclude that lives within these particular categories are not always worth living, a statement borne out by the Oregon experience, where over 40% of EAS recipients over the past 18 years cite “being a burden” as one of the reasons for ending their lives.<sup>40</sup> Further statistics from Oregon and Washington indicate the main reasons motivating EAS requests are “existential”.<sup>41</sup> This notion of human existence as being “burdensome” has a detrimental impact on societal attitudes toward those living with disabilities and their inherent dignity, and on the worth of all people regardless of limitations or physical health.<sup>42</sup>

#### ***Advance directives***

The notion that some lives are simply not worthy of living or deserving of protection directly impacts those who cannot give contemporaneous consent to assisted suicide or euthanasia. The Supreme Court emphatically and explicitly states that assisted suicide should only be made available where a person “clearly consents to the termination of life”, a concurrent granting of consent.<sup>43</sup> This requirement was applied by the [BC Court of Appeal](#) in deciding not to give effect to an Alzheimer’s patient’s prior directive to be deprived of “nourishments or liquids” because her present wishes suggested otherwise.<sup>44</sup> Courts - and legislatures - must “give effect to the wishes of the patient in the ‘here and now’, even in the face of prior directives”.<sup>45</sup> [Carter](#) was unambiguous on this point: assisted suicide is conditional on the clear consent of the patient.<sup>46</sup> Consent for irreversible decisions such as to terminate one’s life can only be meaningful where it is truly independent and informed, which is virtually impossible in this context:

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<sup>38</sup> Romyne Gallagher, “[Medical assistance in dying: Living with dignity until life naturally ends](#)” (2017) 59 BCMJ 50 at 50-51.

<sup>39</sup> [Dugdale & Callahan](#), *supra* note 30 at 560.

<sup>40</sup> [Romyne Gallagher](#), *supra* note 38 at 50-51.

<sup>41</sup> [Dugdale & Callahan](#), *supra* note 30 at 560.

<sup>42</sup> Studies indicate that the “opinion of others is of importance to many people with dementia ... even to the extent that some of them express being worried about others finding out about their diagnosis or being afraid others won’t listen to them... due to the possibility of stigmatization” and “the way people are treated by medical personnel also influences their well being”; see M de Boer et al, “[Suffering from dementia – the patient’s perspective: A review of the literature](#),” 19 International Psychogeriatrics at 1027-8.

<sup>43</sup> [Carter \(SCC\)](#), *supra* note 6 at paras 127 and 147.

<sup>44</sup> [Bentley v. Maplewood Seniors Care Society](#), 2015 BCCA 91.

<sup>45</sup> *Ibid* at para 18.

<sup>46</sup> [Carter \(SCC\)](#), *supra* note 6 at para 127.

To be capable of independent choice, an individual must be able to understand the important information relevant to that choice. The memory and other cognitive impairments associated with dementia reduce a person's ability to evaluate the choice for PAD. **As a result, many, perhaps most, individuals diagnosed with dementia are incapable of making that choice.**<sup>47</sup>

When the patient is incapable of consent, one must ask whose suffering EAS is intended to alleviate. Patients with "moderate to severe dementia can reliably rate their own quality of life"<sup>48</sup>, and studies reveal that such patients "rate their quality of life higher than do their family members who are influenced by their own distress".<sup>49</sup> This is likely due, in part, to the fact that the patient is able to adapt to the changing situation; a scenario that can lead to the disappearance of former advance desire for euthanasia.<sup>50</sup> Family - and societal - discomfort with illness, disease and physical decline ought not diminish the value and dignity of life. In fact, it ought to prompt societal efforts in the opposite direction, maintaining good contact, and ensuring patients that their lives are worthwhile and useful.<sup>51</sup> Dignity cannot mean simply "life without misery or helplessness" because that is a natural part of all life and all lives.<sup>52</sup> Furthermore, many assumptions about advance directives and dementia patients, for example, are unfounded:

Despite the fact that dementia is accompanied by a lot of negative feelings, the literature on the perspective of the patient offers no solid support to the widespread assumption that dementia is necessarily a state of dreadful suffering, or a disaster without consolation as some clinic psychologists suggest. [...] Furthermore, the adaptive processes which people with dementia go through should be carefully considered in discussions on advance directives, because there is a good chance that, in the end, **people with dementia will not act in accordance with their earlier values and anticipatory beliefs regarding a life with dementia.**<sup>53</sup>

Returning to the concept of dignity, it must not import these erroneous assumptions. Rather, dignity signifies the inherent value of every single person, regardless of disease, disability, or illness and we, as a society "must reclaim" these individuals and the aging process "as part of who we are".<sup>54</sup> Only then will the necessary respect for life and protection for the vulnerable exist in a meaningful way.

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<sup>47</sup> Rebecca Dresser, "[On Legalizing Physician-Assisted Death for Dementia](#)" (2017) 47 Hastings Center Report 5 at 5-6 [emphasis added].

<sup>48</sup> Christopher Beer et al, "[Factors Associated with Self and Informant Ratings of the Quality of Life of People with Dementia Living in Care Facilities: A Cross Sectional Study](#)" (2010) 5 PLoS ONE 1 at 1.

<sup>49</sup> [Romaine Gallagher](#), *supra* note 38 at 51.

<sup>50</sup> E Bolt et al, "[Advance Directive to Euthanasia: Stable Preference in Older People](#)" at 1629.

<sup>51</sup> As noted in a review of literature studying patients with dementia, "a good quality of life was often generated by good contact with other people and the sense of being useful", see [M de Boer](#), *supra* note 42 at 1030.

<sup>52</sup> [Dugdale & Callahan](#), *supra* note 30 at 560.

<sup>53</sup> [M de Boer](#), *supra* note 42 at 1033-4 [emphasis added].

<sup>54</sup> [Romaine Gallagher](#), *supra* note 38 at 51; this is particularly important in light of a study that found patients with an advance directive most likely to follow through with euthanasia were those "worried about a loss of dignity"; see also [E Bolt et al](#), *supra* note 50 at 1631. By affirming certain categories of people are eligible for assisted

## **Section 15 Equality**

In order to understand how EAS expansion in cases of mental illness and advance requests may violate section 15 of the *Charter*, it is necessary to first understand:

- (i) the broader impact of normalizing suicide and its disproportionate impact on persons living with mental illness; and
- (ii) the implications of determining that some that lives are not worth living and its disproportionate impact on the requirement for contemporaneous consent.

Section 15(1) of the *Charter* guarantees that “every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination” based on a variety of enumerated grounds, including age or mental or physical disability.

To access section 15 protection, a claimant must demonstrate that (1) the *Charter* applies because a state actor has infringed equality guarantees through an application of law<sup>55</sup>; (2) the law “creates a distinction on the basis of an enumerated or analogous ground”;<sup>56</sup> and (3) the law “fails to respond to the actual capacities and needs of the members of the group and instead imposes burdens or denies a benefit in a manner that has the effect of reinforcing, perpetuating or exacerbating their disadvantage.”<sup>57</sup>

In this case, the proposed expansion of EAS in the criminal law creates a distinction between Canadians experiencing mental illness and those who are not, as well as between those who are able to consent to medical intervention<sup>58</sup> and those who are not, by virtue of what would be expanded eligibility criteria.<sup>59</sup>

We must also consider whether such distinctions have a discriminatory impact in terms of prejudicing or stereotyping.<sup>60</sup> Prejudice is the “holding of pejorative attitudes based on strongly held views about the appropriate capacities or limits of individuals or the groups of which they are a member.”<sup>61</sup> Stereotyping is a disadvantaging attitude “that attributes characteristics to members of a group regardless of their actual capacities.”<sup>62</sup> The test then boils down to one question: “Does the challenged law violate the

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suicide, it also (erroneously) affirms that those lives are not worth living, and the only “dignity” that remains is to die. It is a self-fulfilling prophecy.

<sup>55</sup> In this instance, the application of the Federal Criminal Law power through expansion of criteria contained in the [Criminal Code](#), RSC 1985, c C-46.

<sup>56</sup> [Kahkewistahaw First Nation v Taypotat](#), 2015 SCC 30 at para 19 [“Taypotat”].

<sup>57</sup> [Ibid](#) at para 20.

<sup>58</sup> Whether assisted suicide should properly be considered “medical care” is not settled.

<sup>59</sup> At this point, of course, it is impossible to point to the precise wording as it has not yet been recommended or developed.

<sup>60</sup> [Withler v Canada \(Attorney General\)](#), 2011 SCC 12 at paras 34, 37, 39 [“Withler”]; [Quebec \(Attorney General\) v A](#), 2013 SCC 5 at para 324 [“Quebec v A”].

<sup>61</sup> [Quebec v A](#), *supra* note 61 at para 326.

<sup>62</sup> [Ibid](#). See also paras 325, 333: Prejudice and stereotyping are not discrete elements of the test that the claimant is obliged to prove, but are indicia that may help answer whether substantive equality is violated. It is also the discriminatory impact, not the attitude at issue. In other words, it matters not whether the government intentionally discriminated.

norm of substantive equality”?<sup>63</sup> In this case, it could be altered to ask, ‘does the proposed expansion of the law violate the norm of substantive equality’?

As Christian Legal Fellowship has argued elsewhere:

If these judgments about the worthlessness of a person’s life are to be decisive, we must remember that when a physician agrees with a patient that his or her life has no value, *that judgment is transitive*; it must logically be applied to *all persons* in the same state, regardless of whether they have requested death.<sup>64</sup>

And as articulated in the context of physical disability and EAS decriminalization:

...the law perpetuates disadvantage. People are categorized according to their abilities and disabilities. Judgments of some regarding their worthlessness are projected onto others. The disadvantages are profound: people in this category lose the benefit of the *Criminal Code* assumption of non-consent;<sup>65</sup> physicians and society assume that individuals in this category prefer death; and health care systems develop different standards of suicide response and care depending on disability and disease.<sup>66</sup>

The same applies to the categories of individuals being considered for EAS eligibility/expansion by the Council. It is discrimination that relates to personal characteristics of an individual or group, and that imposes burdens and disadvantages not imposed upon other individuals or groups, limiting access to opportunities, benefits and advantages available to others.<sup>67</sup> Indeed, it is more than an equality rights violation; it is a societal failing when patients, in the process of mourning a health loss (whether physical or mental) that may result in expressions of depression and despair,<sup>68</sup> are faced with the prejudice that, as a result, finds their lives are less worthy of protection and care.

### **Charter Rights of Health Care Professionals**

Expanding access to euthanasia by advance requests also implicates the *Charter* rights and freedoms of health care professionals, who may have a conscientious/ethical/professional objection to administer lethal drugs to patients who are incapable of providing consent.<sup>69</sup> This has been the experience in the Netherlands, where one Dutch group describes the physician’s experience as follows:

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<sup>63</sup> *Ibid* at para 325, citing *Withler*, *supra* note 58 at para 2.

<sup>64</sup> *Factum of Christian Legal Fellowship*, Intervener in *Carter* (SCC) at para 30.

<sup>65</sup> *Criminal Code*, *supra* note 56, s 14.

<sup>66</sup> *Schutten*, *supra* note 55 at 176-177.

<sup>67</sup> *Law Society of British Columbia v Andrews*, [1989] 1 SCR 143 at 174.

<sup>68</sup> *M de Boer*, *supra* note 42 at 1033.

<sup>69</sup> See Deina Warren and Derek Ross, “*Physicians, conscience, and assisted dying*” (2017) *Policy Options*.



“Imagine...an incompetent but still alert and conscious patient with advanced dementia, to whom we cannot explain that in a long forgotten past this was what he wanted to happen to the demented person he has now become.”<sup>70</sup>

To these physicians, ending the life of such a patient would entail “killing a person with dementia,” rather than respecting that person’s autonomy.<sup>71</sup> Similar considerations apply in the context of administering euthanasia to minors and patients with mental illness, adding further and important justification for maintaining EAS limits in accordance with the Supreme Court’s parameters in *Carter*.

### **Lack of palliative care**

The fundamental rights and freedoms of Canadian patients are further at risk where EAS is publicly funded and widely available, but medical care aimed at alleviating suffering - such as palliative care - is not.

In expanding access to the former and not the latter, the government is undermining meaningful options for patients to pursue a life of autonomy, dignity, and hope. It is troubling that so much emphasis has been placed, both in this consultation and in public policy generally, on ensuring and expanding access to medical assistance in **dying**, when many Canadians do not even have meaningful access to medical assistance in **living**.

Palliative care provides “many benefits for patients and their families, including: greater involvement in healthcare decisions about treatment and care; better quality-of-life; longer life; and fewer hospitalizations.”<sup>72</sup>

In the EAS context, patients are experiencing suffering and/or stress at such a high level that they are considering ending their lives. If patients had access to palliative care that could adequately control their symptoms, they would often live over a premature death.<sup>73</sup> Patients who do not have such access and instead choose EAS suffer diminished autonomy and a premature death. The lack of access to palliative care, which has been judicially acknowledged<sup>74</sup>, therefore exacerbates the *Charter* rights infringements discussed in this paper, and indeed, may itself constitute an unjustifiable violation of the *Charter* in some cases (a discussion of which is beyond the scope of this paper).

While the Supreme Court in *Carter* indicated that s. 7 does not require that “all human life be preserved at all costs”<sup>75</sup>, it does not mean that death should be promoted as an appropriate solution to suffering,

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<sup>70</sup> [Dresser](#), *supra* note 47 at 6.

<sup>71</sup> C. Hertogh et al, “[Beyond a Dworkinian View on Autonomy and Advance Directives in Dementia](#),” (2007) 7 American Journal of Bioethics W4-W6 at W5.

<sup>72</sup> McMaster University, “[The McMaster Health Forum](#)” (2013) at 4.

<sup>73</sup> See discussion in [Carter \(BCSC\)](#), *supra* note 4 at paras 821-831.

<sup>74</sup> In [Carter \(BCSC\)](#), *supra* note 4, at para 192 Justice Smith observed that “high quality palliative care is far from universally available in Canada” and cited evidence that “only 16-30% of Canadians receive palliative care as part of their life-threatening illness” and that “there are many places in Canada, particularly in rural or remote areas, where there is little or no access to palliative care specialist nurses or physicians.”

<sup>75</sup> [Carter \(SCC\)](#), *supra* note 6 at para 63.



and certainly not as a *more* accessible solution than life-enhancing treatment such as palliative care. As the Supreme Court affirmed in *Carter*, the sanctity of life is “one of our most fundamental societal values” and section 7 of the Charter is “rooted in a profound respect for the value of human life”.<sup>76</sup>

### **Conclusion**

In light of these submissions, CLF urges the Council to consider not only whether assisted suicide should be expanded (and CLF submits that it should not), but whether the reasons outlined above justify additional restrictions and protections within the current regime (and CLF submits that they do).

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<sup>76</sup> [\*Ibid.\*](#)

## APPENDIX “A”

### CHRISTIAN LEGAL FELLOWSHIP: RELEVANT KNOWLEDGE

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Christian Legal Fellowship (CLF) is a national charitable association representing over 700 lawyers, law students, professors, and others who support its work. Over nearly two decades, CLF has intervened in more than 20 separate proceedings involving *Charter* issues, including several before the Supreme Court of Canada, seeking to advance justice, protect the vulnerable, promote equality, and advocate for freedom of religion, conscience, and expression.

The CLF has appeared before Parliamentary committees and made representations to provincial governments on issues of conscience, religious freedom, inviolability of life, and human rights. CLF has also been granted Special Consultative Status as an NGO with the Economic and Social Council of the United Nations, and has been involved in numerous international matters.

CLF has developed considerable expertise in legal issues surrounding assisted suicide and euthanasia. In 2012, CLF was recognized by the Quebec Superior Court as “possess[ing] an important degree of expertise in the areas of philosophy, morality, and ethics which areas could be useful for the defense considering the Plaintiff’s request that article 241 (b) of the Criminal Code be declared unconstitutional.” (Leblanc v. Attorney General of Canada et al at p. 45).

CLF was one of the few organizations to intervene in all levels of court in *Carter*, including the post-judgment motion for a further extension of time at the Supreme Court. CLF also intervened in both levels of court in *D’Amico c. Québec (Procureure générale)* concerning the constitutionality of Quebec’s assisted suicide legislation (a case which remains ongoing). CLF participated, by invitation, in the consultations of the federal External Panel on Options for a Legislative Response to *Carter v Canada* and the Provincial/ Territorial Expert Advisory Group on Physician-Assisted Dying. CLF also participated in the consultations of the medical Colleges of Saskatchewan, Manitoba, Ontario, and New Brunswick on this issue. CLF filed detailed legal submissions to the Ontario and Alberta governments in response to their consultation on the issue of assisted suicide and euthanasia. CLF also made submissions to the Special Joint Parliamentary Committee on Physician-Assisted Dying, and to both the House of Commons and the Senate’s Standing Committees on Bill C-14. Further details and links to each of CLF’s submissions are below:

\* \* \*

### CHRISTIAN LEGAL FELLOWSHIP: RELEVANT KNOWLEDGE

- April 2017: [Factum](#) filed jointly with the Evangelical Fellowship of Canada and the Assembly of Catholic Bishops in the case of *Christian Medical and Dental Society et al v. College of Physicians and Surgeons of Ontario*. The case involves a *Charter* challenge to (1) a Human Rights policy mandating effective referrals and obligatory emergency care even if it conflicts with conscience or religious beliefs; and (2) a Medical Assistance in Dying policy that specifically requires effective referrals for assisted suicide.
- March 2017: [Oral](#) and [written](#) submissions before Ontario's Standing Committee on Finance and Economics re the Medical Aid in Dying bill (Bill 84).
- August 2016: [Written submissions](#) urging the Government of Manitoba to introduce legislation protecting freedom of conscience for health care professionals and explaining why forcing health care providers to participate in facilitating the death of a patient would violate the *Canadian Charter of Rights and Freedoms*. The government subsequently introduced Bill C-34, *The Medical Assistance in Dying (Protection for Health Professionals and Others) Act*, which specifically protects the rights of those who refuse to aid in the provision of medical assistance in dying on the basis of his or her personal convictions.
- May 2016: Written [submission](#) filed with the Senate Standing Committee on Legal and Constitutional Affairs concerning Bill C-14.
- May 2016: Oral [submissions](#) before the federal House of Commons Standing Committee on Justice and Human Rights concerning Bill C-14.
- May 2016: Written [submission](#) filed with the federal House of Commons Standing Committee on Justice and Human Rights concerning the government's proposed assisted-dying legislation, Bill C-14.
- March 2016: Written [submission](#) filed with Alberta's Minister of Health, Minister of Seniors, Justice Minister, Solicitor General and Minister of Aboriginal Relations of Alberta in response to the provincial government's consultation concerning physician-assisted dying and end-of-life decisions.
- March 2016: [Open letter](#) to Jody Wilson-Raybould, Minister of Justice of Canada and the Auditor General of Canada, to "express concern about and to rectify certain misunderstandings reflected in the Special Joint Committee's Report regarding the scope of the *Carter* ruling and its implications for Parliament's legislative response."
- February 2016: Written [submission](#) filed with the federal Special Joint Parliamentary Committee on Physician-Assisted Dying.
- January 2016: Written [submission](#) to Ontario's Attorney General and Minister of Health in response to the provincial government's consultation concerning physician-assisted dying and end-of-life decisions.
- January 2016: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Ontario, urging freedom of conscience for health care professionals.
- January 2016: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of New Brunswick, urging freedom of conscience for health care professionals.
- December 2015: [Factum](#) filed with the Supreme Court of Canada in "*Carter II*", urging the Court to extend time for Parliament to pass a euthanasia law and to maintain a national prohibition on euthanasia in the interim.

- November 2015: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Manitoba, urging freedom of conscience for health care professionals.
- November 2015: Written [submission](#) in response to invitation, with the federal External Panel on Options for a Legislative Response to *Carter v. Canada*
- October 2015: Written [submission](#) concerning physician-assisted dying with the College of Physicians and Surgeons of Saskatchewan, urging freedom of conscience for health care professionals.
- September 2015: [Recommendations](#) concerning the Supreme Court's decision in *Carter* to the provincial/territorial Expert Advisory Group on Physician-Assisted Dying.
- August 2014: [Factum](#) filed with the Supreme Court of Canada in the second appeal for *Carter v Canada*.
- December 2012: [Factum](#) filed with the British Columbia Court of Appeal in the first appeal for *Carter v Canada*.
- December 2012: [Factum](#) filed with Superior Court for the District of Trois-Rivières in *Leblanc v Canada* (Quebec).
- July 2012: CLF [granted](#) the right to intervene, make written and oral submissions and cross-examine witnesses in *Leblanc v Canada (Attorney General) & Québec (Attorney General)*.
- December 2011: [Factum](#) filed with the Supreme Court of British Columbia in *Carter et al v Canada*.

**1. Quels sont les principaux problèmes de votre organisme concernant les demandes d'AMM effectuées par des mineurs matures, les demandes anticipées ou demandes se rapportant à des situations où la maladie mentale est le seul problème de santé sous-jacent? [1000 mots maximum]**

Le Collège des médecins du Québec (le Collège) souhaite faire part au comité d'experts de ses principales préoccupations quant au sujet de l'AMM : la protection des patients susceptibles de la demander et le respect de la profession médicale à qui est confiée la tâche de l'administrer. En préambule, il lui semble important de considérer l'ensemble des soins offerts aux grands malades. Alors que les demandes d'AMM sont de plus en plus fréquentes depuis l'entrée en vigueur des lois qui l'autorisent à certaines conditions, que les médias en font la promotion sans discernement et que ceux qui n'y ont pas droit contestent lois et mesures de sauvegarde, il est trop souvent oublié que la société canadienne dispose d'un système de santé moderne et organisé et de ressources considérables qui permettent depuis des siècles de prendre en charge les patients les plus malades et les plus souffrants dans le respect de leurs droits et de leur dignité. Comment leur prodiguer les soins les plus appropriés? Si la question demeure malgré tout, l'AMM n'est qu'exceptionnellement la meilleure solution. Pour se pencher sur les questions particulières qui lui sont posées, le comité ne pourra pas faire abstraction d'une telle observation (KNMG, 2015).

La réflexion actuelle du Collège en la matière se base sur celle entamée en 2006 par son groupe de travail en éthique clinique (CMQ, 2008) et qui stipule qu'un soin est d'autant plus approprié qu'il est le fruit d'un processus décisionnel bien mené entre le patient et le médecin. Un tel processus permet au patient d'exprimer pleinement ses volontés concernant ses soins et au médecin de lui apporter des réponses d'ordre médical, respectueuses des lois et autres normes cliniques et déontologiques qui en encadrent les pratiques. Cette réflexion suggère d'utiliser le prisme du raisonnement clinique pour répondre aux questions soulevées par qui souhaite encadrer autrement le processus décisionnel mené entre le patient qui demande une AMM et le médecin qui pourrait la lui administrer, y compris dans certains cas particuliers : patient mineur, inapte ou souffrant d'une seule maladie mentale.

Le raisonnement clinique est au cœur des normes cliniques sur l'AMM qui ont été élaborées par le Collège, en collaboration avec l'Ordre des pharmaciens et l'Ordre des infirmières et infirmiers du Québec à la suite de l'adoption de la Loi concernant les soins de fin de vie (LCSFV) au Québec (CMQ, 2015). La LCSFV encadre en effet le processus décisionnel susceptible de mener à l'euthanasie, qu'elle considère comme un soin de fin de vie, en exigeant le respect de certains critères d'ordre juridique et médical (art. 26 à 32).

Si le législateur peut faire abstraction de la logique de soins et des normes professionnelles qui guident la pratique médicale en matière d'AMM, celles-ci sont cependant incontournables au chevet du patient. L'expérience néerlandaise est instructive à cet égard (Younger et Kimsma, 2012). Un exemple local l'illustre bien : bien qu'à certaines conditions le suicide médicalement assisté ne soit plus interdit par le Code criminel au Canada, il est prohibé par les ordres professionnels concernés du Québec pour des raisons essentiellement médicales et pharmacologiques.

Le comité devrait garder cela en tête au moment de se pencher sur chacune des questions particulières qui lui ont été confiées. Celle des demandes anticipées retient l'attention du Collège, puisqu'au Québec la LCSFV a instauré un régime de directives médicales anticipées (DMA) ayant des particularités inédites (art. 51 à 64). L'une d'elles et non la moindre est qu'elles ont la même valeur que des volontés exprimées par une personne apte à consentir aux soins (art. 58). Elles portent sur le consentement ou le refus d'un soin parmi cinq soins

spécifiques, requis par son état de santé et proposé par le médecin, par la personne devenue inapte, si elle se trouve dans l'une ou l'autre de deux situations cliniques particulières. Le fait que la personne puisse décider de ses soins de manière anticipée, sans discussion avec le médecin, va à l'encontre de la notion de soins appropriés résultant d'un processus décisionnel partagé entre patient et médecin. Les DMA au sens de la LCSFV ne permettent pas de demander une AMM et l'on comprend pourquoi dans ce contexte!

Par ailleurs, un groupe de travail conjoint, mené par le Collège, avait entamé une réflexion sur l'AMM et les personnes atteintes d'une démence (CMQ, 2013). Le groupe de travail avait abordé la question sous l'angle de la responsabilité décisionnelle, qu'il souhaitait partagée. Cependant, il avait fait abstraction des impacts qu'une telle décision pouvait avoir sur le médecin chargé ultimement de mettre fin à la vie du patient concerné, devenu inapte à consentir, qui ne se rappelle pas en avoir fait la demande, ne comprend pas ce qu'on lui fait, voire qui s'y oppose avec une force telle qu'il faut lui imposer une contention pour procéder à l'injection létale... Cet élément nous semble fondamental à prendre en considération au moment d'envisager l'AMM pour des personnes incapables de consentir à leurs soins. L'expérience des pays européens dont les lois permettent des demandes d'euthanasie anticipées à certaines conditions devrait être prise en considération par le comité dans le cadre de son analyse. Par ailleurs, alors que la LCSFV et la loi fédérale ne sont en vigueur que depuis quelques mois, il est surprenant de constater à quelle vitesse leurs balises ont été contestées. Alors que personne n'a encore acquis une expérience certaine envers l'AMM, il n'est sûrement pas temps de les remettre en question. Si la société, cependant, est prête à les ôter, au nom de l'autonomie de la personne et de la défense de ses droits, la profession médicale, quant à elle, ne pourra continuer à participer à cet acte que dans un cadre clinique qui tient compte des règles qui la définissent.

Le Collège invite donc à la prudence le législateur qui souhaiterait élargir les balises actuelles limitant l'accès à l'AMM. Il suggère par ailleurs au comité de prendre connaissance de l'ouvrage publié récemment par Dre Michelle Marchand (Marchand, 2017) qui reprend dans le détail plusieurs des éléments présentés ici.

**2. Veuillez indiquer ou fournir les renseignements\* pertinents que votre organisation souhaiterait voir pris en considération par le comité d'experts sur l'AMM du CAC en matière de demandes de mineurs matures, de demandes anticipées ou de demandes se rapportant à des situations où la maladie mentale est le seul problème de santé sous-jacent. Ces renseignements sont à transmettre sous forme d'hyperliens, de références ou de pièces jointes.**

*\*Les renseignements pertinents incluent, entre autres : études, enquêtes, réglementations, lignes directrices, connaissances traditionnelles, pratiques et cas cliniques.*

COLLÈGE DES MÉDECINS DU QUÉBEC (2008). Pour des soins appropriés au début, tout au long et en fin de vie : Rapport du groupe de travail en éthique clinique, CMQ, Montréal, 17 octobre, 50 p.  
[<http://www.cmq.org/publications-pdf/p-1-2008-10-01-fr-pour-des-soins-appropries-au-debut-tout-au-long-et-en-fin-de-vie.pdf>]

COLLÈGE DES MÉDECINS DU QUÉBEC (2013). Rapport du groupe de travail conjoint sur l'aide médicale à mourir, CMQ, Montréal, mars, 34 p.  
[<http://www.cmq.org/publications-pdf/p-1-2013-03-01-fr-rapport-aide-medicales-a-mourir.pdf>]

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MARCHAND, M. (2017). L'aide médicale à mourir au Québec : Pourquoi tant de prudence, Liber, Montréal, 84 p.

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[<http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2014C2F.PDF>]

KONINKLIJKE NEDERLANDSCHE MAATSCHAPIJ TOT BEVORDERING DES GENEESKUNST (KNMG) (2015). Stuurgroep Passende zorg in de laatste levensfase. Niet alles wat kan, hoeft, Utrecht, 91 p. [Version en anglais disponible dans le site Web du KNMG]  
[<https://www.knmg.nl/advies-richtlijnen/dossiers/niet-alles-wat-kan-hoef.htm>]

YOUNGNER, S. J. et G. KIMSMA (2012). Physician-Assisted Death in Perspective - Assessing the Dutch Experience, Cambridge University Press, USA, juillet, 400 p.

College of Physicians and Surgeons of Ontario

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attachment.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attachment.





**Submission to the Council of Canadian Academies: Expert  
Panel on Medical Assistance in Dying in Canada**

**College of Physicians and Surgeons of Ontario**

**October 2, 2017**

The College of Physicians and Surgeons of Ontario (College) appreciates the opportunity to make a submission to the Council of Canadian Academies' Expert Panel on Medical Assistance in Dying in Canada.

As Canada's largest medical regulatory authority, the College has a legal mandate to serve and protect the public interest. All of our work, including that on medical assistance in dying (MAID), is undertaken with a view toward fulfilling our mandate. Core College responsibilities include:

- Issuing certificates of registration to physicians to allow them to practice medicine in Ontario;
- Monitoring and maintaining standards of practice through peer assessment and remediation;
- Investigating complaints about physicians on behalf of the public;
- Conducting discipline hearings when physicians may have committed an act of professional misconduct or may be incompetent;
- Articulating expectations for physician conduct on professionalism, medico-legal and other issues that are relevant to the practice of medicine through the [Practice Guide](#) and over fifty [College policies](#).

With respect to the last listed core responsibility, the College has articulated expectations for physician conduct in relation to MAID in our [Medical Assistance in Dying](#) policy. This policy was finalized in June 2017 and reflects the federal law pertaining to MAID along with relevant Ontario law and existing College policies. The *Medical Assistance in Dying* policy is supplemented by numerous supporting documents posted on the College's website. This includes [Frequently Asked Questions for Physicians](#), an information resource for the [Public](#), a [Fact Sheet](#) relating to effective referrals, and an [Early Lessons Learned](#) document developed in collaboration with the Office of the Chief Coroner of Ontario.

The College has considered carefully each of the three topics that are the subject of the Expert Panel's independent review: mature minors, advance requests and mental illness as a sole underlying condition. In this submission, the College does not take an explicit position on any of the three topics, but rather highlights for the Panel the key issues and considerations that the College believes should form part of the Panel's analysis. The comments set out in this submission are consistent with the College's work on MAID to date, including our

[Submission](#) to the Senate Standing Committee on Legal and Constitutional Affairs that considered Bill C-14, and our mandate to protect and serve the public interest.

Our submission is in two parts. First, we identify core principles or considerations that we believe are applicable to all three topics. Second, we highlight key considerations specific to each topic of independent review.

## **I. Core Principles and Considerations**

Four core principles or considerations have grounded the College's thinking on the three topics under review.

### **1. Capacity**

The College recognizes the central role that capacity plays in healthcare decision making and how under both federal legislation relating to MAID and Ontario's [Health Care Consent Act, 1996](#)<sup>1</sup> (*HCCA*), capable individuals are entitled to make their own healthcare decisions. We also recognize that under the *HCCA* and common law, the prior capable wishes of incapable patients can directly inform decisions made by substitute decision makers and clinicians. These may be wishes expressed verbally or in written advance directives.<sup>2</sup>

### **2. Consistency**

We believe it is essential to locate MAID within the broader context of healthcare so that the Expert Panel is able to consider the three topics of study comprehensively to ensure consistency in relation to respect for patient autonomy, applicable safeguards and requirements for healthcare decision making.

### **3. Clinician<sup>3</sup> Competence**

The College is aware that in relation to MAID to date, questions have emerged from clinicians about the competence required to assess patient eligibility for MAID and to provide MAID. The Expert Panel may wish to consider whether the three topics under review have implications for clinician competence; specifically whether there should be

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<sup>1</sup> S.O. 1996, c. 2, Sched. A.

<sup>2</sup> Section 5(2) of the *HCCA*.

<sup>3</sup> 'Clinician' is used in this submission to be inclusive of both nurse practitioners and physicians, as both are authorized to provide MAID under federal law. The College's jurisdiction is limited to physicians and the comments included in this submission represent those of the College alone, and not the College of Nurses of Ontario.

specific professional competencies or areas of expertise and experience that are required as prerequisites for clinician involvement. In doing so, however, the Panel should equally consider the impact that setting such prerequisites may have on the number of willing providers available as this will directly impact access to care for eligible patients.

#### **4. Clarity and Confidence of Clinicians**

In accordance with the federal legislation, and as affirmed in the recent decision, [\*A.B. v. Canada \(Attorney General\)\*](#)<sup>4</sup>, the responsibility for determining patient eligibility for MAID has been assigned to clinicians. There remains much in the current federal legislation that is unclear. The issues that the Expert Panel is considering could add additional complexity. It is essential that regardless of the position the federal government ultimately takes in relation to the topics under review, careful consideration needs to be given to the challenges facing clinicians in interpreting and applying legislation and efforts made to ensure that any resulting legislative provisions are clear.

## **II. Key Issues and Considerations**

In our remarks on each topic, the College will touch on the core principles outlined above and identify additional key issues for the Expert Panel's consideration.

### **1. Mature Minors**

The *HCCA* and the Supreme Court of Canada's decision in [\*AC v. Manitoba \(Director of Child and Family Services\)\*](#)<sup>5</sup>, ('AC') will be instructive to the Expert Panel on the issue of mature minors.

Under the *HCCA*, capacity is determined by a functional test, not chronological age. Patients are deemed to have capacity to consent to treatment if they are: able to understand the information that is relevant to making a decision about the treatment, and able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.<sup>6</sup> Patients are presumed to have capacity under the *HCCA* unless there are reasonable grounds to believe

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<sup>4</sup> 2017 ONSC 3759.

<sup>5</sup> 2009 SCC 30, [2009] 2 SCR 181.

<sup>6</sup> Section 4(1) of the *HCCA*.

otherwise<sup>7</sup>, and findings of incapacity can be challenged by application to the [Consent and Capacity Board](#) (CCB)<sup>8</sup>, an independent, multidisciplinary board created under the *HCCA*<sup>9</sup>.

In the *AC* decision, the Supreme Court of Canada recognized that minors may have the capacity to make treatment decisions, that they have the right to prove they are capable, and that a rigid statutory framework based on age would fail to reflect the realities of child development.<sup>10</sup>

As alluded to the College's Submission to the Senate Standing Committee, linking capacity to age for the purposes of MAID gives rise to an inconsistency between federal legislation and the *HCCA*. Patients under eighteen may be deemed capable of making healthcare decisions by virtue of the *HCCA*, (including decisions comparable to MAID such as withdrawal of life-sustaining treatment) but may be ineligible to access MAID simply because of their age.

We would encourage the Expert Panel to consider:

- First, whether the inconsistency created between the federal legislation and the *HCCA* with respect to age and capacity is appropriate and the supporting justification or rationale; and
- Second, the potential human rights implications that may be associated with limiting the autonomy of a capable patient solely on the basis of that patient's age.

The College acknowledges that an important part of the Expert Panel's evaluation of mature minors will likely entail a consideration of whether existing safeguards included in the federal legislation are sufficient or whether additional safeguards, specific to mature minors are required. We would note for the Panel that individuals referred to as mature minors can vary

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<sup>7</sup> Section 4(2) and 4(3) of the *HCCA*.

<sup>8</sup> Section 32 of the *HCCA*.

<sup>9</sup> The CCB is created under the *HCCA* and it conducts hearings under the *Mental Health Act*, the *HCCA*, the *Personal Health Information Protection Act, 2004*, the *Substitute Decisions Act* and the *Mandatory Blood Testing Act, 2006*. The Board is multidisciplinary, comprised of psychiatrists, lawyers and members of the general public appointed by the Lieutenant Governor in Council. For more information see Part V of the *HCCA*.

<sup>10</sup> See, for example, Justice Abella's comments at paragraph 87: "If, after a careful and sophisticated analysis of the young person's ability to exercise mature, independent judgment, the court is persuaded that the necessary level of maturity exists, it seems to me necessarily to follow that the adolescent's views ought to be respected." Additionally, Justice Abella's comments at paragraph 107: "Given the significance we attach to bodily integrity, it would be arbitrary to assume that no one under the age of 16 has capacity to make medical decisions. It is not, however, arbitrary to give them the opportunity to prove that they have sufficient maturity to do so."

significantly in terms of life experience, and maturity. Some may have limited life experiences, some may be emancipated minors, and some may have dealt with illness their entire lives to date. As such, the safeguards required, including whether and when parental consent should be required, may indeed vary widely from patient to patient. While safeguards are an important part of the system, safeguards must not, without adequate justification, limit the autonomy of capable patients, and/or frustrate access to MAID for eligible patients.

With respect to clinician competence, it is an expectation of the College that Ontario physicians provide care within the scope of their knowledge, skill and judgement.<sup>11</sup> The College acknowledges that clinicians trained and experienced in providing pediatric and adolescent care have a unique skill set and perspective. We encourage the Expert Panel to seek the input of pediatric specialists and societies such as the [Canadian Pediatric Society](#) and the [Pediatric Chairs of Canada](#) to get expert advice as to whether only those with training and experience in pediatrics or adolescent care should provide MAID to mature minors. Through these discussions, the College encourages the Expert Panel to also examine the availability and accessibility of pediatricians across different communities, particularly those outside of large urban centres and their willingness to be involved in MAID. Should the number of willing providers be low, this may pose very real challenges to access to care for eligible patients.

## 2. Advance Requests

We note that the term ‘advance requests’ has not been defined in the Expert Panel’s Call for Input and that there are two distinct scenarios (each with distinct implications) that could be captured by this language:

- Scenario #1: a capable patient makes a request for MAID but loses capacity at some point before MAID is provided;
- Scenario #2: a substitute decision maker requests MAID on behalf of an incapable patient, on the basis of the patient’s prior capable wish or advance directive.

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<sup>11</sup> Section 2(1)(c) of O.Reg. 865/93, Registration, enacted under the *Medicine Act, 1991*, S.O. 1991, c.30.

For the purposes of this submission, the College will assume that both Scenario #1 and #2 are contemplated by ‘advance requests’. It will be essential for the Expert Panel to clarify how it is using the term and what specific scenarios ‘advance requests’ will capture.

On a related point, the Expert Panel may also wish to consider and clarify the intersection of advance requests with the two other topics for review: mature minors and mental illness as a sole underlying condition. That is, whether it is contemplated that the incapable patient making an advance request could be a mature minor and/or could be a patient whose sole underlying condition is mental illness. The College notes that with respect to mature minors, the *HCCA* refers to prior capable wishes as those made by individuals sixteen (16) years of age or older.<sup>12</sup>

Requirements with respect to healthcare decision making for incapable patients are set out in the *HCCA*. The College highlights the following elements of the statute for the Expert Panel’s information:

- When making a decision for an incapable patient, substitute decision makers must do so either in accordance with the patient’s prior capable wish, if applicable, or with the patient’s best interests.<sup>13</sup>
- Substitute decision makers are entitled to make treatment decisions on behalf of incapable patients<sup>14</sup>. ‘Treatment’ is defined broadly in the *HCCA*<sup>15</sup> and can include decisions that are comparable to MAID such as those to refuse or to withdraw life-sustaining treatment.
- The *HCCA* sets out those individuals who can act as a substitute decision maker.<sup>16</sup> Included in this list are individuals who have a close relationship with the patient, and who therefore are likely to be involved in the patient’s personal care and/or likely to be listed as a beneficiary in the patient’s will.<sup>17</sup>

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<sup>12</sup> Section 21(1) of the *HCCA*.

<sup>13</sup> Section 21(1) and (2) of the *HCCA*.

<sup>14</sup> Section 10(1) of the *HCCA*.

<sup>15</sup> Section 2(1) of the *HCCA*.

<sup>16</sup> Section 20 of the *HCCA*.

<sup>17</sup> The Panel may wish to note that the individuals who can act as a substitute decision maker under the *HCCA* would be precluded from even acting as a witness to a capable patient’s request for MAID by virtue of section 241.2(5) of the *Criminal Code* R.S.C., 1985, c. C-46.

- Should the health practitioner believe that the substitute decision maker is not acting in accordance with the patient's prior capable wishes or the patient's best interests, the health practitioner can challenge the substitute decision maker's decision by making an application to the CCB.<sup>18</sup>

In light of these provisions, the Expert Panel may wish to consider the inconsistency that exists between the federal law and the *HCCA* with respect to decision making for incapable patients. Similar to our comments in relation to mature minors, the Expert Panel may wish to consider this inconsistency with the following factors in mind:

- First, whether the inconsistency created between the federal legislation, the *HCCA* and common law related to advance directives is appropriate and the supporting justification or rationale;
- Second, if prior capable wishes or advance directives of patients are deemed not applicable or not binding on MAID, the potential implications this may have on public and physician clarity and comprehension of advance care planning in relation to other treatment decisions;
- Third, the potential impact on clinicians if there are different requirements with respect to healthcare decision making for MAID and for other treatments; and
- Fourth, the implications for patients, specifically access to care, and respect for patient autonomy and prior capable wishes.

A key objective underpinning the federal legislation on MAID is the protection of vulnerable populations. The College supports that objective and acknowledges that risks to incapable patients and appropriate corresponding safeguards should form part of the Expert Panel's study. As with mature minors, the Panel may wish to consider the safeguards included in the *HCCA* to determine whether its provisions related to substitute decision making and the CCB strike an appropriate balance between ensuring sufficient protections for incapable patients, respect for patient autonomy through prior capable wishes or advance directives, and access to care for eligible patients.

With respect to the practical application of advance requests and the need for clinician clarity and confidence, the College anticipates that clinicians will need clarity regarding the individuals

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<sup>18</sup> Section 37 of the *HCCA*. See also sections 35 and 36 of the *HCCA* where substitute decision makers or health practitioners can apply to the CCB to seek direction in relation to prior capable wishes (s.35), and direction to depart from wishes (s.36).



who can act as a substitute decision maker in relation to MAID. This will be particularly vital if the individuals who can act as substitute decision makers for MAID differ from those who can act in relation to other healthcare decisions. Second, should the federal government opt to allow for MAID to be requested on behalf of an incapable patient (scenario #2 noted above), it will be essential that the patient's wishes are expressed clearly. We understand that often in practice, advance directives are not clearly written and questions arise as to their enforceability due to ambiguous language or concerns as to whether the advance directive represents the current views or wishes of the patient.

Finally, we flag a practical issue. In practice, there can be a striking contrast between a patient's prior capable wish and the patient's conduct when incapable. Specifically, there may be situations where a patient has expressed a prior capable wish to receive a particular treatment, but then physically recoil or verbally protest when clinicians attempt to provide that very treatment. Clinicians will need clarity about how to proceed in these instances in relation to MAID.

### **3. Mental Illness as sole underlying condition**

The College recognizes that individuals with mental illness who meet the criteria in the federal legislation are currently eligible for MAID. That said, the consideration of mental illness as a sole underlying condition raises a number of complex issues to be considered.

The College strongly encourages the Expert Panel to seek the input of individual experts in psychiatry and relevant organizations such as the [Canadian Psychiatric Association](#) , along with individuals in jurisdictions who currently offer MAID to patients with mental illness.

We note there are a range of illnesses, conditions and disorders that can be understood as mental illness and they may each give rise to unique considerations in relation to MAID. The Expert Panel may wish to consider clarifying how mental illness is to be understood and defined in relation to MAID.

As we have noted in our remarks on the two previous topics, capacity is a key element of healthcare decision making. We note that although mental illness can render a patient incapable, many patients with mental illness do have decision making capacity. We have

provided elsewhere links to the *HCCA* and note that that statute explicitly acknowledges the nuances associated with capacity: that capacity is specific to the treatment proposed; that capacity, when lost, can return; and that capacity or incapacity is not global in all areas of a patient's decision making.<sup>19</sup> The College suggests that those provisions and their underlying principles regarding capacity and incapacity form part of the Expert Panel's deliberations on this topic.

Related to capacity and respect for patient autonomy, should the Expert Panel consider the possibility of granting patients with mental illness as a sole underlying condition access to MAID, the College believes it is essential that patients be informed of means available to relieve the suffering caused by their illness, such as mental healthcare and psycho-social supports. Doing so will demonstrate respect for patient autonomy and will enable patients to make an informed decision about MAID.

Related to the clarity and confidence of clinicians, we would note that important interpretive issues arise when thinking about the application of the current eligibility criteria for MAID to patients who have mental illness as a sole underlying condition. We flag below issues related to 'incurable' 'irremediable' and 'reasonably foreseeable death'.

In relation to the concepts of 'incurable' and 'irremediable', we note that,

- Mental illness is typically assessed through subjective means which rely heavily on the patient's own experience or perception of the illness. The patient's perception, however, can be directly impacted by the mental illness itself.
- Mental illness can affect the patient's willingness to try treatments or to continue complying with existing treatment.
- Mental illness can also impact the patient's emotional regulation. Impaired emotional regulation can shape the patient's views of the future, and the extent to which the patient will have a sense of hope or despair about living with their condition and the prospect of recovery.
- We understand that in treating mental illness, the philosophical approach that underpins psychiatric treatment is one of 'recovery' as opposed to 'cure'.

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<sup>19</sup> Sections 4, 15, and 16 of the *HCCA*.

In relation to the requirement that the patient's 'natural death be reasonably foreseeable', the College notes that many mental illnesses may carry a risk of suicide. If a patient has a mental illness that carries a risk of suicide, but is otherwise eligible for MAID could his or her death be considered 'reasonably foreseeable'? That is, could the risk of suicide associated with the illness itself be sufficient to satisfy this criterion?

Consideration must be given to what if any, changes may be required to eligibility for MAID or how existing eligibility criteria, if retained, are to be interpreted in relation to mental illness. For instance, it would be important to consider on what standard mental illness would be considered 'incurable' for the purposes of MAID: subjective (patient's views), objective (clinician's views) or a subjective/objective standard.

Should the federal government permit individuals with mental illness as a sole underlying condition to access MAID, it will be important to consider how patient autonomy can be respected and balanced with appropriate safeguards when the patient's wishes and beliefs are linked so inexorably with the mental illness. Safeguards are an important part of the system, yet it is essential to ensure that the autonomy of capable patients is respected and that the safeguards or process steps implemented do not have a discriminatory effect on those with mental illness.

The College offers two comments in relation to clinician competence. First, consistent with our earlier comments regarding mature minors, the College encourages the Expert Panel to evaluate whether it is essential that only those with training and experience in psychiatry and mental health issues provide MAID to those with mental illness as a sole underlying condition. The Canadian Psychiatric Association may be able to assist the Panel in evaluating this matter. Through these discussions, the College encourages the Expert Panel to also examine the availability and accessibility of psychiatrists across different communities, particularly those outside of large urban centres and their willingness to be involved in MAID. Should the number of willing providers be low and yet desired safeguards require the involvement of a psychiatrist, this may pose very real challenges to access to care for eligible patients.

We trust our comments and suggestions are useful to the Expert Panel as it proceeds with its independent reviews of these three topics. We would be happy to provide any further assistance that may be helpful.

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Among other considerations, these ought to be examined in the context of the health care decisions that are permitted and limited in similar situations. For example, what are the morally relevant similarities and differences between MAID and other health care decisions permitted by mature minors, people whose wishes are expressed by advance directive, and people with significant mental illness? The factors justifying a differential approach should be described in detail if the current restrictions are to be upheld. The three situations are examined in order from least to most ethically problematic.

**Mature Minors**

The major issue for mature minors and MAID is going to be capacity for appreciating the implications of the decision. Currently, age is being treated as a stronger or more important consideration than capacity in the case of MAID, therefore being a minor justifies overriding the individual's autonomy. As with any patient, the most undesirable outcome would be the death of someone who did not fully appreciate the implications of their decision, or who was not completely certain. The most desirable outcome, presumably, is one where suffering is minimized. An age restriction errs on the side of privileging the former, by assuming that a minor is more vulnerable to influence and/or less likely to fully understand the implications of their decision. However, our society respects the choices of minors in other major decisions concerning their health care, dependent on their capacity for appreciating the consequences. If we are to treat MAID differently for this group, we need to understand how it is different from other kinds of health care decisions with similar outcomes. For example, what are the morally relevant differences between MAID and cessation of dialysis or chemotherapy for mature minors? The risks of limiting access to people of a particular age include extending the suffering of ineligible patients, and unequal treatment based only on age. The risks of allowing a mature minor access to MAID, all other criteria being met, will have to be seen as no greater for a mature minor than for an adult. This would need to be judged on a case-by-case basis, but of the three conditions discussed here, this is possibly the least ethically problematic. If it cannot be shown that there is a morally relevant factor that privileges age over capacity, it will be difficult to continue justifying limiting access to MAID to adults. Indeed, it would be helpful to have further guidance on capacity as it is plausible that there are children more capable of appreciating the material risks and benefits of MAID than many adults.

**Advance Requests**

The ethical debate around advance requests for MAID center on respect for autonomy. Advance requests in the form of advance directives are foundational to most health care, and are generally seen as definitive in terms of the deference providers pay when determining a care plan for someone who is unable to speak for themselves. Can providers truly be certain about whether the patient would still want an assisted death, if they are unable to communicate it? If not, would a provider be comfortable with the uncertainty? Some factors that might contribute to a stronger certainty about the provision of MAID to a person who is unable to consent at the very moment of the procedure:

- How long has it been since the person made the request?
- Were they aware of their diagnosis and how it might progress?
- How specific were the instructions in terms of timing of death related to advancing symptoms?
- Was the request made formally, in a legal document, or verbally, in a more casual manner?

- Is the patient's situation at the time a MAID intervention is requested on their behalf consistent with what they had described as being intolerable?

Each of these factors would point to the degree to which the patient had considered and understood the implications of the request. The more confident the clinician could be in their assessment that the patient's request would apply in the circumstances under which the procedure would be provided, the more certain they would be that they were respecting the individual's autonomy, and acting in their best interests. It would be difficult to codify the entire set of possible circumstances under which a clinician could act with ethical certainty on an advance request for MAID. However, it should be possible to set some criteria to increase the clinician's confidence that provision of MAID is consistent with the patient's values and wishes. For example, a request in response to a specific diagnosis, with a description of the level of suffering the patient would consider unbearable, made within a specific time frame of the request for MAID would be helpful. If it is not clear whether the patient's circumstances are consistent with an advance request for MAID, comfort care rather than active treatment will continue to be an option. As with any request for MAID, each case would need to be evaluated on its merits.

#### Mental illness as the sole underlying medical condition

This is perhaps the most ethically challenging of the three situations discussed here. It may be hard to determine the true wishes of the patient with severe mental illness because mental illnesses can compromise insight and decisional capacity. It is also not clear when suffering associated with mental illnesses is permanent, when a person with mental illness as their sole medical condition is in an advanced state of irreversible decline, or when their death is reasonably foreseeable. It will be difficult to know what will do the most good and the least harm, when there is a possibility that symptoms could be improved. Especially when there is a reluctance to try treatments that would improve suffering without causing death, it would be reasonable for a clinician to be concerned about the moral hazards of causing a death needlessly (i.e. of a person who could go on to live a fulfilling life, were symptoms controlled). While it is clear that there are many people who suffer profoundly from their mental illnesses, it is very difficult to know if the illness itself compromises the individual's insight into the possibility that the suffering might be remediable. A question that will need to be considered is whether the person with uncontrolled (as distinct from intractable) symptoms of mental illness can have the required capacity to fully appreciate the implications of the decision. A more philosophical debate is whether the patient is the same person when symptomatic as they are/would be when symptoms are controlled, and therefore whether the wishes and values of a symptomatic person carry the same weight as those of the patient when they are successfully treated, or whether overriding them is justified on the grounds of paternalism or beneficence. The nature and severity of symptoms could both qualify and disqualify a patient for MAID. In addition the nature of mental illnesses do not generally prevent a person from being physically able to act on a desire to die, unlike the advanced physical illnesses addressed by the Carter decision, raising the question of whether there is an element of ambivalence on the part of the patient who asks for help to die. For a clinician to provide MAID to a person with any ambivalence would be morally hazardous, and would risk a death that was not truly desired. Again, patient requests should be considered on a case-by-case basis. It is expected, however, that situations where mental illness is the sole underlying medical condition will be more contingent, and therefore more difficult to codify in order to provide clinicians with sufficient clinical and ethical guidance to assess eligibility for MAID.

General ethical considerations for all three conditions:

Values: What is important to the patient? Do the values of the patient, provider and/or family

conflict? Can values be determined? Are clinicians certain about what is the right thing to do?

Autonomy: What best demonstrates respect for the person, their values and their choices? How important, when compared with doing good and preventing harm, is respecting the person's request? In other words, can respect for autonomy be justified as the primary or dominant ethical consideration? How is it balanced against other ethical principles?

Beneficence and non-maleficence: What will do the most good and the least harm? How should these be quantified and ranked against the other ethical considerations? I.e. how should a clinician decide whether or not to provide MAID in situations where the patient's expressed wish appears to be incompatible with their best interests? What should take priority? Who determines what is in a patient's best interests?

Justice: what is just? How can we best treat people with fairness and equity? How can we ensure all people have equal opportunities? How would we justify treating some people differently than others? That is, what are the morally relevant factors that justify differential treatments?

Consequences: what are the risks of expanding eligibility to each of these conditions? What are the risks of continuing to restrict? What are the benefits of restricting and expanding for each? How much risk are we, as a society, willing to tolerate? How much moral and professional risk is a clinician expected to assume?

Relational ethics: For patients, what is the context of the request? For clinicians, what is the best way to demonstrate respect and caring? How do we establish and maintain caring and trusting relationships? How can we best mitigate power imbalance? Ultimately, the provider has the power to decide if the patient is eligible or not, so any guidance for providers that will help them negotiate the uncertainty will be helpful.

Duties and obligations: what is consistent with professional codes of ethics? Standards of practice? How can we best provide individualized care based on the patient's needs and values? What are the fiduciary duties of health care providers and the system? How best can they be fulfilled in this context? How do we promote and maintain trust relationships between clinicians and patients? Between society and the health care system? When values are truly incompatible, how should they be prioritized?

Registered Nurses are guided by the CNA Code of Ethics, and the CNA National Nursing Framework on MAID, Licensed Practical Nurses are guided by the Code of Ethics for Licensed Practical Nurses. These documents set out values and responsibilities for nurses. The relevant Values are set out starting on Page 9 of the National Framework document (<https://www.cna-aaiic.ca/~media/cna/page-content/pdf-en/cna-national-nursing-framework-on-maid.pdf>). For nurses caring for any patient who has requested MAID, these values and responsibilities will need to be deliberately included in any decision concerning care, and especially for patients who fall into the three categories considered in this document, irrespective of whether or not the criteria are expanded. For example:

A. Providing safe, compassionate and ethical care –may require speaking up if there are concerns about a patient's capacity.

B. Promoting health and well-being - examining the ethical considerations as listed above (especially values, respect for autonomy, beneficence, non-maleficence, justice, consequences and relationships) for each patient requesting MAID.

C. Respecting informed decision-making – ensuring consent is fully informed and that patient decisions are respected as much as possible, including those expressed by substitute decision-makers, advance care plans, and best interests.

D. Honouring dignity – including patient values and beliefs in care planning, working to relieve

pain and suffering, encouraging wishes about end-of-life are clear.

F. Promoting justice – ensuring non-discrimination (including on the basis of age and mental ability), advocating for fair treatment.

G. Being accountable - proceeding in compliance with law and standards.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Medical Assistance in Dying: Guidelines for Nurses

<https://www.cnm.mb.ca/uploads/ck/files/MAID%20guideline%20FINAL.pdf>

Canadian Nurses Association Code of Ethics for Registered Nurses 2017 <https://cna-aiic.ca/~media/cna/page-content/pdf-en/code-of-ethics-2017-edition-secure-interactive.pdf?la=en>

Code of Ethics for Licensed Practical Nurses. <http://www.clpnm.ca/standards-guidelines/code-of-ethics/>



College of Registered Psychiatric Nurses of Manitoba

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached submission.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached submission.

## **Response on Call for Input on Medical Assistance in Dying in Canada: Underlying Medical Condition – Mental Illness**

The College of Registered Psychiatric Nurses of Manitoba (CRPNM) consulted with Registered Psychiatric Nurses (RPNs), in advanced practice roles, the College of Licensed Practical Nurses of Manitoba (CLPNM) the College of Registered Nurses of Manitoba (CRNM) on the issue of accessing Medical Assistance in Dying when the primary underlying medical condition is a mental illness. The following outlines the issues/concerns identified from those consultations.

While there are specific criteria to diagnose a mental illness, there is no ability to predict the trajectory of that illness based on the diagnosis. As noted in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), “there is no assumption that each category of mental disorder is a complete discrete entity with absolute boundaries dividing it from other mental disorders or no mental disorder. Symptoms and patterns exist along a continuum” (p. xxxi). While one might argue that there is a predictable pattern to the course of an illness, this may or may not be the case with some, or any mental illnesses. Therefore, the determination that death may occur in the foreseeable future cannot solely rely on the opinion or professional judgement of one health care professional. Furthermore, assessments regarding eligibility for Medical Assistance in Dying will need to achieve the delicate balance between professional judgement and opinion and an individual’s right to self-determination; that is, to determine how they wish to live, or end, their life. Without a reliable way to determine if death would be reasonably foreseeable, appropriate safeguards will need to be out in place. At a minimum, assessments must be done by qualified and appropriately educated mental health professionals who have significant clinical experience in the assessment, diagnosis and treatment of mental disorders.

Suicide is also a factor to consider. If individuals with a primary diagnosis of a mental illness are not provided with the same freedom and liberties to be eligible for Medical Assistance in Dying, circumstances may arise where a competent individual will be faced with lesser humane ways to end their life. If death by suicide is inevitable, does the health care system have a moral obligation to provide a more humane option to end suffering? If individuals with a primary underlying condition of a mental illness are not provided with options for their suffering, some may see suicide as their only option. This issue is fraught with ethical considerations for both the individual who is suffering and for the health care professionals involved in the assessment processes. Consideration must also be given to the potential conflicts between these ethical issues and the legal frameworks of the mental health system. Specifically, how will the system

address individuals who are deemed ineligible for Medical Assistance in Dying but who present as an imminent risk to themselves?

Further to the conversation about self-determination is the right to refuse treatment. The protection of individual autonomy is a fundamental *Charter* right and provincial mental health legislation often explicitly addresses the right to consent to or refuse psychiatric and other medical treatment. These are important human rights protections but, unlike a refusal of chemotherapy to treat cancer where a competent person decides to allow the disease to proceed in its natural course, the refusal of treatment for a mental illness may result in deterioration in thought, mood, judgment and behavior which could, in fact, lead to issues with respect to competency and capacity for decision making. Alternatively, the decision to refuse treatment, in and of itself, leaves the individual vulnerable to questions about their competency; which may or may not be affected by their mental condition.

The determination of competency is a significant issue that requires careful consideration and that appropriate safeguards are put into place. An individual is presumed to be competent to make decisions unless there are significant grounds to warrant otherwise. The individual requesting Medical Assistance in Dying will have to demonstrate insight and the capacity for decision making. Sufficient time and attention is required to assess competency and must include direct observation and conversation with the individual and information from significant others. The assessment of competency is complex and must be done by qualified and appropriately educated mental health professionals who have specific education and experience in this area. In our view, this means that the competency of the professionals who have this responsibility is an equally important consideration. This was echoed in a study conducted in the Netherlands where “although the Dutch Supreme Court did not state whether the expert is consulted has to be a psychiatrist, nearly all the respondents stated that one or more psychiatrists should be consulted when physician-assisted suicide is considered for a psychiatric patient.” (Groenewoud, Van der Maas, Van der Wal, Hengeveld, Tholen, Schudel & Van der Heide, 1997).

Considerations will need to be given to which mental health professionals have the education and training to assume such roles. Fair and equitable access to Medical Assistance in Dying for individuals with mental illness will require that competency assessments will not just be performed by psychiatrists and psychologists. In Oregon, “the legal statutes recommend that a psychologist become involved in PAS when there are concerns regarding the patient’s decisional capacity due to the presence of psychopathology, such as depression.” (Johnson, Cramer, Conroy and Gardner, 2014). However, the size and availability of these particular professionals, in some provinces, is such that persons with mental illnesses may have unreasonably long waits to have their request for Medical Assistance in Dying assessed. Consideration should be given to



the role of psychiatric/mental health nurses and Registered Psychiatric Nurses (RPNs) in the process. Regulatory safeguards should include clear criteria for the education, experience and training of all assessors and there should be a process whereby at least two separate assessments for competency occur and one where at least one of the assessors is independent of the treatment relationship with the patient.

One suggestion for future consideration is the establishment of a provincial/national registry of providers who are deemed able to perform a competency assessment for the purposes of accessing Medical Assistance in Dying. With the addition of a national/provincial registry, accessibility to Medical Assistance in Dying is more readily available and also allows for increased collaboration in and amongst health care providers- especially for those providers who may have a conscientious objection or may not feel competent to perform a competency assessment. This can be facilitated through the establishment of a national/provincial training program to provide consistency throughout Canadian jurisdictions.

Additional considerations might also include what treatment options (pharmacological, psychosocial, psychotherapy) are available and what options have been tried and exhausted. There is a strong argument that some of the suffering experienced by persons with mental illness has been socially constructed (societal norms/expectations) and, as such, this suffering can be remediated by proper supports and attention to the social determinants of health. If the Canadian health and social care systems are incapable of realistically addressing these social determinants and providing the support that is required, would an individual be unfairly determined to be ineligible for Medical Assistance in Dying because all of the options were not exhausted? This raises some very fundamental moral, ethical, ideological and social issues that extend far beyond Medical Assistance in Dying to a needed national discourse about the Canadian mental health system.

The CRPNM appreciates the opportunity to provide this response to the Council of Canadian Academies (CCA) on Medical Assistance in Dying in Canada and look forward to further collaboration opportunities as the subject of mental illness as the sole underlying medical condition for MEDICAL ASSISTANCE IN DYING is further explored and developed.



Further resources that would be of benefit for the CCA expert panel to explore include:

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

Bilsen, J., Vander Stichele, R., Mortier, F., & Deliens, L. (2004). Involvement of nurses in physician-assisted dying. *Journal of Advanced Nursing*, 47(6), 1-9.

De Beer, T., Gastmans, C., & Dierckx de Casterle. (2003). Involvement of nurses in euthanasia: a review of the literature. *Journal of Medical Ethics*, 30, 494-498.

Dierickz, S., Deliens, L., Cohen, J. & Chambaere, K. (2017). Euthanasia for people with psychiatric disorder or dementia in Belgium: analysis of officially reported cases. *BMC Psychiatry*, 17(203).

Groenewoud, J., Van der Maas, P., Van der Wal, G., Hengeveld, M., Tholen, A., Schudel, W., & Van der Heide, A. (1997). Physician-Assisted Death in Psychiatric Practice in the Netherlands. *The New England Journal of Medicine*, 336(25), 1795- 1801.

Johnson, S., Cramer, R., Conroy, M. & Garder, B. (2014). The Role and Challenges for Psychologists in Physician Assisted Suicide. *Death Studies*, 38, 582-586.

**CRPNM Resources:**

<http://www.crpnm.mb.ca/news/nursing-colleges-release-new-medical-assistance-in-dying-aid-guidelines/>

<http://www.crpnm.mb.ca/psychiatric-nursing/standards-and-code-of-ethics/>

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**Mature minors**

Capable minors can currently make health decisions that lead to their death (i.e. refusal of treatment). Minors can be more competent than adults. There is no age of consent so no different for MAID. A mature minor has a right to be an active participant in their care. This is heavily influenced by guiding nursing values of: acting in the best interest of vulnerable patients, the principles of respect, justice, autonomy, beneficence and integrity.

There are a number of issues with regards to MAID for mature minors. The current process used to assess competence (i.e. consent to treat, consent to use/disclose records) has no standard process for a minor. An inconsistent and subjective process of assessing can be problematic as physicians may rely more heavily on their own discretion and judgment in the decision of whether the mature minor is a candidate for MAID, rather than objective criteria. An objective and systematic assessment tool must be devised and tested prior to the consideration of MAID for minors.

Family involvement in the MAID process and their bearing on the mature minor's decision may impact. It can be difficult for youth to make a decision when family members are divided. There are concerns regarding the influence of family members' views on the world view of the mature minor. Individuals under the age of 16 are heavily influenced by their parent's views and might not have had the opportunity to formulate their own conceptions about life and death. Mature minors might feel like a physical or financial burden to their parents and could be more likely to request MAID to alleviate that stress. When a child is making a decision for MAID because he/she feels like a burden on the family, this is not in the best interest of the child. Mature minors are members of a vulnerable population and the possibility for abuse exists, in that mature minors might be encouraged by their families to request MAID in order to remove the burden on the family.

**Recommendations:**

A standardized tool for competence assessment in minors that includes guidance questions to aid the health care professional (HCP) in competence assessment. It may also be important to include motivation for the MAID request.

Parents/guardians should not be able to request MAID for a child that is not competent.

**Advance requests**

An individual diagnosed with a condition that has a predictable trajectory and results in a severe decrease in quality of life or if an individual is diagnosed with a fatal condition should have a right to MAID, but with stipulations.

- How early in the trajectory of the condition an individual would be allowed to request MAID exist. What measures will ensure the individual is both informed and competent to make that decision?

- The "reasonably foreseeable" death criterion must be considered. Would advance requests pertain to conditions that may not increase mortality, but decrease quality of life – such as dementia? Would there need to be limitations to certain conditions such as these that are not fatal? Would the physical limitations that might result from the diagnosed condition take precedence in MAID requests, or would psychological and emotional issues carry the same weight in assessing the MAID request? How would the guidelines be implemented?

- Consideration as to how advance requests will be handled if a cure becomes available after

MAID has been requested. Would the accountability and liability fall upon the HCP who signed off on MAID, if an individual passes away after a cure has been found? Does the request become VOID if an individual has not yet undergone MAID and a cure is found?

Recommendations:

The patient should be able to make the request but would need clear guidelines as to when the procedure will occur so that it does not become the decision of the family/HCP including: clearly identify at which point they want it and conditions must be clearly identified (i.e. don't want to be spoon fed, bedridden). Would patient education regarding their illness and the resulting symptoms be a mandatory requirement for MAID with advance requests?

Need safeguards to prevent familial exploitation; (ie: client would specify request for when/ where/ circumstances).

Mental illness

Assessment of the competency of a patient with a mental illness who seeks MAID is key.

Ensure consistency between providers and determine how and by whom this is done. It is hard to assess decisional capacity – especially for those with severe illness. Need assessment tools of emotional status (separate assessment form for mental health requests). Prevent impulsive decisions that accompany certain conditions. Consider a longer reflection period.

Criteria could include length of time an individual is suffering, the severity of condition – regardless of how acute? Currently, no universal standards defining incurability in most mental illness.

Suffering from mental illness is frequently compounded by psychosocial factors including lack of housing, unemployment, financial stresses and isolation to be considered. Are they exclusion criteria? How will the health care system support holistic health services for patients who might want treatment, but not have the resources to pay for a professional clinical psychologist? Situational depression in minors/young adults and depressive disorder during high school or university must be safeguarded.

Will mental health professionals, (overwhelmed and under resourced) or stressed-out family may give up on difficult cases, perhaps even subtly encouraging patients to MAID?

Recommendations:

Consider an age cut-off. Careful of ADHD, etc. Minors should not be able to access MAID based on mental illness alone.

MAID requests are followed by referral to a mental health professional (i.e.: psychiatrist, psychologist, social worker) for in-depth psychiatric assessment.

Treatment should include social supports. HCP should explore all options before MAID. (Similar to ensuring palliative care before MAID) Currently, individuals do not need to have treatment for their condition before consenting to MAID, Recommend clients be treated for their mental illness before accessing MAID. Unless treatment-resistant, an important step to ensure that all possible avenues are exhausted.

Specialized assessment must consider emotional status, impulsiveness, social supports, treatment history.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations,*

*guidelines, traditional knowledge, practices, and clinical cases.*

#### Mature Minors

[https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster\\_Nov%209%202016.pdf](https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster_Nov%209%202016.pdf)

#### Advance requests:

Medical Assistance in Dying: A Patient-Centred Approach - Report of the Special Joint Committee on Physician-Assisted Dying available at <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&DocId=8120006&File=18>

#### Mental illness:

Appelbaum, P. S. (2017). Should mental disorders be a basis for physician-assisted death? *Psychiatric Services*, 68(4), 315-317. doi: 10.1176/appi.ps.201700013.

Kim, S. Y. & Lemmens, T. (2016). Should assisted dying for psychiatric disorders be legalized in Canada? *Canadian Medical Association Journal*, 188(14), E337-E339. doi: 10.1503/cmaj.160365.

Schwartz, Y. & Shaul, R. Z. (2016). Ethics and implications of the “minor” exclusion. Bioethics Department at the Hospital for Sick Children. Retrieved from: [https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster\\_Nov%209%202016.pdf](https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster_Nov%209%202016.pdf)

Sheehan, K., Gaiind K. S., & Downar, J. (2017). Medical assistance in dying: Special issues for patients with mental illness. *Current Opinion Psychiatry*, 30(1), 26-30. doi: 10.1097/YCO.0000000000000298.



## **CCA Expert Panel on Medical Assistance in Dying in Canada**

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**[1000 word maximum]**

### **Mature minors - issues:**

Capable minors in Canada can currently make health care decisions that lead to their death (i.e. refusal of treatment). Minors can be more competent than adults give them credit for. There is no age of consent for anything else so why would it be different for MAID if the minor were able to consent? We stand behind the right of a mature minor to be an active participant in his/ her care, and this is heavily influenced by guiding nursing values of: acting in the best interest of vulnerable patients, the principles of respect, justice, autonomy, beneficence and integrity.

With that said, there are a number of issues that we have with regards to MAID for mature minors. The first issue concerns the current process used to assess competence (i.e. consent to treat, consent to use/disclose records). Although currently a mature minor has this right, there is no standard process for assessing the competence of a minor. An inconsistent and subjective process of assessing competence can be problematic as physicians may rely more heavily on their own discretion and judgment in the decision of whether the mature minor is a candidate for MAID, rather than objective criteria. Therefore, we believe that an objective and systematic assessment tool must be devised and tested prior to the consideration of MAID for mature minors.

Another issue concerns family involvement in the MAID process and their bearing on the mature minor's decision. For one, it can be difficult for kids to make a decision when family members are divided on the decision. Beyond this, we have concerns regarding the influence of family members' views on the worldview of the mature minor. Individuals under the age of 16 are heavily influenced by their parent's views and might not have had the opportunity to formulate their own conceptions about life and death. Our final concern regarding family involvement is that mature minors who might feel like a physical or financial burden to their parents might be more likely to request MAID in order to alleviate that stress. When a child is making a decision for MAID because he/ she feels like a burden on the family, this is not in the best interest of the child. We also acknowledge that mature minors are members of a vulnerable population and that the possibility for abuse exists, in that mature minors might be encouraged by their families to request MAID in order to remove the burden of the illness on the family.

### **Mature minors – recommendations:**

Recommend standardized tool for competence assessment in minors. Tool should include guidance questions to aid the health care professional (HCP) in competence assessment. It may also be important to include motivation for the MAID request.

Parents/guardians should not be able to request MAID for a child that is not competent.

**Advance requests – issues:**

If an individual is diagnosed with a condition that has a predictable trajectory and results in a severe decrease in quality of life or if an individual is diagnosed with a fatal condition, we believe that an individual should have a right to MAID, but of course with certain stipulations.

Our first issue concerns how early in the trajectory of the condition an individual would be allowed to request MAID. What measures will be put into place to ensure that the individual requesting MAID is both informed and competent to make that decision?

In addition, if advance requests are to be considered, the “reasonably foreseeable” death criterion must be brought into question. Would advance requests pertain to conditions that may not increase mortality, but decrease quality of life – such as dementia? Would there need to be limitations to certain conditions such as these that are not fatal? Would the physical limitations that might result from the diagnosed condition take precedence in MAID requests, or would psychological and emotional issues carry the same weight in assessing the MAID request? How would the guidelines be implemented?

Another important consideration is how advance requests will be handled if a cure becomes available after MAID has been requested. Would the accountability and liability fall upon the HCP who signed off on MAID, if an individual passes away after a cure has been found? Does the request become VOID if an individual has not yet undergone MAID and a cure is found?

**Advance Requests – recommendations:**

Yes, the patient should be able to make the request but would need clear guidelines as to when the procedure will occur so that it does not become the decision of the family/HCP. How do you clearly identify at which point you want it? How do you make that clear (i.e. don’t want to be spoon fed, bedridden). Would patient education regarding their illness and the resulting symptoms be a mandatory requirement for MAID with advance requests?

Need safeguards to prevent familial exploitation; ie: client would specify request for when/ where/ circumstances.

**Mental illness – issues:**

Concerns exist regarding assessment of the competency of a patient with a mental illness who seeks MAID. Need to ensure consistency between providers. How would this be done and by whom? It is hard to assess decisional capacity – especially for those with severe mental illness. Need a clear assessment tool of emotional status. Prevent impulsive decisions that accompany certain mental health conditions. Consider a longer reflection period.

How would we document that other options were explored; do we need a separate assessment form for mental health requests?

Would it be based on the length of time an individual is suffering, the severity of the condition – regardless of how acute? Currently, there are no universal standards defining incurability in most cases of mental illness.

Suffering from mental illness is frequently compounded by psychosocial factors including lack of adequate housing, under or unemployment, financial stresses and social isolation. These factors should be considered when assessing for MAID. Are they exclusion criteria? How will the health care system be reformed to support holistic health services for patients who might want treatment, but not have the resources to pay for a professional clinical psychologist?

Situational depression in minors/young adults: How would individuals who are suffering from major depressive disorder during high school or university be safeguarded?

Will mental health professionals, who are often overwhelmed and under resourced, be more likely to give up treating difficult cases, perhaps even subtly encouraging patients to seek assistance in dying instead? Might stressed-out family members do the same?

#### **Mental Illness – recommendations:**

Consider an age cut-off. Careful of ADHD, etc. Minors should not be able to access MAID based on mental illness alone.

MAID requests are followed by referral to a mental health professional (i.e.: psychiatrist, psychologist, social worker) for in-depth psychiatric assessment.

Treatment should be made available including social supports for social isolation. HCP should explore all options before MAID. (Similarly to ensuring patients have access to palliative care before MAID.) Currently, individuals do not need to have treatment for their condition before consenting to MAID, but we recommend that they should be treated for their mental illness before accessing MAID. Unless an individual is treatment-resistant, this is an important step to ensure that all possible avenues are exhausted prior to considering medical assistance in dying.

Specialized assessment form that considers emotional status, impulsiveness, social supports, treatment history.

2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.

*\*Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

#### Mature Minors

[https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster\\_Nov%209%202016.pdf](https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster_Nov%209%202016.pdf)

#### Advance requests:

Medical Assistance in Dying: A Patient-Centred Approach - Report of the Special Joint Committee on Physician-Assisted Dying available at

<http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&DocId=8120006&File=18>

#### Mental illness (excerpts directly copied and pasted from pertinent articles):

- Kim et al. [11&&] described 66 consecutive cases of MAID for primary psychiatric illness in the **Netherlands** over a 4-year period. Most cases were women, typically over the age of 50, with a long history of psychiatric illness, including a history of attempted suicide and social isolation. The majority also had a chronic medical condition, and almost half had some degree of functional dependence. Although most suffered from depression or anxiety, there were 9 cases of various psychotic disorders, 8 of somatoform disorders, 2 cases each of autism spectrum and prolonged grief disorder, and 1 case each of alexithymia, Cotard syndrome, dissociative disorder, factitious disorder, reactive attachment disorder, and kleptomania. Notably, 32% of the cohort had been refused MAID by a physician at some point, and in 24% of cases the assessing physicians disagreed about eligibility, highlighting the subjectivity of determining decisional capacity or the futility of further treatment in psychiatric illness. Eleven percent received MAID without an independent psychiatric opinion (only the primary psychiatrist provided input). One case was found to not meet legal due care criteria
- Thienpoint et al. [12&&] reported the **Belgian** experience of 100 consecutive patients requesting MAID for a primary psychiatric illness over a 4-year period. Again, the demographics revealed a predominantly female population usually suffering from depression, although personality disorders were present in half of referrals and 12 were ultimately felt to have autism spectrum disorder. In total, 48 of the requests were accepted and 35 were carried out. Eight of those who did not proceed with MAID were satisfied just to have the option at some point. Notably, five of the 52 patients who were not accepted for MAID ended their life by suicide without medical assistance. The authors quoted federal statistics suggesting that only 2–3% of all MAID cases were for a primary psychiatric illness in a patient who was not otherwise terminally ill (Sheehan, Gaiand & Downer, 2017)
- What would be the point of demarcation for when a mental illness is considered ‘irremediable’
  - Would it be based on the length of time an individual is suffering, the severity of the condition – regardless of how acute?

- Currently, there are no universal standards defining incurability in most cases of MI
- Response to treatment in the full range of biopsychosocial domains is more challenging to assess in mental disorders compared with physical conditions (Sheehan, Gaid & Downar, 2017)
  - Suffering from MI is frequently compounded by psychosocial factors including lack of adequate housing, under or unemployment, financial stresses and social isolation
    - When these factors are present, clinicians may be hard pressed to determine if they could or should be considered irremediable as well
- For individuals who do request MAID as a result of mental illness...
  - **Will the Canadian health care system be reformed to ensure that individuals have full access to holistic mental health treatment that is cost-effective and accessible?**
  - In the Netherlands, social isolation was reported as problem in 56% of cases
    - It is a troubling prospect that death might serve as an alternative to provision of adequate social supports and other community-based programs
      - Again, will federal and provincial legislation ensure that they are armed with these supports so that individuals who are despondent and isolated, can find supports?
- Demoralization and hopelessness are often part of the mental disorder itself, thus heightening the risk of inaccurately characterizing a patient as having an intractable condition (Appelbaum, 2017)
  - Individuals who have personality disorders – these are conditions that exacerbate the risk of impulsive decisions in reaction to interpersonal issues or environmental stress (Appelbaum, 2017)
- The impact on the treatment system of an assisted- death option is also of concern
  - Will mental health professionals, who are often overwhelmed and underresourced, be more likely to give up treating difficult cases, perhaps even subtly encouraging patients to seek assistance in dying instead? Might stressed-out family members do the same?
    - *\*NOTE: this brings us back to the vulnerable patients points – this is especially relevant for MATURE MINORS*
- The Parliamentary Special Joint Committee on Physician-Assisted Dying’s recommendation that “irremediable... does not require the patient to undertake treatments that are not acceptable to the individual” could be particularly consequential for patients with psychiatric conditions
  - It is one thing for a patient with a terminal illness to refuse a last-ditch effort, but quite another to set aside a core clinical imperative in psychiatric treatment: compassionately and skillfully helping patients even through periods of sustained suffering during which people often lose the will to live and despair about whether things will get better
  - A review of 66 case summaries of euthanasia published by Dutch regional euthanasia review committees found that most patients who received assisted dying for a psychiatric condition were deemed to have met the criterion while refusing recommended treatments; many likely did not receive all indicated treatments. (Kim & Lemmens, 2016)
- Judgments of medical futility vary between physicians
  - in the Netherlands study, physicians disagreed about medical futility in almost a quarter of the cases.<sup>6</sup> In a case series, a psychiatrist assessed 100 consecutive cases of Belgian patients with psychiatric conditions who requested assisted dying;<sup>5</sup> all 100 patients

were deemed have “no prospect of improvement” due to “treatment resistance,” which suggests vagueness of the applied criterion (Kim & Lemmens, 2016)

- Public outcry – will this allow for enough public support for legalization
  - In a recent public opinion poll of 1517 Canadians, only 22% supported legalizing assisted dying for psychological suffering (Kim & Lemmens, 2016)

## References

- Appelbaum, P. S. (2017). Should mental disorders be a basis for physician-assisted death? *Psychiatric Services*, 68(4), 315-317. doi: 10.1176/appi.ps.201700013.
- Kim, S. Y. & Lemmens, T. (2016). Should assisted dying for psychiatric disorders be legalized in Canada? *Canadian Medical Association Journal*, 188(14), E337-E339. doi: 10.1503/cmaj.160365.
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[https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster\\_Nov%209%202016.pdf](https://www.bioethics.ca/resources/Yael%20Schwartz%20MAID%20in%20Paediatrics-Poster_Nov%209%202016.pdf)
- Sheehan, K., Gaid K. S., & Downar, J. (2017). Medical assistance in dying: Special issues for patients with mental illness. *Current Opinion Psychiatry*, 30(1), 26-30. doi: 10.1097/YCO.0000000000000298.

Covenant Health

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

We are pleased to provide feedback to inform the work of the CCA Expert Panel on Medical Assistance in Dying in Canada.

As one of the largest Catholic health care organizations in Canada, Covenant Health (including Covenant Care and Covenant Living) has considerable experience in responding to requests from persons in our care seeking information, eligibility assessment, and access to medical assistance in dying facilitated through the provincial care coordination system.

Despite our consistent, conscientious objection to MAID, we do not abandon people in our care; rather, we respond to every patient/resident request, trending at 1-2 per week, with approximately 25% of these individuals transferring to receive MAID at home or a non-Covenant facility.

This activity dates back to the pre-legislative, court application period, and continuously since the passing of Bill C-14. In fact, our Covenant organizations collectively have had the most experience than any other Catholic health care institution in Canada, and been proactive in developing policy and transparently communicating our position publicly with national partners, and with media, drawing attention from interest groups around the world (see: <https://www.covenanthealth.ca/ethics-centre/publications-links/medical-assistance-in-dying/>)

During this time, as leaders in palliative care, Covenant has remained focused on providing quality end-of-life care services consistent with our mission, values, and renowned reputation. In November 2016, Covenant Health hosted the Palliative Care Matters consensus conference in Ottawa (<http://www.palliativecarematters.ca/home/>). This landmark event brought together lay and expert panel voices, informing the need for a national strategy to advance comprehensive palliative and hospice care for all Canadians.

Moreover, Covenant Health made submissions to both the Alberta government and other federally-appointed advisory bodies, including appearances before the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, as well as co-representing the Catholic Health Alliance of Canada before the External Panel on Options for a Legislative Response to Carter v. Canada, addressing the need for appropriate safeguards while positively contributing in defining what safe and timely transfer could look like from an objecting facility, respecting the needs of all.

Based on this extensive clinical experience, stakeholder engagement, and ongoing advocacy, we offer these observations and cautions:

**Relevant Observations and Issues:**

We note a trend that those requesting MAID are already in close proximity to death; the majority of them admitted to our palliative, hospice units and other clinical settings where quality end-of-life services are provided. Given this population's already fragile clinical status, we have observed that typically in the 75% of cases when eligibility assessments or provision of MAID are not completed that it is often due to a patient's loss of capacity, change of mind, or death by natural causes.

From a safeguard perspective, therefore, we believe this documented evidence underscores the importance of staying engaged with the people in our care, ensuring exploratory discussions around end-of-life options continue, including provision of quality, palliative care.

The prospect of broadening legislation to include advance requests, recognizing that personal directives may be written long before a person is ever diagnosed with a fatal, irreversible pathology, and especially without the first-hand experience of interacting with skilled palliative care providers offering reassurance that pain and symptom management needs can be adequately addressed, may result in a disproportionate number of people believing MAID is the only alternative at the end-of-life.

We believe the same risk applies to those choosing MAID before exhausting every clinical benefit that mental health practitioners offer patients, especially in the absence of any other underlying medical condition. Given the importance of the therapeutic patient-physician relationship in psychiatric care, decisions made to pursue MAID without fully leveraging the trust of skilled practitioners committed to a person's sustained recovery and chronic management is, in our opinion, tantamount to abandonment among society's most vulnerable citizens.

Finally, we believe mature minors is a particular vulnerable group in which safeguards concerning MAID must be ensured. Ultimately, this likely constitutes an insurmountable emotional, political, and social justice hurdle for society to overcome, especially in light of the tragic epidemic of youth suicide on some First Nations communities in which the experience of hopelessness and abandonment has been contributory.

Sanctioning access to MAID by mature minors, notwithstanding the capacity of informed young people being able to appreciate the risks, benefits and consequences of personal health decisions they make, potentially opens up other societal harms that government must be prepared to reconcile. We believe the inconsistency of this stance, and the risks of even one young person making a poorly informed decision to undergo MAID only coming to light after their death will be too much for society to accept.

### Informed Public Engagement

Our leadership in the Palliative Care Matters consensus development process, as well as our clinical experience in responding to requests for MAID underscores there is still a lack of public awareness regarding access to quality, integrated palliative and end-of-life services.

We note, for example, during a one year reporting period from FY 2016/17, we provided palliative and hospice end-of-life care to well over 1500 persons in our facilities. During that same period, only 4.5% requested MAID (n68), with 1.2 % (n18) transferring to receive MAID elsewhere. Despite this documented fact, there remains a lack of proportionate public attention for hospice and palliative care. We are concerned that broadening legislation for medical assistance in dying poses not only a safeguard risk to vulnerable Canadians noted above, but misrepresents the needs of the majority of Canadians who would opt for hospice and palliative care if it was as readily available in every community as has been the efforts to ensure MAID is accessible; practically on-demand.

Covenant Health has been consistent in our opposition to MAID, based on our Catholic ethical, moral and social justice tradition. This same tradition also calls us to advocate for system change and transformation, ensuring quality, palliative and hospice care for the majority of



Canadians who seek, and expect, our publicly-funded facilities to provide. In Question 2 we cite research and clinical findings to support this claim, and why broadening the legislation misrepresents the needs and best interests of the wider Canadian public.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

To supplement the above observations, we point out that:

Palliative Care Matters included a 2016 Ipsos national online survey showing only 58% of Canadians have a basic understanding of palliative care, which constitute a major barrier to accessing quality care. The Ipsos survey also found that 91 per cent of Canadians support the development of information materials to improve knowledge about the quality of palliative care, and 85 per cent agree that an awareness campaign should inform Canadians about palliative care services and standards. (See: <https://static1.squarespace.com/static/5755e91b044262d8f43cf6fa/t/57e2b1b3d2b8579de605c555/1474474421962/Palliative+Care+Matters++Ipsos+Report.pdf> )

As well, the Ipsos survey shows that only 36% of Canadians know what advance care planning means, a theme that emerged during the recent 6th International Conference on Advance Care Planning and End of Life Care (ACPEL) in Banff which Covenant Health hosted; the first time the global conference was held in Canada. This is relevant given that of the 51% of Canadians who had had someone important to them receive palliative care in the past 10 years, 89% are satisfied, underscoring the importance of people engaged in advance care planning to be informed of the entirety of choice available to them, including palliative care services.

The international ACP conference examined the need for continued strategies to advocate for universal access to quality advance care planning in both the health care setting and in public forums. We cite this as relevant to the work of the Council of Canadian Academies, compelling the Expert Panel to report back to government based on what Canadians have already said, that Canadians ought to make a fully informed choice at the time of developing advance care plans about what is, and what should be available to them as far as timely access to integrated, palliative care services.

<https://static1.squarespace.com/static/587d3cb08419c228b247fa98/t/59b3fadbf14aa14c97ac318a/1504967393649/ACPEL+++Program+++Final.pdf>

We identify some other inherently problematic issues that will need to be considered regarding inclusion of advance care plans under the current legislative framework:

- the role of the agent and their willingness to faithfully represent the wishes of a person requesting an action that directly ends the person's life; not simply limits life-prolonging, medically inappropriate, or futile therapies;

- ensuring that there is clarity in interpreting precisely at what point along a conceivably long trajectory in which capacity has been lost that a person intended to be voluntarily euthanized;

for example, with progressive illnesses such as dementia while there yet may still be reasonable quality of life, but death is not yet imminent;

-consideration of the role of physicians and nurse practitioners in which such value judgments will be invariably shifted to them and their non-objecting willingness to participate in same (at minimum, recommend that CMA/CNA and provincial colleges survey members);

-the need to ensure provincial personal directive acts are reviewed and reconciled.

As regards the issue of mature minors and where mental health is the sole underlying medical condition, we offer the following observations and references:

It is well-established in the medical literature that the adolescent brain is a developing and not a developed brain. In particular the developing adolescent brain has been shown to have limited decision-making capacity. These facts for example have translated into the American Courts accepting medically informed input into the alleged criminal acts of adolescents as being not on the same level as the decisions of adults.

We maintain that the neuroscience on the adolescent brain and decision-making capacity are relevant factors that should be duly considered by the Expert Panel.

For example:

A recent review and opinion paper

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5422908/#!po=25.7042>

Nature Neuroscience review

<http://www.nature.com/neuro/journal/v15/n9/full/nn.3177.html?foxtrotcallback=true>

American Academy of Child and Adolescent Psychiatry

[https://www.aacap.org/aacap/families\\_and\\_youth/facts\\_for\\_families/Facts\\_for\\_Families\\_Pages/The\\_Teen\\_Brain\\_Behavior\\_Problem\\_Solving\\_and\\_Decision\\_Making\\_95.aspx](https://www.aacap.org/aacap/families_and_youth/facts_for_families/Facts_for_Families_Pages/The_Teen_Brain_Behavior_Problem_Solving_and_Decision_Making_95.aspx)

American Psychological Association book

<http://psycnet.apa.org/PsycBOOKS/toc/13493>

Finally, the leadership role of faith-based organizations in establishing health care in Canada and their commitment to compassionate care, especially those most vulnerable, is a historic fact. Moreover, it is faith-based organizations who continue to be the primary providers of compassionate care in our country, bound by a consistent ethic of life and social justice tradition that upholds the inalienable dignity of all human beings no matter what their faith, culture or circumstance.

The Catholic social justice tradition has long maintained that the moral test of a society is how it treats its most vulnerable citizens. We argue that widening the legislative framework for MAID to include mental health when it is the sole underlying medical condition despite other compassionate and practical resources are readily available to support people living with mental illness is a fundamental failure of this test. Expansion of MAID is likely to result in irreversible harms to the most vulnerable served by Canada's historical and primary movers of health care, particularly if MAID is made mandatory at/in any institutions receiving any level of public funding.

A key factor in the *Carter v Canada* decision was the potential for an individual to lose the physical ability to commit suicide. The decision keyed in the possibility that such a person might prematurely suicide and therefore be prematurely deprived of a period of quality of life acceptable to the person, hence becoming a Charter issue in the view of The Court.

Psychiatric conditions generally do not lead to loss of ability to commit suicide. Therefore, deeming a person eligible for MAID when mental health is the sole underlying medical condition is arguably inconsistent with the Court decision, but more importantly, overlooks that recovery is indeed a well-founded and supported concept.

We appeal to the Expert Panels to bring a consistent ethical lens and singular message to inform its work. This would balance the minority rights of those who advocate for a more permissive legislative regime with the needs of the majority of Canadians, especially the most vulnerable who would benefit from greater, not lesser safeguards, including more robust mental health programs and services to support their recovery.

Thank you again for your invitation to solicit input. If you need further information or clarification, please do not hesitate to contact us.

## Dying with Dignity

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached PDF.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached PDF.



**Submission to the Council of Canadian Academies Expert Panel on  
Medical Assistance in Dying in Canada**

**Dying With Dignity Canada**

**October 6, 2017**

## Table of Contents

Dying With Dignity Canada's official response.....	3
Advance requests .....	6
Supplementary material related to advance requests for MAID .....	7
Personal stories and letters re: advance requests.....	9
Mental illness as the sole underlying medical condition .....	639
Studies, articles, and presentations related to MAID and mental illness .....	640
Personal stories and letters re: mental illness.....	642
Mature minors .....	696
Supplementary material related to mature minors and MAID.....	697
Personal stories and letters re: Bill C-14's eligibility criteria .....	698
Personal stories and letters re: general support .....	781

## Dying With Dignity Canada's official response

In *Carter v. Canada*, the Supreme Court established medical assistance in dying (MAID) as a right for Canadians who are suffering intolerably as the result of a grievous and irremediable medical condition. However, Bill C-14's eligibility criteria is much narrower in scope and assisted dying remains out of reach for thousands of desperately ill Canadians who face the prospect of living for years in a state of unbearable suffering. This has a significant impact on these individuals' *Charter* rights, which the federal government fully acknowledged in its analysis of Bill C-14 prior to its passing.<sup>1</sup> The decision, then, to pass Bill C-14 with these restrictions raises troubling questions about the constitutionality of Canada's assisted dying law.

As the leading organization defending Canadians' right to a peaceful death, Dying With Dignity Canada is well-positioned to speak out against the discriminatory and harmful exclusions of advance requests, mental illness, and mature minors. Our official submission includes relevant knowledge in the form of studies, articles, and most importantly, personal letters from 746 Canadians. We believe the stories and perspectives of everyday Canadians are the best possible evidence we can provide the Expert Panels. These reflections detail the devastating impacts on the groups of people who are currently prohibited from accessing MAID because of the unconstitutional provisions in Bill C-14.

### Advance requests

Bill C-14 discriminates against Canadians whose chronic medical conditions rob them of mental capacity as a matter of course. For some, the combined effects of the safeguard banning advance requests and Bill C-14's eligibility criteria mean that they will never qualify for MAID. This is inconsistent with the beliefs of the 80 per cent of Canadians who support advance requests for assisted dying.<sup>2</sup>

Under the current legislation, patients are required to consent to MAID immediately before assistance is provided. The unintended consequences of this rule are twofold. First, the requirement denies access to people who have already been approved for MAID by two clinicians but lose capacity in the waiting period. This is explored in a May 2017 paper written by clinicians with Toronto's University Health Network (UHN) and published in *The New England Journal of Medicine*. The article identifies a stark dilemma posed by the ban on advance requests for MAID: "This stipulation... has unintentionally caused some patients to feel pressured to request MAID prematurely or to accept the risk of becoming incapacitated and thereby losing the right to receive MAID."<sup>3</sup> In addition, the authors note,

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<sup>1</sup> Canada. Department of Justice. *Legislative background: Medical assistance in dying (Bill C-14, as Assented to on June 17, 2016)*, 2016, part 4. <http://www.justice.gc.ca/eng/rp-pr/other-autre/adra-amr/p4.html#p4>.

<sup>2</sup> "8 in 10 Canadians support the right to advance consent for assisted dying." *Dying With Dignity Canada*. Feb. 11, 2016. <http://www.dyingwithdignity.ca/advance-consent-assisted-dying-poll>.

<sup>3</sup> Li, Madeline, et al., "[Medical assistance in dying — Implementing a hospital-based program in Canada](#)." *The New England Journal of Medicine*. Vol. 376, No. 21 (2017): 2082-2088.

individuals who request MAID while they are actively dying sometimes refuse pain medication — and thus, compromise efforts to control their symptoms — in order to maintain their capacity to consent.<sup>4</sup>

Second, without the option to make an advance request for MAID, many Canadians face a “cruel choice” similar to the one that led the Supreme Court to decriminalize assisted dying in the first place.<sup>5</sup> They may languish for months or years in the very same state of intolerable suffering that they desperately sought to avoid. They may end their own lives while they still can in a violent manner, potentially traumatizing their loved ones and impacting their “right to life” under the *Charter*. Those who can afford it may choose to travel overseas, spending tens of thousands of dollars to access a right that should be available at home. Our organization is aware of at least four Canadians who have travelled to Switzerland to access MAID after Bill C-14 was passed in Parliament.

We believe that the ban on advance requests significantly impacts Canadians’ *Charter* rights and the spirit of the *Carter* ruling. And unless federal lawmakers address this fundamental flaw in Bill C-14, we believe the law will remain vulnerable to constitutional challenges.

## **Mental illness**

While the current legislation does not explicitly ban individuals whose sole underlying medical condition is a mental illness, government officials made it clear that Bill C-14’s eligibility criteria, taken as a whole, were intended to prevent individuals whose suffering stems from severe mental illness from accessing MAID. Former Health Minister Jane Philpott clarified in May 2016 that the law “does not permit eligibility solely on the basis of suffering from mental illness.”<sup>6</sup>

The government also attempted to appeal the decision to allow an Alberta woman, E.F., whose medical condition was considered psychiatric at its root to access MAID. Thankfully, the appeal court rejected the government’s assertion that the *Carter* ruling only applied to individuals who were at or near end of life, writing that “Persons with a psychiatric illness are not explicitly or inferentially excluded if they fit the criteria.”<sup>7</sup> The government’s intervention in E.F.’s case, however, provided clear evidence that Bill C-14 was designed to keep Canadians like E.F. alive in a state of intractable suffering, against their wishes, in violation of their *Charter* rights.

A November 2016 paper published in the *Journal of Ethics in Mental Health* found that people with conditions like anorexia may be eligible under the law, if their health has

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<sup>4</sup> Ibid., 2087.

<sup>5</sup> *Carter v. Canada* (Attorney General), 2015, Para. 13.

<sup>6</sup> Canada. Parliament. House of Commons. Standing Committee on Justice and Human Rights. *Minutes of Proceedings*. 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament, Meeting No. 10, 2016.

<sup>7</sup> *Canada (Attorney General) v. EF*, 2016. 155 (Court of Appeal of Alberta, May 17), Para. 59.



deteriorated to the point that imminent death is likely.<sup>8</sup> However, people with severe mental illnesses who are not in an “advanced state of irreversible decline” and whose deaths are not “reasonably foreseeable” are currently excluded. This raises questions about discrimination and the fairness of forcing people to suffer from chronic and treatment-refractory illnesses for years simply because their conditions are psychiatric at its root. The law should not invalidate people’s rights and further stigmatize people with mental illness by choosing to honour the rights of Canadians with physical medical conditions over those whose suffering is the result of a psychiatric condition.

### **Mature minors**

In many jurisdictions across Canada, mature minors already have the right to make important decisions regarding their care. This includes the right to consent to or refuse life-saving medical treatment. We question the constitutionality of allowing a 70 year old with terminal cancer the choice of a peaceful death, but denying a 17 year old who has been given the same prognosis and demonstrates a clear capacity to make the decision as an adult, simply because they have not reached the arbitrary age of 18 years.

To conclude our submission, DWDC thanks the Council of Canadian Academies for this opportunity to provide input to the Expert Panels as they continue with their independent reviews. We’d also like to inform the CCA Expert Panel of our intention to send a copy of our official submission to the federal government. We are happy to provide further clarification or assistance that may be helpful.

**IMPORTANT NOTE: The personal stories and letters included in our submission are strictly confidential and ARE NOT to be made public under any circumstances.**

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<sup>8</sup> Downie, Jocelyn, and Justine Dembo. “[Medical assistance in dying and mental illness under the new Canadian law.](#)” *Journal of Ethics in Mental Health*. Open volume (2016): 1-9.

Advance requests

## **Supplementary material related to advance requests for MAID**

Studies, surveys, and reports:

[Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report. \(2015\).](#)

[Dying With Dignity Canada/Ipsos Reid poll. \(2016\). 8 in 10 Canadians support the right to advance consent for assisted dying.](#)

[Li, Madeline, et al. \(2017\). Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada, \*The New England Journal of Medicine\*, 376:21, 2082-2088.](#)

News articles and personal stories:

[Cook, Michael. \(2011\). Informed Consent in Netherlands: Euthanasia. \*BioEdge\*.](#)

[Most Canadians Disagree with Liberals, Want Advance Consent for Assisted Death: Ipsos Poll. \(2016\). \*Global News\*.](#)

[Fayerman, Pamela. \(2016\). Margot Bentley dies, a finality that couldn't come too soon for anguished family, \*Vancouver Sun\*.](#)

[Picard, André. \(2017\). CMA Poll Finds Rising Support for Medically Assisted Death, \*The Globe and Mail\*.](#)

[Derfel, Aaron. \(2017\). Most Caregivers Favour Assisted Dying for Alzheimer's Patients: Survey, \*Montreal Gazette\*.](#)

[Chalifoux, Danielle. \(2017\). Une directive médicale anticipée devrait permettre l'accès à l'aide médicale à mourir, \*HuffPost Quebec\*.](#)

[Life on the Locked Unit: An Employee at a Long-Term Care Facility Shares Why She Supports Advance Requests.](#)

[Barb B.'s story about her mother's battle with dementia.](#)

[Linda's Story: I Saw My Mother as a Brave Woman Who Had the Courage to Die.](#)

Videos:

[Dying With Dignity Canada's Presentation to the Special Joint Parliamentary Committee on Physician-Assisted Dying](#)

[British Columbia Civil Liberties Association's Presentation to Parliament's Committee on Physician-Assisted Dying](#)

[Dying With Dignity Canada CEO Shanaaz Gokool's Presentation to the House Standing Committee on Justice and Human Rights](#)

Mental illness as the sole underlying medical condition

**Studies, articles, and presentations related to MAID and mental illness**

News articles and features:

[Franzoi, Catrina \(2016\). As a Person with Mental Illness, Here's Why I Support Medically Assisted Death, \*The Globe and Mail\*.](#)

[Browne, Rachel \(2016\). Fighting to Die, VICE News Canada.](#)

[Xing, Lisa. \(2016\). 'My Life is a Nightmare': Windsor Man, 27, Wants Legally Assisted Death, \*CBC News Windsor\*.](#)

[Picard, André. \(2017\). The Mentally Ill Must Be Part of the Assisted-Dying Debate, \*The Globe and Mail\*.](#)

[Martin, Sandra. \(2017\). Canada's Assisted-Dying Laws Must Be Open to Those With Mental Illness, \*The Globe and Mail\*.](#)

[Cross, Brian. \(2017\). Horrible Suffering Became Too Much for Adam Maier-Clayton, \*The Windsor Star\*.](#)

[CBC News. \(2017\). Adam Maier-Clayton's Assisted-Dying Advocacy Work Will Continue After His Death, \*CBC News Windsor\*.](#)

[Hughes, Stuart. \(2017\). Adam Maier-Clayton's Controversial Right-to-Die Campaign, \*BBC News\*.](#)

Academia:

[Cassell, Eric J. \(1999\). Diagnosing suffering: A perspective.](#)

[Fekadu, Abebaw, et al. \(2009\). What Happens to Patients with Treatment-Resistant Depression? A Systematic Review of Medium to Long Term Outcome Studies, \*Journal of Affective Disorders\*, 116, 4-11.](#)

[Dembo, Justine. \(2010\). Addressing Treatment Futility and Assisted Suicide in Psychiatry, \*Journal of Ethics in Mental Health\*, 5:1, 1-3.](#)

[Dembo, Justine. \(2013\). Are Decisions Made 'In the Throes' of Treatment-Refractory Mental Illness Truly Invalid?, \*The American Journal of Bioethics\*, 13:3, 16-18.](#)

[Downie, Jocelyn, and Justine Dembo. \(2016\). Medical Assistance in Dying and Mental Illness Under the New Canadian Law, \*Journal of Ethics in Mental Health\*, open vol., 1-9.](#)

[Dembo, Justine, and Derryck Smith. \(2016\). Bill C-14's 'reasonably foreseeable' consequences. \*The Chronicle of Neurology + Psychiatry\*.](#)

[Dembo, Justine, and Derryck Smith. \(2016\). Letter to the Editor: Assisted dying for patients with psychiatric disorders. \*Canadian Medical Association Journal\*.](#)

[Dembo, Justine. \(2017\). The Uneasy Gatekeeper: Capacity Assessment in MAID presentation.](#)

[Dembo, Justine. \(2017\). Considering MAID in Severe, Refractory Mental Illness presentation.](#)

[Dembo, Justine. \(2017\). Narrative and Notes for ICEL2: Considering MAID in Severe, Refractory Mental Illness. Word document.](#)

[Dembo, Justine. \(2017\). Pressure Points: Mental Illness as a Sole Underlying Condition presentation.](#)

[Dembo, Justine. \(2017\). A Psychiatrist's Perspective on the Concepts of Dignity and Identity in the Context of Assisted Death presentation.](#)

Mature minors



**Supplementary material related to mature minors and MAID**

[Kirkey, Sharon. \(2015\). Terminally Ill Children as Young as 12 Should Have Euthanasia Choice, Expert Panel Urges, \*National Post\*.](#)

[Kirkey, Sharon. \(2016\). If Doctors Have Exhausted Every Last Option, is it Ethical to Grant a Child's Wish to Die? \*National Post\*.](#)

[Hurley, Meghan. \(2016\). Strong Emotions at Public Consultation on Assisted Death, \*Ottawa Citizen\*.](#)

[Southwick, Reid. \(2016\). Alberta Doctors Divided on Assisted Death for Minors, \*Calgary Herald\*.](#)

## Empowerment Council

### **1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Empowerment Council (EC) is an organization funded by the Centre for Addiction and Mental Health (CAMH) to do systemic advocacy on behalf of mental health and addiction clients. Our members are either people living with mental health issues and/or addiction currently or in the past. Although we are based at CAMH, we also serve people in the community. We provide educational events for service users, services providers and other members in the community.

Our activities include but are not limited to:

- Consulting clients, through meetings, about people's needs, wants, experiences and thoughts;
- Advocating for what is important to clients to whatever body is most effective for achieving clients' priorities: CAMH, the government, the courts;
- Working at effecting change at CAMH by having a meaningful voice at committees, focus groups, working groups, etc.;
- Educating clients and others about client rights, from the CAMH Bill of Client Rights and freedoms protected by the Canadian Charter.

The EC notes that our greatest concern is one of access, inclusion and participation of service users who undoubtedly have much to contribute to this conversation. While there have been numerous committees organized and struck to prompt medical and legal opinion and perspectives, there has been very little from service users themselves. This is understandable given the lack of resources both in cities and rural locations, locally and provincially across the country. Our colleagues and allies in the physical disability community have been quite active and vocal in organizing and communicating the implications of euthanasia or assistance in dying for people with physical disabilities.

Much of this activity can be in part attributed to high-profile media stories and legal cases which have galvanized a voice in the disability community.

In the mental health service-user community, our trajectory is uniquely different and only recently emergent. While there is much literature and first-person accounts with regard to experiences of psychiatric disability, diagnoses, quality of life and more specifically suicide, there has yet to be in the jurisdiction of Canada a broad-based consultation on how to approach assistance in dying when mental illness is the sole underlying condition. The irremediableness of psychiatric disability has been a conversation left solely to the deliberations of medical discourse and discussions about best medical "evidence" on the matter. While our organization in no way wants to promote the view that psychiatric disability should be considered irremediable (particularly when so much of our work is to promote, support and enhance the worth of individuals with mental health issues and the reality that many people who live with psychiatric disability and intersecting medical/disability-related concerns, can have worthwhile and full lives), we are concerned that without a robust and proper innovative consultation process on the matter, our community will be left once again on the margins of major health and state interventions.

From the very limited and brief work the EC has done on MAiD, it is clear to us that service users have much to say on issues of capacity, and capacity assessments with requests for MAiD, advance directives, and the predominance of psychiatry's selective utilization of

“recovery” discourse in the complex lives and realities of people who come in contact with the mental health system. As Ganzini and Prigerson have noted: “Just as the legalization of physician-assisted suicide may become a slippery slope to reckless killing, the use of psychiatric labels to prevent euthanasia may become a slippery slope to unwarranted paternalism.”

On June 5, 2017, the EC collaborated with CAMH to host an event centering the perspectives of service users – all of whom have interfaced a number of times with mental health services. Some felt it was important to protect the vulnerability of service users particularly in the midst of symptoms and impaired judgment. There was also clear sentiment that denying the possibility of MAiD to people whose psychiatric disability may cause them prolonged, intolerable suffering and has implications not only for the individuals themselves but also for their families and care providers, and for society as a whole. More than once, panelists and audience members expressed some urgency: denial of access to MAiD may increase the likelihood that people will resort to desperate means to end their own lives; and secondly, exclusion denies people with psychiatric disability a right which is now granted to other members of society: the ability to make a decision concerning their right to die. While our event does not in any way represent the entirety of opinions, it was a start, and it is precisely because there is more to be done by including service users in these deliberations that we strongly request the CCA both acknowledge this shortcoming and consider how it can be ameliorated in the future – across both urban and rural sites where the conversation and capacity needs for community building are multifaceted and complex. Our audience was very clear in articulating that it was important to attend to the views and experience of diversely situated individuals.

As a result of our initial consultation with members of the community, the EC recommends that mental health organizations consult with their client base, and independent service user organisations to make recommendations that are not rooted in arbitrary paradigms or medical paternalism. The EC is in the process of organizing a second group discussion on the issue of MAiD following CAMH’s release of their position paper. The purpose of this second meeting is to do further capacity building, share updates and determine next steps if any. AS part of the CCA’s consideration of all written material, the EC recommends that best practices are followed in ensuring engagement of service users in ongoing work pertaining to MAiD.

Service users, together with the professionals and others who support them, should be the ones to inform and lead discussions of MAiD. In other words, it is unprincipled to allow the shepherding of this important conversation to continue in the absence of meaningful service-user voice. Our medical and legal colleagues have important professional views, but so too do services users who also study and write, live with psychiatric disability and have much experiential knowledge about the access and lack of access to healthcare in their lives.

#### Notes

L. Ganzini and H. Prigerson, “The Other Side of the Slippery Slope,” The Hastings Center Report, July/August 2004, 34(4).

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

On June 5, 2017, the EC held a panel discussion and Q&A among former and current service users to discuss this issue. Following the panel discussion, audience members contributed their own opinions in a robust and emotional conversation on themes including dignity, consent, suffering, spirituality, empathy and equity. The full discussion is available at [http://www.camh.ca/en/hospital/about\\_camh/newsroom/CAMH\\_in\\_the\\_headlines/stories/Pages/Clients-and-Service-Users-attend-panel-and-discussion-on-MAiD.aspx](http://www.camh.ca/en/hospital/about_camh/newsroom/CAMH_in_the_headlines/stories/Pages/Clients-and-Service-Users-attend-panel-and-discussion-on-MAiD.aspx)

As mentioned, audience members contributed to a number of points including:

- the experience of mental health care being substandard compared to physical health care (e.g., availability/affordability of psychotherapy; inability of the medical model to meet all clients' needs; poor follow-up with clients transitioning from residential care to community)
- the importance of the social determinants of mental health
- the importance of further conversations about the collection and use of data on MAiD in Canada, and in countries with laws that permit assistance with death (particularly Belgium, the Netherlands, Luxembourg and Switzerland, which permit MAiD in cases where mental illness is the sole underlying condition)
- the critical importance of allowing mental health service users to lead conversations about the future of MAiD
- the need for further consultation to ensure that all service user perspectives are heard, especially the voices of racialized, immigrant and Indigenous communities, as the debate evolves.

In order to facilitate discussion the EC also created a social media site with both pro / con perspectives on the inclusion of mental illness as criteria for access to MAiD or euthanasia depending on the jurisdiction. We expect the CCA panel will be very familiar with some of these views but we suggest that this is the only site (as far as we know) that assembles the various conversations and opinions as led by service users only.

[mentalhealthandassisteddeath.wordpress.com](http://mentalhealthandassisteddeath.wordpress.com)



The Empowerment Council: A Voice for the Clients of CAMH  
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**SUBMISSION TO THE COUNCIL OF CANADIAN ACADEMIES**  
**DESIGNATED EXPERT PANEL ON MEDICAL ASSISTANCE IN DYING (MAID)**  
Requests for MAID Where Mental Illness is the Sole Underlying Medical Condition

October 6, 2017

*1. What are your organization's main issues concerning requests for MAID ... where mental illness is the sole underlying medical condition?*

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The EC notes that our greatest concern is one of access, inclusion and participation of service users who undoubtedly have much to contribute to this conversation. While there have been numerous committees organized and struck to prompt medical and legal opinion and perspectives, there has been very little from service users themselves. This is understandable given the lack of resources both in cities and rural locations, locally and provincially across the country. Our colleagues and allies in the physical disability community have been quite active and vocal in organizing and communicating the implications of euthanasia or assistance in dying for people with physical disabilities. Much of this activity can be in part attributed to high-profile media stories and legal cases which have galvanized a voice in the disability community.

In the mental health service-user community, our trajectory is uniquely different and only recently emergent. While there is much literature and first-person accounts with regard to experiences of psychiatric disability, diagnoses, quality of life and more specifically

suicide, there has yet to be in the jurisdiction of Canada a broad-based consultation on how to approach assistance in dying when mental illness is the sole underlying condition. The irremediableness of psychiatric disability has been a conversation left solely to the deliberations of medical discourse and discussions about best medical “evidence” on the matter. While our organization in no way wants to promote the view that psychiatric disability should be considered irremediable (particularly when so much of our work is to promote, support and enhance the worth of individuals with mental health issues and the reality that many people who live with psychiatric disability and intersecting medical/disability-related concerns, can have worthwhile and full lives), we are concerned that without a robust and proper innovative consultation process on the matter, our community will be left once again on the margins of major health and state interventions.

From the very limited and brief work the EC has done on MAiD, it is clear to us that service users have much to say on issues of capacity, and capacity assessments with requests for MAiD, advance directives, and the predominance of psychiatry’s selective utilization of “recovery” discourse in the complex lives and realities of people who come in contact with the mental health system. As Ganzini and Prigerson have noted: “Just as the legalization of physician-assisted suicide may become a slippery slope to reckless killing, the use of psychiatric labels to prevent euthanasia may become a slippery slope to unwarranted paternalism.”

On June 5, 2017, the EC collaborated with CAMH to host an event centring the perspectives of service users – all of whom have interfaced a number of times with mental health services. Some felt it was important to protect the vulnerability of service users particularly in the midst of symptoms and impaired judgment. There was also clear sentiment that denying the possibility of MAiD to people whose psychiatric disability may cause them prolonged, intolerable suffering and has implications not only for the individuals themselves but also for their families and care providers, and for society as a whole. More than once, panelists and audience members expressed some urgency: denial of access to MAiD may increase the likelihood that people will resort to desperate means to end their own lives; and secondly, exclusion denies people with psychiatric disability a right which is now granted to other members of society: the ability to make a decision concerning their right to die. While our event does not in any way represent the entirety of opinions, it was a start, and it is precisely because there is more to be done by including service users in these deliberations that we strongly request the CCA both acknowledge this shortcoming and consider how it can be ameliorated in the future – across both urban and rural sites where the conversation and capacity needs for community building are multifaceted and complex. Our audience was very clear in articulating that it was important to attend to the views and experience of diversely situated individuals.

As a result of our initial consultation with members of the community, the EC recommends that mental health organizations consult with their client base, and independent service user organisations to make recommendations that are not rooted in arbitrary paradigms or medical paternalism. The EC is in the process of organizing a

second group discussion on the issue of MAiD following CAMH's release of their position paper. The purpose of this second meeting is to do further capacity building, share updates and determine next steps if any. As part of the CCA's consideration of all written material, the EC recommends that best practices are followed in ensuring engagement of service users in ongoing work pertaining to MAiD.

Service users, together with the professionals and others who support them, should be the ones to inform and lead discussions of MAiD. In other words, it is unprincipled to allow the shepherding of this important conversation to continue in the absence of meaningful service-user voice. Our medical and legal colleagues have important professional views, but so too do services users who also study and write, live with psychiatric disability and have much experiential knowledge about the access and lack of access to healthcare in their lives.

### **Notes**

L. Ganzini and H. Prigerson, "The Other Side of the Slippery Slope," *The Hastings Center Report*, July/August 2004, 34(4).

*2. Please identify or provide relevant knowledge that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to ... mental illness as the sole underlying medical condition. Please provide web links, references, or attachments.*

On June 5, 2017, the EC held a panel discussion and Q&A among former and current service users to discuss this issue. Following the panel discussion, audience members contributed their own opinions in a robust and emotional conversation on themes including dignity, consent, suffering, spirituality, empathy and equity. The full discussion is available at

[http://www.camh.ca/en/hospital/about\\_camh/newsroom/CAMH\\_in\\_the\\_headlines/stories/Pages/Clients-and-Service-Users-attend-panel-and-discussion-on-MAiD.aspx](http://www.camh.ca/en/hospital/about_camh/newsroom/CAMH_in_the_headlines/stories/Pages/Clients-and-Service-Users-attend-panel-and-discussion-on-MAiD.aspx)

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[mentalhealthandassisteddeath.wordpress.com](http://mentalhealthandassisteddeath.wordpress.com)



The Evangelical Fellowship of Canada

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached.



# EFC

The Evangelical  
Fellowship of Canada

Submission of the Evangelical Fellowship of Canada  
to the Council of Canadian Academies  
on

**Medical Assistance in Dying in Canada**

October 3, 2017

[www.theefc.ca](http://www.theefc.ca)

**Q1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Evangelical Fellowship of Canada (EFC) is the national association of evangelical Christians in Canada. The EFC upholds respect for human life and care of vulnerable persons. Expanding access to euthanasia and assisted suicide (EAS) would place the most vulnerable Canadians at risk and further undermine societal respect for life.

Human life has intrinsic worth. Allowing EAS communicates that some lives are less valuable than others.

The requirements and guidelines to fulfill in order to perform EAS can lack clarity even in cases not involving mental illness, mature minors or advance requests. These potentially more complicated cases, involving some of the most vulnerable of Canadians, would increase the potential for abuse and would be even more difficult to govern.

***Mental illness***

Canadians affected by mental illness are a vulnerable and stigmatized population.

**Persons experiencing mental illness can be particularly vulnerable to suicidal ideation.** As Broome and de Cates' said of depression, "Indeed hopelessness, closure of the future, and suicidal ideation are key features of the illness" (2015, p. 587).

**Mental illness may vitiate the ability to give informed consent to death** (S. Kim & Lemmens, 2016). An article that noted evidence from clinical ethics and empirical studies indicating that decision-making capacity is often impaired in those with severe depressive illness, went on to recommend: "In contrast to other areas where capacity is assumed as a default, that in these cases it should be assumed to be absent unless assessed thoroughly" (Broome & de Cates, 2015, p. 587).

**Capacity can be difficult to assess.** A study by Kim, De Vries and Peteet of psychiatric EAS cases in the Netherlands, from 2011 to 2014, indicated there was a disagreement among the consultants in one-quarter (24%) of the requests (2016, p. 362). The study goes on to note that EAS proceeded with the disagreements unresolved for most cases.

**Research and resources on evaluating capacity are lacking** (S. Kim & Lemmens, 2016, p. E338).

**The preservation of hope is absolutely paramount** (Park & Chen, 2016, p. 34). However, extending the option of euthanasia or assisted suicide (EAS) implies there is no hope of recovery.

One of the key problems that arises with respect to euthanasia in patients with intolerable suffering due to a psychiatric condition, as noted by Vandenberghe, is that “The process of carefully evaluating a euthanasia request inevitably takes time, in the meantime undermining hope and orientation toward life, both crucial to safeguard the chances for partial recovery” (2012, p. 1).

**Mental illness may not follow a predictable progression.** As well, with depression, for example, remission is always a possibility and there is hope as new treatments are developed (Whitley, Palmer, & Gunn, 2015).

Mental illness is experienced by many in Canada, but there is limited treatment available. As a nation, we must not offer death in the absence of treatment.

### ***Mature minors***

The EFC absolutely rejects the idea that EAS should be made available to minors.

Children are a vulnerable population. Canada’s first priority must be to provide high quality medical care for children. To consider expanding EAS to mature minors in the absence of widely available, high quality mental health services and palliative care would be unethical.

Even within Canada, across provincial jurisdictions, the age of consent for medical treatment varies. There is no agreement about whether minors have a capacity to consent for EAS. Salter’s discussion of adolescent decision-making states: “We haven’t yet agreed on a stable definition of capacity in this population, much less a reliable instrument for measuring capacity” (2017, p. 35).

The law sets an age at which Canadians may make significant decisions, such as voting or purchasing alcohol, and it is appropriate and reasonable to set a minimum age for the decision to end life.

**In general, the less weighty the outcome, the more a minor plays a role in the decision.** EAS cannot be undone or mitigated, it is intended to kill, and thus it cannot be considered like any other type of medical treatment over which minors may have legal decision-making power.

**There is a moral and ethical difference between refusing or withdrawing treatment and EAS.** In cases where a minor participates in a decision that results in his or her death, the minor is refusing treatment, not consenting to a lethal injection. The intention to end a life, rather than to alleviate pain, makes euthanasia and assisted suicide fundamentally different than end of life care.

Canadian courts will override a minor’s refusal if the odds of survival are good with treatment.

### ***Advance requests***

The EFC opposes allowing EAS by advance request. Competency at the time of EAS is a critical safeguard against involuntary euthanasia.

**Advance directives are very complex and difficult to carry out** because of the nuances and specifics of complicated medical conditions and interventions (“Evidence - PDAM (42-1) - No. 11 - Parliament of Canada,” 2016).

**Predictions about future suffering are speculative.** As Franklin noted in an article on dementia and euthanasia: “there is simply no way to know how the disease will affect a person or how the person will feel about their quality of life once the disease has set in” (2014, p. 568).

**Advance requests put significant additional responsibility on the physician,** who must decide at what point a patient’s life will end. It’s an interpretive role but also a progression in role. The doctor goes beyond carrying out the patient’s request to interpreting the request, possibly in the midst of unforeseen circumstances and complications, and deciding on the timing.

**People change their minds.** As a study by Emanuel, Fairclough and Emanuel noted, half of the terminally ill patients who had seriously considered EAS for themselves changed their minds (2000).

**Q2. Please identify or provide relevant knowledge that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

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### **Other Relevant Works**

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Federation of Medical Regulatory Authorities of Canada

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please refer to the attachment.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please refer to the attachment.



**COUNCIL OF CANADIAN ACADEMIES  
CALL FOR INPUT  
CCA EXPERT PANEL ON MEDICAL ASSISTANCE IN DYING IN CANADA**

**ATTACHMENT**

**Input from the Federation of Medical Regulatory Authorities of Canada  
September 2017**

**FMRAC's Mission and Its Members**

The Federation of Medical Regulatory Authorities of Canada (FMRAC) represents the 13 provincial and medical regulatory authorities (MRAs) across Canada. Its mission is, "To advance medical regulation on behalf of the public through collaboration, common standards and best practices."

FMRAC's members, the MRAs, serve the public by licensing and regulating physicians in their respective jurisdictions, *in accordance with the relevant legislation*. This role includes issuing certificates of registration to allow doctors to practise medicine; investigating complaints against doctors on behalf of the public; and disciplining doctors who have committed an act of professional misconduct or who are incompetent.

**Clarity of Language – FMRAC's Main Concern**

It is the collective experience of the Medical Regulatory Authorities that clarity of language in any new legislation relating to advance requests, mature minors and/or where mental illness is the sole underlying medical condition, will be critical to ensure that the MRAs' guidance to physicians is clear and unambiguous. This is imperative because the MRAs' role includes articulating expectations for physician conduct on issues that are relevant to the practise of medicine, including Medical Assistance in Dying (MAiD). This role also includes developing and enforcing policy that outlines professional and legal obligations and criteria for MAiD, together with specific practice-related steps to follow. These policy and expectations are wholly dependent on, and reflect, the clarity of applicable legislation and impact the MRAs' duty to serve the public interest, including issues such as access to care and patient autonomy.

FMRAC and its Members look forward to making a submission on these and related issues through the legislative process, when the opportunity so arises. In the meantime, we thank the Council of Canadian Academies for considering the aforementioned issue.

Thank you.

Fleur-Ange Lefebvre  
Executive Director & CEO

**1. Quels sont les principaux problèmes de votre organisme concernant les demandes d'AMM effectuées par des mineurs matures, les demandes anticipées ou demandes se rapportant à des situations où la maladie mentale est le seul problème de santé sous-jacent? [1000 mots maximum]**

**2. Veuillez indiquer ou fournir les renseignements\* pertinents que votre organisation souhaiterait voir pris en considération par le comité d'experts sur l'AMM du CAC en matière de demandes de mineurs matures, de demandes anticipées ou de demandes se rapportant à des situations où la maladie mentale est le seul problème de santé sous-jacent. Ces renseignements sont à transmettre sous forme d'hyperliens, de références ou de pièces jointes.**

*\*Les renseignements pertinents incluent, entre autres : études, enquêtes, réglementations, lignes directrices, connaissances traditionnelles, pratiques et cas cliniques.*

## **Contribution de l'Institut de planification des soins**

Question 1. Quels sont les principaux problèmes rencontrés par votre organisme (cette contribution ne s'adresse qu'à la question des directives médicales anticipées)

1. Notre organisme ne peut présentement répondre adéquatement à la demande des citoyens, qui demandent de pouvoir bénéficier de l'aide médicale à mourir, par une demande anticipée en prévision de leur inaptitude
  - I. Les membres du Conseil d'administration de l'Institut de planification des soins proviennent soit du milieu de la santé, du droit, de la gestion de résidences pour personnes âgées et sont très souvent sollicitées pour soit : rédiger des directives médicales anticipées demandant l'aide médicale à mourir, soit que l'aide médicale à mourir soit administrée à des proches déments. Ils ne peuvent que constater leur impuissance à cet égard.
  - II. Lors des nombreuses conférences que les membres de l'Institut de planification des soins donnent au Québec, les personnes qui y assistent font régulièrement état de leur volonté de demander à l'avance l'AMM.
  - III. Les membres du Conseil d'administration de l'Institut de planification des soins, à titre corroboratif, réfèrent le Conseil des Académies au récent sondage IPSOS qui démontre que l'ensemble de la population canadienne est largement favorable au consentement préalable à l'AMM, dans proportion de 80%. (cf. texte plus élaboré ci-joint)
2. Les soins traditionnels sont peu appropriés :

Certains membres du CA, tant des juristes que des personnes du milieu des soins ou de l'hébergement constatent que les soins traditionnels n'offrent que peu de possibilité de pouvoir assurer aux patients déments, une mort digne et avec le moins de souffrance possible, selon leurs volontés qui ont pu avoir été exprimées antérieurement. La médication puissante utilisée entraîne souvent des effets néfastes non désirés ou de l'intolérance aux médicaments et il persiste souvent des symptômes réfractaires. Quant à la sédation prolongée et permanente, elle ne peut être offerte qu'environ deux semaines avant le décès prévu, alors que les pathologies entraînent souvent des douleurs et souffrances qui s'échelonnent pendant de nombreuses années.

3. Les personnes démentes souffrent souvent de manière persistante et intolérable

Certains membres du Conseil d'administration ont constaté que les personnes démentes (atteintes d'Alzheimer ou autre maladies apparentées) souffrent souvent de divers symptômes qui entraînent beaucoup d'anxiété et de détresse qu'ils manifestent dans leurs comportements le plus souvent non verbaux, à qui les observent. Ces personnes démentes peuvent crier constamment, être agressives, se sentir persécutées, avoir des visions et hallucinations, faire de l'errance, être délirantes etc. ceci en plus des symptômes de dégénérescence cognitive, de désorientation et de désorganisation générale.

4. Il est possible d'évaluer la douleur ou souffrance des personnes démentes

On prétend souvent que les personnes démentes sont incapables d'évaluer leur propre souffrance et d'en communiquer l'intensité et donc qu'il ne pourrait être satisfait à cette condition d'ouverture à l'aide médicale à mourir.

L'Institut de planification des soins est en désaccord avec cette opinion. Les personnes démentes manifestent leur douleur ou souffrance par d'autres moyens que la parole et d'ailleurs des outils ont été développés et sont couramment utilisés pour évaluer la douleur des personnes non communicantes. Ces outils, qui se présentent généralement sous forme d'échelles, sont suffisamment fiables pour pouvoir établir un degré de souffrance qui serait intolérable pour une personne ordinaire placée dans les mêmes circonstances. (cf. texte plus élaboré ci-joint)

5. Ne pas permettre l'AMM par DMA est discriminatoire :

La *Loi québécoise concernant les soins de fin de vie* contient à son article 51 une prohibition explicite de faire une demande anticipée d'aide médicale à mourir. Selon l'Institut de planification des soins, ne pas permettre l'utilisation d'un outil, par ailleurs totalement légal, c'est-à-dire la directive anticipée, pour aider une personne à mourir dans des conditions spécifiques et lorsque ses souffrances sont devenues intolérables, et ceci en raison de sa seule inaptitude mentale, est en soi discriminatoire. (voir document plus élaboré ci-joint)

6. Les difficultés particulières de la DMA en matière d'AMM :

L'Institut de planification de soins reconnaît que des difficultés particulières entourent la question de la demande d'AMM par DMA. Cependant, en prenant par exemple, la situation dans les Pays-Bas et dans une moindre mesure en Belgique, on peut conclure que ces difficultés peuvent être surmontées avec des mesures et balises additionnelles. L'Institut de planification des soins considère que l'on devrait prendre en compte les solutions suivantes:

7. Solutions suggérées par l'Institut de planification des soins aux problèmes rencontrés :

En plus des règles déjà existantes pour les demandes contemporaines de la part des personnes aptes, l'Institut de planification des soins croit que les difficultés actuelles rencontrées pourraient être contrées avec l'ajout de quelques mesures additionnelles à celles déjà existantes, soit :

1. Que la DMA ait été formulée par écrit, qu'elle respecte les règles générales en vigueur mutatis mutandis, qu'elle contienne la définition claire de ce que la personne entend par souffrance physique ou psychologique intolérable
2. Pour assurer une certaine contemporanéité que la DMA ait été rédigée après que la personne ait reçu un diagnostic d'une maladie qui vraisemblablement entraînera son inaptitude
3. Que l'évaluation du degré de douleur ou souffrance physique ou psychologique soit faite par un médecin compétent en évaluation de la douleur chez les personnes non communicantes
4. Que les proches et responsables légaux de la personne aient pu discuter, au moment de la mise en œuvre, avec l'équipe de professionnels de la santé pour les aider à évaluer toutes les circonstances et le contexte particulier, le cas échéant
5. Dans le cas d'une personne isolée ou en cas de difficulté, que la revue de toute la procédure suivie dans un cas particulier, soit faite avant l'administration de l'AMM par un organisme tel un comité d'éthique, une commission spécialisée ou même un tribunal, pour en garantir l'intégrité et la légalité

6. Que le refus catégorique de la personne devenue inapte soit soumis aux règles ordinaires prévues dans ces cas, par les diverses juridictions.

Question 2. Il serait utile pour le Conseil des Académies de consulter les annexes ci-jointes, ainsi que les références qui y sont citées.

Respectueusement soumis et approuvé par le Conseil d'administration de l'Institut de Planification des soins, lors de sa réunion du 19 septembre 2017

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Me Danielle Chalifoux, présidente

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Mme Suzanne Boyd, vice-présidente,  
Directrice générale et trésorière

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Me Denise Boulet, secrétaire

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## ***INSTITUT DE PLANIFICATION DES SOINS***

Mémoire adressé au Conseil des académies canadiennes

relatif aux

Directives médicales anticipées et l'aide médicale à mourir

Septembre 2017

***Institut de planification des soins***

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## Introduction :

Les directives médicales anticipées (DMA) sont le meilleur moyen de faire connaître ses volontés de fin de vie, cela est établi et en effet, toutes les provinces du Canada ont des dispositions légales permettant de faire de telles directives.<sup>1</sup>

Les DMA permettent aussi d'éviter les conflits de valeurs à l'intérieur des familles qui ont à décider pour leurs proches, lorsqu'il n'y a pas de directive claire et libèrent la personne appelée à prendre la décision pour autrui du lourd fardeau d'avoir à prendre des décisions pouvant résulter dans le décès de leurs proches.

La question de pouvoir faire de telles directives en matière d'aide médicale à mourir (AMM) est présentement à l'étude et soulève quelques controverses. On notera que dans la *Loi concernant les soins de fin de vie du Québec*, la DMA en matière d'AMM est spécifiquement interdite<sup>2</sup>.

L'Institut de planification des soins est en faveur de l'établissement d'un mécanisme de DMA qui pourrait être mis sur pied pour permettre l'AMM par DMA et ceci, pour plusieurs raisons. En voici les principales :

### 1. La population le demande dans une très grande majorité

- 1.1. Les membres du Conseil d'administration de l'Institut de planification des soins proviennent soit du milieu de la santé, du droit, de la gestion d'habitations pour personnes âgées et sont très souvent sollicitées pour soit : rédiger des directives médicales anticipées demandant l'aide médicale à mourir, faire en sorte que l'aide médicale à mourir soit administrée à des proches déments. Ils ne peuvent que constater leur impuissance à cet égard. Lors des nombreuses conférences que les membres de l'Institut de planification des soins donnent au Québec, les personnes qui y assistent font régulièrement état de leur volonté de demander à l'avance l'AMM et déplorent le fait qu'il n'y ait pas de possibilité à cet égard, pour elles et pour les personnes dont elles sont responsables ou qui leur sont proches.

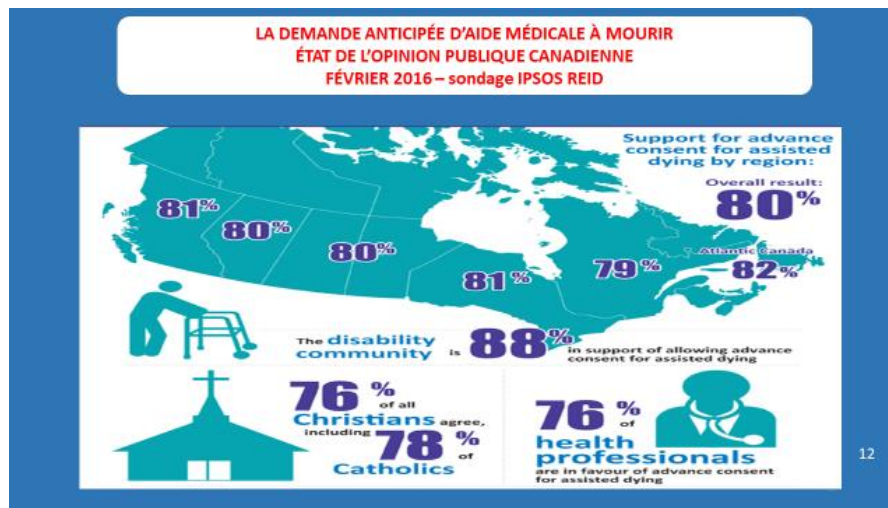
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<sup>1</sup> Danielle Chalifoux, Pouvoirs publics et protection : *Les directives préalables de fin de vie et les pouvoirs publics*, Barreau du Québec, 2003, vol. 182, éd. Yvon Blais.

<sup>2</sup> Cf. art. 51 de la *Loi concernant les soins de fin de vie*, L.Q. ch. S-32.0001. L'Institut de planification des soins a fait des représentations à cet égard, voir : Danielle Chalifoux, Denise Boulet et Pierre-Gabriel Jobin, Complément de mémoire, Commission spéciale sur la question de mourir dans la dignité, Assemblée nationale du Québec, Septembre 2010.



- 1.2. De plus, un récent sondage IPSOS démontre que l'ensemble de la population canadienne est largement favorable au consentement préalable à l'AMM :



## 2. Les soins traditionnels sont peu appropriés

- 2.1. Les soins de fin de vie présentement légalement permis, consistent principalement en la sédation palliative continue. Cette forme de sédation est dispensée généralement à la toute fin de la vie et ne représente pas une solution appropriée pour des pathologies qui peuvent se prolonger pendant des années. Certains membres de notre Conseil d'administration ayant côtoyé ou soigné des personnes atteintes de la maladie d'Alzheimer ou autres pathologies apparentées, sont bien au fait de la détresse et de la souffrance tant des personnes atteintes que des proches<sup>3</sup>.
- 2.2. Les choix qui sont possibles ne résident que dans la médication analgésique, antipsychotique, anticonvulsive, antidépressive ou autres médications analogues, ou par la sédation palliative profonde et permanente. Or, il a été démontré que ces outils ne sont pas toujours bien adaptés à des personnes démentes, puisque ces pathologies peuvent s'échelonner sur de très nombreuses années et entraîner dès leur apparition, des souffrances intolérables qu'on ne peut soulager par les méthodes traditionnelles. Quant à la sédation palliative profonde et permanente, elle est peu utile, puisqu'elle ne peut être offerte que dans les jours précédant la mort anticipée.<sup>4</sup>

<sup>3</sup> Extrait du témoignage d'une proche à l'occasion du décès de sa mère : « Mourir jusqu'à ce que ton dernier souffle arrive, par la fatigue et la déshydratation, à te rendre à l'état squelettique. C'est affreux et inhumain... » <http://www.lapresse.ca/la-voix-de-lest/opinions/courrier-des-lecteurs/201706/02/01-5103855-mourir-de-lalzheimer.php>

<sup>4</sup> Inspiré de: La sédation palliative en fin de vie: Guide d'exercice, Société québécoise des médecins en soins palliatifs et Collège des médecins du Québec, 2016: <http://www.cmq.org/publications-pdf/p-1-2016-08-29-fr-sedation-palliative-fin-de-vie.pdf>

### 3. Les personnes démentes souffrent souvent de manière persistante et intolérable

Il faut souligner que les personnes démentes (atteintes d'Alzheimer ou autres maladies apparentées) souffrent souvent de divers symptômes qui entraînent beaucoup d'anxiété et de détresse qu'ils manifestent dans leurs comportements le plus souvent non verbaux, à qui les observent. Elles peuvent crier constamment, être agressives, se sentir persécutées, avoir des visions et hallucinations, faire de l'errance, être délirantes etc., ceci en plus des symptômes de dégénérescence cognitive, de désorientation et de désorganisation générale.

Des membres du Conseil d'administration de l'Institut de planification des soins ont été à même de constater des situations dans lesquelles des personnes démentes réagissent agressivement aux soins qui leur sont nécessaires et il est documenté qu'il arrive même que des soignants soient blessés par elles<sup>5</sup>.

### 4. Il est possible d'évaluer la douleur ou souffrance des personnes démentes

Outre le fait que les personnes atteintes de démence sont inaptes à prendre une décision libre et éclairée, on prétend souvent qu'elles sont incapables d'évaluer leur propre souffrance et d'en communiquer l'intensité. Puisque la loi prévoit une évaluation subjective faite par la personne elle-même, il ne serait pas possible pour une personne inapte de satisfaire à cette obligation.

L'Institut de planification des soins est en désaccord avec cette opinion. Il considère qu'une évaluation subjective/objective, comme on en rencontre souvent en droit, peut être faite dans ces cas. D'une part, les personnes démentes manifestent effectivement leur douleur et/ou souffrance mais par d'autres moyens que la parole. D'ailleurs des outils ont été développés et sont couramment utilisés pour évaluer la douleur des personnes non communicantes. Ces outils sont suffisamment fiables pour pouvoir établir un degré de souffrance qui serait intolérable pour une personne ordinaire placée dans les mêmes circonstances.

En effet, présentement, ces échelles<sup>6</sup>, utilisées par des personnes expérimentées, permettent de contrôler les nombreux médicaments et leur posologie dont les personnes démentes ont besoin pour soulager leurs symptômes. Pour soigner adéquatement ces personnes, il faut faire de telles prescriptions et donc nécessairement être capable d'évaluer leur degré de douleur ou souffrance physique ou psychique. Ces outils pourraient aussi bien servir pour déterminer le degré de souffrance requis pour dispenser l'AMM, en lien avec la

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<sup>5</sup> Maladie d'Alzheimer et maladies apparentées : prise en charge des troubles du comportement perturbateurs: [http://www.has-sante.fr/portail/upload/docs/application/pdf/2009-07/maladie\\_dalzheimer-troubles\\_du\\_comportement\\_perturbateurs-recommandations.pdf](http://www.has-sante.fr/portail/upload/docs/application/pdf/2009-07/maladie_dalzheimer-troubles_du_comportement_perturbateurs-recommandations.pdf)

<sup>6</sup> Exemples: échelle DOLOPLUS ou Grille d'observation PACSLAC-C

description que la personne en aurait faite dans sa DMA. Il s'agirait donc d'une évaluation à la fois objective et subjective.

#### 5. Ne pas permettre l'AMM par DMA est discriminatoire

La *Loi québécoise concernant les soins de fin de vie* contient à son article 51 une prohibition explicite de faire une demande anticipée d'aide médicale à mourir<sup>7</sup>. La Loi fédérale ne contient pas une telle prohibition expresse. En fait, la Cour Suprême dans *Carter*<sup>8</sup> n'a pas abordé comme telle la question des directives médicales anticipées, mais elle a bien affirmé qu'en matière de consentement, les règles déjà en vigueur s'appliquent. Comme ces règles reconnaissent la validité des demandes anticipées, on pourrait en déduire que le législateur fédéral ou même provincial, selon les champs de compétence de chacun, pourrait émettre des règles concernant les demandes anticipées d'aide médicale à mourir, sans enfreindre les principes de l'arrêt *Carter*.

De plus, juridiquement, ne pas permettre l'utilisation d'un outil, par ailleurs totalement légal, c'est-à-dire la directive anticipée, pour aider une personne à mourir dans des conditions spécifiques et lorsque ses souffrances sont devenues intolérables, et ceci en raison de sa seule inaptitude mentale, est en soi discriminatoire.<sup>9</sup>

#### 6. Les difficultés particulières de la DMA en matière d'AMM

L'Institut de planification de soins reconnaît que des difficultés particulières entourent la question de la demande d'AMM par DMA. Cependant, en prenant par exemple, la situation dans les Pays-Bas et dans une moindre mesure en Belgique<sup>10</sup>, on peut conclure que ces difficultés peuvent être surmontées avec des mesures et balises additionnelles. L'Institut de planification des soins considère que l'on devrait prendre en compte les situations suivantes:

##### 6.1. Au moment de la rédaction de la demande

6.1.1. Il s'agit surtout de la détermination de l'aptitude de la personne et du caractère libre et éclairé de la demande. L'Institut de planification des soins est d'avis qu'une consultation médicale devrait être obligatoire pour que la personne soit reconnue apte à consentir de manière libre et éclairée et qu'effectivement on s'assure

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<sup>7</sup> Voir note no. 2

<sup>8</sup> *Carter c. Canada* (procureur général), 2015 CSC 5, [2015]

<sup>9</sup> Le caractère discriminatoire de cette situation a été souligné : cf. Danielle Chalifoux, *La Loi concernant les soins de fin de vie, les directives médicales anticipées et les niveaux de soins: accommodements raisonnables?* Dans: La protection des personnes vulnérables, Barreau du Québec (2015) vol. 402

<sup>10</sup> Voir à cet égard : Euthanasie - La Hollande et la Belgique ont légalisé la mort volontaire Quand la souffrance est devenue insupportable : <http://www.ledevoir.com/societe/actualites-en-societe/16813/euthanasie-la-hollande-et-la-belgique-ont-legalise-la-mort-volontaire>

qu'elle a reçu toutes les informations nécessaires à sa prise de décision, notamment quant aux règles qui s'appliquent (ou s'appliqueraient le cas échéant).

6.1.2. Au niveau de la définition de ce qu'est la souffrance intolérable pour la personne qui demande l'aide médicale à mourir, c'est-à-dire du moment où il sera approprié de lui administrer l'aide médicale à mourir, l'Institut est favorable, comme **aux** Pays-Bas, à ce que la demande contienne une définition élaborée clairement par la personne elle-même, de ce qu'est la souffrance intolérable pour elle, dans le cadre de sa demande l'AMM.<sup>11</sup>

6.1.3. Il va sans dire que la demande anticipée devrait se faire dans le cadre des critères appliqués généralement quant à l'AMM : la demande anticipée ne devrait pas bénéficier d'un statut spécial. Par exemple, on devra aviser la personne que la simple mention : « *au moment où je ne reconnaitrai plus les miens* » ne serait pas suffisante pour déclencher le processus d'AMM, car cette condition n'engendre pas nécessairement, comme telle, une douleur ou souffrance persistante et intolérable. On voit couramment des personnes démentes qui ne présentent pas de symptômes de douleur ou souffrance notables. Ces personnes, si elles étaient aptes, ne seraient pas candidates à l'AMM.

6.1.4. De plus, il est généralement reconnu que la directive médicale anticipée devrait avoir été rédigée à un moment **où** la personne aurait reçu un diagnostic qui risque d'entraîner son inaptitude. Par exemple, on pense aux maladies d'Alzheimer ou autres qui lui sont apparentées<sup>12</sup>. Il nous semble que cette condition garantirait une certaine contemporanéité et que la décision a été prise dans un contexte qui s'y prête bien.

## 6.2. Au niveau de la détermination du moment approprié de dispenser l'AMM

6.2.1. L'Institut de planification des soins est persuadé qu'il faut que les professionnels de la santé puissent déterminer avec certitude que le moment approprié est bien

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<sup>11</sup> « Certaines personnes pensent qu'il serait souhaitable pour elles de recevoir l'euthanasie, si éventuellement elles se retrouvent dans une situation particulière qu'elles considèrent aujourd'hui comme étant intolérable et qui n'offre aucune possibilité d'amélioration.

Le cas échéant, la meilleure façon d'agir est de discuter de la situation avec leur médecin de famille et de faire une directive anticipée écrite qui décrit les circonstances particulières pour lesquelles elles désirent recevoir l'euthanasie. Cette directive anticipée doit définir précisément ces circonstances. Le document constitue une directive adressée à un médecin et doit refléter l'expression de la volonté du patient, exprimée de façon claire et sans ambiguïté. » Traduction libre de l'anglais, à consulter à :

<https://www.government.nl/topics/euthanasia/contents/euthanasia-assisted-suicide-and-non-resuscitation-on-request>

<sup>12</sup> Cette question fait l'objet d'une recommandation spécifique (no. 12) du rapport final du Groupe consultatif provincial-territorial d'experts sur l'aide médicale à mourir, du 30 novembre 2015 ainsi qu'une recommandation (no. 7) du rapport du Comité mixte spécial sur l'aide médicale à mourir du Parlement du Canada, de février 2016

survenu : c'est-à-dire que la personne remplit bien les critères d'ouverture, particulièrement quant à la détermination de la souffrance persistante et intolérable. La personne étant inapte, cela ne veut pas dire qu'elle ne souffre pas, mais simplement qu'elle n'est pas en mesure de communiquer sa souffrance de la même manière qu'une personne apte. L'évaluation subjective-objective décrite plus haut devrait être appliquée.

6.2.2. Il est utile ici de mentionner que ce genre de raisonnement n'est pas nouveau. Les juristes connaissent fort bien les situations où il faut évaluer des intentions ou conduites à l'aide de tests subjectifs-objectifs ou de celles où on fait appel au critère de la personne prudente et raisonnable, placée dans les mêmes circonstances.

## 7. Pistes de solutions à envisager :

En plus des règles déjà existantes pour les demandes contemporaines de la part des personnes aptes, l'Institut de planification des soins souhaite qu'il soit possible de mieux répondre aux besoins qui sont exprimés par la grande majorité des citoyens en cette matière, et qu'en ce sens, la Loi permette l'aide médicale à mourir par directive médicale anticipée, en prévoyant les mesures additionnelles suivantes :

- 7.1. Que la DMA ait été formulée par écrit, qu'elle respecte les règles générales en vigueur mutatis mutandis, qu'elle contienne la définition claire de ce que la personne entend par souffrance physique ou psychologique intolérable.
- 7.2. Que la DMA ait été rédigée après que la personne ait reçu un diagnostic d'une maladie qui vraisemblablement entraînera son inaptitude.
- 7.3. Que l'évaluation du degré de douleur ou souffrance physique ou psychologique soit faite par un médecin compétent en évaluation de la douleur chez les personnes non communicantes.
- 7.4. Que les proches et responsables légaux de la personne aient pu discuter, au moment de la mise en œuvre, avec l'équipe de professionnels de la santé pour les aider à évaluer toutes les circonstances et le contexte particulier, le cas échéant.
- 7.5. Dans le cas d'une personne qui est isolée, ou en cas de difficulté, que la revue de toute la procédure suivie, soit faite avant l'administration de l'AMM par un organisme tel un comité d'éthique, une commission spécialisée ou même un tribunal, pour en garantir l'intégrité et la légalité.

7.6. Que le refus catégorique de la personne devenue inapte soit soumis aux règles ordinaires prévues dans ces cas, par les diverses juridictions.

Respectueusement soumis et approuvé par le Conseil d'administration de l'Institut de Planification des soins, lors de sa réunion du 19 septembre 2017.

Signé, le 19 septembre 2017, au nom du Conseil d'administration de l'Institut de Planification des soins par :

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Me Danielle Chalifoux, présidente

## Manitoba Provincial MAID Clinical Team

### **1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

#### Mature Minors

- not against this but question if there should be a firm lower age under which it is not allowed and/or if there is a role for parental consent

#### Advance Directives

- would like to differentiate between short vs long term advance direction with more support for short term than long term

Short term would include: patients who request MAID & are eligible under current criteria but want to spend as much time with family as possible so request MAID to be provided once they become confused/comatose, etc. MAID would then be provided based on recent approval + consent but without patient consent IMMEDIATELY prior to administration of medications.

MAID would be provided by one of the two assessors who have been directly involved in determining eligibility and obtaining consent. Short term may also include patients who lose capacity prior to MAID but have made it clear this is their wish although this is less clear as to acceptability.

Long term would be for patients who request MAID well in advance of meeting eligibility criteria and as such may not be directly involved in MAID approval process. This scenario is of some concern especially if MAID provider does not have a previous relationship with the patient. I would find it difficult to be comfortable providing MAID to a patient without discussing it directly with them (& receiving confirmation from them in close proximity to the provision). If MAID provider very familiar with the patient and involved in multiple discussions over the years then this may be different scenario. So MAID via long term advance direction would require more safeguards, etc.

#### Mental Illness as sole medical condition

- not in support of this in general
- obviously this would require a change in current eligibility criteria particularly 'natural death reasonably foreseeable'. Concerns include: difficulty with prognosis, whether mental illness is ever truly 'irremediable', etc.. Our approach is to have the relevant specialist determine diagnosis + prognosis with MAID provider confirming eligibility criteria are met but not directly determining the illness severity/treatment options, etc.. So our approach would require a psychiatrist to deem the mental illness 'grievous & irremediable'. Our experience (in the last 1.5 years of providing MAID) with requests from persons with mental illness alone is that many are young, isolated, actively sick and have often refused to try recommended mental health interventions. Not sure adequate safeguards could be put in place

### **2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

None.

Nurse Practitioner Association of Manitoba

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

In Manitoba, nurse practitioners are unable to complete death certificates, which is a barrier to provide Medical Assistance in Dying (MAID). The Federal Vital Statistics Act has been amended to include NPs but the Manitoba Provincial medical examiner does not support the federal legislation.

The College of RN of Manitoba has recently changed the title in Manitoba to RN(NP). Thus, a member of the public or other health professionals could interpret the change to mean RNs hold the authority to enact MAID legislation, as the RN title is also paired with NP. Using the title RN(NP) would confuse the public and healthcare providers who would logically conclude that RNs hold the scope and authority to provide medical assistance in dying. As indicated in the new federal legislation (MAID) the title nurse practitioner is used as a standalone title, the confusion lies with the nurse regulator in Manitoba using a new title that has not been used in Manitoba to promote the role of the NP for the past 15 years.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

a) The results of the November 2016 College of Registered Nurses of Manitoba NPs regarding MAID. Contact [www.crnmb.ca](http://www.crnmb.ca)

b) <https://www.crnmb.ca/connect/search?q=MAID>

c) The results of the September 2016 CNA survey of NPs regarding MAID. i.e. The Canadian Nurses Association, in collaboration with a national task force, is developing a nursing framework for medical assistance in dying (MAID). The purpose of the framework is to provide information and highlight key considerations to help nurses reflect on the ethical and practice issues that may arise with MAID. The framework will also support stakeholders in nursing education, regulation, research, policy and administration. If you have any questions, please contact Josette Roussel at 1-800-361-8404, ext. 229, or at [jroussel@cna-aiic.ca](mailto:jroussel@cna-aiic.ca).

d) The results of the December 2016 The College of Nursing, University of Manitoba survey of NPs regarding MAID. The study was to increase our understanding of Canadian nurses' perspectives on medical assistance in dying and conscientious objection. Contact Marie Edwards, RN, PhD, Associate Professor, College of Nursing, [Marie.Edwards@umanitoba.ca](mailto:Marie.Edwards@umanitoba.ca)

e) The expert panel should include a nurse practitioner and a member from Manitoba, I see that there is a gap in the panel with no NP representation or a member from the province of Manitoba.

The Nurse Practitioner Association of Manitoba appreciates contributing to the panel. Thank-you.



Ottawa Catholic Physicians' Guild

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see attached submission by the Ottawa Catholic Physicians' Guild.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see attached submission by the Ottawa Catholic Physicians' Guild.

## **Submission by the *Ottawa Catholic Physicians' Guild*<sup>a</sup>**

For the Council of Canadian Academies Expert Panel on Medical Assistance in Dying

October 6, 2017

This submission will focus largely on the issue of extending Medical Aid in Dying (MAID) to cases where the sole source of suffering is psychological, and briefly touch on the issues of advanced consent, and MAID for mature minors.

Footnotes with additional evidence are alphabetized, and numeral references are provided as endnotes.

### **PSYCHOLOGICAL ILLNESS**

#### **Undermining Psychiatric Care**

One in five Canadians suffers from a mental illness in any given year,<sup>1</sup> and one of the many manifestations of mental illness is the experience of having suicidal thoughts. Allowing for the expansion of euthanasia and physician-assisted suicide (E/PAS), now referred to as Medical Assistance in Dying (MAID) in Canada, to people suffering solely from mental illness would place the work of psychiatrists and mental health professionals directly at odds with permissive legislation.<sup>b</sup> It would also undermine efforts to provide appropriate psychiatric care to a very significant proportion of the Canadian population. It makes little sense to offer assisted-suicide as a “treatment option” to this population of people when suicide prevention is fundamental to appropriate care. Suicide prevention strategies involve taking away patients’ access to lethal means<sup>2,3</sup>; permitting MAID for solely psychological reasons does exactly the opposite.

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<sup>a</sup> Founded in 1990, the *Ottawa Catholic Physicians' Guild* is an Ottawa-based society of physicians and healthcare professionals that undertakes the study of medical ethics in the light of Catholic teaching. We oppose euthanasia and assisted-suicide in principle because they are gross violations against the respect for the sanctity of human life, and we affirm the dignity of every human being at all stages of life. This submission, which outlines concerns from the perspectives of our physician members in light of available evidence, was discussed, amended, and endorsed by members at a meeting of the guild on September 29, 2017 and finalized on October 3, 2017.

<sup>b</sup> For example, in Ontario, legislation (the Mental Health Act) allows for patients to be admitted to a psychiatric facility if they are deemed to be a safety risk to themselves or others.

Suicidal ideation is often a marker of severity of mental illness. Tampering with the trust needed in the doctor-patient relationship, by inserting the possibility of (E/PAS) as an outcome, may undermine psychiatric treatment; ambivalent patients, knowing that E/PAS could be placed on the table as a treatment option, but not really wanting death, may avoid disclosing their suicidal ideations to their physician for fear of having MAID foisted upon them. Consequently, the psychiatrist's ability to properly assess the effects of medication on such patients (some of which may increase the risk of suicidal ideation) will be hampered.

While in Canada it is no longer illegal to commit suicide, there is no *right*, per se, to commit suicide; if there were such a right, it would necessarily entail a duty *not* to treat individuals who have attempted suicide.<sup>4</sup> However, this is not currently the case.<sup>c,d,5,6</sup> If psychological illnesses were included under MAID this would create further complications for physicians faced with patients who present after having attempted suicide: If the patient is potentially eligible for MAID, should the physician on duty attempt resuscitation? This scenario has already surfaced in Quebec as detailed in footnote (d). In the future, would physicians be sued for trying to save a life?

### **Medicine and the Role of the Physician**

There is a need to clarify the primary purpose of medicine, and the role of the physician. For many psychiatrists, assisting patients to die is incompatible with a healthy therapeutic relationship, runs counter to the physician's role as an agent of healing, and undermines the foundations of the therapeutic process.<sup>7</sup> Several professional organizations, including the American Psychiatric Association<sup>e</sup>, the American Medical Association<sup>f</sup>, and the World

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<sup>c</sup> "Psychiatrists who fail to take reasonable care that their patients do not commit suicide, including by failing to order their involuntary hospitalization to prevent them committing suicide, when a reasonably careful psychiatrist would not have failed to do so, can be liable for medical malpractice, unprofessional conduct, and even, in extreme cases, criminal negligence." (Boudreau and Somerville, 2014).

<sup>d</sup> Quebec's College of Physicians issued a bulletin in 2016, following the legalization of E/PAS in their province, after concerning reports that physicians failed to offer life-saving treatments to patients presenting to the emergency department following suicide attempts. The College reminded doctors that it would be *negligent not* to save life in these circumstances. It appears that the legalization of E/PAS may have contributed to ambiguity around the ethical duty of doctors to preserve life. (Hamilton, 2016).

<sup>e</sup> "The American Psychiatric Association, in concert with the American Medical Association's position on Medical Euthanasia, holds that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death." (APA, 2016).

<sup>f</sup> "Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks." (American Medical Association, 2016).

Medical Association<sup>8</sup>, have taken a stand against participating in medical euthanasia due to the ethical conflicts that would arise within the profession.<sup>8,9,10,11,12</sup>

Consequently, the role of psychiatry in the diagnosis and management of mental illness is currently being questioned: In a discussion at a University Psychiatry Grand Rounds presentation in Ottawa this year,<sup>13</sup> a psychiatry resident who provided consultations for a medical service shared her experience that she was seen as “getting in the way” of obtaining MAID by the patient/family simply because she had done her job in diagnosing a clinical depression in the patient.

Her experience is not unique; at the 2017 Canadian Psychiatric Association (CPA) Conference held in Ottawa, a senior psychiatry resident from another province shared her experience that one of her patients whom she was consulted to assess was *offered* MAID by his primary treating physician to hasten his death, despite well-controlled cancer, and without taking into consideration that her diagnoses of bereavement and adjustment disorder with depressed mood could be the underlying source of the patient’s distress.<sup>14</sup> It was even more concerning that the patient had shown ambivalence towards proceeding to MAID, but due to, what seemed to be systemic pressures, resolved to proceed with it nonetheless, and at a time that seemed to be more convenient for the physician providing MAID, than for the patient.

### **Unintended Effects**

The spirit of the law that legalized (E/PAS) allowed access to MAID for those whose “death was reasonably foreseeable,” as it was assumed they would be incapable of ending their own life due to a debilitating condition. Death via natural means is not an anticipated short-term outcome for most people suffering from a solely psychological illness and who are otherwise healthy. If the “reasonably foreseeable death” clause were to be removed in order to allow for those with solely mental illness to access MAID, it would eliminate a criterion that currently protects vulnerable people, resulting in mass reinforcement of the destructive tendencies brought forth by mental illness, upon an entire population of vulnerable people that the State has a duty to protect.

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<sup>8</sup> *“The World Medical Association reaffirms its strong belief that euthanasia is in conflict with basic ethical principles of medical practice, and The World Medical Association strongly encourages all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions.”* (WMA Resolution on Euthanasia, 2013).

There can be significant inconsistency between evaluators, both for the areas of capacity and diagnosis, in deciding whether a patient meets criteria for E/PAS.<sup>15</sup> Allowing MAID for some patients while denying it to others, through the non-uniform application of the MAID criteria, invalidates the suffering of those whose requests are denied, and may further increase their despair.<sup>16,17</sup> A prohibition of MAID, in principle, for solely psychological illnesses may help to shift the mindset of the majority of patients suffering from these illnesses back towards a model of recovery that includes living with the effects of the illness.<sup>h</sup>

Patients under stress have a tendency to choose their preferred means of coping. For example, opioid addicts, who may be abusing substances as a means to escape from stressors, tend to request prescriptions for narcotics from physicians whom they know have the ability to give them access, rather than follow the much more demanding path of addictions rehabilitation therapy. Similarly, patients experiencing psychological suffering with acute or chronic suicidal tendencies will preferentially choose suicide as an escape if that option becomes readily available. Will it be easier for physicians to simply acquiesce to their patients' requests for death, rather than persevere in the task to help these patients find ways to cope and relieve their suffering?<sup>i,18</sup>

### **Practical Considerations for Psychological Illness**

Expedient access to mental health services is sorely lacking in Canada.<sup>j,19,20,21</sup> Access to mental health resources in rural areas is even sparser, and due to the volume of patients that need to be seen, the quality of diagnostic assessments and management may be questionable. High volume of patients and time pressures on clinicians often lead to inaccurate diagnoses and improper or inadequate treatment.

And yet, if legislation for MAID were to be extended to include psychological illness, it would be imperative for the safeguarding of vulnerable patients for a psychiatrist to assess any such requests. It is concerning that in the experience of other permissive jurisdictions,

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<sup>h</sup> **Case Example:** A patient with schizophrenia and new onset suicidal ideation was advised that his condition did not meet legal criteria for MAID when he explored that option. He therefore turned his attention away from that possibility. Medication, suspected of inducing the suicidal ideation, was changed, and suicidal ideation remitted completely. He is now learning to adapt to his mental health condition.

<sup>i</sup> *"Will psychiatrists conclude from the legalization of assisted death that it is acceptable to give up on treating some patients? If so, how far will the influence of that belief spread?"* (Appelbaum, 2016).

<sup>j</sup> In Ottawa, for example, wait times to see a psychiatrist in the community for mood and anxiety disorders is on *average* at least 6 months to a year if not longer, including wait times for specialized services at the Royal Ottawa Mental Health Centre for more complex cases, and other specialized psychotherapy programs.

the frequency of psychiatric consultations is low.<sup>k,22,23</sup> It is doubtful that within the constraints of the current Canadian system, patients will be able to readily access a second psychiatric opinion, despite the importance of such consultations to ensure a thorough evaluation of all contributing factors to the patients' distress, as well as mitigating any external pressures to end the patient's life. Expanding the criteria for MAID to include psychological illness would place a further burden on a system that is already severely overloaded.

### **Assessing Requests for MAID**

In the assessment and granting of MAID requests, the issue of transference and countertransference (i.e. how a patient and therapist unconsciously react to each other) in the therapeutic relationship must be identified and addressed to avoid colluding in the hopelessness of patients.<sup>l,24</sup>

Physicians may also find themselves in a double bind as they face pressure from their patients to provide MAID, with the simultaneous threat of suicide if those MAID requests are not granted.<sup>25</sup>

Finally, there is the difficulty of assessing capacity and the "irremediable" criteria of patients with solely psychiatric illnesses. There is no current standard that objectively measures "irremediable" in the context of mental health, and this is made even more difficult to ascertain in recovery models<sup>m</sup> of mental health care.<sup>26,27</sup> Current Canadian legislation<sup>28</sup> does not require patients who request MAID to exhaust reasonable treatment

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<sup>k</sup> In the **Netherlands, even though the KNMG guidelines encourage consulting with psychiatrists about PAD requests if the patient is suffering from a mental illness, the frequency of such consultations was low.** About 1 out of 4 consultations with a psychiatrist was initiated by another psychiatrist. The main questions asked were whether the patient had a treatable mental disorder (68%) and whether the patient's request was well-considered (66%). In only 24% of cases was a psychiatrist consulted to assess the presence of counter-transference or psychodynamic issues that may be confounding the decision-making process. (Pols, 2013).

Despite recommendations for psychiatric consultation, in **Oregon**, according to 2016 stats, only 5 (3.8%) people received a psychiatric consultation (down from 5.3% in previous years). (Oregon Death with Dignity Act, 2016).

<sup>l</sup> Less conscientious or less skilled psychiatrists may collude in the hopelessness of their patients, confusing their own shortcomings with solidarity with the patient, and leave unchallenged the demoralized perspective of the patient (Berghmans, 2013).

<sup>m</sup> Recovery is defined as: *"A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony, 1993).

possibilities,<sup>n</sup> compared to legislation in the Netherlands which requires that both the patient *and* physician come to a conclusion that there is “no reasonable alternative.”<sup>29</sup> If patients may access MAID despite refusing available standards of care, what will be the test for being irremediable? Compared to physical illness which may have a more predictable course of illness, it is much more difficult to assess, in cases of purely psychological illness, the competence of a patient and the irremediable nature of their illness, as the desire to die is often part of the psychiatric disorder and the outcome of treatment is often difficult to predict.<sup>30</sup>

Due to the emotionally and ethically demanding nature of MAID requests, requests for death should be addressed by a multidisciplinary team, as the necessary deliberations to reach a conclusion would be far too great for any one individual physician.<sup>31</sup> Yet, in the Canadian context, the possibility that this can practically occur is slim.

### **Discrepancies in Skill and Rapid Advances in the Field**

The competence of psychiatrists is not equivalent, some being more familiar than others with managing treatment-resistant cases. The consequence is that a number of patients may be inaccurately deemed “treatment-resistant” by a less skilled physician.<sup>o,p,q,32,33,34</sup> What shall become, then, of the patient who is led to believe there are no further effective treatment options, and the availability of a competent second psychiatric opinion is lacking

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<sup>n</sup> Bill C-14, which was passed with Royal Assent on June 17, 2016, stipulates under “Grievous and irremediable medical condition: **(c)** *that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions **that they consider acceptable*** [emphasis added].

<sup>o</sup> **Case example** (by a psychiatrist member of our guild): “A suicidal patient came in to see me for her first psychiatric consultation, her “last resort” after years of therapy. She expressed a desire to receive MAID if it were available. However, upon further evaluation, despite twenty years of therapy, including lengthy hospitalizations, it was discovered that she had not been offered the basic medication management for her diagnosis. After letting her know there were actually quite a few options yet to be tried, she agreed to not end her life just yet, and allowed another chance for treatment.” Patients like these who, because of lack of proper care and expertise, are left without hope that things will get better, and may end up choosing E/PAS if it is readily available to the psychologically ill. This patient was given some hope for a better future, and because of that, was given more time to live against the ever-looming presence of death. The more readily accessible euthanasia becomes for those who want it, the more patients are drifting towards wanting it. Although E/PAS was a welcome option for this patient, inflicting death would have been a fatal failure of our health care system to provide proper diagnosis and management to a vulnerable individual.

<sup>p</sup> Only 38% of cases of Major Depressive Disorder receive adequate treatment in the United States (Wang et al, 2005).

<sup>q</sup> Dr. Valérie Tourjman, Medical Chief of the Anxiety and Mood Disorders Program at the Institut universitaire en santé mentale de Montréal, stated at the 2017 CPA conference that she routinely sees patients referred for Electroconvulsive Therapy (ECT) as a treatment of last resort, when in actual fact, they had not adequately tried other effective treatment modalities.

due to scarcity of resources? How can it be ethical to provide death as a treatment when psychiatric services and expertise are still so poorly available and accessible? It is a great disservice to the thousands of suffering patients who would rather die sooner because that would be an easier more readily available option, than wait a year or more for scarce psychiatric services.

The field of psychiatry is also rapidly progressing with new advances being made in novel and effective treatment modalities for suicidal ideation, for example, intravenous ketamine infusions for treatment-resistant depression and suicidal ideation.<sup>35</sup> Terminating a patient's life without having first exhausted all appropriate means of therapy would seem to be a gross violation of the ethical principle to first "do no harm."

Some of the concerns raised in this submission are illustrated by Mark Henick, a mental health patient and advocate with the Canadian Mental Health Association (CMHA), who made this poignant statement to physician attendees at the 2017 CPA conference, paraphrased here:

*If I had died at the time that I wanted to, at all the times that I wanted to, I would never have been given the time to figure out that I didn't want to...Patients turn to [their doctors] for help and for hope. If you [physicians] don't fight back to fight for our lives, we won't be alive today. Patients need to know that there are people they can turn to who will help them and fight for them.*<sup>36</sup>

Patients who are psychiatrically ill are, more than others, vulnerable to their underlying illness, and currently, only a solid law prohibiting E/AS continues to protect these patients.

### **ADVANCED CONSENT**

Allowing advanced directives may trigger people to be killed prematurely based solely on *anticipated* suffering which may never materialize. Allowing for advanced consent plays into people's natural fears, instead of working with them to overcome the challenges of a medical illness. Appropriate and accurate assessment of suffering can only be made at the moment of death, and thus advance directives lose legitimacy. Furthermore, competency to consent excludes those who have lost the capacity to consent, and thus advance directives lose validity.



Rescinding a request would also not be possible in the case of advanced consent where a person may become incompetent, for example, in advanced/severe dementia. This places the person in a position vulnerable to abuse.<sup>r</sup> What happens if a person with dementia changes their mind and expresses the desire to live? Is it sufficient grounds to kill a person according to their own advance directives in these situations?<sup>s,37</sup> A permissive law in this scenario would have the effect of enabling a fatal assault upon a person by carrying out an advanced directive. One might say that there would need to be a further objective assessment by a third party to confirm that a person is indeed suffering “unbearably” at the time that their life is scheduled to be terminated; however, this situation places the life of a cognitively impaired individual in the hands of a third party who may not always be disinterested. Furthermore, how does somebody judge, as being unbearable, the suffering of another, which is by nature subjective? These situations also place the burden of determining whether to live or die on a person other than the patient, and leave the patient vulnerable to the negative evaluations of others on their quality of life which has consistently been shown to be grossly underestimated.<sup>38,39,40,41</sup> Tendencies to make biased judgments about the experienced quality of life of another person place vulnerable people at risk.<sup>42</sup> The practical considerations surrounding the administration of MAID to those who have lost competency and are unable to rescind their requests are far too complicated and prone to violations and abuse.

Advance consent for MAID should not be allowed for patients prior to receiving a diagnosis of an illness, as it would not be possible for the patient to receive fully informed consent. Without a diagnosis, the patient will not have had the opportunity to meet with medical professionals and other specialists to be able to know what services and supports would be available to mitigate the impact of a particular illness.

Furthermore, in assessing requests for advanced consent, how do we define competency? For example, would the advance consent of an individual in a depressed state be considered valid, and who would be evaluating the emotional state of an individual making such a request? Evaluations of advanced consent would need to take into consideration the motives, underlying pressures (both internal and external), and psychological state of those initiating the request. Given the resource constraints of the mental health system in

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<sup>r</sup> Using the example of dementia, if the criteria for suffering is purely subjective such that it would be deemed, for example, unbearable suffering to lose the capacity of recognizing loved ones, the person with cognitive impairment may not actually be suffering when they lose capacity to consent to treatment, and their expressed wishes to live or die may fluctuate at that time.

<sup>s</sup> In a controversial case, a Dutch physician was cleared of wrongdoing after she euthanized an elderly woman with dementia for whom she determined the “time was right”, as per the patient’s prior wishes. The patient had been given a sleep-inducing drug in her coffee, but woke up and tried to resist the procedure. The physician consequently asked family members to hold down the patient while the lethal injection was administered. (Roberts, 2017).

Canada, as previously outlined, it is very unlikely that the appropriate oversight would be available.

## **MINORS**

### **Capacity to Consent**

Valid consent must be free and informed.<sup>43</sup> It must also be competent.<sup>t</sup> It is questionable that a child would have the capacity to give informed consent to MAID as recommended by the Federation of Medical Regulatory Authorities of Canada.<sup>u,44</sup> Society has long recognized that a child's capacity to think and make appropriate decisions differs from those of adults, hence the legal ages to vote or to drive. Likewise, children lack the intellectual capacity and experiential knowledge to develop a sufficiently informed decision in favour of death and against palliative interventions of last resort.<sup>45</sup>

In their ruling in *Carter vs Canada*, the Supreme Court of Canada quoted the trial judge's finding that:

... there is a strong consensus that [physician-assisted-death] would only be ethical with respect to *voluntary adults* [emphasis added] who are competent, informed, grievously and irremediably ill, and where the assistance is "clearly consistent with the patient's wishes and best interests, and [provided] in order to relieve suffering" (para. 358).<sup>46</sup>

Expanding MAID to include minors would be an example of the practical slippery slope in action where MAID is granted to people who were never eligible at the outset.

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<sup>t</sup> Competency is based upon a person's ability to *understand* information relevant to the decision and *appreciate* the nature and consequences of the specific decision.

<sup>u</sup> "The attending physician must disclose to the patient information regarding their health status, **diagnosis, prognosis, the certainty of death upon taking the lethal medication, and alternatives**, including comfort care, **palliative and hospice care, pain and symptom control** and other available resources **to avoid the loss of personal dignity**. The physician must advise the patient of any counseling resources that are available to assist the patient. The attending physician must inform the patient of his or her right to rescind the request at any time. The attending physician has an obligation to take reasonable steps to ensure that the patient has understood the information that has been provided." [Emphases added]. (Federation of Medical Regulatory Authorities of Canada, 2015).

## **Minors and Psychological Illness**

Loosening the criteria for MAID to include minors, combined with “psychological suffering” as the sole criteria of eligibility, and the removal of the “reasonably foreseeable death” clause in the current legislation, would place emotionally unstable youth at risk. Suicide is the second leading cause of death for Canadians between the ages of 10 and 24,<sup>47</sup> and teen suicides are on the rise amongst Canadian girls.<sup>48</sup> If E/PAS become an option for minors with solely psychological suffering, what legal means would there be to stop them from receiving an assisted suicide? Situations which appear to be irremediable today, are not necessarily indisputably so, and the earlier a person has access to MAID, the sooner their futures will be irrevocably ended.

## **A SLIPPERY SLOPE**

It is evident that in jurisdictions where E/PAS have been legalized, the expansion of the eligibility criteria has occurred with unstoppable momentum.<sup>v,49</sup> Euthanasia initially legalized for adults in the Netherlands, is now being administered to neonates who are severely ill according to the Groningen Protocol.<sup>50, 51</sup> In the Netherlands, ethicist Theor Boer<sup>52</sup> and psychiatrist Dr. Boudewijn Chabot,<sup>53</sup> and in Canada, Dr. Robert Yves<sup>54</sup> of the Collège des Médecins de Quebec, previously all ardent supporters of E/PAS in their respective jurisdictions, have publicly expressed their dismay at how lax the criteria for provision of E/PAS have become, and urged for a period of pause and reflection before proceeding further.<sup>55</sup> Furthermore, it is noteworthy that the High Court of Ireland in *Fleming vs Ireland*<sup>56</sup> reviewed the available evidence from other jurisdictions that

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<sup>v</sup> **Slippery slope in the Netherlands:** during a one year period after the End-of-Life Clinic was established in 2012 in the Netherlands, 645 people applied. 25.1% of those cases were approved. Of those, **6.8% of those who successfully obtained E/PAS were categorized as “tired of living”; 3.7% reported only psychological suffering; 49.1% of those whose requests were granted characterized part of their suffering as “loneliness”.** In Belgium, trends to lessen the stringency of initial criteria are seen as applicants are allowed to list “tiredness of life” in their requests in 2013, but not so in 2007 (Lerner and Caplan, 2015).

liberalized legislation and concluded that there *was* evidence of abuse (contrary to the findings of the Canadian Court.)<sup>w</sup>

In the event that MAID expands to include solely subjective psychological suffering, there would be nothing to stop MAID from being successfully granted to those requesting it because they are suffering secondary to loneliness, or being “tired of life.”<sup>57</sup> Notwithstanding that granting MAID for these reasons would be an utter failure of our society to care for those in need, and overlooks the numerous social determinants of health that may lead to a person’s distress, it also begs the question of why MAID should even be considered a “medical” intervention provided by physicians, when the criteria for access can be so subjectively based that it becomes nearly devoid of any medical meaning, and is based solely on the legal right of a person’s autonomy over their own body.

Canada is currently on the brink of a precipice, teetering between savings lives, and ending them, and unless it stands firm to prevent further expansion of the MAID criteria in legislation, we may face the same unsettling fate as other permissive jurisdictions.

## **CONCLUSIONS**

The desire of one individual to die must never infringe, even indirectly through social policies and laws, upon the right of another person to live, as the right to life is the most fundamental right and from which all other rights flow. There is a need to balance the rights of individuals with the well-being of society as a whole, being mindful of what values must be protected to preserve the healthy functioning of society at large. Individual rights fit within this larger social context, and our social responsibility towards caring for the socially disadvantaged and the sick need to be upheld.

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<sup>w</sup> “The medical literature documents specific examples of abuse which, even if exceptional, are nonetheless deeply disturbing. Moreover, contrary to the views of the Canadian court, there is evidence from this literature that certain groups (such as disabled neonates and disabled or demented elderly persons) are vulnerable to abuse. Above all, the fact that the number of LAWER (“legally assisted deaths without explicit request”) cases remains strikingly high in jurisdictions which have liberalised their law on assisted suicide (Switzerland, Netherlands and Belgium) – ranging from 0.4% to over 1% of all deaths in these jurisdictions according to the latest figures - without any obvious official response speaks for itself as to the risks involved.” (Fleming vs Ireland & Others, [2013] IEHC 2).

The Supreme Court of Canada acknowledged that the object of prohibition on E/PAS is “to protect vulnerable persons from being induced to commit suicide at a time of weakness.”<sup>58</sup> If the State has an objective and duty to protect its citizens, its efforts to do so would be severely undermined if criteria for MAID expand to include these three categories of people. The question is not whether MAID should be prohibited as a matter of default to any one category of people. Rather, it is a question of whether permitting MAID to individual persons who fall within these categories consequently endangers the lives of others.

Justice Smith in *Carter vs Canada* acknowledged the risks inherent to legalizing E/PAS, but deemed those risks acceptable within a framework that sought to minimize those risks.<sup>59</sup> She also differentiated between “vulnerable” and “non-vulnerable” persons where the former require State protection and the latter presumably do not.<sup>60</sup> However, the effort required to differentiate between a “vulnerable” person entitled to the right to life and equal protection under the law,<sup>61</sup> and a “non-vulnerable” person not requiring this protection, is significant and time-intensive if we wish to protect against error; in the Canadian context where time and healthcare resources are stretched, the chances of erring in this assessment, and falling short to protect the vulnerable person who legitimately requires State protection, cannot be dismissed as an “acceptable risk” due to the high stakes involved.

Thus, it is our position that the further extension of MAID to include the three categories currently being studied, increases the risk to society at large to an unacceptable level, and thus should be restricted on such grounds.

### **Recommendations**

1. Maintaining a prohibition of E/PAS, or MAID, for solely psychological suffering, advance consent, and minors will be the surest way of protecting the vulnerable.
2. Physicians, and especially psychiatrists, should not be gatekeepers to E/PAS, as it conflicts with their primary role in suicide prevention. In keeping with this, palliative care teams (such as at the Ottawa Hospital), have declined to provide MAID as part of their mandate of care, as it conflicted with their primary duty as palliative care physicians to provide symptom management and pain relief that does

not intentionally “hasten death.”<sup>x</sup> Likewise, if society insists that E/PAS be administered by physicians, psychiatrists as a specialized group should be exempt from having to endorse MAID for their patients, and instead be given the role of consultants in providing an opinion on the diagnosis, prognosis, and recommended management for their patients using the recovery model as their framework. The administrator of E/PAS would need to rely on professional opinion and evidence, preferably derived from multi-disciplinary expertise, in deciding whether or not a patient qualifies for MAID. This ensures that there is at least one step between the professionals who provide care, and those who administer death, minimizing the subtle nuances within a therapeutic relationship that may lead a person to choose one path over another.

3. Advanced directives for E/PAS should not be permitted given the great potential for abuse.
4. Given that E/PAS is allowed at all, to minimize the risk of harm to vulnerable persons, the restriction of MAID to competent *adults* must be upheld, in accordance with the Supreme Court’s original intention.
5. Public advocacy work needs to reinforce the view that teen suicides are tragedies to be prevented, not facilitated.
6. Increased education and guidance around the provision of aggressive palliative care for all patients, including children at end-of-life facing unbearable pain should be offered in lieu of MAID.
7. Non-voluntary euthanasia of patients, including neo-natal euthanasia<sup>62</sup> should be actively prohibited.
8. Since E/PAS, or MAID, is construed as a medical act, like any other medical innovation, “it demands careful evaluation and methodological rigour, including fixed eligibility criteria, detailed data collection, objective monitoring of outcomes and tracking of adverse effects; [and] the ability to analyze cumulative data.”<sup>63</sup> It is recommended that such rigorous evaluation of current procedures be carried out prior to any consideration of extending the eligibility criteria.

The practicalities of administering a permissive E/PAS regime raise more questions than it provides answers. Suffice it to say, there is great need for pause and reflection before we take our country further down a path from which there may be no return.

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<sup>x</sup> The assessment and administration of MAID at the Ottawa Hospital has been delegated to a special multidisciplinary team formed for such a purpose.

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- <sup>61</sup> *Canadian Charter of Rights and Freedoms*, s 7 and 15, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c. 11.
- <sup>62</sup> Vizcarrondo FE. Neonatal euthanasia: The Groningen Protocol. *Linacre Q*. 2014;81(4):388-392.
- <sup>63</sup> Chochinov HM. The puzzle of physician-hastened death. *Toronto Star*. April 10, 2016. <https://www.thestar.com/opinion/commentary/2016/04/10/the-puzzle-of-physician-hastened-death.html>. Accessed September 30, 2017.

Ontario Psychiatric Association

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Our organization represents psychiatrists in Ontario. We will provide feedback on situation where a mental illness may be the sole underlying medical condition that an individual requesting MAID suffers from. We will focus on issues specific to our scope of practice in psychiatry, including but not limited to capacity to consent, irremediability, prognosis and other related factors to the current MAID criteria.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

We plan to provide such knowledge in our submission.

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

I wanted to share the abstract for a study I conducted below that is in the process of being published. The main objective was to understand how people make decisions about future care particularly when a diagnosis of dementia is considered to affect them down the road. Most of the participants had significant knowledge about dementia and before gaining further knowledge or consolidation of their knowledge, did not want active treatments for the severe stage of dementia. Several participants on their own mentioned that they would hope even 'euthanasia' would be available at the point of progressing into the severe stage of a dementing illness. I thought it would be useful to share this small study's findings due to the importance that one's experience with an illness and educational background can influence decisions for future care.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

**Objective:** The primary objective of this study was to determine whether a brief education session about Alzheimer's Disease (AD) stages and associated behavioral and psychological symptoms of dementia (BPSD) changes healthy seniors' treatment choices. A secondary objective was to determine whether pharmacotherapy to reduce BPSD would be preferred over other potentially more restrictive interventions.

**Design:** Participants were assigned to one of ten group sessions during which they received information about AD and BPSD. Our a-priori hypotheses were: (1) education about AD stages significantly changes care preferences in moderate and severe stages, i.e., less active treatment options (no CPR/hospitalization) are chosen as the disease progresses; and (2) most participants prefer pharmacotherapy over restraints and seclusion to manage BPSD. The main outcome measure was a change in the interventions chosen including CPR and hospitalization.

**Setting:** Community senior centers and a psychiatric hospital.

**Participants:** 24 women and 8 men age 65 years and older with no self-reported dementia diagnosis.

**Measurement:** Participants completed 3 questionnaires and 2 decisional grids before and after the information session. Qualitative data were derived from discussions during the session.

**Results:** Participants expressed a wide range of attitudes about AD, BPSD, and their management. Participants knowing or caring for someone with AD and those with more education preferred significantly less interventions if they developed AD. Pharmacological measures were preferred over restraints.

**Conclusions:** Education about dementia and advance directives should consider the person's educational background and experience with dementia. Discussing BPSD may impact a

person's advance directives and preferences.

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Ontario Shores Centre for Mental Health Sciences (Ontario Shores) is a public teaching hospital specializing in comprehensive mental health and addiction services for those with complex, serious, and persistent mental illness. The facility is located in Whitby, Ontario and has 16 specialized inpatient units (6 of which are part of the provincial forensic program) and extensive outpatient and community services serving a total regional population of approximately 2.8 million. The organization is staffed by approximately 1300 employees with 326 inpatient beds and approximately 60,000 annual outpatient visits. We provide a range of specialized assessment and treatment services to those living with complex and serious mental illness. Ontario Shores' main issue concerning requests for MAiD is where mental illness is the sole underlying medical condition. The debate thus far has centered on a few key arguments: 1) the concern that people living with mental illness do not have the capacity to consent to MAiD; 2) that people with mental illness are vulnerable and in need of protection; 3) all physicians, particularly psychiatrists, have an ethical obligation to "do no harm" and to prevent suicide at all cost, and are not socialized to the act of intentionally hastening death; 4) there are no mental illnesses that can be determined to be irremediable; and 5) the majority of mental health professionals believe that the recovery philosophy of care in mental health is not compatible with the provision of MAiD services. To inform our MAiD policy, we reviewed the literature and noticed a significant gap in the final argument: our primary concern is that the entire mental health population is excluded without consideration for the service user's individual need or recovery journey.

The recovery model of care has been mandated as the model of mental health service delivery in Canada. Unlike the medical model of care, in which "recovery" is considered as the absence of symptoms, recovery in mental health care does not require people to experience reduced symptoms, but to regain control of one's life despite the illness. Ontario Shores strongly supports this approach and we have implemented recovery-oriented care throughout our organization. Personal recovery is generally the most recognized component of recovery-oriented practice but is often misunderstood as a framework for prescribing recovery in practice. Personally defined recovery is only one of four domains of recovery-oriented practice which also includes promoting citizenship, organizational commitment, and working relationship. Within the personal recovery domain of recovery-oriented practice, there are five recognized dimensions. Most opponents of MAiD in mental health care focus on the dimension of hope mostly ignoring connectedness, identity, meaning in life and empowerment. Unfortunately, the definition of hope used by MAiD opponents remains extremely narrow.

In our decision making process around MAiD policy, we completed a comprehensive ethical analysis to examine the compatibility of the ethical principles laid out by the Joint Centre for Bioethics to guide decision-making around MAiD (accountability, collaboration, dignity, equity, respect, transparency) with the principles of recovery-oriented care. The following is a brief summary of our analysis. Our full discussion paper has been submitted for publication and we would be pleased to provide further information at your request.

There are four recovery-oriented practice domains:

1. Promoting Citizenship – refers in part to the practitioner's role in supporting the individual as an equal citizen. Allowing the mental health population the same rights and responsibilities as

other citizens to request MAiD upholds the ethical principles guiding MAiD decision-making of dignity and equity.

2. Organizational Commitment - requires the commitment of the facility to enable the practice of recovery-oriented care across all services. This includes ensuring that service users are able to access information to be fully aware of all treatment options and explore best options. The availability of MAiD education and protocols for service users, family and providers to adequately support MAiD requests, upholds the ethical principles guiding MAiD decision-making of accountability and transparency.

3. Working Relationship - refers to the therapeutic alliance where the provider is open to hearing and genuinely listening to the service user's needs and wants. MAiD is meant to be a careful and thoughtful process during which a provider carefully assesses the service user to ensure that the request is well-reasoned and founded on a decision to wish to end suffering rather than a symptom of depression or mental illness. This aligns with the ethical principles guiding MAiD decision-making of collaboration and respect.

4. Personally Defined Recovery - consists of five dimensions: a) connectedness; b) hope and optimism about the future; c) identity; d) meaning in life; and e) empowerment.

a) Connectedness refers to relationship building and support from peers, family, friends and community. The collaborative MAiD process supports this connectedness and also promotes the ethical principles guiding MAiD decision-making of respect and transparency.

b) Hope and optimism about the future are not singular phenomena, but are in fact complex and individualistic constructs, which can take on a variety of unique definitions. The MAiD principles of dignity, respect and equity may be upheld depending on the service user's personal concept of hope.

c) Identity refers to the process of re-establishing a positive identity and overcoming stigma. The service users' ability to step outside the sick role and identify themselves as autonomous leaders and decision makers is a key element of their recovery. Denying access to MAiD for this population contributes to further stigmatization and paternalism. Promoting positive identity aligns with the ethical principles of dignity, respect and equity guiding MAiD decision-making.

d) Meaning in life encompasses spirituality and quality of life. For those who view the life cycle as including death, meaning may be found by applying personal values to life decisions, including decisions around death. This recovery dimension aligns with the MAiD ethical principle of dignity.

e) Empowerment is the final dimension of personal recovery, which is directly aligned with the ethical principles of respect for autonomy and self-determination and allows the service user to be accountable for their own recovery journey.

Our ethical analysis comparing these principles shows that there is significant overlap and illustrates that MAiD and recovery are not mutually exclusive. As such, MAiD could be included as one of a number of service options for people with mental illness, even within the context of recovery-oriented service delivery. Denying access to the entire mental health population does not align with recovery principles and can lead to further discrimination and stigmatization of this population. Since each person with mental illness is a unique individual and has the right to determine his or her own path as it relates to mental health and well-being, it is important that the individual's choice be heard, respected and explored. Individuals who are capable of making informed end of life decisions should not be denied access to services that are available to other Canadian citizens.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Mental Health Commission Canada, (2015). Guidelines for Recovery-Oriented Practice. Retrieved from Ottawa, ON.

Le Boutillier, C., Leamy, M., Bird, V. J., Davidson, L., Williams, J., & Slade, M. (2011). What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance. *Psychiatric services*, 62(12), 1470-1476.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, 199(6), 445-452.

## Review article

## Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis

Mary Leamy,\* Victoria Bird,\* Clair Le Boutillier, Julie Williams and Mike Slade

**Background**

No systematic review and narrative synthesis on personal recovery in mental illness has been undertaken.

**Aims**

To synthesise published descriptions and models of personal recovery into an empirically based conceptual framework.

**Method**

Systematic review and modified narrative synthesis.

**Results**

Out of 5208 papers that were identified and 366 that were reviewed, a total of 97 papers were included in this review. The emergent conceptual framework consists of: (a) 13 characteristics of the recovery journey; (b) five recovery processes comprising: connectedness; hope and optimism about the future; identity; meaning in life; and empowerment

(giving the acronym CHIME); and (c) recovery stage descriptions which mapped onto the transtheoretical model of change. Studies that focused on recovery for individuals of Black and minority ethnic (BME) origin showed a greater emphasis on spirituality and stigma and also identified two additional themes: culturally specific facilitating factors and collectivist notions of recovery.

**Conclusions**

The conceptual framework is a theoretically defensible and robust synthesis of people's experiences of recovery in mental illness. This provides an empirical basis for future recovery-oriented research and practice.

**Declaration of interest**

None.

Personal recovery has been defined as 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles . . . a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness'.<sup>1</sup> A recovery orientation is mental health policy in most Anglophone countries. For example, the mental health plan for England 2009–2019 has the 'expectation that services to treat and care for people with mental health problems will be . . . based on the best available evidence and focused on recovery, as defined in discussion with the service user'.<sup>2</sup> The implications of a recovery orientation for working practice are unclear, and guidelines for developing recovery-oriented services are only recently becoming available.<sup>3,4</sup> Comprehensive reviews of the recovery literature have concluded that there is a need for conceptual clarity on recovery.<sup>5,6</sup> Current approaches to understanding personal recovery are primarily based on qualitative research<sup>7</sup> or consensus methods.<sup>8</sup> No systematic review and synthesis of personal recovery in mental illness has been undertaken.

The aims of this study were (a) to undertake the first systematic review of the available literature on personal recovery and (b) to use a modified narrative synthesis to develop a new conceptual framework for recovery. A conceptual framework, defined as 'a network, or a plane, of interlinked concepts that together provide a comprehensive understanding of a phenomenon or phenomena',<sup>9</sup> provides an empirical basis for future recovery-oriented research and practice.

illness. A conceptualisation of recovery was defined as either a visual or narrative model of recovery, or themes of recovery, which emerged from a synthesis of secondary data or an analysis of primary data. Inclusion criteria for studies were:

- (a) contains a conceptualisation of personal recovery from which a succinct summary could be extracted;
- (b) presented an original model or framework of recovery;
- (c) was based on either secondary research synthesising the available literature or primary research involving quantitative or qualitative data based on at least three participants;
- (d) was available in printed or downloadable form;
- (e) was available in English.

Exclusion criteria were:

- (a) studies solely focusing on clinical recovery<sup>4</sup> (i.e. using a predefined and invariant 'getting back to normal' definition of recovery through symptom remission and restoration of functioning);
- (b) studies involving modelling of predictors of clinical recovery;
- (c) studies defining remission criteria or recovery from substance misuse, addiction or eating disorders;
- (d) dissertations and doctoral theses (because of availability).

**Search strategy and data sources**

Three search strategies were used to identify relevant studies: electronic database searching, hand-searching and web-based searching.

Electronic database searching

Twelve bibliographic databases were initially searched using three different interfaces: Applied and Complimentary Medicine

**Method****Eligibility criteria**

The review sought to identify papers that explicitly described or developed a conceptualisation of personal recovery from mental

\*Joint first authors.



Database (AMED); British Nursing Index; EMBASE; MEDLINE; PsycINFO; Social Science Policy (accessed via OVID SP); CINAHL; International Bibliography of Social Science (accessed via EBSCOhost); Applied Social Science Index and Abstracts (ASSIA); British Humanities Index; sociological abstracts; and Social Services abstracts (accessed via CSA Illumina). All databases were searched from inception to September 2009 using the following terms identified from the title, abstract, keywords or medical subject headings: ('mental health' OR 'mental illness' OR 'mental disorder' OR 'mental disease' OR 'mental problem') AND 'recover' AND ('theor' OR 'framework' OR 'model' OR 'dimension' OR 'paradigm' OR 'concept'). The search was adapted for the individual databases and interfaces as needed. For example, CSA Illumina only allows the combination of three 'units' each made up of three search terms at any one time, for example ('mental health' OR 'mental illness\*' OR 'mental disorder') AND 'recover\*' AND ('theor' OR 'framework' OR 'concept'). As a sensitivity check, ten papers were identified by the research team as highly influential, based on number of times cited and credibility of the authors (included papers 3, 9, 10, 19, 29, 34, 35, 40, 68 and 75 in online Table DS1). These papers were assessed for additional terms, subject headings and key words, with the aim of identifying relevant papers not retrieved using the original search strategy. This led to the use of the following additional search terms: ('psychol\$ health' OR 'psychol\$ illness' OR 'psychol\$ disorder' OR 'psychol\$ problem' OR 'psychiatr\$ health' OR 'psychiatr\$ illness' OR 'psychiatr\$ disorder' OR 'psychiatr\$ problem') AND 'recover\$' AND ('theme\$' OR 'stages' OR 'processes'). Duplicate articles were removed within the original database interfaces using Reference Manager Software Version 11 for Windows.

#### Hand-searching

The tables of contents of journals which published key articles (*Psychiatric Rehabilitation Journal*, *British Journal of Psychiatry* and *American Journal of Psychiatry*) and recent literature reviews of recovery (included papers 4, 37 and 89 in online Table DS1) were hand-searched.

#### Web-based searching

Web-based resources were identified by internet searches using Google and Google Scholar and through searching specific recovery-oriented websites (Scottish Recovery Network: [www.scottishrecovery.net](http://www.scottishrecovery.net); Boston University Repository of Recovery Resources: [www.bu.edu/cpr/repository/index.html](http://www.bu.edu/cpr/repository/index.html); Recovery Devon: [www.recoverydevon.co.uk](http://www.recoverydevon.co.uk); and Social Perspectives Network: [www.spn.org.uk](http://www.spn.org.uk)).

### Data extraction and quality assessment

One rater (V.B.) extracted data and assessed the eligibility criteria for all retrieved papers, with a random subsample of 88 papers independently rated by a second rater (J.W. or C.L.B.). Disagreements between raters were resolved by a third rater (M.L.). Acceptable concordance was predefined as agreement on at least 90% of ratings. A concordance of 91% was achieved. Data were extracted and tabulated for all papers rated as eligible for the review.

Included qualitative papers were initially quality assessed by three raters (V.B., J.W. and C.L.B.) using the RATS (relevance, appropriateness, transparency, soundness) qualitative research review guidelines.<sup>10</sup> The RATS scale comprises 25 questions about the relevance of the study question, appropriateness of qualitative method, transparency of procedures, and soundness of interpretive approach. In order to make judgements about quality of papers, we dichotomised each question to yes (1 point) or no

(0 points), giving a scale ranging from 0 (poor quality) to 25 (high quality). A random subsample of ten qualitative studies were independently rated using the RATS guidelines by a second rater (M.L.). The mean score from rating 1 was 14.8 and from rating 2 was 15.1, with a mean difference in ratings of 0.3 indicating acceptable concordance. The Effective Public Health Practice Project (EPHPP)<sup>11</sup> quality assessment tool for quantitative studies was used to rate the two quantitative studies. Independent ratings were made by two reviewers (V.B. and M.L.) of Ellis & King<sup>12</sup> and Resnick *et al.*,<sup>13</sup> who agreed on rating both papers as moderate.

### Data analysis

The conceptual framework was developed using a modified narrative synthesis approach.<sup>14</sup> The three stages of the narrative synthesis comprised: (1) developing a preliminary synthesis; (2) exploring relationships within and between studies; and (3) assessing the robustness of the synthesis. For clarity, the development of the conceptual framework (Stages 1 and 3) is presented in the Results before the subgroup comparison (Stage 2).

#### Stage 1: developing a preliminary synthesis

A preliminary synthesis was developed using tabulation, translating data through thematic analysis of good-quality primary data, and vote counting of emergent themes. For each included paper, the following data were extracted and tabulated: type of paper, methodological approach, participant information and inclusion criteria, study location, and summary of main study findings. An initial coding framework was developed and used to thematically analyse a subsample of qualitative research studies with the highest RATS quality rating (i.e. RATS score of 15 or above), using NVIVO QSR International qualitative analysis software (Version 8) for Windows. The main overarching themes and related subthemes occurring across the tabulated data were identified, using inductive, open coding techniques. Additional codes were created by all analysts where needed and these new codes were regularly merged with the NVIVO master copy, and then this copy was shared with other analysts, so all new codes were applied to the entire subsample.

Finally, once the themes had been created, vote counting was used to identify the frequency with which themes appeared in all of the 97 included papers. The vote count for each category comprised the number of papers mentioning either the category itself or a subordinate category. On completion of the thematic analysis and vote counting, the draft conceptual framework was discussed and refined by all authors. Some new categories were created, and others were subsumed within existing categories, given less prominence or deleted. This process produced the preliminary conceptual framework.

#### Stage 2: exploring relationships within and between studies

Papers were identified from the full review which reported data from people from Black and minority ethnic (BME) backgrounds. These papers were thematically analysed separately, and the emergent themes compared with the preliminary conceptual framework. The thematic analysis utilised a more fine-grained approach, in which a second analyst (V.B.) went through the papers in a detailed and line-by-line manner. The aim of the subgroup analysis was to specifically identify any additional themes as well as any difference in emphasis placed on areas of the preliminary framework. Thus, our purpose was to identify areas of different emphasis in this subgroup of studies, not to perform a validity check.

### Stage 3: assessing robustness of the synthesis

Two approaches were used to assess the robustness of the synthesis. First, qualitative studies which were rated as moderate quality on the RATS scale (i.e. RATS score of 14) were thematically analysed until category saturation was achieved. The resulting themes were then compared with the preliminary conceptual framework developed in Stages 1 and 2. Second, the preliminary conceptual framework was sent to an expert consultation panel. The panel comprised 54 advisory committee members of the REFOCUS Programme (see [www.researchintorecovery.com](http://www.researchintorecovery.com) for further details) who had academic, clinical or personal expertise about recovery. They were asked to comment on the positioning of concepts within different hierarchical levels of the conceptual framework, identify any important areas of recovery which they felt had been omitted and make any general observations. The preliminary conceptual framework was modified in response to these comments, to produce the final conceptual framework.

## Results

The flow diagram for the 97 included papers is shown in Fig. 1 and online Table DS1 lists those papers that were included.

The 97 papers comprised qualitative studies ( $n=37$ ), narrative literature reviews ( $n=20$ ), book chapters ( $n=7$ ), consultation documents reporting the use of consensus methods ( $n=5$ ), opinion pieces or editorials ( $n=5$ ), quantitative studies ( $n=2$ ), combining of a narrative literature review with personal opinion or where there is insufficient information on method for a judgement to be made ( $n=11$ ), and elaborations of other identified papers ( $n=10$ ). In summary, 87 distinct studies were identified. The ten elaborating papers included in the thematic analysis but not in the vote counting were papers 11, 15, 16, 19, 26, 48, 50, 53, 71 and 73 in online Table DS1.

The 97 papers described studies conducted in 13 countries, including the USA ( $n=50$ ), the UK ( $n=20$ ), Australia ( $n=8$ ) and Canada ( $n=6$ ). Participants were recruited from a range of settings, including community mental health teams and facilities, self-help groups, consumer-operated mental health services and supported housing facilities. The majority of studies used inclusion criteria that covered any diagnosis of severe mental illness. A few studies only included participants who had been diagnosed with a specific mental illness (e.g. schizophrenia, depression). The sample sizes in qualitative data papers ranged from 4 to 90 participants, with a mean sample size of 27. The

sample sizes in the two quantitative papers were 19<sup>12</sup> and 1076.<sup>13</sup> The former was a pilot study of 15 service users with experience of psychotic illness and 4 case managers using the Recovery Interventions Questionnaire, carried out in Australia. The latter study analysed data from two sources, the Schizophrenia Patient Outcomes Research Team (PORT) client survey, which examined usual care in a random sample of people with schizophrenia in two US states, and an extension to this survey which provided a comparison group.

There were various approaches to determining the stage of recovery of participants. Most studies rated stage of recovery using criteria such as: the person defined themselves as 'being in recovery'; not hospitalised during the previous 12 months; relatively well and symptom free; providing peer support to others; or working or living in semi-independent settings. Only a few studies specifically used professional opinion – clinical judgement or scores on clinical assessments – about whether people had recovered.

The mean RATS score for the 36 qualitative studies was 14.9 (range 8–20). One qualitative study was not rated using the RATS guidelines because there was insufficient information on methodology within this paper. A RATS score of 15 or above, indicating high quality, was obtained by 16 papers and used to develop a preliminary synthesis. A RATS score of 14, indicating moderate quality, was obtained by five papers. Independent ratings were made of the two quantitative papers, Ellis & King<sup>12</sup> and Resnick *et al.*,<sup>13</sup> which were rated as moderate by two reviewers (V.B. and M.L.). Given this quality assessment, no greater weight was put on the quantitative studies in developing the category structure.

### Conceptual framework for personal recovery

A preliminary conceptual framework was developed, which comprised five superordinate categories: values of recovery, beliefs about recovery, recovery-promoting attitudes of staff, constituent processes of recovery, and stages of recovery.

The robustness of the synthesis underpinning the preliminary conceptual framework was assessed in two steps: by re-analysing a subsample of qualitative studies and through expert consultation.

#### Subsample re-analysis

In addition to the higher-quality qualitative studies analysed in the preliminary synthesis stage, an additional five moderate-quality

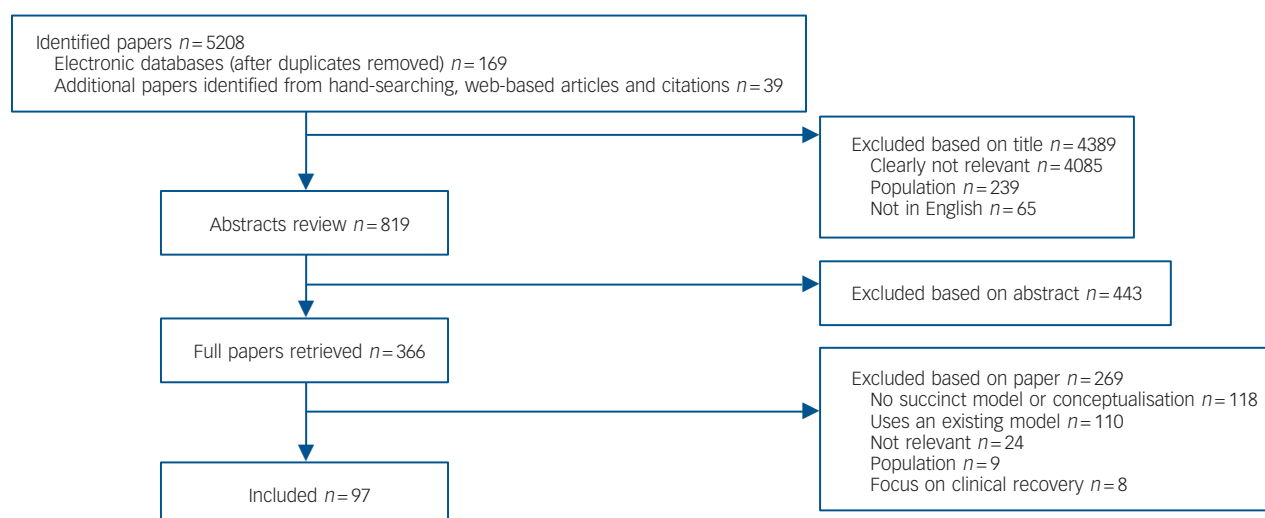


Fig. 1 Flow chart to show assessment of eligibility of identified studies.

(RATS score of 14) qualitative studies were analysed, which confirmed that category saturation had been achieved, indicating that the categories are robust.

Expert consultation

A response was received from 23 (43%) of the 54 consulted experts with international and national academic, clinical, and/or personal expertise and experiences of recovery, who are advisory committee members of the REFOCUS programme into recovery. Responses were themed under the following headings: conceptual (dangers of reductionism, separating processes from stages, confusing critical impetus for behaviours with actual behaviour, limitations of stage models); structural (complete omissions, lack of emphasis or overemphasis on specific areas of recovery); language (too technical); and bias (potential geographical bias). In response to this consultation, the preliminary conceptual framework was simplified, so the final conceptual framework now has three rather than five superordinate categories. Some subcategories were repositioned within recovery processes, and some category headings changed. Some responses identified areas of omission, such as the role of past trauma, hurt and physical health in recovery. However, no alteration was made to the conceptual framework as these did not emerge from the thematic analysis. Other points regarding the strengths and limitations of the framework are addressed in the Discussion. Overall, the expert consultation process provided a validity check on content of conceptual framework, although we were careful not to make radical changes which would have been unjustified, given the weight of evidence provided from preliminary analysis of the included papers.

The final conceptual framework comprises three interlinked, superordinate categories: characteristics of the recovery journey; recovery processes; and recovery stages.

Characteristics of the recovery journey were identified in all 87 studies, and vote-counting was used to indicate their frequency (Table 1).

The categories of recovery processes and their vote counts, indicating frequency of the process being identified, for the two highest category levels are shown in Table 2.

The full description of recovery processes categories and the vote counting results are shown in online Table DS2.

Table 1 Characteristics of the recovery journey	
Characteristics	Number (%) of 87 studies identifying the characteristics
Recovery is an active process	44 (50)
Individual and unique process	25 (29)
Non-linear process	21 (24)
Recovery as a journey	17 (20)
Recovery as stages or phases	15 (17)
Recovery as a struggle	14 (16)
Multidimensional process	13 (15)
Recovery is a gradual process	13 (15)
Recovery as a life-changing experience	11 (13)
Recovery without cure	9 (10)
Recovery is aided by supportive and healing environment	6 (7)
Recovery can occur without professional intervention	6 (7)
Trial and error process	6 (7)

Fifteen studies developed recovery stage models. The studies were organised using the transtheoretical model of change,<sup>15</sup> as shown in Table 3.

Recovery in individuals of BME origin

As part of Stage 2 of the narrative synthesis process, six studies of recovery from the perspective of individuals of BME origin were identified within the 87 studies. These six studies were re-analysed by a second analyst (V.B.), using a more fine-grained, line-by-line approach to thematic analysis. These comprised a survey of 50 recipients of a community development project in Scotland,<sup>16</sup> a qualitative interview study of African Americans,<sup>17</sup> a narrative literature review,<sup>18</sup> a qualitative study of 40 Maori and non-Maori New Zealanders,<sup>19</sup> a pilot study to test whether the Recovery Star measure was applicable to Black and Asian ethnic minority populations<sup>20</sup> and a mixed method study of 91 males from African–Caribbean backgrounds.<sup>21</sup> These papers provide some preliminary insights into a small number of distinct ethnic minority perspectives, which do not represent a culturally homogeneous group, although some similarities in experience can be observed. Although these six papers were included in the vote-counting process, four of the six BME papers<sup>16–18,20</sup> were not used in the first-stage thematic analysis. The line-by-line secondary analysis allowed us to explore in greater detail any differences in emphasis and additional themes present in these papers.

The main finding of the subgroup analysis indicated that there was substantial similarity between studies focusing on ethnic minority communities and those focusing on ethnic majority populations. All of the themes of the conceptual framework were present in all six of the BME papers. Despite this overall similarity, there was a greater emphasis in the BME papers on two areas in the recovery processes: spirituality and stigma; and two additional

Table 2 Recovery processes	
Recovery processes	Number (%) of 87 studies identifying the process
Category 1: Connectedness	75 (86)
Peer support and support groups	39 (45)
Relationships	33 (38)
Support from others	53 (61)
Being part of the community	35 (40)
Category 2: Hope and optimism about the future	69 (79)
Belief in possibility of recovery	30 (34)
Motivation to change	15 (17)
Hope-inspiring relationships	12 (14)
Positive thinking and valuing success	10 (11)
Having dreams and aspirations	7 (8)
Category 3: Identity	65 (75)
Dimensions of identity	8 (9)
Rebuilding/redefining positive sense of identity	57 (66)
Overcoming stigma	40 (46)
Category 4: Meaning in life	59 (66)
Meaning of mental illness experiences	30 (34)
Spirituality	6 (41)
Quality of life	57 (65)
Meaningful life and social roles	40 (46)
Meaningful life and social goals	15 (17)
Rebuilding life	19 (22)
Category 5: Empowerment	79 (91)
Personal responsibility	79 (91)
Control over life	78 (90)
Focusing upon strengths	14 (16)

**Table 3** Recovery stages mapped onto the transtheoretical model of change

Table DS1 study number	Precontemplation	Contemplation	Preparation	Action	Maintenance and growth
32		Novitiate recovery – struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
73	Stuck	Accepting help	Believing	Learning	Self-reliant
3	Descent into hell	Igniting a spark of hope	Developing insight/activating instinct to fight back	Discovering keys to well-being	Maintaining equilibrium between internal and external forces
44	Demoralisation		Developing and establishing independence		Efforts towards community integration
36	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
14	Dependent/unaware	Dependent/aware		Independent/aware	Interdependent/aware
29	Moratorium	Awareness	Preparation	Rebuilding	Growth
78		Glimpses of recovery	Turning points	Road to recovery	
61		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
40	Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability
35	Initiating recovery			Regaining what was lost/moving forward	Improving quality of life
59	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
43		Turning point	Determination		Self-esteem

categories: culture-specific factors and collectivist notions of recovery.

In relation to spirituality, being part of a faith community and having a religious affiliation was seen as an important component of an individual's recovery. People from ethnic minority groups more often described spirituality in terms of religion and a belief in God as a higher power, whereas participants in the non-BME studies tended to conceptualise spirituality as encompassing a wider range of beliefs and activities.

In relation to stigma, BME studies emphasised the stigma associated with race, culture and ethnicity, in addition to the stigma associated with having a mental illness. Furthermore, being an individual from a minority ethnic group seemed to accentuate the stigma of mental illness, as the person often viewed themselves as belonging to multiple stigmatised and disadvantaged groups. Individuals from ethnic minority groups saw themselves as recovering from racial discrimination, stigma and violence, and not just from a period of mental illness.

The new category of culture-specific factors included the use of traditional therapies and faith healers, and belonging to a particular cultural group or community. Finally, collectivist notions of recovery were emphasised as both positive and negative factors. Many individuals discussed the hope and support they received from their collectivist identity, but for others the community added to the pressures of mental illness. This was particularly true where communities lacked information and awareness regarding mental illness. Furthermore, the negative impact of the community was felt not only at the level of the individual, but also at the collectivist level, with the whole family being adversely affected by stigma.

## Discussion

This is the first systematic review and narrative synthesis of personal recovery. A conceptual framework was developed using a narrative synthesis which identified three superordinate

categories: characteristics of the recovery journey, recovery processes and recovery stages. For each superordinate category, key dimensions were synthesised. The recovery processes that have the most proximal relevance to clinical research and practice are: connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (giving the acronym CHIME). The robustness of the category structure was enhanced by the systematic nature of the review, the quality assessment of included studies, the category saturation reached in the analysis, and the content validity of the expert consultation. Heterogeneity between studies was explored descriptively. A subgroup comparison between the experiences of recovery from the perspective of individuals of BME origin identified similar themes, with a greater emphasis on spirituality and stigma, and two additional themes: culture-specific factors, and collectivist notions of recovery.

## Implications for research and practice

Key knowledge gaps have been identified as the need for clarity about the underpinning philosophy of recovery,<sup>22</sup> better understanding of the stages and processes of recovery,<sup>5</sup> and valid measurement tools.<sup>23</sup> This study can inform each of these gaps.

Recovery has been conceptualised as a vision, a philosophy, a process, an attitude, a life orientation, an outcome and a set of outcomes.<sup>5</sup> This has led to the concern that 'its scope can make a cow-catcher on the front of a road train look discriminating'.<sup>24</sup> An empirically based conceptual framework can bring some order to this potential chaos. Characteristics of the recovery journey provide conceptual clarity about the philosophy. Recovery processes can be understood as measurable dimensions of change, which typically occur during recovery and provide a taxonomy of recovery outcomes.<sup>25</sup> Finally, recovery stages provide a framework for guiding stage-specific clinical interventions and evaluation strategies.

The framework contributes to the understanding about stages and processes of recovery in two ways. First, it allows available



evidence to be more easily identified. A recovery orientation has overlap with the literature on well-being,<sup>26</sup> positive psychology<sup>27</sup> and self-management,<sup>28</sup> and systematic reviewing is hampered by the absence of relevant MeSH (Medical Sub-Headings) headings relating to recovery concepts. The coding framework provides keywords for use when undertaking secondary research, and the identification of related terms provides a taxonomy which will be useable in reviews.

Second, the framework provides a structure around which research and clinical efforts can be oriented. The relative contribution of each recovery process, investigating interventions which can support these processes, and the synchrony between recovery processes and stages are all testable research questions. For clinical practice, the CHIME recovery processes support reflective practice. If the goal of mental health professionals is to support recovery then one possible way forward is for each working practice to be evaluated in relation to its impact on these processes. This has the potential to contribute to current debates about recovery and, for example, assertive outreach,<sup>29</sup> risk<sup>30</sup> and community psychiatry.<sup>31</sup>

Finally, the conceptual framework can contribute to the development of measures of personal recovery. Compendia of existing measures have been developed,<sup>32,33</sup> showing that the conceptual basis of measures is diverse. The conceptual framework provides a foundation for developing standardised recovery measures, and is the basis for a new measure currently being developed by the authors to evaluate the contribution of mental health services to an individual's recovery. The challenge will then be to incorporate a focus on recovery outcomes and associated concepts such as well-being<sup>27</sup> into routine clinical practice.<sup>34</sup>

## Limitations

The study has three methodological and two conceptual limitations. The first methodological limitation is that the narrative synthesis approach was modified, and could have been widened. For example, the exploration in Stage 2 of relationships between studies could have considered the subgroup of studies which had higher levels of consumer involvement in their design, but it proved impossible to reliably rate identified studies in this dimension. The second technical limitation is that the emergent categories were only one way of grouping the findings, and the categories changed as a result of expert consultation. In particular, the three superordinate categories are not separate, since processes clearly occur within the identified stages, and the characteristics of recovery describe an overall movement through stages of recovery. Our categorical separation brings structure, but a replication study may not arrive at the same overall thematic structure. The final technical limitation is that analysis synthesised the interpretation of the primary data in each paper rather than considering the primary data directly. Future research could compare papers generated by different stakeholder groups, such as consumer researchers, clinical researchers and policy makers.

The first conceptual limitation is that this review, although synthesising the current literature on personal recovery, should not be seen as definitive. A key scientific challenge is that the philosophy of recovery gives primacy to individual experience and meaning ('idiographic' knowledge), whereas mental health systems and current dominant scientific paradigms give prominence to group-level aggregated data ('nomothetic' knowledge).<sup>4</sup> The practical impact is that current recovery research is primarily focused at the bottom of the hierarchy of evidence.<sup>35</sup> This was our finding, with qualitative, case study and expert opinion methodologies dominating. A motivator for the current study was to provide evidence of the form viewed as

high quality within the current scientific paradigm, but several of our expert consultants highlighted the dangers of closing down discourse. Since recovery is individual, idiosyncratic and complex, this review is not intended to be a rigid model of what recovery 'is'. Rather, it is better understood as a resource to inform future research and clinical practice. The second conceptual limitation relates to the subgroup analysis looking at papers focusing on non-majority populations. Owing to a lack of research, it was not possible to look at the experience and perspectives of individuals from different ethnic minority groups. Therefore, the BME subgroup represents a heterogeneous and incredibly diverse set of populations. However, it was felt that all the populations included in these papers shared a common experience of belonging to an ethnic minority group, and that this experience may have important implications for the meaning of personal recovery, and for the experience of mental health services in general. The lack of data, coupled with the areas of difference found in the present review, highlights a need for further work to be conducted with people from ethnic minority communities.

## Future research

This systematic review and narrative synthesis has highlighted the dominance of recovery literature emanating from the USA. Culturally, the USA neglects character strengths such as patience and tolerance,<sup>36</sup> and favours individualistic over collectivist understandings of identity. Although there were very few studies which looked at recovery experiences of individuals from BME backgrounds, the subsample of BME studies indicated that there are important differences in emphasis. There is a need for research involving more diverse samples of people from different ethnic and cultural backgrounds, at differing stages of recovery and experiencing different types of mental illness.

The complexity of personal recovery requires a range of theoretical inquiry positions. This review focused on research into first-person accounts of recovery, where individual meanings of recovery have dominated. This has led to a framework which may underemphasise the importance of the wider socio-environmental context, including important aspects such as stigma and discrimination. Viewing recovery within an ecological framework, as suggested by Onken and colleagues,<sup>35</sup> encompasses an individual's life context (characteristics of the individual such as hope and identity) as well as environmental factors (such as opportunities for employment and community integration) and the interaction between the two (such as choice). A more complete understanding of recovery requires greater attention to all these levels of understanding, for instance, how power is related to characteristics of individuals or groups (e.g. race and culture), how clinicians and patients interact at different stages of recovery and how these interactions change over time. There is also a need for future research to increase our understanding of how subtle micro-processes of recovery are operating, such as how hope is reawakened and sustained.

Supporting recovery processes may be the future mental health research priority. The 13 dimensions identified as characteristics of the recovery journey capture much of the experience and complexities of recovery, and further research may not have a high scientific pay-off. Similarly, although the recovery stages could be mapped onto the transtheoretical model of change,<sup>15</sup> there was little consensus about the number of recovery phases. It may therefore be more helpful to undertake evaluative research addressing specific service-level questions (such as whether people using a service are making recovery gains over time<sup>37</sup> or in different service settings<sup>38</sup>), rather than further studies seeking conceptual clarity. Overall, the emergent priority

is the development and evaluation of interventions to support the five CHIME recovery processes. The subordinate categories point to the need for a greater emphasis on assessment of strengths and support for self-narrative development, promoting the role of mental health systems in developing inclusive communities enabling access to peer support as well as providing retreats, and clinical interaction styles which promote empowerment and self-management. The CHIME categories are potential clinical end-points for interventions, in contrast to the current dominance of clinical recovery end-points such as symptomatology or hospitalisation rates. They also provide a framework for empirical investigation of the relationship between recovery outcomes, using methodologies developed in relation to clinical outcomes.<sup>39</sup> This area of enquiry is currently small<sup>40</sup> but an important priority if potential trade-offs between desirable outcomes are to be identified.<sup>41</sup>

Orienting mental health services towards recovery will involve system transformation.<sup>42</sup> The research challenge is to develop an evidence base which simultaneously helps mental health professionals to support recovery and respects the understanding that recovery is a unique and individual experience rather than something the mental health system does to a person. This conceptual framework for personal recovery, which has been developed through a systematic review and narrative synthesis, provides a useful starting point for meeting this challenge.

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- 40 Andresen R, Caputi P, Oades L. Do clinical outcome measures assess consumer-defined recovery? *Psychiatry Res* 2010; **177**: 309–17.
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- 42 Shepherd G, Boardman J, Burns M. *Implementing Recovery. A Methodology for Organisation Change*. Sainsbury Centre for Mental Health, 2010.



## poems by doctors

### Street-wise

Wendy French

Somewhere in a North London street near Northwick Park  
a retired doctor pins his butterflies, worries about sex.

Elsewhere in the street a siren stops outside  
a two-up, two-down where paramedics collect  
a woman with a fluttering heart.

Somewhere in an East London street near the London  
a young doctor revising for her MRCP dreams of take-aways,

Chicken Biriyanis, Tarka Dal.  
Elsewhere a man dials 999, he doesn't want to die.  
Whisky half drunk and paracetamol gone.

Somewhere in a South London street near King's  
a woman gazes into the gas fire, thinks about her husband

and the locum who came at 3am, drank tea.  
His own father recently dead and his mother who keeps  
all doors unlocked for her husband's return.

Elsewhere near UCH a woman's contractions  
Increase as she phones her partner, he's not at his desk

so the neighbour drives her as fast as he can and leaves her  
to the student on duty who comforts her between groans.  
The partner enjoys a light lunch. Pint of pride.

Somewhere in a London street a man comes near to dying.  
His car skids sideways on ice. Approaching cars close in.

He thinks after one death there is no other.  
A stranger helps him shuffle along  
until stillness returns.

In the same street the old doctor remembers climbing  
the snow-ridden hills, a bride by his side and he still feels

her bracelets, purse, red felt hat.  
And there's his grandson with Down's who loves to touch velvet,  
collect stamps and who lives in a home on a West London street

where the Hammersmith closes. Wards full of flu-ridden adults.  
Next door to the doctor little Louise in the wheelchair

drinks orange through a straw, cries throughout the night.  
The physician turns back to his moth, the Bloodvein,  
a splayed sacrifice and sighs.

This poem is from *The Hippocrates Prize 2011*, published by The Hippocrates Prize in association with Top Edge Press.

Chosen by Femi Oyeboode.

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199, 452. doi: 10.1192/bjp.bp.111.103085

**Table DS1 Included studies (n=97)**

	Full reference	Country	Method	Quality rating
1	Provencher H, Gregg R, Mead S, Mueser K. The role of work in the recovery of persons with psychiatric disabilities, <i>Psychiatr Rehab. J</i> , 2002, <b>26</b> (2), 132-144.	USA	Semi-structured individual interviews (n=14 participants with psychiatric disabilities)	13/25
2	Kelly M, Gamble C. Exploring the concept of recovery in schizophrenia, <i>J Psychiatr Ment Health Nurs</i> . 2005 Aug; <b>12</b> (4):386.	Unclear	Literature review	Not rated
3	Noiseux S, Ricard N. Recovery as perceived by people with schizophrenia, family members and health professionals: A grounded theory. <i>Int. J of Nurs. Studies</i> , 2008, <b>45</b> (8), 1148-1162	Canada	Semi-structured interviews and field notes (n=41 people with schizophrenia, family members and health professionals)	18/25
4	Social Care Institute for Excellence, A common purpose: Recovery in future mental health services, 2007.	UK	Literature review	Not rated
5	Schon UK, Denhov A, Topor A. Social relationships as a decisive factor in recovering from severe mental illness, <i>Int. J of Soc Psychiatry</i> , 2009, <b>55</b> (4) 336-347.	Sweden	Interviews (n=58 people who had recovered from serious mental illness)	13/25
6	Smith M. Recovery from severe psychiatric disability: Findings of a qualitative study, <i>Psychiatr Rehab. J</i> , 2000, <b>24</b> (2), 149-158	USA	Semi-structured interviews (n=10 participants with serious mental illness)	13/25
7	Tooth B, Kalyanasundaram V, Glover H, Momenzadah S. Factors consumers identify as important to recovery from schizophrenia, <i>Australasian Psychiatry</i> , 2003, <b>11</b> (1), 70-77.	Australia	Focus groups (n=57 people in recovery from schizophrenia)	12/25
8	Libermann R, Kopelowicz A, Ventura J, Gutkind D. Operational criteria and factors related to recovery from schizophrenia, <i>Int. Review of Psychiatry</i> , 2002a. <b>14</b> (4), 256-272.	USA	Literature review, focus groups, case vignettes of people recovering from schizophrenia	Not rated
9	Ramon S, Healy B, Renouf N. Recovery from Mental Illness as an Emergent Concept and Practice in Australia and the UK, <i>Int.. J. Soc Psychiatry</i> , <b>53</b> , 108-122.	UK and Australia	Literature review	Not rated
10	Mancini MA. A qualitative analysis of turning points in the recovery process, <i>American J of Psychiatr Rehab.</i> , 2007, <b>10</b> (3), 223-244.	USA	Semi-structured interviews (n=16 participants recovering from serious psychiatric disability)	13/25
11	Mezzina R, Davidson L, Borg M, Marin I, Topor A, Sells D. The social nature of recovery: Discussion and implications for practice, <i>American J of Psychiatr Rehab.</i> 2006, 9(1), 63-80.	Italy and USA	Literature review and conceptual paper	Not rated
12	Fallot R. Spiritual and religious dimensions of mental illness recovery narratives, <i>New directions for mental health services</i> , <b>80</b> , Winter, 1998.	Unclear	Personal narratives and literature review	Not rated
13	Morse G. On being homeless and mentally ill: A multitude of losses and the possibility of recovery, chapter 16, in Harvey J & Miller E (Eds). <i>Loss and trauma: General and close relationship perspectives</i> . New York, US: Brunner-Routledge, 2000	Unclear	Personal narratives and literature review	Not rated
14	<i>Emerging best practices in mental health recovery</i> , National Institute for Mental Health in England., Great Britain. National Health Service, 2004.	UK	Based on Ohio Department of Mental Health work on the meaning and process of recovery.	Not rated
15	Piat M, Sabetti J, Couture A, Sylvestre J, Provencher H, Botschner J, Stayner D. What does recovery mean for me? Perspectives of Canadian mental health consumers, <i>Psychiatr Rehab. J</i> , 2009, <b>32</b> (3), 199-207.	Canada	Qualitative interviews (n= 60 consumers of mental health services)	18/25



16	Davidson L, O'Connell M, Staeheli M, Weingarten R, Tondora J, Evans A. Concepts of recovery in Behavioral health: History, review of the evidence, and critique, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M, <i>A practical guide to recovery-oriented practice</i> . Oxford. Oxford University Press, 2009.	USA	Literature review	Not rated
17	Diamond R. Recovery from a psychiatrist's viewpoint, <i>Postgraduate Medicine</i> , 2006, <b>Sept.</b> Special, 54-62	Unclear	Literature review	Not rated
18	Gagne C, White W, Anthony W. Recovery: A common Vision for the fields of mental health and addiction, <i>Psychiatr Rehab. J</i> , 2007, <b>31</b> (1), 32-37.	USA	Literature review	Not rated
19	Davidson L, O'Connell M, Tondora J, Lawless M, Evans A. Recovery in Serious Mental Illness: A New Wine or Just a New Bottle? <i>Professional Psychology: Research and Practice</i> , <b>36</b> (5), 480-487	USA	Literature review and concept map	Not rated
20	Davidson L, O'Connell M, Staeheli M, Weingarten R, Tondora J, Evans A A model of being in recovery as a foundation for recovery-oriented practice, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M <i>A practical guide to recovery-oriented practice</i> . Oxford. Oxford University Press, 2009.	USA	Interviews (n=100 consumers and people who have lived with mental illness)	Not rated
21	Slade M. 'Recovery-focussed mental health services: The personal recovery framework', in <i>Personal recovery and mental illness: A guide for mental health professionals</i> , Cambridge University Press, 2009.	UK	Literature review	Not rated
22	Repper J, Perkins R. 'The individual's recovery journey: towards a model for mental health practice, in Repper, J. & Perkins, R. <i>Social inclusion and recovery: a model for mental health practice</i> , Bailliere Tindall, 2003.	UK	Literature review	Not rated
23	Markowitz FE. Sociological Models of Recovery, chapter 4, in Ralph, R. & Corrigan, P. <i>Recovery in mental illness: Broadening our understanding of wellness</i> . Washington, DC, US: American Psychological Association, 2005.	USA	Literature review	Quality not assessed
24	Ralph R. Verbal Definitions and Visual Models of Recovery: Focus on the Recovery Model, in Ralph R, Corrigan P. <i>Recovery in Mental illness: Broadening our understanding and wellness</i> , Washington, DC, US: American Psychological Association, 2005.	USA	Literature review	Not rated
25	Libermann RP, Kopelowicz A. Recovery from schizophrenia: A challenge for the 21st century, <i>Int. Review of Psychiatry</i> , 2002, 14(4) 245-255.	USA	Literature review	Not rated
26	Libermann R, Kopelowicz A. Open forum. Recovery from schizophrenia: a concept in search of research, <i>Psychiatr Services</i> , 2005, <b>56</b> (6), 735-742	USA	Literature review	Not rated
27	Whitehorn D, Brown J, Richard J, Rui Q, Kopala L Multiple dimensions of recovery in early psychosis, <i>Int. Review of Psychiatry</i> , 2002, 14(4), 273-283.	Canada	Literature review	Not rated
28	Ellis G, King R. Recovery focused interventions: Perceptions of mental health consumers and their case managers. <i>Australian e-J for the Advancement of Ment. Health</i> , 2003, <b>2</b> (2).	Australia	Literature review and piloting of a consumer and case manager questionnaire	Not rated
29	Andresen R, Oades L, Caputi P. The experience of recovery from schizophrenia: towards an empirically validated stage model, <i>Australian &amp; New Zealand J of Psychiatry</i> , 2003, <b>37</b> (5), 586-594.	Australia	Literature review and qualitative analysis	Not rated
30	Torrey W, Wyzik, P. The recovery vision as a service improvement guide for community mental health center providers. <i>Community Ment. Health J</i> , 2000, <b>36</b> (2):209-216.	USA	Opinion piece	Not rated
31	Cleary A, Dowling M. The road to recovery, <i>Ment. Health Practice</i> , 2009, <b>12</b> (5), 28-	Ireland	Literature review	Not rated

31.				
32	Song L-Y, Shih C-Y. Factors, process and outcome of recovery from psychiatric disability the utility model, <i>Int. J of Social Psychiatry</i> , 2009, <b>55</b> (4), 348-360.	Taiwan	Qualitative interviews (n=15 consumers in recovery and their caregivers)	15/25
33	Resnick S, Fontana A, Lehman A, Rosenheck R. An empirical conceptualization of the recovery orientation, <i>Schizophrenia Research</i> , 2005, <b>75</b> , 119-128.	USA	Survey on the treatment of schizophrenia (n=1,076)	Not rated
34	Jacobson N. Experiencing recovery: A dimensional analysis of recovery narratives, <i>Psychiatr Rehab. J</i> 2001 Winter; <b>24</b> (3):248-56.	USA	Dimensional analysis of 30 narratives of recovery.	Not rated
35	Young S, Ensing D. Exploring recovery from the perspective of people with psychiatric disabilities, <i>Psychiatr Rehab. J</i> , 1999, <b>22</b> (3), 219-231.	USA	Semi-structured interviews (n= 18 people with psychiatric disabilities) and focus groups (n=2, 11 participants in total)	15/25
36	Merryman M, Riegel S. The recovery process and people with serious mental illness living in the community: An occupational therapy perspective, <i>Occupational Therapy in Ment. Health</i> . 2007, <b>23</b> (2), 51-73.	USA	Interviews (n=20 service users)	16/25
37	Ralph R. Recovery, <i>Psychiatr Rehab. Skills</i> , 2000, <b>4</b> (3), 480-517.	USA	Literature review	Not rated
38	Jensen L, Wadkins T. Mental health success stories: finding paths to recovery, <i>Issues in Ment. Health Nurs.</i> , 2007, <b>28</b> (4), 325-340.	USA	Semi-structured interviews (n=20 service users)	13/25
39	Schrank B, Slade M. Recovery in psychiatry, <i>Psychiatr Bulletin</i> , 2007, <b>31</b> (9), 321-325.	Austria, UK	Literature review	Not rated
40	Spaniol S, Wewiorski N, Gagne C, Anthony W. The process of recovery from schizophrenia, <i>Int. review of psychiatry</i> , 2002, <b>14</b> , 327-336.	USA	Interviews (n=12 consumers, conducted every four to eight months, over a 4 year period)	16/25
41	Mental Health Recovery Study Working group, <i>Mental Health 'Recovery': users and refusers. What do psychiatric survivors in Toronto think about Mental Health Recovery?</i> Wellesley Institute, 2009.	Canada	Community-based participatory research approach., focus groups (n=7)	Not rated
42	Hopper K. Rethinking social recovery in schizophrenia: what a capabilities approach might offer, <i>Social Science and Medicine</i> , 2007, <b>65</b> (5), 868-879.	USA	Literature review	Not rated
43	Peden A. Recovering in depressed women: research with Peplau's theory. <i>Nurs Sci Q</i> , 1993, <b>6</b> (3), 140-146	USA	Semi-structured interviews (n= 7 participants recovering from depression)	14/25
44	Bradshaw W, Armour M, Roseborough D. Finding a place in the World: The experience of Recovery from Severe Mental Illness, <i>Qual. Social Work</i> , 2007, <b>6</b> (1), 27-47. Sage Publications, UK.	USA	Semi-structured interviews (n= 45 with severe mental illness, conducted over 3 years)	18/25
45	Sung K, Kim S, Puskar K, Kim E. Comparing Life Experiences of College Students with Differing Courses of Schizophrenia in Korea: Case Studies Perspectives in <i>Psychiatric Care</i> , 2006, <b>42</b> (2), 82-94.	South Korea	In-depth interviews (n= 8 people diagnosed with schizophrenia)	17/25
46	NHS Scotland, Finding strength from within, Report on three local projects looking at mental health and recovery with people from some of black and minority ethnic communities in Edinburgh, 2008.	Scotland	Exploratory community development project (n= 50 people from BME communities with personal experience of recovery)	Not rated
47	Ajayi S, Billsborough J, Bowyer T, Brown P, Hicks A, Larsen J, Mailey P, Sayers R, Smith R. Getting back into the world: Reflections on lived experiences of recovery, <i>Rethink recovery series: 2.</i> , 2009.	UK	Interviews (n=48 people with personal experience of mental illness)	18/25
48	Connecticut Department of Mental Health Addiction Services: Proposed model of mental health recovery and recovery-oriented services, in Davidson L, Rowe M, Tondora J, O'Connell M, Lawless M, <i>A practical guide to recovery-oriented practice</i> . Oxford. Oxford University Press, 2009.	USA	Position paper	Not rated

49	Mancini A. Self-determination theory: A framework for the recovery paradigm, <i>Adv. in Psychiatr Treatment</i> .2008, <b>14</b> (5),358-365.	USA	Literature review	Not rated
50	Armour M, Bradshaw W. Roseborough D. African Americans and recovery from severe mental illness, <i>Social Work in Ment. Health</i> , 2009, <b>7</b> (6), 602-622.	USA	Semi-structured interviews (n=9 African-American with serious and persistent mental illness, conducted with each participant 3 times)	11/25
51	Davidson L, Andres-Hyman R, Bedregal L, Tondora J, Fry J, Kirk T. From 'Double trouble to Dual recovery': Integrating models of recovery in addiction and mental health, <i>J of Dual Diagnosis</i> , <b>4</b> (3), 2008, 273-290.	USA	Literature review and consultation (n=45 people with addictions or in recovery from serious mental illness.	8/25
52	Sullivan W. A long and winding road: The process of recovery from severe mental illness, in Spaniol L, Gagne C, Koehler M, (eds) <i>Psychological and social aspects of Psychiatr disabilities</i> , Boston University Center, 1997.	USA	Semi-structured interviews (n=46 current and former service users)	13/25
53	Mancini M. Consumer-providers' theories about recovery from serious psychiatric disabilities, chapter 2, from Rosenberg, <i>Community Mental Health: Challenges for the 21st Century</i> , Routledge, 2006.	USA	Semi-structured interviews (n==15 people diagnosed with a psychiatric disability who also provide peer-support services to others)	11/25
54	Ridge D, Ziebland S. "The old me could never have done that": how people give meaning to recovery following depression, <i>Qual. Health Research</i> , 2006, <b>16</b> (8), 1038-1053.	UK	Open-ended interviews (n=38 people who have had depression)	CHECK RATS
55	Sydney West Area Health Service, (2008) Maintaining wellness and promoting recovery, sections 4-6, in <i>The wellness guide – a resource to support the recovery journey</i> , March 2008.	Australia	Part of a Wellness Guide developed in partnership between consumers and clinicians.	
56	Armstrong N, Steffen J. The Recovery Promotion Fidelity Scale: Assessing the organizational promotion of recovery, <i>Community Ment. Health J</i> , 2009, <b>45</b> (3), 163-170.	USA	Literature review and concept mapping (n= 5 focus groups) and survey	16/25
57	Noordsy D, Toeey W, Mueser K, O'Keefe C, Fox L. Recovery from severe mental illness: an intrapersonal and functional outcome definition, <i>Int. Review of Psychiatry</i> , 2002, <b>14</b> , 318-326.	USA	Focus groups and observation	Not rated
58	Forchuk C, Jewell J, Tweedell D, Steinnage IL. Reconnecting the client experience of recovery from psychosis, <i>Perspectives in Psychiatr Care</i> , 2003, <b>39</b> (4) 141-150.	Canada	Interviews and observation (n=10 patients over the initial year of treatment with clozapine or risperidone)	16/25
59	Baxter E, Diehl S. Emotional stages: Consumers and family members recovering from the trauma of mental illness, <i>Psychiatr Rehab. J</i> , 1998, <b>21</b> (4), 349-355.	USA	Interviews (n=40 consumers)	11/25
60	Oades L, Deane F, Crowe T, Lambert W, Kavanagh D, Lloyd C. Collaborative recovery: An integrative model for working with individuals who experience chronic and recurring mental illness. <i>Australasian Psychiatry</i> , 2005, <b>13</b> (3), 279-284.	Australia	Multi-site study in 9 organisations	Not rated
61	Glover H. Lived experience perspectives, in <i>Handbook of psychosocial rehabilitation</i> , King R, Lloyd C, Meehan T, Wiley-Blackwell, 2007.	Australia	Literature review and personal narrative	Not rated
61	Ridgeway P. Re-Storying psychiatric disability: Learning from first person recovery narratives, <i>Psychiatr Rehab. J</i> , 2001, <b>24</b> (4), 335-343	USA	Grounded theory analysis of 4 existing 'seminal' narratives	17/25
63	Bonney S, Stickley T. Recovery and mental health: A review of the British literature, <i>J of Psychiatr and Ment. Health Nurs.</i> , 2008, <b>15</b> (2), 140-153.	UK	Literature review	Not rated
64	Mead S, Copeland M. What recovery means to us: Consumers' perspectives,	USA	Personal narratives and opinion piece	8/25

	<i>Community Ment. Health J</i> , 2000, <b>36</b> (3), 315-328.			
65	Sowers W. Transforming systems of care: the American Association of Community Psychiatrists guidelines for recovery oriented services, <i>Community Ment. Health J</i> , 2005, <b>41</b> (6), 757-774	USA	Literature review	Not rated
66	Plum K. How patients view recovery: what helps, what hinders, <i>Archives of Psychiatr Nurs.</i> , 1987, <b>1</b> (4), 285-293.	USA	Analysis of narratives (n=20)	13/25
67	Ahern L, Fisher D. Recovery at your own PACE (Personal Assistance in Community existence). <i>J of Psychosocial Nurs. &amp; Ment. Health Services</i> , 2001, <b>39</b> (4), 22-32.	USA	Literature review and qualitative research	Not rated
68	Jacobson N, Curtis L. Recovery as policy in mental health services: Strategies emerging from the states, <i>Psychiatr Rehab. J</i> , 2000, <b>23</b> (4), 333-341.	USA	Literature review	Not rated
69	Lunt A. A theory of recovery. <i>J of Psychosocial Nurs. &amp; Ment. Health Services</i> , 2002, <b>40</b> (12), 32-39.	USA	Literature review and opinion piece	Not rated
70	Nicholls V. <i>Feeding the flowers: SPN perspective on recovery</i> , 2007.	UK	Literature review and qualitative research	Not rated
71	Ralph R, Risman J, Kidder, K. <i>The Maine contingent of the recovery advisory group</i> , May, 1999.	USA	Personal narratives and literature review	6/25
72	Mental Health Providers Forum, <i>The recovery star model</i> , 2008.	UK	Measure development	Not rated
73	Mental health providers forum, <i>The recovery star model and cultural competency</i> , BAME Pilot Report, 2009.	UK	Pilot study to test measure with BME population	Not rated
74	Brown M, Essien P, Etim-Ubah P et al. <i>Report of the community led research project focussing on male African and African Caribbean perspectives on recovery</i> , Southside Partnership Fanon, 2008.	UK	Semi-structured interviews and questionnaires (n=91)	20/25
75	Mancini M, Hardiman E, Lawson H. Making Sense of It All: Consumer Providers' Theories about Factors Facilitating and Impeding Recovery from Psychiatric Disabilities, <i>Psychiatr Rehab. J</i> , 2005, <b>29</b> (1), 48-55.	USA	Semi-structured interviews (n=15 adults recovering from serious psychiatric disability and leading consumer provision of mental health services)	14/25
76	Bradstreet S, Brown W. Elements of recovery: Int. learning and the Scottish context, <i>SRN Discussion Paper Series Report No. 1</i> . 2004.	UK	Literature review	Not rated
77	Jacobson N, Greenley D. ( 2001) What is recovery? A conceptual model and explication. <i>Psychiatr Services</i> , <b>52</b> (4), 482-485.	USA	Synthesis of consumer narratives	Not rated
78	Lapsley H, Waimarie Nikora L, Black R. <i>Kia Mauri Tau! Narratives of recovery from disabling mental health problems</i> . Report of the University of Waikato Mental Health Narratives Project. Wellington: Mental Health Commission, 2002.	New Zealand	Interviews (n=40 who once had a disabling mental health problem)	20/25
79	Jenkins J, Carpenter-Song E. The new paradigm of recovery from schizophrenia: cultural conundrums of improvement without cure, <i>Culture, Medicine and Psychiatry</i> , 2006, <b>29</b> (4), 379-414.	USA	Interviews (n=90 people attending community out-patient clinics)	18/25
80	Barton R. The rehabilitation-recovery paradigm: A statement of philosophy for a public mental health system, <i>Psychiatr Rehab. Skills</i> , 1998, <b>2</b> (2), 171-187.	USA	Literature review	Not rated
81	Spaniol L, Gagne C, Koehler M. The recovery framework in rehabilitation and mental health, chapter 4, in Moxley, D. & Finch, J. <i>Sourcebook of rehabilitation and mental health practice</i> . New York, US: Kluwer Academic/Plenum, 2003.	USA	Literature review	Not rated
82	Glover H. Recovery based service delivery: Are we ready to transform the words into a paradigm shift? <i>Australian e-J for the Advancement of Ment. Health</i> , 2005, <b>4</b> (3), 1-4.	Australia	Opinion piece	Not rated

83	Irish Mental Health Commission. <i>A recovery approach within the Irish mental health services: A framework for development</i> , 2008.	Ireland	Literature review	Not rated
84	Ochocka J, Nelson G, Janzen R. Moving Forward: Negotiating Self and External Circumstances in Recovery, <i>Psychiatr Rehab. J</i> , 2005, <b>28</b> (4), 315-322.	Canada	In-depth interviews (n=28 people who had experienced serious mental health problems)	14/25
85	Brown W. The possibility of wellness, <i>Ment. Health Today</i> , 2007, <b>Sept.</b> 23-26.	Scotland	Semi-structured interviews (n=64)	12/25
86	Steen M. Essential structure and meaning of recovery from clinical depression for middle-adult women: a phenomenological study, <i>Issues in Ment. Health Nurs.</i> , 1996, <b>17</b> (2), 73-92.	USA	Interviews (n=22 participants with clinical, unipolar depression)	13/25
87	Fisher D. Healthcare reform based on an empowerment model of recovery by people with psychiatric disabilities, <i>Hospital and community psychiatry</i> , 1994, <b>45</b> (9), 913-915.	USA	Opinion paper	Not rated
88	Substance Abuse and Mental Health Service Administration, <i>National Consensus statement on mental health recovery</i> , 2004.	USA	Consensus methods (n= 110 expert panellists)	Not rated
89	Onken S, Craig C, Ridgway P, Ralph R, Cook J. An analysis of the definitions and elements of recovery: A review of the literature. <i>Psychiatr Rehab. J</i> , <b>31</b> (1), 9-22. 2007	USA	Literature review	Not rated
90	Anthony W. Recovery from mental illness: The guiding vision of the mental health service system in the 1990s, <i>Psychosocial Rehab. J</i> , 1993, <b>16</b> (4), 11-23.	USA	Opinion piece and literature review	Not rated
91	Pitt L, Kilbride M, Nothard S, Welford M, Morrison A. Researching recovery from psychosis: a user-led project, <i>Psychiatr Bulletin</i> , 2007, <b>31</b> , 55 - 60.	UK	User-led interview study (n= 7 people in recovery)	19/25
92	Anderson B, Munchel W. <i>Opportunity on the doorstep: recovery-oriented leadership</i> , 2005 Village ISA and Community Activators, Inc.	USA	Opinion piece	Not rated
93	Borg M, Davidson, L. The nature of recovery as lived in everyday experience, <i>J of Ment. Health</i> , 2008, <b>17</b> (2), 129-140.	Norway	Interviews (n=13 individuals in recovery)	14/25
94	Asmundsdottir E. Creation of New Services: Collaboration Between Mental Health Consumers and Occupational Therapists, <i>Occupational Therapy in Ment. Health</i> , 2009, <b>25</b> (2), 115-126.	Iceland	Interviews and focus groups (n=25)	14/25
95	Davis E, Velleman R, Smith G, Drage M. Psychosocial developments: Towards a model of recovery, in Velleman R, Davies E, Smith G, & Drage M. (eds.) <i>Changing outcomes in Psychosis, Collaborative cases from practitioners, users and carers</i> , pp1-21., BPS Blackwell, 2006.	UK	Literature review	Not rated
96	Warren K. <i>Exploring the concept of recovery from the perspective of people with mental health problems</i> . Norwich School of Social Work and Psychosocial Studies, University of East Anglia, 2003.	UK	Literature review, narrative analysis, interviews	9/25
97	Piat M, Sabetti J, Bloom D. The importance of medication in consumer definitions of recovery from serious mental illness: A qualitative study, <i>Issues in Ment. health Nurs.</i> , 2009, <b>30</b> (8), 482-490.	Canada	Semi-structured interviews (n= 54 consumers of mental health services)	18/25

For full list of excluded studies, please contact Dr Mary Leamy (mary.leamy@kcl.ac.uk).

**Table DS2 Vote counting of recovery processes**

<b>Recovery processes</b>	<b>Number (%) of 87 studies</b>
<b>Category 1: Connectedness</b>	<b>75 (86%)</b>
<i>1.1 Peer support and support groups</i>	39 (45%)
1.1.1 Availability of peer support	22 (25%)
1.1.2 Becoming a peer support worker or advocate	17 (20%)
<i>1.2 Relationships</i>	33 (38%)
1.2.1 Building upon existing relationships	19 (22%)
1.2.2 Intimate relationships	9 (10%)
1.2.3 Establishing new relationships	8 (9%)
<i>1.3 Support from others</i>	53 (61%)
1.3.1 Support from professionals	42 (48%)
1.3.2 Supportive people enabling the journey	27 (31%)
1.3.3 Family support	26 (30%)
1.3.4 Friends and peer support	18 (21%)
1.3.5 Active or practical support	4 (5%)
<i>1.4 Being part of the community</i>	35 (40%)
1.4.1 Contributing and giving back to the community	21 (24%)
1.4.2 Membership of community organisations	13 (15%)
1.4.3 Becoming an active citizen	11 (13%)
<b>Category 2: Hope and optimism about the future</b>	<b>69 (79%)</b>
<i>2.1 Belief in possibility of recovery</i>	30 (34%)
<i>2.2 Motivation to change</i>	15 (17%)
<i>2.3 Hope-inspiring relationships</i>	12 (14%)
2.3.1 Role-models	8 (9%)
<i>2.3 Positive thinking and valuing success</i>	10 (11%)
<i>2.4 Having dreams and aspirations</i>	7 (8%)
<b>Category 3: Identity</b>	<b>65 (75%)</b>
<i>3.1 Dimensions of identity</i>	8 (9%)
3.1.1 Culturally specific factors	7 (8%)
3.1.2 Sexual identity	2 (2%)
3.1.3 Ethnic identity	4 (5%)
3.1.4 Collectivist notions of identity	6 (7%)
<i>3.2 Rebuilding/redefining positive sense of self</i>	57 (66%)
3.2.1 Self-esteem	21 (24%)
3.2.2 Acceptance	21 (24%)

3.2.3 Self-confidence and self-belief	11 (13%)
3.3 <i>Over-coming stigma</i>	40 (46%)
3.3.1 Self-stigma	27 (31%)
3.3.2 Stigma at a societal level	32 (37%)
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<b>Category 4: Meaning in life</b>	<b>59 (66%)</b>
4.1 <i>Meaning of mental illness experiences</i>	30 (34%)
4.1.1 Accepting or normalising the illness	22 (25%)
4.2 <i>Spirituality (including development of spirituality)</i>	36 (41%)
4.3 <i>Quality of life</i>	57 (65%)
4.3.1 Well-being	27 (31%)
4.3.2 Meeting basic needs	18 (21%)
4.3.3 Paid voluntary work or work related activities	19 (22%)
4.3.4 Recreational and leisure activities	8 (9%)
4.3.5 Education	7 (8%)
4.4 <i>Meaningful social and life goals</i>	15 (17%)
4.4.1 Active pursuit of previous or new life or social goals	15 (17%)
4.4.2 Identification of previous of new life or social goals	8 (9%)
4.5 <i>Meaningful life and social roles</i>	40 (46%)
4.5.1 Active pursuit of previous or new life or social roles	40 (46%)
4.5.2 Identification of previous of new life or social roles	34 (39%)
4.6 <i>Rebuilding of life</i>	20 (23%)
4.6.1 Resuming with daily activities and daily routine	12 (14%)
4.6.2 Developing new skills	8 (9%)
<hr/>	
<b>Category 5: Empowerment</b>	<b>79 (91%)</b>
5.1 <i>Personal responsibility</i>	79 (91%)
5.1.1 Self-management	60 (69%)
Coping skills	25 (29%)
Managing symptoms	22 (25%)
Self-help	12 (14%)
Resilience	25 (29%)
Maintaining good physical health and well-being	12 (14%)
5.1.2 Positive risk-taking	17 (20%)
5.2 <i>Control over life</i>	78 (90%)
5.2.1 Choice	31 (36%)
Knowledge about illness	17 (20%)
Knowledge about treatments	7 (8%)
5.2.2 Regaining independence and autonomy	23 (26%)

5.2.3 Involvement in decision-making	23(26%)
Care planning	35 (40%)
Crisis planning	7 (8%)
Goal setting	12 (14%)
Strategies for medication	25 (29%)
Medication not whole solution	11 (13%)
5.2.4 Access to services and interventions	13 (15%)
5.3 <i>Focussing upon strengths</i>	14 (16%)



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## Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis

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# What Does Recovery Mean in Practice? A Qualitative Analysis of International Recovery-Oriented Practice Guidance

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**Objectives:** Recovery is a multifaceted concept, and the need for operationalization in practice has been identified. Although guidance on recovery-oriented practice exists, it is from disparate sources and is difficult to apply. The aims of the study were to identify the key characteristics of recovery-oriented practice guidance on the basis of current international perspectives and to develop an overarching conceptual framework to aid the translation of recovery guidance into practice.

**Methods:** A qualitative analysis of 30 international documents offering recovery-oriented practice guidance was conducted. Inductive, semantic-level, thematic analysis was used to identify dominant themes. Interpretive analysis was then undertaken to group the themes into practice domains. **Results:** The guidance documents were diverse; from six countries—the United States, England, Scotland, Republic of Ireland, Denmark, and New Zealand—and varied in document type, categories of guidance, and level of service user involvement in guidance development. The emerging conceptual framework consists of 16 dominant themes, grouped into four practice domains: promoting citizenship, organizational commitment, supporting personally defined recovery, and working relationship. **Conclusions:** A key challenge for mental health services is the lack of clarity about what constitutes recovery-oriented practice. The conceptual framework contributes to this knowledge gap and provides a synthesis of recovery-oriented practice guidance. (*Psychiatric Services* 62:1470–1476, 2011)

The concept of recovery is increasingly prominent in mental health research and policy, and mental health services are encouraged to consider their role in supporting the recovery of individuals who experience mental illness (1–3).

Recovery offers a transformational ideology for services and suggests reforms in how mental illness is understood and managed, as well as in how people living with mental illness are understood and helped (4). This guiding philosophy challenges ideas and

beliefs about the etiology and treatment of mental illness, including the way in which mental health practice is organized and implemented to ensure that people living with mental illness are allowed the opportunity to lead meaningful and productive lives (5,6). This vision values greater independence of people living with mental illness and adopts a shift from paternalistic mental health practices to practices that support autonomy (7).

Although key building blocks for recovery-oriented practice have been proposed in international policy (8–10), research literature (11,12), and first-person narratives (13,14), it is a nebulous concept that is understood in a number of ways and is difficult to apply (15). The term “recovery” is commonly used to refer to the process of how each individual comes to terms with and overcomes challenges associated with having a mental illness (1,5). On the other hand, mental health practitioners lean toward different meanings (16) and often consider recovery in terms of symptomatology and view it primarily as improvement in mental health outcomes (17). The subjective nature of recovery also means that individual practitioners emphasize different characteristics of recovery within their own practice, making routine operationalization (18) and conceptualization of recovery a further challenge (19,20). The need for a consistent understanding and operational-

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ization of recovery into mental health practice has been identified (17,18).

The aims of this study were to synthesize the characteristics of recovery-oriented practice guidance on the basis of international perspectives and to develop a useful overarching conceptual framework for translating recovery guidance into mental health practice. A conceptual framework provides an interpretive approach to the understanding of concepts and the relationships among them, which is developed through iterative qualitative analysis (21).

## Methods

### Design

A literature search was conducted to identify recovery-oriented practice guidance. Each document was analyzed by using inductive thematic analysis, in which analytical concepts and perspectives are derived from the data in a deliberate and systematic way (22). This approach allows exploration of the way that each document describes recovery-oriented practice, allows unexpected themes to emerge, and does not restrict the investigation to predetermined concepts or pre-judge the significance of concepts.

### Procedures

**Guidance identification.** The literature search sought to identify guidance that explicitly describes or develops a conceptualization of recovery-oriented mental health practice. The term “guidance” is used to describe the range of documents included in the study, which was not limited to guidelines or practice standards. Guidance on recovery-oriented mental health practice was defined as recommendations developed as a guide to mental health services and mental health practitioners on supporting the recovery of people living with mental illness, guidance for users of mental health services to support self-advocacy of best practices and high-quality service delivery, an analysis of primary data, or a synthesis of secondary data. In addition, the guidance needed to be available in printed or downloadable form and written in English.

Three data sources were used to conduct the literature search. First, experts were asked to identify influ-

ential international policy and practice guidance. Second, an Internet search via Google Scholar using the key terms “recovery-oriented practice” AND “guidelines” OR “standards” OR “indicators” OR “competencies” was conducted. Third, manual search of reference lists of retrieved documents was undertaken. An electronic database search (for example, Medline) was not undertaken as policy and practice documents were sought rather than peer-reviewed articles in academic journals. The search was conducted in January 2010.

**Analysis.** The characteristics of the eligible documents were identified in order to describe and define the guidance. The level of service user involvement in guidance development was rated by using three categories: control, collaboration, and consultation (23). Control involves research in which service users take a lead, collaboration is defined as a shared partnership between service users and researchers in the research process, and consultation occurs when researchers consult service users about the research.

Inductive thematic analysis (24) was used to systematically identify and synthesize the range and diversity of the key concepts of recovery-oriented practice identified in existing guidance. To meet aim 1, data extracts from each document were selected by two raters on the basis of the following criteria: described characteristics of recovery-oriented practice, provided definitions of recovery-oriented practice, or offered standards or indicators of recovery-oriented practice from which a succinct summary could be extracted. Initial semantic-level analysis was then undertaken by four analysts. Equal attention was paid to each data extract to identify initial codes, and individual extracts were coded under one or several themes to fully capture their meaning. An initial coding frame was developed; all extracts were double-coded by at least two raters, and a third rater resolved any differences.

To meet aim 2, interpretive analysis was undertaken to organize the themes into practice domains. Thematic maps were used to organize the

themes by clustering all codes according to connections in the data and by considering the patterns and relationships between themes. Additional codes, refinements to the specifics of themes, and thematic patterns continued until theoretical saturation was achieved (24).

### Ethical approval

The study was conducted as part of a larger program of research, which has ethical approval obtained from the joint South London and Maudsley and the Institute of Psychiatry National Health Service research ethics committee.

## Results

### Guidance identification

Thirty documents were identified. [A list of the documents is available in an online supplement to this article at [ps.psychiatryonline.org](http://ps.psychiatryonline.org).] Documents came from six countries—United States, England, Scotland, Republic of Ireland, Denmark, and New Zealand—and ranged in length from three to 149 pages. Their characteristics are shown in Table 1.

The nature of the guidance was diverse, with 15 self-ascribed categories of guidance. The level of service user involvement in the guideline development varied: user-controlled, N=3; collaboration, N=8; and consultation, N=10.

### Aim 1: characteristics of practice guidance

A total of 498 units of text were extracted from the 30 documents. Each unit of text varied in length from one sentence to one paragraph and described one or more components of recovery-oriented practice, resulting in 100 pages of coded data. Inductive semantic thematic analysis identified 16 dominant themes, which are shown in Table 2 and discussed below. Because of space limitations, subthemes are not specified in this article. [The full conceptual framework is outlined in the online data supplement at [ps.psychiatryonline.org](http://ps.psychiatryonline.org).]

**Seeing beyond “service user.”** A shift in within-service attitude from “service user” to person is specified. Individuals who access mental health services are people first and are not

**Table 1**

Characteristics of recovery-oriented practice guidance from six countries

Document number <sup>a</sup>	Country	Type of document	Self-ascribed document classification	N of items extracted	Level of service user involvement
1	United States	Policy	Goals and principles	10	Collaboration
2	England	Policy	Standards	4	Consultation
3	England	Policy	Not specified	7	None specified
4	New Zealand	Policy	Competencies	10	Control
5	England	Policy	Capabilities	10	Consultation
6	England	Policy	Principles	12	Collaboration
7	England	Policy	Principles	6	None specified
8	England	Policy	Recommendations	17	Consultation
9	Scotland	Policy	Knowledge, skills, and values framework	3	Consultation
10	New Zealand	Policy	Vision	15	Collaboration
11	Republic of Ireland	Policy	Criteria	27	Consultation
12	England	Policy	Not specified	1	Consultation
13	United States	Research based	Indicators	53	Consultation
14	England	Book chapter	Components	3	Collaboration
15	United States	Book chapter	Standards	126	Consultation
16	England	Book chapter	Characteristics	6	None specified
17	United States	Opinion	Not specified	8	Control
18	United States	Opinion	Standards	23	None specified
19	United Kingdom	Opinion	Steps	21	None specified
20	United States	Opinion	Standards	16	Collaboration
21	United States	Opinion	Implementation framework	12	None specified
22	United States	Opinion	Components	19	None specified
23	New Zealand	Opinion	Framework	7	Control
24	England	Opinion	Action points	24	None specified
25	United States	Practice based	Standards	13	Collaboration
26	United States	Practice based	Principles	8	Collaboration
27	Denmark	Practice based	Goals	12	Consultation
28	England	Practice based	Standards	10	Collaboration
29	England	Practice based	Vision and principles	5	Consultation
30	England	Practice based	Benchmark	10	None specified

<sup>a</sup> The document numbers correspond to those on the list of 30 documents in the online supplement at [ps.psychiatryonline.org](http://ps.psychiatryonline.org).

defined by their service use or diagnosis. In addition to within-service attitude, societal stigma and discrimination are also challenged.

**Service user rights.** The rights of individuals living with mental illness and of families and caregivers are respected. Practitioners have an awareness of human rights issues and are able to refer to or provide advocacy support. Guidance provided in New Zealand addresses this issue (25). "A competent mental health worker understands and actively protects service users' rights. They demonstrate knowledge of human rights principles and issues . . . [T]hey demonstrate knowledge of service users' rights within mental health services and elsewhere. . . . [T]hey demonstrate the ability to promote and fulfil service users' rights."

**Social inclusion.** This theme addresses the improvement in the individual's quality of participation in

community life. Practitioners work closely with mainstream organizations and personal social networks to promote opportunities for community integration outside the mental health service. As stated in the guidance from Devon, United Kingdom (26), "All services demonstrate socially inclusive practice which is supportive of people living ordinary lives in ordinary settings and considers, in particular, peoples' needs for accommodation, occupation, education, personal relationships, money and participation in community life."

**Meaningful occupation.** Individuals are supported to participate in meaningful occupations and to identify a purposeful lifestyle within and beyond the limits of mental illness. Practitioners facilitate decision making about valued life roles and support individuals to create, develop, or maintain their chosen valued roles.

**Recovery vision.** Recovery is

viewed as the overarching vision of services, and mission and vision statements articulate an organizational commitment to recovery values and practices.

**Workplace support structures.** Recovery principles are embedded in existing workplace support structures and give practitioners permission to support recovery values. This agreement is reflected in policies, as well as in contracting and commissioning arrangements that promote recovery philosophies. Guidance from the American Association of Community Psychiatrists (11) states, "Recovery oriented service design will be reflected in policy and procedure documents, including financial structures that encourage such service development."

**Quality improvement.** Individuals living with mental illness, their families and caregivers, and practitioners are encouraged to make meaningful

**Table 2**

Sixteen dominant themes in four practice domains identified in 30 documents offering recovery-oriented practice guidance in six countries<sup>a</sup>

	Promoting citizenship				Organizational commitment				Supporting personally defined recovery					Working relationship		
Docu- ment	Seeing beyond “service user”	Service user rights	Social inclu- sion	Mean- ingful occu- pation	Re- covery vision	Work- place support struc- tures	Quality improve- ment	Care path- way	Work- force plan- ning	Indi- vidu- ality	In- formed choice	Peer sup- port	Strengths focus	Holis- tic ap- proach	Part- ner- ships	Inspir- ing hope
1						✓	✓	✓	✓	✓	✓			✓	✓	
2	✓														✓	
3	✓	✓	✓	✓	✓			✓	✓		✓					
4	✓	✓	✓		✓		✓		✓	✓	✓	✓		✓	✓	✓
5	✓	✓		✓			✓	✓	✓		✓		✓	✓	✓	✓
6			✓	✓	✓			✓		✓	✓		✓	✓	✓	✓
7	✓				✓					✓			✓			
8	✓		✓	✓		✓	✓		✓	✓	✓			✓	✓	✓
9	✓	✓	✓	✓			✓		✓	✓	✓	✓	✓	✓		✓
10	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓		✓	✓	
11	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓
12		✓							✓						✓	
13		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	
14			✓													✓
15	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
16		✓			✓		✓			✓	✓		✓	✓	✓	✓
17			✓	✓	✓	✓	✓		✓	✓	✓	✓		✓		✓
18		✓	✓		✓	✓	✓	✓	✓	✓	✓	✓		✓		
19				✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓
20			✓		✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
21			✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓
22		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓		✓	✓	✓
23	✓	✓	✓	✓		✓	✓			✓	✓	✓		✓	✓	✓
24	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
25	✓		✓						✓	✓	✓					✓
26			✓		✓		✓	✓		✓			✓	✓	✓	
27			✓	✓			✓		✓	✓	✓				✓	✓
28	✓		✓				✓	✓	✓		✓			✓		
29	✓	✓	✓	✓		✓			✓	✓	✓	✓		✓	✓	✓
30	✓		✓	✓						✓	✓					✓
Total	16	15	23	18	17	13	21	13	21	23	24	13	12	21	21	20

<sup>a</sup> The document numbers correspond to those on the list of 30 documents in the online supplement at [ps.psychiatryonline.org](http://ps.psychiatryonline.org).

contributions to the design, delivery, and monitoring of mental health service provision. Central to this theme is the ability of mental health practitioners to support the involvement of service users in quality improvement and to actively encourage service user participation in service development and evaluation.

*Care pathway.* Individuals are supported to gain access to and participate in services. Mental health services are encouraged to operate outside usual working hours to allow access by people who work and to support activity in the evenings and on weekends. Nonlinear continuums of care are accepted, and services are designed to allow people to move in and

out of the system as required. Services do not exclude people from care on the basis of their symptoms, substance use, or unwillingness to participate in service provision options. Principles of the National Institute of Mental Health England (27) state, “The user of services decides if and when to begin the recovery process and directs it; therefore, service user direction is essential throughout the process.”

*Workforce planning.* Training and staff development is prioritized as an essential function to increase individual practitioners’ competencies in recovery-oriented practice and to provide opportunities for staff growth, independence, and wellness. The

workforce is representative of the community it serves, and recruitment is guided by recovery values. “Staff can support recovery by . . . recruiting people with recovery competencies, by interviewing with questions such as ‘Why do you suppose people with mental illness want to work?’ to give a chance for applicants to demonstrate their values, assessing whether key knowledge, attitudes, and skills about recovery are present” (28).

*Individuality.* Service users’ individuality is promoted, and autonomy is supported. Practitioners promote individual preference, self-determination over life, the dignity of risk, and the right to failure.

*Informed choice.* Individuals have



access to timely and accurate information that provides options and supports personal choice and decision making. Care planning is related to the attainment of personally defined goals and not solely to clinical outcomes. "The service focuses on people's right to make individual decisions or choices about all aspects of their own recovery process, including areas such as the desired goals and outcomes, preferred services used to achieve the outcomes, preferred moments to engage or disengage in services"(29) .

*Peer support.* People in recovery are available to model empowerment and to share their own recovery stories to promote learning, self-management, and personal responsibility.

*Strengths focus.* The strengths and natural supports of individuals who live with mental illness are acknowledged and encouraged. A strengths model and a discussion of strengths is the central focus of every assessment and care plan. "In addition to the assessment of individual capacities, it is beneficial to explore other areas not traditionally considered 'strengths,' e.g., the individual's most significant or most valued accomplishments, ways of relaxing and having fun, ways of calming down when upset, personal heroes, educational achievements, etc." (30).

*Holistic approach.* A holistic approach is offered that includes a range of options to meet medical, physical, social, occupational, psychological, emotional, spiritual, and religious needs. Individuals are supported to develop a recovery plan that focuses on wellness, the treatments and supports that will facilitate recovery, and the resources that will support the recovery process.

*Partnerships.* Individuals who live with mental illness are partners in all aspects of their care. Practitioners provide coaching support to promote autonomy over authority.

*Inspiring hope.* Individuals who live with mental illness are valued as experts in their own experience. Practitioners value and believe in service users' abilities and foster hope and optimism in their work. "The system is grounded in a belief that recovery is possible and is expected outcome of treatment" (31).

## ***Aim 2: develop a conceptual framework***

Interpretive analysis was undertaken to group the themes into practice domains by identifying connections and relationships between themes. Four overarching conceptual practice domains were identified: promoting citizenship, organizational commitment, supporting personally defined recovery, and working relationship. Each practice domain is as important as the next, and there is no hierarchical order. The grouping of themes and distribution of themes across documents is shown in Table 2. Informed choice was the most prominent theme, appearing in the extracted data of 24 of the 30 documents. Representation of themes across documents is apparent; of potential interest is the recognition of an organizational perspective in data from the documents in which service users played a leading role.

The four practice domains are described below in further detail.

*Promoting citizenship.* The core aim of services is to support people who live with mental illness to reintegrate into society and to live as equal citizens. Citizenship is central to supporting recovery, in which the right to a meaningful life for people living with severe and enduring mental illness is advocated. Seeing beyond "service user," service user rights, social inclusion, and meaningful occupation are grouped in this practice domain.

*Organizational commitment.* Organizations that support recovery orientation demonstrate a commitment to ensure that the work environment and service structure are conducive to promoting recovery-oriented practice. The organizational culture gives primacy to recovery and focuses on and adapts to the needs of people rather than those of services. Recovery vision, workplace support structures, quality improvement, care pathway, and workforce planning are included in this practice domain.

*Supporting personally defined recovery.* Practitioners focus on supporting personally defined recovery and view recovery as being at the heart of practice and not as an additional task. Individuals are supported to define their own needs, goals, dreams, and plans for the future to

shape the content of care. Individuality, informed choice, peer support, strengths focus, and holistic approach are contained in this practice domain.

*Working relationship.* Practitioner interactions demonstrate a genuine desire to support individuals and their families to fulfill their potential and to shape their own future. A therapeutic relationship is essential to supporting recovery in which partnership working and hope is promoted.

## **Discussion**

The goals of this study were to determine the characteristics of recovery-oriented practice guidance on the basis of current international perspectives and to develop an overarching conceptual framework that can be used to aid the translation of recovery guidance into clinical practice. A conceptual framework was developed by using inductive thematic analysis, which identified four practice domains: promoting citizenship, organizational commitment, supporting personally defined recovery, and working relationship.

## ***Implications for policy and practice***

The emerging conceptual framework is wide ranging, encompassing sociopolitical involvement and ethical responsibilities that may be outside the usual sphere of practice. Davidson (7) argued for a conceptual framework that supports the fundamental role of independence and self-determination in enabling people who live with mental illness to exercise their rights of citizenship and to live meaningful lives. The view that promoting citizenship is the job of the mental health system may be challenging. It suggests that "becoming social activists who challenge stigma and discrimination, and promoting societal well-being may need to become the norm rather than the exception for mental health professionals in the 21st Century" (32).

The involvement of organizations is also highlighted (33), pointing to the need to develop a whole-systems approach. To operate within a recovery framework, services need to balance the tension between addressing both the priorities of service users and the

wider expectations of the community (18). Addressing organizational commitment may be difficult, because it challenges the view that the organization merely provides the infrastructure for service delivery and quality assurance. This raises questions about the purpose of mental health services and how their effectiveness should be evaluated (34).

The process of supporting personally defined recovery reflects the complexity and dimensions of practice across both evidence-based practice and illness experience. This is enhanced by working relationships that recognize the value of therapeutic and real relationships (6). Although the understanding of recovery-oriented practice is still developing, practices that are reflective of the four practice domains should be promoted (7,35).

There is an expectation that practitioners embed a recovery framework in their existing perspectives of disability and health (3,36). The conceptual framework can be used to address this need. One example is viewing recovery-oriented practice within an ecological perspective (37), where the life context, the environment, and the relationship between individuals and their environment are considered (14,30). The conceptual framework promotes awareness of the impact of ecological factors, such as health care systems and societal and life context, on recovery (38).

The conceptual framework can be used to aid the understanding and translation of recovery-oriented practice guidance into practice. Although the conceptual framework provides a conceptual overview built from robust analysis, it is not a definitive guide. The complexity of translating recovery into practice dictates the need for context-specific guidance. The synthesis of guidance provides a foundation for structuring local guidelines and future policy (3), benchmarking recovery-oriented practice (for example, for developing an accreditation process for services (39), and supporting staff development within existing practice competencies (40)).

### ***Strengths and limitations***

This study considered a broad range of documents to explore the breadth

of recovery-oriented practice, and although the sample size was influenced by what was considered feasible for a qualitative analysis, it is substantially larger than is usual for a study of this type. Robust qualitative methodology was used to maximize the quality of the synthesis. The main limitation is the nonsystematic approach to identifying the guidance documents. The rationale for analyzing widely used documents is that recovery orientation is a developing area of research and practice, and its evolving meaning is both represented and influenced by prominent policy and practice documents. The literature search was a systematized review rather than a systematic review (41); therefore, not all existing guidance documents were identified in the search, which resulted in reduced coverage of important guidance, for example, from Canada (42) and Australia (43). Informal analysis indicates that these documents are consistent with our findings, but the conceptual framework should be considered a heuristic to be further developed and refined.

### ***Future research***

The diversity of guidance highlights the complexity of translating recovery into practice. Future research to apply the conceptual framework in practice and to develop associated quality indicators would begin to bridge this gap (44). A second strand of research will be empirical investigation of the relationship between practices and outcomes associated with personal recovery and clinical recovery (39). A third strand will involve collation of more guidance developed by service users for comparative analysis to identify different emphases in user controlled guidance.

Despite the attention to practice guidelines and practitioner attitudes (15) and research on recovery experiences of individuals receiving mental health services (45), research on the implementation experiences of persons providing mental health services is a relatively unexplored area in need of further development (46–49). Although practice guidance exists, a translational gap between knowledge and routine implementation in men-

tal health practice has been cited as a major challenge to innovation in mental health care (50,51). Recent advances in recovery research measure fidelity to a specific recovery intervention (52–54). A fourth strand will be research to address the translational gap in order to enhance implementation efforts (2,12).

### **Conclusions**

A key challenge for mental health services is the lack of clarity about what constitutes recovery-oriented practice. This synthesis of guidance contributes to the understanding of recovery orientation, and the resulting conceptual framework can be used to aid the translation of recovery-oriented guidance into practice.

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# Guidelines for Recovery-Oriented Practice

**Hope. Dignity. Inclusion.**

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# Contents

<b>4</b>	<b>Forewords</b>
<b>8</b>	<b>INTRODUCTION:</b> Guidelines for Recovery-Oriented Practice in Canada
<b>19</b>	<b>CHAPTER 1:</b> Creating a Culture and Language of Hope
<b>22</b>	Guideline 1: Promoting a Culture and Language of Hope and Optimism
<b>24</b>	<b>CHAPTER 2:</b> Recovery is Personal
<b>30</b>	Guideline 2A: Recovery is Person First and Holistic
<b>32</b>	Guideline 2B: Affirming Autonomy and Self-Determination
<b>34</b>	Guideline 2C: Focusing on Strengths and Personal Responsibility
<b>36</b>	Guideline 2D: Building Collaborative Relationships and Reflective Practice
<b>38</b>	<b>CHAPTER 3:</b> Recovery Occurs in the Context of One's Life
<b>44</b>	Guideline 3A: Recognizing the Value of Family, Friends and Community
<b>46</b>	Guideline 3B: Supporting Social Inclusion and Advocacy on Social Determinants
<b>48</b>	Guideline 3C: Addressing Stigma and Discrimination
<b>50</b>	Guideline 3D: Building Partnerships with Community
<b>52</b>	<b>CHAPTER 4:</b> Responding to the Diverse Needs of Everyone Living in Canada
<b>58</b>	Guideline 4A: Responsive to the Diverse Needs of Everyone Living in Canada
<b>60</b>	Guideline 4B: Responsive to Needs across the Lifespan
<b>62</b>	Guideline 4C: Responsive to the Needs of Immigrants, Refugees, Ethno-Cultural and Racialized (IRER) Communities.
<b>64</b>	Guideline 4D: Responsive to Gender Differences and to the Needs of Lesbian, Gay, Bisexual, Two-Spirited, Trans-Gendered, and Trans-Sexual People, their Families of Choice and Communities.
<b>66</b>	<b>CHAPTER 5:</b> Working with First Nations, Inuit and Métis
<b>74</b>	Guideline 5: Working with First Nations, Inuit and Métis
<b>78</b>	<b>CHAPTER 6:</b> Recovery is About Transforming Services and Systems
<b>84</b>	Guideline 6A: Recovery Vision, Commitment and Culture
<b>86</b>	Guideline 6B: Acknowledging, Valuing and Learning from People's Experiential Knowledge and from Families, Staff and Communities
<b>88</b>	Guideline 6C: Recovery-Promoting Service Partnerships
<b>90</b>	Guideline 6D: Workforce Development and Planning
<b>92</b>	<b>Getting Started and Measuring Progress</b>
<b>97</b>	<b>Conclusion</b>

It is with great pleasure and pride that I present the Guidelines for Recovery-Oriented Practice. Since its inception, the Mental Health Commission of Canada has made it a priority to work with people from across the country on ways to improve mental health systems based on a recovery orientation.

Recovery approaches stand on two pillars. First, they recognize that each person is a unique individual with the right to determine his or her own path towards mental health and well-being. Second, they also understand that we all live our lives in complex societies where many intersecting factors (biological, psychological, social, economic, cultural and spiritual) have an impact on mental health and well-being. These Guidelines encompass both dimensions, and in so doing address everyone with direct experience of mental health problems and those who support them, as well as the many communities – in all their diversity – in which people live, work and play.

The development of these Guidelines flows directly from recommendations in *Changing Directions, Changing Lives: The Mental Health Strategy for Canada*, released in May 2012. However, the impetus in Canada for embracing a recovery orientation stretches further back to the landmark Senate Committee report, *Out of the Shadows at Last* (2006). The roots of the recovery “movement” lie deeper still, nourished by decades of experience and advocacy by people with lived experience of mental health problems and illnesses and by the pioneering work of early champions and practitioners. This movement has been embraced in many countries, to the point that it has been called the new “paradigm” for mental health.

My enthusiasm for these Guidelines does not stem only from my conviction that they represent another step towards the creation of a mental health system that can respond to the full range of mental health needs of everyone living in Canada. It also reflects the personal values and commitments that have guided me during my many years of work at every level of the mental health system. The Guidelines concretize what a recovery-oriented system looks like and will help us build a holistic, person-centred and person-directed system, one that is grounded in best and leading practices and treats all people with dignity and respect.

Moreover, I am proud to say that, while the MHCC is always learning how to better incorporate a recovery perspective in its work, the recovery principles that infuse the Guidelines are already embedded in its initiatives. They are clearly visible in areas such as housing and homelessness and our ongoing efforts to address



stigma and discrimination; they are likewise reflected in the importance the Commission has attached to improving mental health in the workplace.

These Guidelines help to strengthen the foundation for change. They have drawn on the best international practice as well as on the knowledge and experience of people from coast to coast to coast in Canada. They provide support and encouragement for the many excellent recovery-oriented initiatives already underway, as well as inspiration for new ways of thinking and doing. To help them come alive, we need to make them a reference point for everyone who is part of, or who engages with, the mental health system, as well as all those who are working in areas that have an impact on people's mental health and well-being.

The mental health landscape in Canada has changed significantly for the better over the past decade. These Guidelines are a major addition to our collective resources and will help ensure that the momentum for change continues unabated.

**Louise Bradley**

**President and Chief Executive Officer,** Mental Health Commission of Canada

Recovery is on the lips of many in the mental health community, and those of us who live and breathe this practice know that the tide is turning in our mental health system. It is with great enthusiasm that I support the Mental Health Commission of Canada (MHCC) as it launches these recovery-oriented guidelines. With the support of service providers and policy makers across the country who have already embraced a recovery approach, the guidelines will help change the way we practice mental health care in this country.

For many of us experiencing mental health challenges and illnesses, recovery – the practice, the philosophy and the hard work – is not just a word, but an actual process. Recovery is made possible by having a safe space to be ourselves, and to find friends, family and peers who know and understand our experiences; it's nurtured when our voices are heard, and we get to speak our stories of courage and resilience. Recovery is about hope.

Every day, as the director of a peer-run mental health service, I see the real effects of discrimination and stigma. Recovery is quite difficult when your experience has marginalized you – by racism, sexism, homophobia, poverty, transphobia, histories of trauma and colonization, as well as by mental illness. A recovery lens allows us to appreciate the various ways we engage with the mental health system; it recognizes the value of working collaboratively across sectors, the important practices of peer support, respectful relationships, mutuality and equity, the social determinants of health and, of course, advocacy. Recovery-oriented practice can help us trust in the work that happens on the ground and at the grassroots in order to make fundamental changes to our mental health system.

We are in the midst of a powerful movement started by those with lived experience of mental illness, who knew that there was something much more to life besides diagnoses and dire conclusions that nothing would get better – a movement that is gaining ground and changing lives. I am eager to see how these guidelines are embraced by all of us in mental health care. I am inspired by the MHCC and all who have worked hard to develop the practices that are vital for keeping this movement marching forward.

### Shana Calixte

**Executive Director**, NISA/Northern Initiative for Social Action





What does recovery mean to those of us living with a mental health problem? It does not necessarily mean regaining the life and person we were before. Often, recovery is a journey towards a new life that better reflects our identity, our needs and our deepest desires. Recovery can bring us precious and unexpected gifts.

Yes, recovery is currently trending. And trendy words can sometimes become empty vessels that certain people will fill with their own interests, whether political, economic, corporate or clinical. For example, some of us believe, not without reason, that there is a risk of some of the principles associated with the recovery approach, such as autonomy and peer accountability, being hijacked. We fear seeing the approach being used to justify cutting services and, consequently, downloading even more of the weight of the recovery process onto the already overloaded shoulders of our peers and the members of their networks.

Since it is an approach whose roots are entwined with the very roots of the user movement, it is up to us to remain vigilant so that recovery retains its true nature. For this reason, I am pleased to support the efforts of the Mental Health Commission of Canada in publishing and disseminating the Guidelines for Recovery-Oriented Practice, a document that, in my view, infuses the term recovery with the full meaning we want it to have. It is no surprise that at least half of the team contributing to the Guidelines have lived experience of recovery.

Empowerment is not a privilege bestowed on someone but a right that peers must acknowledge. For this condition to become an integral part of our Canadian mental health system, leaders of the user movement must come together to embody this empowerment and ensure that the roots of our movement constitute the core of the identity and values of the broader recovery movement. It is only through a massive alliance of all players in the mental health environment and in the community that recovery will become a word that brings profound and positive change to mental health services – and to lives!

The Guidelines are definitely an important step in that direction.

### **Luc Vigneault**

**President,** Les Porte-voix du Rétablissement

The Quebec association of persons living with (or having experienced) a mental health problem



## INTRODUCTION

# Guidelines for Recovery-Oriented Practice in Canada

In the spring of 2006, the landmark report *Out of the Shadows at Last* called for recovery to be “placed at the centre of mental health reform”<sup>1</sup> in Canada. Since then impressive strides have been made across the country to embrace and implement a “recovery orientation,” both in policy and in practice. Many provinces and territories have incorporated the concept of recovery into their strategic and planning documents, and some have begun important initiatives to support recovery-oriented change.<sup>2</sup> Many health and mental health facilities have embraced recovery as the goal and transformed the way they work.<sup>3</sup> Recovery-oriented services and supports based in the community are becoming more widely available throughout Canada.

A recovery orientation also lies at the heart of *Changing Directions, Changing Lives: The Mental Health Strategy for Canada* released in 2012. In the words of the Strategy:

*An orientation toward recovery is helping to bring about important changes in the mental health systems of many countries. Here in Canada, recovery has strong roots in the advocacy efforts of people with lived experience and in the psychosocial rehabilitation field.... Recovery and well-being form the base of this Strategy and are now embraced by most provincial and territorial mental health policies.*<sup>4</sup>

The Strategy put forward two specific recommendations to help strengthen the commitment to a recovery orientation and its implementation across the mental health system:

- 2.1.1** Implement a range of recovery-oriented initiatives in Canada, including the development and implementation of recovery guidelines, and
- 2.1.2** Promote the education and training of mental health professionals, health professionals, and other service providers in recovery-oriented approaches.<sup>5</sup>

These Guidelines for Recovery-Oriented Practice represent an important contribution to achieving these recommendations. They constitute a key element of the work undertaken by the Mental Health Commission of Canada (MHCC) to build on the significant pockets of practice already oriented towards recovery and well-being across the country. Over the past two years, stakeholders and recovery champions have worked with the Commission to identify objectives that will help accelerate the implementation of recovery-oriented approaches across the mental health system.

The Guidelines have been written to provide a comprehensive Canadian reference document for understanding recovery and to promote a consistent application of recovery principles. They seek to build a common understanding, shared language and knowledge about recovery in order to:

- Provide a conceptual framework to help transform culture and practice.
- Promote the centrality of supporting people with lived experience, along with their families and caregivers, to play an active leadership role in their personal recovery; delivering ser-



vices; program design and development; policy setting; recruitment and development of staff; and evaluating services.

- Identify principles, values, knowledge, skills and behaviour that underlie recovery-oriented services and supports.
- Assist in implementing a recovery orientation across the country at a policy, program and practice level.
- Provide a benchmark against which to measure service alignment with evidence-informed recovery-oriented practices.

### **MOVING THE RECOVERY CONCEPT FORWARD**

The idea of recovery and the need for a mental health system geared to its promotion is not a new one. A key impetus for the development of the concept came directly from people with a lived experience of mental health problems in the 1980s and 1990s. They described their own experience and journeys and affirmed their personal identity beyond their diagnoses. They advocated for a system that provided hope, treated people with dignity and respect and supported everyone in finding their path to better mental health and well-being.

At the same time, there are many ideas that underpin the recovery philosophy – such as self-help, empowerment and advocacy – that have an even longer history, both inside and outside the mental health field. Some of these ideas had their roots in the Civil Rights movements of the 1960s and 1970s in the United States and in self-help groups such as Alcoholics Anonymous, where the concept of being “in recovery” remains a central tenet.

Recovery was key to the approach taken by pioneer psychiatric rehabilitation professionals in the United States, who began to challenge mental health services to adopt a recovery vision and transform their services to a recovery orientation. In Canada, PSR providers have long incorporated recovery ideas and practices and have actively advocated for the widespread adoption of a recovery orientation [see box].

## **PSYCHOSOCIAL REHABILITATION AND RECOVERY**

Psychosocial rehabilitation (PSR) approaches include programs, services and practices with documented effectiveness in facilitating recovery. PSR services are collaborative, person-centred, and individualized. They build upon each individual's strengths and skills and support people in accessing the resources they need for successful and satisfying lives in the communities of their choice.

PSR approaches include the best and most promising practices in key domains – including housing, employment, education, leisure, wellness and living skills – and draw upon emerging areas of family involvement, peer support and peer-delivered services. Supportive PSR services such as recovery-oriented Assertive Community Treatment (ACT) Teams are effective in enabling people with complex and persistent conditions to live successfully in the community and in helping to reduce emergency hospitalizations.

PSR researchers and practitioners have developed tools for individuals, their peers, families and service providers to facilitate recovery. PSR approaches contribute to the transformation to effective, recovery-oriented mental health services and systems. They can play an important role in supporting people in their journeys to wellness, and in improving housing, educational and employment outcomes, social supports and successful community living. Their adoption can also help to limit the personal, social and system costs associated with avoidable emergency admissions, hospitalizations, reliance on social assistance and involvement with law enforcement.

PSR/RPS Canada has developed Competencies of Practice for Canadian Recovery-Oriented Psychosocial Rehabilitation Practitioners, available at <http://www.psrrpscanada.ca/index.php?src=gen-docs&ref=competencies&category=Main>

The Commission launched its “Recovery Initiative” to help accelerate the movement to adopt recovery-oriented practice in Canada by developing the following three tools:

- 1 The Recovery Declaration – a tool to facilitate dialogue
- 2 An online inventory of recovery resources ([www.mentalhealthcommission.ca/inventory](http://www.mentalhealthcommission.ca/inventory)) and,
- 3 The development of Recovery Guidelines, presented here.

The release of the Declaration and the launch of the Inventory preceded the publication of these Guidelines.

Progress in advancing recovery as a foundational concept for the mental health system has not, however, been easy or straightforward. One of the challenges associated with broadening the uptake of a recovery orientation has been the need to help people understand what recovery-oriented practice means in concrete terms. These Guidelines will help answer the question “What does a recovery orientation look like in actual practice?”

For some, however, it is the recovery approach itself, or its implications for mental health practice, that remains challenging. Some concerns relate to the ways in which recovery is understood or interpreted, including that:

- The language of recovery may not be seen to reflect people’s historical, linguistic or cultural background and experience.
- The exact meaning of the term recovery is not always well defined, and may be interpreted by some to mean “cure.”
- The spectrum of mental health problems and illnesses to which recovery is applicable may not always be clear.
- Recovery may not be seen as relevant to children, youth and seniors.
- A recovery orientation may sometimes be thought to imply the wholesale rejection of existing practices in the mental health field, for example the use of psychopharmacology or involuntary treatment.

Other concerns arise from the perceived consequences of implementing a recovery orientation, including that:

- Emphasis on recovery may encourage a “false” sense of hope.
- Promoting self-reliance could lead to reduced public support for mental health services.
- A focus on the individual nature of a person’s recovery journey may lead to less attention being paid to the broader social factors that influence mental health.
- A recovery label could sometimes be applied to programs without reflecting real change.
- As recovery is more widely embraced, it may no longer reflect the values defined by people with lived experience.

These concerns reflect a variety of perspectives. While these Guidelines do not explicitly address them all, they do embody responses to them. Not everyone will agree with the approach taken in this document, but the Commission’s experience with promoting recovery, and of grappling with the many concerns about recovery, has informed the content of the Guidelines. The Commission wishes to highlight a few key elements of its approach as readers review and consider the Guidelines:

- Recovery does not equate with “cure,” but refers to “living a satisfying, hopeful and contributing life, even when there are ongoing limitations caused by mental health problems and illnesses.”<sup>6</sup>
- The underlying principles and philosophy of a recovery approach are applicable to all providers of mental health services, regardless of setting or type of mental health problem being addressed.
- The Guidelines present a foundational approach that will need to be adapted to the wide variety of mental health needs manifested across the population and complemented by other approaches.
- Upholding people’s ability to choose the type of support most suited to their needs implies that the “system” as a whole is able to make available the requisite range of services, treatments and supports from which people can in fact choose.
- While each person’s journey of recovery is unique, people do not journey alone; their journeys take place within a social, familial, political, economic, cultural and spiritual context that impacts their mental health and well-being.
- There may be different views on how best to implement a recovery-oriented practice, and it is important to allow these to be aired openly, collegially and widely.

The approach to these Guidelines was informed by a review of the literature, international guidelines and best practices. The format was inspired by an Australian model, articulated in the 2012 National Recovery-Oriented Mental Health Practice Framework, following extensive research and consultations over a two-year period. We are grateful to the Government of Australia for permission to borrow from its content and approach. The Guidelines were further developed and adapted to the Canadian context through consultation with recovery leaders and experts (including experts by experience) here in Canada; we are indebted to them for having shared their insights and experience with us. People with lived experience have also played a central role in the drafting and review of the Guidelines.

## USING THE GUIDELINES

Recovery-oriented approaches are inclusive, participatory and seek involvement of everyone to advance mental health and well-being. All people employed in the mental health service system, regardless of their role, profession, discipline, seniority or degree of contact with people using services are encouraged to draw upon these Guidelines. This document describes the dimensions of recovery-oriented practice and the key capabilities needed for the mental health workforce to function in accordance with recovery-oriented principles. It provides guidance on tailoring recovery-oriented approaches to respond to the diversity of people living with mental health problems and illnesses –people with a wide range of life circumstances and at different ages and stages of life. It complements existing professional standards and competency frameworks.

The experience and insights of people living with mental health problems and their families are at the heart of recovery-oriented culture. Recovery-oriented approaches recognize the value of this lived experience and bring it together with the expertise, knowledge and skills of mental health practitioners, many of whom have experienced mental health problems in their own lives or in their close relationships. Recovery approaches challenge traditional notions of professional power and expertise by helping to break down the conventional demarcation between

service users and staff. Within recovery paradigms, all people are respected for the experience, expertise and strengths they contribute.

Respecting peoples' experience means being open to diverse perspectives on mental health and wellness. A recovery approach is well suited to enabling bridges to be built across cultures and traditions. Although there may be elements in the language of "recovery" that do not immediately resonate with everyone, the foundational approach of adapting to people's needs, respecting people's strengths and experiences, adopting a holistic approach and understanding the impact of people's individual and collective histories on their well-being constitute a solid basis for mutual understanding and learning from one another.

For example, although First Nations, Inuit and Métis represent distinct cultural groups, they also largely share a common understanding of well-being or wellness as something that comes from a balance of body, mind, emotion and spirit and is embedded in culture and tied to the land. A strong belief in family, community and self-determination is also a common element. This rich cultural heritage and holistic understanding of the world have much to contribute to strengthening a recovery orientation and to the transformation of the mental health system in Canada.

Indigenous peoples in Canada are developing innovative approaches to healing and wellness that can have value for us all and are largely compatible with recovery-oriented practice.

For example, many Indigenous-led programs draw on the importance of cultural identity and self-determination, integrate traditional knowledge and the wisdom of elders with non-Indigenous approaches and recognize the close relationship between mental health, addictions, and inter-generational trauma.

More recently, Indigenous peoples in Canada have begun to refine and adapt the concept and practice of cultural safety first developed by Maori nurses in New Zealand. While the dialogue in Canada continues to evolve, cultural safety aims not only to improve the health outcomes of First Nations, Inuit and Métis, but also to help transform how the broader health system responds to diverse needs across multiple cultural dimensions. In particular, it draws our attention to the need for people of all origins to think critically about their own approach to mental health and mental illness and to seek ways to address the power imbalances and inequities that can have a major impact on health and social outcomes. This, too, mirrors a recovery approach.

These Guidelines present a set of values, attitudes, knowledge and skills that form a comprehensive approach to promoting recovery and provide a basis for reflection about how to align resources and organizational culture with a recovery approach. As such, the Guidelines contain a great deal of information and, even for those who have already committed to a recovery-oriented practice, it will take time and effort to figure out how to put them all into practice. The ways these guidelines are used will vary according to the circumstances of each organization or service and, in particular, the extent to which steps may already have been undertaken to embrace recovery-oriented culture and practice. The Guidelines can be used to help develop step-by-step plans that build on current strengths, advance practice changes already underway and help set goals. They can assist in developing procedures, establishing benchmarks and measuring outcomes.

Although not everyone will necessarily use the full array of elements they contain, the Guidelines are intended for use by a wide audience, including:

- Mental health professionals in a broad range of settings
- Staff and volunteers who have contact with people accessing mental health and support services, their families and supporters
- Policy and decision makers
- Professionals in other service systems or sectors that contribute to mental health and well-being, and
- All people accessing mental health services and their supporters.

While the Guidelines can apply across the spectrum of mental health conditions and are relevant to the full diversity of Canada's population across the lifespan, they will also require further "customization" to fully reflect the realities of different populations (e.g., children and youth, seniors, LGBTQ people), to more specifically address the learning needs of particular stakeholder groups (e.g., psychiatric nurses, social workers, employment counselors) or to provide more detailed guidance with respect to particular issues or situations (e.g., involuntary treatment and the use of seclusion and restraint).

In this sense, these Guidelines are a foundational document from which additional tools for knowledge exchange, implementation, evaluation, research and curricula can be developed. Implementing recovery-oriented practice will involve training and education, as well as reflection about values, beliefs and ways of working together. As educators consider curriculum changes to professional training, the core principles identified within the Guidelines can be helpful in identifying the knowledge, skills and behaviour required to ensure recovery-oriented practice. They

## SUBSTANCE ABUSE AND RECOVERY

Prevalence studies confirm that many, many individuals of all ages and backgrounds experience co-occurring mental health and substance use problems, as well as other forms of addiction. The relationship between mental illnesses and problematic substance use is complex. For some people, mental health problems can be risk factors for problematic substance use; for others, problematic substance use contributes to the development of mental health problems.<sup>7</sup>

Despite some differences in approaches to providing support and treatment, the vision and principles for recovery in addictions and mental health are complementary and overlapping. They both:

- Acknowledge the multidimensional nature and complexity of issues
- Appreciate that recovery is a personal journey, with goals defined by the individual
- Recognize the significance of family, peers, workplaces and a community of support
- Understand the need for collaboration across sectors, particularly in relation to social determinants
- Are founded upon hopeful, strengths-based approaches in pursuit of well-being, quality of life and full citizenship

There are multiple possible pathways to recovery in both mental health and addictions. For some who live with an addiction, this may mean pursuing abstinence. Recovery-oriented services do not address addictions and mental health problems sequentially, do not use exclusion criteria or impose treatments. Recovery-oriented practitioners and providers in both mental health and addictions services work with people at whatever happens to be their current state and respect the choices, autonomy, dignity and self-determination of service users. They see to people's safety and offer support for harm reduction, positive risk-taking and continual personal growth. Integrating mental health and addictions services at both the systems and practice levels provides the most helpful support for recovery.<sup>8</sup>

can inform the work of accreditation bodies so that recovery-oriented practices are defined as core elements of care and service delivery can be better aligned with recovery outcomes. The Commission will work with stakeholders to identify and further refine recovery-oriented tools to promote learning and accelerate change.

As emphasized throughout the Guidelines, advancing recovery also depends on the involvement of non-mental health organizations and groups, as well as the community as a whole. The Guidelines can serve as a common basis for creating collaborative partnerships between organizations and agencies, forging stronger relationships for shared learning, improving access to resource planning, engaging in advocacy and exploring ways to broaden social and economic opportunities for people living with mental health problems and illnesses. The Commission will continue to work with all stakeholders to weave together the many initiatives underway that improve the mental health of people living in Canada and build an inclusive community that values the diversity of all people.

## **THE DIMENSIONS OF RECOVERY PRACTICE**

The Guidelines have been organized into six key dimensions of recovery practice and are presented in a series of tables. Each Guideline table identifies the core principles and key capabilities for recovery-oriented practitioners and providers. The tables include a series of “reflective questions” for practitioners and leaders to encourage critical consideration of what they are doing and also suggest opportunities that could assist during implementation, as well as pointing to additional resources. Each “dimension” is introduced by a section that summarizes key issues.

**The elements of each Guideline are presented under the following headings:**

### **Core principles:**

those aspects that are foundational to the entire set of values, knowledge, skills, behaviour and practice and are relevant to the particular chapter topic (not recovery in its entirety).

### **Values:**

those values, beliefs and attitudes held by individuals that shape or influence behaviour, noting that values have an emotive component.

### **Knowledge:**

that which is intellectually understood or can be learned; the tables do not distinguish between levels or types of knowledge.

### **Skills and Behaviours:**

that which is manifested as observable actions.

### **Good practice reflective questions:**

intended to support individual practitioners’ efforts to translate recovery principles into their daily practice.

### **Good leadership reflective questions:**

directed at service providers, managers and leaders, these describe activities and governance structures that could be expected of a recovery-oriented organization.

**Opportunities:**

suggestions of types of activities that could assist during implementation.

**Resource materials:**

additional references to guide and support implementation.

Despite some overlap, each dimension has its own specific focus, and the dimensions are intended to be used concurrently. The order in which the dimensions are presented does not reflect their importance. It is anticipated that some readers may find certain chapters more helpful than others given their role or the nature of their service.

**The six dimensions of recovery-oriented practice are summarized below.**

**Dimension 1: Creating a Culture and Language of Hope**

Recovery is possible for everyone. Hope stimulates recovery, and acquiring the capabilities to nurture hope is the starting point for building a mental health system geared to fostering recovery. In this sense, recovery is fundamentally about hope. This chapter contains a single, overarching Guideline that describes how to communicate positive expectations and to promote hope and optimism in order to create a service culture and language that leads to a person feeling valued, important, welcomed and safe.

**Dimension 2: Recovery is Personal**

Core to a recovery orientation is the recognition of each person's uniqueness and their right to determine, to the greatest extent possible, their own path to mental health and well-being. Recovery acknowledges the individual nature of each person's journey of wellness and each person's right to find their own way to living a life of value and purpose in the community of their choice. This chapter is about viewing a person's life situation holistically, putting people at the centre of mental health practice and having practitioners partner with them to build on their strengths and foster autonomy.

**This chapter contains four Guidelines:**

- 1** Recovery is Person-First and Holistic
- 2** Affirming Autonomy and Self-Determination
- 3** Focusing on Strengths and Personal Responsibility
- 4** Building Collaborative Relationships and Reflective Practice



### **Dimension 3: Recovery Occurs in the Context of One's Life**

Since most of a person's recovery journey occurs outside the mental health system, fostering recovery necessitates understanding people within the context of their lives. Family, friends, neighbours, local community, schools, workplaces, spiritual and cultural communities all influence mental health and well-being and can play an important role in supporting recovery. Recovery-oriented practice works with people to help them lead a full and meaningful life, sustain their relationship to the world around them and participate as equal citizens in the social and economic life of their community.

**This chapter sets out the Guidelines** required for recovery-oriented practice to address the multiple factors that contribute to mental health problems and illnesses; it contains four Guidelines:

- 1** Recognizing the Value of Family, Friends and Community
- 2** Supporting Social Inclusion and Advocacy on Social Determinants
- 3** Addressing Stigma and Discrimination
- 4** Building Partnerships with Community

### **Dimension 4: Responding to the Diverse Needs of Everyone Living in Canada**

Recovery-oriented practice is grounded in principles that encourage and enable respect for diversity and that are consistent with culturally responsive, safe and competent practices. As well, the principles that inform a recovery orientation – such as fostering hope, enabling choice, encouraging responsibility and promoting dignity and respect – can, and indeed must, apply to people of all ages (taking into account their developmental stage) and to meeting the needs of lesbian, gay, bisexual, transgender and intersex people. Recovery-oriented practice is about appreciating the rich diversity of Canada's population in order to better respect the choices people make throughout their recovery process and determine how best to adapt services to meet their needs.

**This chapter contains four Guidelines:**

- 1** Responsive to the Diverse Needs of Everyone Living in Canada
- 2** Responsive to Needs Across the Lifespan
- 3** Responsive to the Needs of Immigrants, Refugees, Ethnocultural and Racialized Communities.
- 4** Responsive to Gender Differences and to the Needs of Lesbian, Gay, Bisexual, Two-Spirited, Transgender and Transsexual People, their Families of Choice and their Communities.



## **Dimension 5: Working with First Nations, Inuit and Métis**

There is common ground between recovery principles and shared Indigenous understandings of wellness that provides a rich opportunity for learning and for strengthening mental health policy and practice. Many principles that are grounded in Indigenous knowledge and cultures, such as promoting self-determination and dignity, adopting a holistic and strengths-based approach, fostering hope and purpose and sustaining meaningful relationships, also form the foundation of a recovery orientation. At the same time, recovery-oriented practitioners must recognize the distinct cultures, rights and circumstances of First Nations, Inuit and Métis, and understand how recovery for Indigenous peoples is uniquely shaped by Canada's history of colonization.

**This chapter contains one Guideline** which describes how recovery-oriented practice learns from Indigenous understandings of wellness and cultural safety and provides specific guidance on how service providers can best respect, work with and learn from First Nations, Inuit and Métis.

## **Dimension 6: Recovery is about Transforming Services and Systems**

Achieving a fully integrated recovery-oriented mental health system is an ongoing process that will take time to implement. Recovery is a journey not only for people living with mental illness and their families but for everyone involved in providing support and service. Irrespective of the type of service, service location, population served or professional roles, the commitment to recovery needs to find expression in everything an organization does, including ensuring support for a workforce that has the skills and resources required to deliver recovery-oriented practice.

**This chapter contains four Guidelines:**

- 1** Recovery Vision, Commitment and Culture
- 2** Acknowledging, Valuing and Learning from People's Experiential Knowledge and from Families, Staff and Communities
- 3** Recovery-Promoting Service Partnerships
- 4** Workforce Development and Planning

These Guidelines provide a reference point both for those who may be just beginning to think about how to implement a recovery orientation as well as for those who have already embarked on significant learning and promotion of recovery ideas and practice. There are also many aspects of these Guidelines that will benefit from additional dialogue, deeper reflection and further research. As we all continue the journey of learning and change, the Commission looks forward to working with people across the country to implement these guidelines and, where necessary, to further particularize them for specific disciplines, service sectors or populations.

## ENDNOTES FOR INTRODUCTION

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## CHAPTER 1

# Creating a Culture and Language of Hope

Hope is the foundation on which a journey of recovery is built. A recovery approach focuses on the values, hopes and dreams of each person, while never losing sight of the impact of the social context on people's lives. Feeling positive about the future contributes to everyone's mental health and well-being and is of particular importance when people are living with mental health problems and illnesses. Too often, people who experience the onset of a mental illness are led to believe that they should not expect to be able to function at work, in school, within society or be capable of caring for themselves independently. This lack of optimism can crush hope and limit a person's ability to recover.

On the contrary, despite the challenges, people can thrive and succeed. Long-term outcome studies and promising research on successful interventions and on the ability of our brains to adapt are inspiring hope and challenging pessimistic beliefs about the chronicity of mental health problems and illnesses.<sup>1</sup> Research shows that having hope plays an integral role in the process of recovery and in fact is essential to achieving the best possible outcome.<sup>2</sup> Having hope is equally important for family members and others supporting people on their journey of recovery, including health and mental health providers.

Hope is not an abstract concept, nor is it an unreasonable expectation. At its core, being hopeful means holding an expectation for positive development. Hope helps provide the motivation and sustain the strength required to confront the many challenges posed by mental health problems and illnesses. It can

be activated by accepting people for who they are and holding a belief in everyone's potential to build a life of meaning and purpose.<sup>3</sup>

Hope has many expressions – there is no standardized path of recovery or single definition of what it means for each person. For some it will mean returning to their previous life, even if symptoms persist. For others, the recovery journey may represent a new beginning and an experience leading to positive transformation. The specifics of what one hopes for will vary from person to person; the need to have hope, however, is common to all.

Fostering hope does not mean ignoring the real distress people experience or the challenges they may face. During times of diminished hope, it is often the support of caring others that holds the key to a brighter future. Hope is sometimes an ember that can be fanned into the flame that makes recovery possible. In first-person stories of recovery, people frequently remark on how it was the sustained support of just one individual, able to see their potential and mirror it back, that helped to kick-start their recovery process.<sup>4</sup>

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**By embedding, modelling and communicating a culture of hope in everything they do, mental health providers can make a significant contribution to a person's recovery journey.**

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## “Family”

Throughout these Guidelines the term “family” will be used to describe those who are within a person’s chosen circle of support, which may include family members and loved ones. Some refer to this as a “family of choice.”

Health and mental health service providers can play a critical role in influencing hope through their words and actions. To consistently encourage hope and the expectation of recovery, mental health providers may need to reflect on their own experience. They often see people in their most vulnerable and distressed state and may only rarely have the opportunity to follow people as they get better. As a consequence, some may hold pessimistic and potentially stigmatizing attitudes about the possibility for recovery.<sup>5</sup>

A key source of hope comes from looking beyond the challenges that may accompany illness to see people’s unique strengths, character, innate abilities and potential for growth. By embedding, modelling and communicating a culture of hope in everything they do, mental health providers can make a significant contribution to a person’s recovery journey. Hope is also fostered by peers with lived experience who can share their own path of recovery, the actions they have taken, the resources they have drawn upon and the tools they have used to build a new meaningful life for themselves.

Recovery is nurtured by working with people to help activate their internal resources so they are able to retain and deepen a belief in their abilities, strengthen their sense of personal agency and acquire control over their journey of recovery and well-being. When people are encouraged to focus on their strengths and what they can do—rather than on their limitations and the barriers they face—they are more likely to access available resources, take risks and explore new opportunities. Recovery-oriented practice enables people to choose from amongst a full range of treatments, supports and services that would benefit them. By demonstrating genuine concern for the person’s well-being and building day-to-day interactions on a foundation of

kindness and mutual respect, practitioners can create a positive culture of healing.

Language matters. Avoiding the use of terms that convey pessimism and helping people to regain a positive sense of identity contribute to supporting recovery. Hope can be encouraged through optimistic representations of people in all their diversity recounting stories of recovery and resilience. Organizations can promote recovery by reflecting hope in all their written material, including mission statements, policies, forms, websites, social media and brochures. Active, nonjudgmental listening, supporting self-determination and choice and promoting opportunities for growth all help reinforce hope. Fostering hope does not mean ignoring the real distress people experience or the challenges they may face.

In addition, organizations can support staff to develop recovery-oriented skills and collaborative partnerships as well as to learn how to encourage positive risk-taking that can contribute to personal growth and empowerment. Supporting self-management and the use of tools such as recovery action

plans and Advanced Care Directives reflect a belief in the person's capabilities, communicates the hope of recovery and helps to align programs and services to reflect recovery values and practices.<sup>6</sup>

Families and friends often provide the bulk of day-to-day support and can be an important part of a person's chosen recovery team. They can be carriers of hope by helping people recall and build upon their successes and positive experiences. Yet, families, friends and a person's wider circle of support can also struggle to maintain optimism in the face of illness. They are entitled to hold hope for themselves, and providers also need to be respectful of their needs and help nurture the recovery of family unity from the stresses associated with mental distress.<sup>7</sup>

Recovery is possible for everyone. Hope stimulates recovery, and acquiring the capabilities to nurture hope is the starting point for building a mental health system geared to fostering recovery. At its core, recovery is fundamentally about hope.

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# Promoting a Culture and Language of Hope and Optimism

**The culture and language of recovery-oriented practice communicates positive expectations and promotes hope so that people feel valued, important, welcome and safe.**

## CORE PRINCIPLES

- » Everyone delivering mental health services, treatments and supports can make a significant contribution to a person's recovery by building respectful person-centred relationships and conveying a culture of hope and personal empowerment.
- » Hope is supported by using positive language, maintaining a focus on strengths, building resources and helping people sustain relationships.
- » Providing the opportunity for people to express their goals and self-direct their care helps to build hope.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Respect and value a person's inherent worth and importance.
- Affirm a belief in a person's capacity to recover, thrive and lead a meaningful and contributing life.
- Celebrate each person's effort and achievements.
- Commit to embedding optimism and the expectation of positive outcomes in language and relationships.

### Knowledge

- Understand the core concepts of recovery and the role people with lived experience have played in its development.
- Maintain knowledge of current issues in recovery literature and research, including from broader fields such as positive psychology and organizational culture change.
- Learn from research undertaken by people with lived experience.
- Understand the research on stigma and discrimination and its implications for hope and optimism.
- Learn and respect the recovery lexicon, and understand the significance of language in promoting hope.

### Skills and Behaviours

- Communicate expectations for positive outcomes as well as hopeful messages about recovery.
- Create a welcoming and accepting environment for growth through the use of non-judgmental listening, genuineness and warmth.
- Utilize hopeful and strength-based language in interactions and in written communication.
- Encourage consideration of culture, social connections and roles, physical activity, sexuality, creative expression and connection to faith communities as potential sources of meaning and hopefulness.
- Support people to explore the impact of external barriers such as limited access to housing or poverty on feelings of hope.
- Encourage connections with peer supporters who can relate to people's challenges and ignite hope.
- Invite people to recall previous achievements and reflect on positive experiences.
- Reframe setbacks in the context of learning opportunities and the prospect for longer-term recovery outcomes.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented Practice

- Do you engage people early in setting personal recovery goals and help people monitor indicators of progress toward their goals?
- How do you model hope and provide ongoing opportunities to discuss, celebrate and promote people's recovery stories and their ability to learn from successes?
- Is there encouragement for team members to learn to be optimistic, use hopeful language and communicate positive expectations?
- How do you systematically engage family members, supporters and caregivers in creating a climate of optimism and encouraging positive outcomes?

**REFLECTIVE PRACTICE QUESTIONS** (Continued)**Recovery-oriented Leadership**

- What are the visible signs of a safe, welcoming and inclusive environment in your organization?
- Are resources made available for people with lived experience, families and caregivers to gather together and share their experience and stories of success?
- Have you ensured adequate training for team members to further develop their own learned optimism and positive mindset?
- Have you taken a critical look at policies and materials used for education, orientation and community engagement – is the language positive, encouraging of inclusion and hopeful?
- What channels, mechanisms and organizational supports are in place to hear challenges or complaints from those who did not experience a positive or hopeful organizational culture?
- Do you model and provide feedback to reinforce recovery-oriented behaviours and language in service planning, coordination and review processes?
- Are leaders of the organization visible and active participants in celebrating achievement, growth and progress towards recovery goals?

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**OPPORTUNITIES FOR LEADERS AND MANAGERS**

- Sponsor service-wide and regional exchange of research and information about recovery concepts; support staff to participate in such conferences and case rounds.
- Encourage the development of peer-produced resources that share and celebrate achievements of people with lived experience; help make these widely available using a variety of means such as films, booklets, art exhibits, newspapers and social media; and publicize these on your program or organization's website and calendar of events.
- Support local recovery champions and introduce them to other local leaders in order to advance community understanding and rally support.
- Initiate conversations with your staff, governing board and regulatory bodies about how to build hopeful and optimistic organizations with positive statements of expectations for clients, staff, volunteers and visitors.
- Facilitate training opportunities for staff in reflective practice, and provide staff with time to engage in this activity.
- Incorporate tools that measure hope and optimism – including amongst staff – as part of your evaluation process.
- Reorient your performance development and coaching tools to incorporate the culture and language of hope and optimism, using specific observable feedback and modelling mutual goal-setting.

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**RESOURCE MATERIALS**

- Hope Studies Central. Research centre in Edmonton committed to the study of hope in human living. See University of Alberta, Faculty of Education, Hope Studies Central, retrieved from [www.ualberta.ca/hope](http://www.ualberta.ca/hope)
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## CHAPTER 2

# Recovery is Personal

This chapter outlines four key sets of capabilities that define the personal dimensions of recovery. Its purpose is to set out how recovery-oriented services and supports can strengthen each person's capacity to undertake a journey towards recovery by fostering individual strengths and encouraging people to be the authors of their own lives. A strong working alliance between people living with mental health problems and illnesses and providers is essential. When such an alliance encourages choice and autonomy, it is positively associated with improved recovery outcomes and greater satisfaction, both for those who receive service and for service providers.

**The following Guidelines are addressed in this chapter:**

- Recovery is Person-First and Holistic
- Affirming Autonomy and Self-Determination
- Focusing on Strengths and Personal Responsibility
- Building Collaborative Relationships and Reflective Practice

Central to a recovery orientation is the recognition of each person's distinctiveness and their right to determine – with as few exceptions as possible – their own path to mental health and well-being. Recovery-oriented practice acknowledges the unique nature of each person's journey of wellness and everyone's right to find their own way to living a life of value and purpose in the community of their choice. A recovery orientation encourages everyone to take charge of improving their own mental health and well-being and understands the very exercise of this ability to be an important contributor to achieving well-being.<sup>1</sup>

However, a recovery orientation also understands that we are not “isolated,” “self-sufficient” individuals, cut off from our histories, backgrounds, cultures, communities and families. Affirming each person's right to determine their own path to well-being does not imply that they journey on their own. Rather, a rich web of relationships to people, places and traditions forms the foundation for each person's individual journey towards improved well-being.<sup>2</sup>

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**A recovery orientation encourages everyone to take charge of improving their own mental health and well-being and understands the very exercise of this ability to be an important contributor to achieving well-being**

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There are also many different beliefs about what it means to be an individual and various ways of approaching how each person relates to the world around them. We each bring our own preferences for how we would like to connect to those around us, and a recovery orientation does not prescribe one formula for what it means to be an individual or the nature of each individual's relationship to their surroundings. For some people, connection to one's biological family may be central, while for others it may be a larger community, a tradition or a set of beliefs that helps them define who they are.<sup>3</sup>



## **A SHIFT FROM PATIENT TO PERSON**

A central shift entailed by embracing a recovery orientation involves seeing each individual not as a "patient" who is fundamentally different or damaged, but as a person striving to live the most fulfilling life possible. Recovery-oriented practice helps to highlight our shared humanity and avoids putting labels on people or defining them by a diagnosis.<sup>4</sup>

Each person brings their own special skills, qualities, values and experience and holds multiple roles and identities that fuel their sense of personal agency and can be drawn upon to support recovery. A holistic recovery-oriented approach seeks to understand the interplay between the multiple factors – including biological, psychological, social, economic, cultural and spiritual ones – that affect each person's well-being.

Focusing on the inherent and diverse strengths and abilities of each person, rather than on their deficits or limitations, motivates people to feel good about themselves and builds confidence and resilience while helping people take action towards achieving their goals. Recovery-oriented practice supports people in identifying sources of personal meaning and valued social roles, along with tools to support resilience, coping and healthy living, including contact with peers.

## **RISK-TAKING IS PART OF GROWTH**

An essential part of our shared human experience is the ability to learn and grow from the decisions we make, and this is no different for people living with mental health problems and illnesses. Recovery-oriented practice facilitates people's ability to choose from amongst all major types of interventions including biological and pharmacological treatments, psychological and psychotherapeutic approaches, psychosocial rehabilitation and support, peer support, physical activity

## **SELF-MANAGEMENT OF MENTAL HEALTH MEDICATION**

Self-management of mental health medication (GAM, in French) is an approach developed by a number of organizations in Quebec<sup>16</sup> to enable people who are taking medication to find the one best suited to their needs and, working with their physician as coach and partner, to take responsibility for their own medication. GAM is one example of an approach designed to make medication part of an overall strategy to improve global quality of life and well-being, and to empower people to regain control over the different dimensions of their lives.

Created from a blend of experiential knowledge (people with lived experience, practitioners, managers) and research, the GAM approach represents a unique and comprehensive way to take into account both the benefits and adverse effects of various medications. The GAM process is founded on respecting a person's desired outcomes. It insists on the necessity of providing people living with mental health problems access to complete information concerning medication and alternative treatments as the basis on which to identify a treatment that will best balance each person's ability to manage symptoms while retaining their optimal mental and physical functioning. Moreover, it allows people to review the very significance of taking medication for their sense of who they are – something that can be as important to people with mental health problems as the actual effects of medication.

This novel approach was developed in the mid-90s in Quebec and has since inspired similar approaches in other provinces, notably Ontario, and other parts of the world, in particular Brazil.

and exercise, alcohol and drug treatment and counselling, traditional healing in different cultures and alternative and complementary treatments.<sup>5</sup>

Recovery practitioners acknowledge that there may be differences of opinion on the best course of action and that the possibility of risk is the inevitable consequence of empowering people to make decisions about their own lives. Respecting the “dignity of risk” means remaining engaged with people even when they take actions that may seem misguided to others. It entails addressing the tension between maximizing personal choice and supporting positive risk-taking on the one hand, and promoting safety on the other. Recovery is not a linear process. Recovery-oriented practice encourages learning and using mistakes or setbacks as opportunities for insight and personal growth. Resilience is developed by engaging, rather than avoiding, life’s challenges.<sup>6</sup>

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**An essential part of our shared human experience is the ability to learn and grow from the decisions we make, and this is no different for people living with mental health problems and illnesses.**

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Supporters and providers may not always agree with the choices people make. Honouring choice does not mean ignoring harmful risks or minimizing safety, but rather allowing each individual’s personal experiences, understandings, priorities and preferences to shape service delivery. It requires developing flexible strategies aimed at preventing or minimizing the potential negative impact of risk-taking. Negotiating differences of opinion

can be an opportunity to share knowledge and perspective and help inform decisions that assist in mitigating harm.<sup>7</sup>

## **RESTRICTIONS ARE MINIMIZED**

Recovery-oriented mental health services commit to reducing restrictions to freedom and involuntary interventions to a minimum. Nonetheless, mental health problems and illnesses can be episodic, and there may be times when people lack the capacity to make important life decisions.<sup>8</sup> During a crisis, should the person temporarily lose their mental ability to make sound decisions and other options have been exhausted, family and professionals may need to intervene on the person’s behalf and seek some form of compulsory treatment. Recovery principles emphasize the importance of working collaboratively with a person and their family irrespective of whether they are receiving treatment voluntarily or involuntarily, or whether that treatment is in a hospital or in the community. They encourage a full, open and honest discussion and negotiation about all legal requirements.

If decision-making responsibility is withdrawn, an important recovery goal is to support people to regain decision-making as quickly as possible. The concepts of self-determination, personal responsibility and self-management and the goals of reclaiming control and choice are pivotal regardless of a person’s legal status. The development of advanced directives, for example, provides an opportunity for open, transparent and honest discussion of perceived risk and safety planning. They can provide guidance to mental health providers in protecting people’s rights and in keeping their values and wishes at the forefront during a crisis.<sup>9</sup> A follow-up review of steps taken to manage the crisis can help people negotiate a preferred course of fu-

ture action and bring to the fore skills and resources they may need to identify risks and manage potential problems down the road.

## **RECOVERY IS STRENGTHENED THROUGH PARTNERSHIP**

Building collaborative, mutually trusting and respectful partnerships with service users, their families and caregivers is foundational to recovery-oriented practice. Recovery-oriented care respects people as partners in all decisions that affect their mental health and emphasizes the importance of autonomy, self-determination and self-management. In recovery-oriented practice, the insight and expertise derived from “lived experience” is valued, and practitioners work alongside the person to co-design service plans, encourage problem solving and provide choices, rather than taking unilateral action to “fix” the problem or the person.<sup>10</sup>

By adopting a hopeful attitude and actively encouraging the person’s leadership in all aspects of decision-making, the focus of support in a recovery-oriented relationship rests on assisting people to build their lives in the ways that they desire. The aim is to shift the balance within the relationship away from taking responsibility for the person and towards walking with the person on their journey of recovery. Professional expertise remains an essential ingredient, but one that is applied to support informed choice, shared decision-making and self-management. Professional expertise, when deployed within a coaching context, can help activate the individual’s self-righting<sup>11</sup> capacity.<sup>12</sup>

Building recovery-oriented partnerships requires practitioners to have personal insight, undertake ongoing critical reflection and maintain openness towards continuous learning. Negotiating and collaborating within a partnership-based relationship involves

## **The “dignity of risk”**

or the “right to failure,” is a value first championed by advocates for people with physical disabilities. It refers to the importance of respecting a person’s right to take risks as part of personal growth.

values awareness by practitioners and self-knowledge about their personal, professional and cultural values and beliefs. Recognizing and acknowledging the power difference that may exist within the relationship can help to minimize bias and the likelihood of using directive and coercive practices.

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**Affirming each person's right to determine their own path to well-being does not imply that they journey on their own.**

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Many professionals working in mental health also bring their own experience with mental health problems or illnesses, either directly or within their family or other relationships.<sup>13</sup> The awareness gained through their own lived experience can be used positively to create empathy and model hope. When managed well, self-disclosure can serve as a therapeutic tool within a counselling relationship,<sup>14</sup> but practitioners need to reflect on the potential impact of their personal experience on decision-making and on their relationship with the people they support.<sup>15</sup>

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## Recovery is Person-First and Holistic

**Recovery-oriented practice acknowledges the range of influences that affect a person's mental health and well-being and provides a range of services, treatment, rehabilitation, psycho-social and recovery support.**

### CORE PRINCIPLES

- » Each person is a unique individual with the right to determine their own path towards mental health and well-being.
- » Recovery is an individual process – care and services are tailored to people's preferences, life circumstances and aspirations and are integrated with their community of supports.
- » Everyone's mental health and well-being is affected by multiple intersecting factors – biological, psychological, social and economic, as well as family context and cultural background, personal values and spiritual beliefs.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Believe in the ability and right of a person to make their own life decisions.
- View people in the context of their whole selves and lives.
- Appreciate the complexity of needs and aspirations across cultural, spiritual, social, economic, emotional and physical realms.
- Accept that identity and personhood are not limited or defined by a person's mental health status.

#### Knowledge

- Understand the individual and personal nature of recovery and recovery approaches, and respect, learn from and understand those developed by people with lived experience.
- Incorporate bio-psychosocial theoretical perspectives on health, mental health and well-being.
- Recognize the interplay between physical health, mental health and coexisting conditions.
- Understand the physical health challenges faced by people living with mental illness and the importance of monitoring health and well-being and treating chronic illness.
- Know the range of treatments and therapies that can contribute to recovery, including biological and pharmacological treatments, psychological and psychotherapeutic approaches, psychosocial rehabilitation and support, peer support, physical health care, alcohol and drug treatment and counseling, nutrition, exercise and recreation interventions, traditional healing in different cultures and alternative and complementary treatments, such as yoga, acupuncture, Ayurveda etc.
- Understand the prevalence and effects of trauma, how to practice trauma informed care and prevent the retriggering of trauma.

#### Skills and Behaviours

- Respectfully explore a person's circumstances and identify what is important and meaningful to them.
- Assist individuals, as well as family members and caregivers, to explore and express their aspirations for recovery and well-being.
- Acknowledge a person's family, caregivers and circles of support, and with the person's consent, work to include them as partners in recovery planning.
- Facilitate access to information, treatment, support and resources in line with a person's recovery goals.
- Describe pros and cons of different treatment options to promote decision-making and support people to make best use of treatments, therapies and services.
- Explore ways to minimize side effects or other potential harm from interventions, as well as ways to achieve an optimal therapeutic level of medication, including withdrawal from medication if a person so chooses.
- Address multiple needs collaboratively and simultaneously, and coordinate a range of relevant services, including: health services, peer support, alcohol and drug services, harm reduction, poverty alleviation, disability management, employment, education and training and housing supports.

## **REFLECTIVE PRACTICE QUESTIONS**

### **Recovery-oriented practice**

- How has your practice been responsive to individuals' expectations, recovery goals and unique needs?
- How have you sought to understand what helps with recovery and learn from those you serve?
- Have you considered what possible alternative service offerings might be appropriate?
- Does the treatment/service plan create opportunities for attention to physical health, exercise, recreation, nutrition, expressions of spirituality, sexuality and creative outlets, in addition to stress and symptom management?
- What do you do to maintain positive connections with referring agencies and service partnerships to be able to offer people a range of options?

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### **Recovery-oriented leadership**

- To what extent can the systems and processes in your setting (e.g., intake, documentation, family involvement) offer flexible and individualized approaches?
- Have you critically reviewed the assessment and care planning processes in use – is there reference to a person's home environment, personal goals, priorities, relationships or natural supports?
- How do you help people obtain access to a broad range of treatment approaches, services and support options?
- In clinical governance, policies and professional development, do leaders reinforce that the person is central to all that is done and create the opportunity for people with lived experience to determine their own path of recovery and participate in decision-making?

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## **OPPORTUNITIES FOR LEADERS AND MANAGERS**

- Use a variety of media and formats to provide program and service information for people with lived experience, families and staff.
- Seek to understand staff beyond their employment identity, and model an approach that recognizes the impact of multiple intersecting factors on mental health and well-being.
- Highlight opportunities for staff to take account of individual variation and particularize recovery goals within standard clinical pathways; help them introduce co-design to replace traditional care plans.
- Collaborate with managers who have expertise in complementary sectors so that staff and clients can experience a broader range of supports.

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## **RESOURCE MATERIALS**

- Conner, A., & Macaskill, D. (n.d.). Providing person-centred support. Realising recovery, Module 4. Glasgow, Scotland: Scottish Recovery Network & NHS Education for Scotland. Retrieved from <http://www.scottishrecovery.net/Professional-Learning-and-Development/realising-recovery.html>
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## Affirming Autonomy and Self-Determination

**Recovery-oriented practice affirms a person's right to exercise self-determination, to exercise personal control, to make decisions and to learn and grow through experience.**

### CORE PRINCIPLES

- » Personal control, self-agency and the ability to choose are fundamental to recovery.
- » A recovery orientation positions and respects people as partners in decisions affecting their mental health care.
- » Personal experiences, understandings, priorities and preferences shape choices and decision-making in the context of service delivery.
- » Safety and well-being of everyone is enhanced by promoting personal efficacy and responsibility.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Afford primacy to the wishes and views of the person accessing the service.
- Respect each person's choices and their right to self-determination.
- Recognize the importance of balancing the rights and interests of individuals against the need to ensure the safety of the individual, family members and others in the broader community.
- Seek alternatives to coercion and involuntary interventions and work to make them unnecessary.

#### Knowledge

- Understand the relationship between autonomy, self-determination, resilience and recovery.
- Understand the role of local advocacy, peer support and rights advisor groups in supporting decision-making.
- Are aware of the research evidence related to trauma and coercive intervention, and its implications for recovery.
- Appreciate the importance of positive learning and risk taking to recovery, and know strategies to enable responsible risk-taking.
- Recognize ethical and legal requirements when making decisions about restricting freedoms.

#### Skills and Behaviours

- Use communication techniques (e.g., motivational interviewing, reflective listening) to promote a person's self-advocacy and help them to articulate their goals, motivations, challenges and priorities.
- Inform people of their rights, and support them in exercising their rights.
- Create safe environments where people can explore options, co-design their service plans, take positive risks and strive for growth.
- Maintain engagement, and offer opportunities for decision-making, including self-determination and choice, taking into account any legal considerations.
- Facilitate availability of advance directives / power of attorney for personal care to enable people to determine their preferred course of action should future crises arise.
- Promote opportunities for maximum autonomy and self-determination during assessment and in the coordination of service referrals.



## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- Do your assessment processes and forms demonstrate evidence of support for personal autonomy and self-determination?
- Do you use recovery and well-being planning tools that have been developed and validated through meaningful consultation with people with lived experience?
- What examples can you provide of how you have removed barriers to enable people to carry on with their tasks of daily living?

### Recovery-oriented leadership

- How do you encourage positive risk-taking, acknowledge progress and reframe setbacks using affirmative language?
- How have you assisted the service team to collaboratively explore strategies for avoiding coercion, including the involvement of persons with lived experience in these efforts?
- Is there evidence of respecting the principles of autonomy and self-determination in service policies and procedures?
- What checks and processes are in place to ensure any limitations on a person's choice, autonomy and self-determination are the least restrictive they can be and removed as soon as possible?
- How do you help staff consider the range of options to promote individual, staff and community safety, and access the best-practice research related to trauma, advance directives and determining capacity?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Visit sites with person-held service records already in use; advocate for action plans that are co-designed and for opportunities for shared charting.
- Ensure that staff understand and appreciate relevant legislation and have access to mental health law resources so they are equipped to promote people's autonomy, protect their rights and support decision-making.
- Expand availability of ethics consultation for clinical staff and organizational decision-makers through collaborative arrangements with groups of organizations or academic centres.
- Expand the availability of peer support to strengthen the person's involvement in decision-making, and aid in the development of Advanced Care Directives and performing safety audits.
- Seek opportunities to enable people with lived experience to lead in defining research priorities and become co-creators of research knowledge.
- Become directly involved in efforts to eliminate coercive practices, and sponsor celebrations to highlight milestone reductions in seclusion and restraint.

## RESOURCE MATERIALS

- Alexander, A. (n.d.). Understanding recovery. Realising recovery, Module 1. Glasgow, Scotland: Scottish Recovery Network & NHS Education for Scotland. Retrieved from <http://www.scottishrecovery.net/Professional-Learning-and-Development/realising-recovery.html>
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## Focusing on Strengths and Personal Responsibility

**Recovery-oriented mental health care focuses on people's strengths and supports resilience and the capacity for personal responsibility, self-advocacy and positive change.**

### CORE PRINCIPLES

- » People have the potential to recover, reclaim and transform their lives.
- » People generally share common hopes, needs and responsibilities; however each person will have a unique approach to achieving them.
- » A focus on strengths and abilities motivates and contributes to building the confidence and resilience necessary for self-agency.
- » Taking responsibility for one's own health and well-being begins the recovery process.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Convey belief in people's capacity to reach their goals and have a life rich in possibility and meaning.
- Commit to focusing on people's strengths in one's attitude, language and actions.
- Recognize that engagement with people and offering support promotes personal recovery.

#### Knowledge

- Know how to apply strengths-based approaches.
- Understand the concepts of resilience, mindfulness and elements of positive psychology.
- Appreciate the implications of power imbalances on therapeutic relationships, and know ways to foster shared responsibility.
- Understand how forms of discrimination can be present within health, mental health and other systems, and be prepared to explore their impact on people.

#### Skills and Behaviours

- Use coaching and motivational techniques to help people use their strengths.
- Explore with people what their recovery path looks like and what works well for them.
- Foster people's belief in their ability to recover.
- Demonstrate confidence in people's ability to fulfill important roles such as parenting.
- Explore options for strengthening self-management of symptoms, monitoring of triggers and identifying environmental stressors and early warning signs of changing capacity.
- Offer education and tools (including technological and on-line self-management tools) to assist in maintaining physical health, employing trauma-informed care, chronic disease and medication management, and to help promote mental health and well-being.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How do your assessment and collaborative service planning processes highlight a person's strengths and assets, foster responsibility, support positive identity and nurture hope?
- How does your documentation reflect a person's strengths and self-defined goals?
- What have you done to prompt family and support people to focus on strengths, enhancing abilities and supporting risk taking?
- How do you encourage the reinforcement of people's successes and resilience on their journey of recovery, along with their ability to draw on these in other life contexts?
- What approaches have you used to actively foster people's resilience and learning?

### Recovery-oriented leadership

- How do you encourage staff and team members to recognize, reflect upon and celebrate a person's achievements and outcomes?
- Do you draw on lived experience and encourage the co-design of policies and procedures?
- Have you critically assessed the language in forms, tools, data collection and education and training materials – do they emphasize strengths, assets, building relationships and providing supports?
- How do you proactively model strengths-based approaches with staff and team members?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Introduce strengths-based discovery and learning tools in continuing education and performance development initiatives.
- Use information resources and communication materials that promote positive messages and emphasize strengths in all settings – with staff, visitors, the general public and the media.
- Engage with others beyond your sector/service setting to foster opportunities for people to apply and build upon their identified strengths and develop transferable skills.
- Support the establishment of Recovery Colleges that focus on enhancing skills, civic engagement and acquiring tools for self-management and career development.

## RESOURCE MATERIALS

- Bird, V. J., Le Boutillier, C., Leamy, M., Larsen, J., Oades, L. G., Williams, J., & Slade, M. (2012). Assessing the strengths of mental health consumers: A systematic review. *Psychological Assessment*, 24(4), 1024–1033. doi: 10.1037/a0028983
- Canadian Mental Health Association Calgary Region. (2012). Self-advocacy guide. Retrieved from <http://calgary.cmha.ca/files/2012/07/Self-Advocacy-Guide-08.pdf>
- Manitoba Trauma Information and Education Centre. (2013a). Introduction to recovery. Retrieved from <http://trauma-recovery.ca/>
- Manitoba Trauma Information and Education Centre. (2013b). Mental health. Retrieved from <http://trauma-recovery.ca/resiliency/mental-health/>
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# Building Collaborative Relationships and Reflective Practice

**Recovery-oriented practitioners demonstrate reflective practice and build collaborative, mutually respectful, partnership-based relationships with people to support them in building their lives in the way they desire.**

## CORE PRINCIPLES

- » Recovery-oriented practice and service delivery are built upon mutually respectful and collaborative partnerships.
- » Supporting another's recovery requires reflection and awareness of one's own culture, values, beliefs and mental health.
- » High quality therapeutic relationships require ongoing critical reflection and continuous learning.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Are open and willing to learn from the person in recovery as well as from their family and circle of support.
- Place the priority on the needs of the person being supported.
- Are open to using their own personal experience as a way to demonstrate empathy and strengthen the collaborative relationship, while maintaining professional boundaries and recognizing how this differs from peer roles.
- Respect others as equal partners in the therapeutic relationship, and acknowledge people as the directors of their own lives.
- Demonstrate commitment to reflective practice and recognize its role in enabling authentic engagement and the development of collaborative relationships.

### Knowledge

- Understand the impact of culture, values, life experiences, roles and power in interactions and relationships.
- Know a range of collaborative practices and communication techniques.
- Know the foundational elements of building trust and how to apply them to developing collaborative therapeutic relationships.
- Understand the relevance of the stages of change in order to align practice with a person's motivational stage and readiness to move forward.

### Skills and Behaviours

- Demonstrate kindness, honesty and empathy in interactions with people as a foundation for being respectful and genuine.
- Offer professional expertise and tools to help the person alleviate distress and lessen the possibility of setbacks or harmful risk.
- Continue respectfully to make oneself available to those who have declined assistance or who might appear to be unmotivated, and develop strategies to foster engagement.
- Encourage open and honest discussion especially when there are differences.
- Share ideas and options within a coaching approach, rather than giving advice in a critical or judgmental fashion.
- Collaboratively work through differences of opinion and points of conflict, and work toward acceptable compromises when necessary.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How have you balanced duty of care and dignity of risk?
- Do you engage people as partners and offer professional expertise without assuming control or discontinuing support if your assistance is declined?
- When appropriate, can you share aspects of your own life experience to model hope, build empathy and deepen trust with a person?
- Have you acknowledged and explored the power imbalances in the therapeutic relationship and their possible impact on recovery?

### Recovery-oriented leadership

- What opportunities have you built for people with lived experience to be collaboratively involved in service change, practice enhancement and professional development?
- Are policies, practices, quality initiatives, education programs, recruitment and supervision all consistent with building collaborative relationships?
- Time spent with people and within the team is necessary for collaborative care – how do you support staff to prioritize the resources (space, time, learning, tools) necessary for collaborative and reflective practice?

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## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Help establish a community of practice, and participate in learning that builds expertise in recovery-oriented collaborative care.
- Advocate for reflective practice and mindfulness as necessary components of collaborative relationships within your own discipline or peer group.
- Reconsider allocation of resources and decision-making criteria to foster the development of collaborative relationships and peer-led initiatives.

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## RESOURCE MATERIALS

- Ackerman, S. J., & Hilsenroth, M. J. (2001). A review of therapist characteristics and techniques negatively impacting the therapeutic alliance. *Psychotherapy: Theory, Research, Practice, Training*, 38, 171–185.
- Clark, C., & Krupa, T. (2002). Reflections on empowerment in community mental health: Giving shape to an elusive idea. *Psychiatric Rehabilitation Journal*, 25(4), 341–349.
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- Copeland, M. E. (n.d.). What is Wellness Recovery Action Plan® (WRAP®)? West Dummerston, VT: Mental Health Recovery. Retrieved from <http://www.mentalhealthrecovery.com/wrap/>
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- Repper, J., & Perkins, R. (2013). The Team Recovery Implementation Plan: A framework for creating recovery-focused services. London, England: Centre for Mental Health & Mental Health Network NHS Confederation, Implementing Recovery through Organisational Change (ImROC). Retrieved from [http://www.centreformentalhealth.org.uk/pdfs/ImROC\\_briefing6\\_TRIP\\_for\\_web.pdf](http://www.centreformentalhealth.org.uk/pdfs/ImROC_briefing6_TRIP_for_web.pdf)
- Schrank, B., Bird, V., Rudnick, A., & Slade, M. (2012). Determinants, self-management strategies and interventions for hope in people with mental disorders: Systematic search and narrative review. *Social Science & Medicine*, 74, 554–564. doi: 10.1016/j.socscimed.2011.11.008

## CHAPTER 3

# Recovery Occurs in the Context of One's Life

The previous chapter looked at the personal nature of recovery and the ways recovery-oriented services can assist an individual to build on their strengths and define their personal road to recovery. This chapter sets out the Guidelines required for recovery-oriented practice to address the multiple factors that contribute to mental health problems and illnesses.

**The chapter includes the following Guidelines:**

- Celebrating the value of family, friends and community
- Addressing stigma and discrimination
- Supporting social inclusion and advocacy on social determinants
- Building partnerships with community

Since most of a person's recovery journey occurs outside the mental health service system, fostering recovery necessitates understanding people within the context of their lives. Family, friends, neighbours, local community, schools, workplaces, spiritual and cultural communities all influence mental health and well-being and can play an important role in supporting recovery. Recovery-oriented practice works with people to help them lead full and meaningful lives and sustain their relationship to the world around them. It fosters their participation as equal citizens in the social and economic life of their community. There is no "right way" for people to understand themselves as individuals and as citizens, or to behave in relation to their family, community, culture or background, and a recovery approach supports

people in learning how to navigate their own path through the web of family, community and society. Recovery-oriented practice helps people give primacy to their identity beyond illness, strengthen their natural network of connections and fulfil important personal and family roles.

### IMPORTANCE OF FAMILIES TO RECOVERY

Families can provide emotional, social and material support critical to quality of life. For many people living with mental health problems and illnesses, family – whether made up of relatives or chosen from a person's broader circle of support – constitutes their primary source of support. Families can help recovery by expressing hope, building on people's ties to others, reminding them of their strengths and capabilities, assisting them in accessing and navigating the mental health system and sustaining their involvement in community life. With the person's permission, recovery-oriented practitioners consistently engage a person's family of choice as early in care as possible. Families also have the right not to participate in a caregiving role, and this choice is respected.

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However, families can be under significant stress during times of crisis when the judgment of their loved one may be impaired by illness. They may also feel compelled to facilitate hospital admissions, which can damage relationships and trust. Listening carefully to the concerns of families and finding ways to facilitate timely access to care can greatly alleviate distress. When the involvement of family is declined, recovery-oriented practice can include providing ongoing support to improve communications and help negotiate family involvement.

### **FAMILIES BENEFIT FROM SUPPORT**

Family caregivers experience a range of emotions when working with a family member with a mental health problem or illness, including despair, guilt, helplessness, fear, grief, loss and sadness. Families also report feeling frustration and anger with the challenges they confront in getting access to appropriate services for their loved ones and in how they are consulted. Caregivers can best contribute to the recovery of their family member when their involvement is welcomed and their experience is acknowledged. Families are also on their own journey, and when their needs are recognized and supported they are better able to support the recovery of their loved one.<sup>1</sup>

Recovery-oriented practitioners understand and show concern for the impact of mental health problems on the family. Supporting families so they can find hope, heal and, when people desire, reconnect in helpful ways is vitally important. Recovery-oriented services seek to collaborate as partners with caregivers and draw on their intimate knowledge of their loved one, routinely encouraging them to play a part in assessment and to provide their perspective when planning care. They understand and respond respectfully to the diversity of families, including their histories, cultures,

values and traditions; to their particular ideas of social interdependence and varying spiritual practices and beliefs; and to the different ways they may understand the nature of mental health and substance use problems.

The inclusion of family peer support workers within services provides a valued source of support and experiential expertise. Linking people to family services and providing timely information, respite, education and training helps to support family members. Families also benefit when there is coordination and communication between and across services. Families can play a valuable role in the development and design of programs and services and in advocating for broader system change.<sup>2</sup>

### **FAMILIES MAY NOT ALWAYS BE SUPPORTIVE**

Recovery-oriented practice begins with the assumption that family can play a positive role in the journey of recovery and well-being. However, there are times when families and people living with mental illness disengage from one another. In some situations, where there is conflict, abuse or a lack of support, it may not be in the person's best interest to involve family members. Legally, the choice of whose, how much, and how often family support is desired rests with the individual. Recovery-oriented services respect this right, while also acknowledging that, at times, a person's condition may compromise their ability to make appropriate judgments and decisions.

People living with mental health problems and illnesses also face complex issues with respect to informed consent and privacy. Finding a balance between facilitating the family's ability to contribute to decision-making and the need to respect the privacy rights of the person living with the mental illness



requires a careful case-by-case review. Family involvement depends on the willingness and the capacity of the family to participate, and on the consent of the person living with the mental health problem or illness.<sup>3</sup>

## STIGMA AND DISCRIMINATION

**Stigma** refers to the internal negative feelings and beliefs people hold, usually based on misinformation, that lead to prejudicial attitudes.

**Discrimination** is the external behaviour that results from prejudice and is also manifested in institutional policies, practices and laws that deny people their rights or limit their inclusion.

**Self-stigma** refers to the internalization of negative social stereotypes, which in turn has an impact on people's sense of identity and leads to reduced self-esteem and diminished expectations.

People living with mental health problems and illnesses and those who care for them report that stigma and discrimination negatively impact almost every area of their lives and can frequently be more harmful than the illness itself. Stigma and discrimination manifest in: high rates of un/underemployment; lower educational achievement; the loss of friendships, kinship and parenting roles; and experiences of persistent poverty, homelessness, and housing instability. They can lead to people losing important civic roles and rights and to being rejected by neighbours or colleagues. For older adults, these can lead to the loss of autonomy and having their abilities minimized. People living with mental health problems and illnesses also report facing stigma from those they rely on for support, including family members and health, mental health and social service providers.<sup>4,5</sup> Stigma by these key players can be manifested when they demonstrate negative attitudes, a lack of respect or pessimism

regarding recovery, or when they take steps to remove control over decision-making; all of these interfere with recovery. At a structural level, the effects of stigma and discrimination can be seen in the chronic underfunding of the mental health system, lack of affordable housing and income and disability supports that do not always meet people's needs.<sup>6</sup>

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**People living with mental health problems and illnesses and those who care for them report that stigma and discrimination negatively impact almost every area of their lives and can frequently be more harmful than the illness itself.**

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Even when effective services are available, many people fear being labelled or judged because of past negative experiences with the mental health system. As a result they fail to seek or prematurely drop out of services. Addressing self-stigma is important because when people anticipate rejection or underestimate their capabilities, their self-esteem is diminished, and they are less likely to pursue opportunities or advocate for their rightful entitlements. Family caregivers also report experiencing the impact of stigma in their dealings with family, friends and health providers, feeling a sense of "shame, blame and contamination" that leads to their isolation and loss of valuable support. For mental health providers, stigma can be experienced through a lack of respect from their peers and the inadequate provision of resources to do their work.



## **SUPPORTING RECOVERY MEANS ADDRESSING STIGMA**

Reducing stigma and discrimination requires a shared effort at a system, community, program and individual level.<sup>7</sup> Recovery-oriented practices contribute by affirming the ability for everyone to recover, emphasizing people's strengths and capabilities, normalizing the experience of mental distress and reinforcing the effectiveness of self-care and treatment. Adopting a holistic view also acknowledges the multiple influences on mental health and the impact of discrimination. Working with people to help them positively reframe their experience within the broader context of their lives, find purpose and meaning and understand and protect their rights can help reduce self-stigma. Peer support, including family peer support, plays a valuable role in assisting people to positively re-define their experience, practise disclosure and become empowered to advocate for their personal rights and greater social equity.

Anti-stigma efforts are best designed and delivered with leadership by, and active participation of, people with lived experience. Providing targeted education to influential groups helps challenge stereotypes by sharing personal journeys of recovery, identifying what helps and hinders recovery and emphasizing ways to enhance social and economic inclusion. This approach has been found to achieve lasting change. Ultimately, addressing stigma and discrimination is an issue of equity. People living with mental health problems and illnesses and their families must be accorded the same respect, rights and entitlements and have the same opportunities as the broader population.

## **The three best stigma-reducing strategies:**

- 1** Positive personal contact.
- 2** Education about the recovery journey.
- 3** Advocacy and supporting empowerment

## IMPACT OF THE SOCIAL DETERMINANTS OF HEALTH

Everyone in Canada should have the opportunity to achieve the best possible mental health and well-being, but currently that opportunity does not come equally. Having a stable adequate income, safe and affordable housing, access to health and social services, the support of family and friends, secure employment, livable communities and dependable transportation are some of the important determinants of health and mental health. It is worth noting that many factors that can contribute to persistent mental illness and the way we perceive people with "serious mental illness" are related to the effects of poverty, social isolation and exclusion, poor education, chronic physical illness, housing instability and unresolved trauma. Addressing these issues can help render the remaining symptoms of mental illness less intense and easier to treat.<sup>8</sup>

Working to reduce disparities in how these determinants of health affect people's opportunities in life and health outcomes will involve efforts at many levels of Canadian society. Such an objective cannot be the exclusive responsibility of the mental health system in general or of recovery-oriented mental health services in particular. It nevertheless constitutes an objective that is integrally linked to providing recovery-oriented services and supports and will require a collaborative effort across systems, sectors and services to accomplish.<sup>9</sup>

By taking time to listen and learn about a person's socioeconomic stressors, recovery-oriented practitioners can help identify ways to address the factors that impact health. This means having knowledge about the broader social system and the availability of resources, and providing practical help across many areas. For example:

- Assisting people to achieve housing and food security.
- Working with people to stabilize income, including by helping them apply for income supports, tax credits and supplements.
- Assisting people to connect to a family physician or community health team in order to address ongoing general health needs and any co-occurring medical conditions.
- Linking people to career planning resources, supporting people's aspirations to work and connecting with best practices for supporting successful employment.
- Helping people to identify their social, creative, spiritual and recreational needs and linking them to appropriate community resources.

## BUILDING PARTNERSHIPS

There is a wealth of knowledge, skills and resources residing in local communities that can be leveraged to support recovery by building service partnerships and nurturing community connections. Engaging community partners to help educate the public, address discrimination and enhance service linkage is a core element of recovery-oriented practice. Recovery-oriented practice encourages the formation of multisector partnerships to promote the development of service agreements that support inclusion and to address policies and practices that restrict opportunity. Collaborative partnerships are enriched by the resilience, expertise and participation of those who have experienced mental health problems, either first-hand or within their families. Advancing recovery includes collaborating with national, provincial and regional initiatives to advance fair and equitable treatment for all, remove barriers to full citizenship and create a social context that fosters mental health and well-being.

The creation of multisector agreements and plans, developed in partnership with people who have lived experience and their families, can help address structural barriers that stand in the way.<sup>10</sup>

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**Everyone in Canada should have the opportunity to achieve the best possible mental health and well-being, but currently that opportunity does not come equally.**

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## Recognizing the Value of Family, Friends and Community

**Recovery-oriented practice and service delivery recognizes the unique role of personal and family relationships in promoting well-being, providing care and fostering recovery across the lifespan; as well as recognizing the needs of families and caregivers themselves.**

### CORE PRINCIPLES

- » Value the role of peers, family and social networks for each as potential resources to facilitate recovery.
- » Mental health practitioners acknowledge families, friends and significant others as partners and are responsive to their need for inclusion, education, guidance and support.
- » Fulfilling valued roles and responsibilities within significant relationships can promote and sustain recovery efforts.
- » The person experiencing mental health problems has the right to define their “circle of support” and how family members, caregivers, peers and significant others should be involved, with consideration for what is age appropriate.
- » Input from family members, caregivers, peers and significant others can help inform personal recovery plans and improve the planning, organization and delivery of mental health treatments, services and supports.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Recognize and affirm the importance of a person’s roles and relationships for their well-being.
- Acknowledge and affirm the ability of family members, caregivers and significant others to support a person’s recovery.
- Respect the choice of the person experiencing mental health problems regarding the involvement of specific family members, caregivers and significant others.
- Appreciate the journey of discovery, healing and well-being that the family and significant others may also be experiencing.

#### Knowledge

- Understand the impact of mental health problems and illnesses on close relationships.
- Understand the stress placed on families when negotiating hospitalization during a crisis and the potential impact on relationships and trust.
- Understand the tensions associated with family dynamics, conflicting aspirations and the need to respect privacy and personal choices.
- Be aware of the diversity of family relationships and responsibilities, including but not limited to different cultures, same-sex relationships and blended families.
- Have up-to-date knowledge of services and supports available to meet the needs of families.

#### Skills and Behaviours

- Invite people to identify close relationships, express their choices and identify needs for support from significant others, and engage those identified as early as possible in the recovery process.
- Assess the needs of family caregivers and support people, and help them to navigate service systems.
- Support positive family communications and foster opportunities to maintain, establish or re-establish relationships with family and support people as part of the service plan.
- Support people to continue to fulfill important roles such as being a parent, spouse, student, employee, friend etc.
- Provide education, communication and an inviting atmosphere for family members and significant others to feel respected, welcome, safe and valued.
- Seek out and incorporate views of family members and caregivers to inform recovery practice, research and delivery of services.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- In what ways have you offered family and other people in a person's support network continuing assistance in navigating service systems and helped them to connect with family support and advocacy groups?
- How have you supported the needs of children and young people in families experiencing mental health challenges?
- What do you do to make sure that people's choices about involving significant others are respected and re-examined regularly?
- How have you helped to mediate tensions and encouraged open dialogue when views and interests are in conflict?
- What have you done to address child custody issues to support people in fulfilling their parenting roles?
- What have you done to support people sharing their recovery goals with family and support people?

### Recovery-oriented leadership

- Have you critically reviewed organizational policies and procedures to make sure they embrace working collaboratively with families, caregivers and support networks?
- What resources have been made available to support involvement of families and caregivers in program and service delivery planning?
- How have you encouraged flexibility in working with families, for example by including opportunities for off-site, after-hours and in-home assessment and services?
- What have you done to ensure that staff, people with lived experience, families and support people are aware of sources of family and caregiver support, including family peer support?
- What process do you use to assess family support needs, and how is the impact of support on family functioning measured?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Establish ongoing connections with family associations, and increase opportunities for the co-design of family peer support programs.
- Identify peer support resources for families within the community, and where these are not present, establish links with peer support specialist training groups.
- Support the use of Advanced Care Directives and substitute decision-making protocols that encourage people to share their preferences and choices with providers, families and caregivers.
- Incorporate ongoing evaluation of satisfaction levels and planning processes to improve the inclusion of, and support for, families and friends.

## RESOURCE MATERIALS

- Canadian Collaborative Mental Health Initiative. (2006). *Working together towards recovery: Consumers, families, caregivers, and providers: A toolkit for consumers, families and caregivers*. Mississauga, ON: Author. Retrieved from [http://www.shared-care.ca/files/EN\\_Workingtogethertowardsrecovery.pdf](http://www.shared-care.ca/files/EN_Workingtogethertowardsrecovery.pdf)
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# Supporting Social Inclusion and Advocacy on Social Determinants

**Recovery-oriented practice and service delivery advocates to address inequitable living circumstances and unequal opportunity that adversely impact personal recovery.**

**CORE PRINCIPLES**

- » People living with mental health problems and illnesses want to and should be able to enjoy the same social, economic, educational and employment opportunities as everyone else.
- » Housing, transport, education, employment, income security, health care and civic participation are some of the determinants of health; poor and unequal conditions in these areas increase the risk of poor health and mental health outcomes and interfere with recovery.
- » Fostering social inclusion means ensuring that people have opportunities for active community involvement and citizen participation.
- » Recovery-oriented mental health services can help connect people to their communities of choice, assist in maintaining people’s naturally occurring supports and networks and promote a focus on social inclusion and the exercise of citizenship rights.

**MENTAL HEALTH PRACTITIONERS AND PROVIDERS...**

**Values and Attitudes**

- Uphold the right of people experiencing mental health problems to participate in community and social settings as full and equal citizens.
- Accept and nurture the contribution of naturally occurring supports, community connections and opportunities outside of mental health services to support a person’s recovery.
- Are willing to take action to challenge barriers to social inclusion, including within their own service, and to advocate for equity.

**Knowledge**

- Understand that social inclusion is a determinant of health and well-being, and know how to make this a focus of practice.
- Recognize the potentially negative impact of poor and unequal living conditions on health, mental health and recovery.
- Have up-to-date information about community services and resources for housing, education, transportation, employment and income supports.
- Maintain knowledge of current legislation, instruments, protocols and procedures governing people’s human and legal rights.

**Skills and Behaviours**

- Proactively draw attention to disparities, and work alongside people with lived experience and through community partnerships to mitigate them.
- Use knowledge of human and legal rights and of the way service systems operate to challenge social exclusion.
- Initiate discussion of recovery goals, and make referrals to services and resources that can contribute to:

Meaningful social engagement  
Education and employment opportunities  
Income security  
Housing stability

Food security  
General health and well-being  
Creating culturally safe and responsive services
- Develop working relationships with police, justice, corrections and probation and parole services.
- Help people connect to a family physician or community health team to address ongoing general health needs and co-occurring medical conditions.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How do support plans and service activities promote the inclusion of a person's existing support network, social connections and opportunities for participation in the community?
- How does your documentation reflect people's aspirations and goals related to education and employment?
- What indicators are you using to measure the impact you are having on advancing social inclusion?

### Recovery-oriented leadership

- What have you done to challenge social exclusion and disadvantage? Have you used knowledge of human and legal rights in this regard?
- How are staff members supported to be active partners in broad-based alliances that advocate for action on the social determinants of health and well-being and address discrimination?
- In what ways have you supported and validated the advocacy efforts of staff, people with lived experience, families and communities?
- How do you model a positive service culture that promotes inclusion of people with lived experience and their families at all levels?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Provide input into relevant public inquiries, community meetings and processes for social reform.
- Encourage strong working relationships with people who are working to create economic, social, recreational and employment opportunities at the local and regional level, including local elected representatives and business leaders.
- Use social media to publicize community resources and information, as well as to leverage open events that your program or organization offers.
- Participate and encourage staff to become involved in a broad range of initiatives (e.g., local food drives, community fairs, microbusinesses and ride-share programs).

## RESOURCE MATERIALS

- Bryant, T. (2009). Housing and health: More than bricks and mortar. In D. Raphael (Ed.), *Social determinants of health: Canadian perspectives* (2nd ed., pp. 235–249). Toronto, ON: Canadian Scholars' Press.
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## Addressing Stigma and Discrimination

**Recovery-oriented practice and service delivery promotes a positive approach to mental health problems and mental illness and challenges stigma and discrimination.**

### CORE PRINCIPLES

- » There is still widespread stigma and discrimination against people with mental health problems and illnesses across society, within communities, service settings and amongst friends and families of people living with mental health problems and illnesses, who can themselves internalize stigmatizing beliefs (self-stigma).
- » The impact of stigma can impair a person's sense of identity, limit their capacity for hope and optimism, and inhibit their prospects for recovery; the effects of stigma can be more damaging than the illness itself.
- » The effects of stigma and discrimination on individuals living with mental health problems and illnesses can be counteracted by facilitating people's empowerment and self-efficacy.
- » Education, advocacy and direct personal contact with people who have experienced mental health problems are effective approaches to reducing stigma, with the research pointing to the latter as holding the greatest promise.
- » Stigmatizing beliefs and discriminatory practices needs to be addressed within organizational policies and directives, management practices and leadership and front-line interactions and services offered.
- » People with lived experience of mental health problems should be involved in the design and delivery of anti-stigma initiatives.
- » The experience of other forms of discrimination—for example based on race, gender, ability, sexual orientation or age—can compound the effects of stigma and discrimination experienced by people with mental health problems.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Accept individual and collective responsibility for challenging stigmatizing and discriminating attitudes and behaviours.
- Embrace, value and celebrate difference.
- Take personal responsibility for demonstrating acceptance and promoting inclusion.

#### Knowledge

- Understand that stigma and discrimination exist at all levels within service settings as well as being internalized among people with lived experience of mental health problems.
- Appreciate the negative impact of stigma and discrimination, including that it can be experienced as trauma.
- Understand the nature of self-stigma, the factors which contribute to it and how self-stigma can hinder access to social opportunities and impede community participation.
- Recognize stigma and discrimination in the health, mental health and related workforces.
- Be aware of the role of media both in perpetrating stereotypes and in contributing to redressing stigma and discrimination.
- Maintain up-to-date knowledge of human rights and antidiscrimination legislation and policy frameworks, as well as of mechanisms for addressing complaints.
- Have knowledge of best practices and research in stigma reduction and of ways to address discrimination.



## MENTAL HEALTH PRACTITIONERS AND PROVIDERS (Continued)

### Skills and Behaviours

- Speak out to actively challenge stigmatizing attitudes within service and community settings and engender hope and positivity.
- Provide accurate information about mental health issues, emphasizing recovery and the efficacy of treatment, while using positive and hopeful messages and images.
- Include people with lived experience as partners in public education and outreach to media.
- Assist people with lived experience, their families and caregivers to explore and work through self-stigma and their own negative beliefs and views.
- Encourage and support appropriate disclosure.

### REFLECTIVE PRACTICE QUESTIONS

#### Recovery-oriented practice

- How do you model non-discriminatory practice, including the use of non-stigmatizing language?
- What have you done to foster leadership by people with lived experience in the design and delivery of anti-stigma initiatives?
- What opportunities have you utilized to encourage and support appropriate disclosure and open discussion about the impact of stigma?
- How do you address the interaction of multiple forms of discrimination and their harmful impact on mental health?

#### Recovery-oriented leadership

- How do your service standards model non-discriminatory practice and non-stigmatizing language and procedures?
- Are complaints mechanisms easily accessible, and do they have clear protocols for redress?
- What resources are available to facilitate and support peer-led anti-stigma initiatives?
- How do you encourage organizational and staff participation in local initiatives that promote positive understanding and reduce stigma and discrimination?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Develop anti-stigma criteria with partners based on the best evidence, and conduct an audit of service delivery against the identified criteria; share action plans to act on any areas needing change.
- Increase employment opportunities for people with lived experience within their field of interest; join employment networks that can audit existing processes for discrimination or inequitable practices.
- Create communication channels that allow all stakeholders to address structures or practices that perpetuate stigmatizing attitudes.
- Facilitate open discussion at staff forums to encourage awareness of, and attention to, stigmatizing behaviour.
- Link with existing advocacy groups and activities from non-health areas (e.g., sports, arts, media) to help increase everyone's learning and understanding; open your space and environment to these groups for shared initiatives.

## RESOURCE MATERIALS

- Canadian Journalism Forum on Violence and Trauma. (2014). Mindset: Reporting on mental health. Retrieved from <https://sites.google.com/a/journalismforum.ca/mindset-mediaguide-ca/mindset-media-guide-eng>
- Great-West Life Centre for Mental Health in the Workplace, Workplace Strategies for Mental Health. (2012). Framework to help eliminate stigma. Retrieved from <https://www.workplacestrategiesformentalhealth.com/psychological-health-and-safety/framework-to-help-eliminate-stigma>
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## Building Partnerships with Community

**Recovery-oriented practice and service delivery seek to maximize recovery by working in partnership with local communities.**

### CORE PRINCIPLES

- » A wealth of diverse knowledge, skills, strengths and resources reside in local communities that can be leveraged to support recovery.
- » Communities value the resources and contributions of local mental health services.
- » Collaborative partnerships are enriched by the resilience, expertise and participation of those who have experienced mental health problems.
- » Strengthening connections between systems and sectors can improve multisector planning and facilitate access to services (e.g., housing and employment services, schools, social services, addictions).
- » Mental health services have a role in supporting communities to become more inclusive.
- » Everyone shares the responsibility to create opportunities for interaction, service access, collaboration and civic participation.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Believe in healthy, inclusive communities in which people with experience of mental health problems flourish and have strong futures.
- Appreciate community as the space for recovery and active citizenship, where people find meaning according to their own customs, traditions, culture and upbringing.
- Acknowledge local diversity, strengths and skills; respect local expectations, values and processes.
- Appreciate collaboration as the means to address community development and learning.

#### Knowledge

- Understand the social nature of communities and how best to work with them.
- Know community leaders, services, agencies, resources, local issues and associations.
- Have up-to-date knowledge of funding sources and resources for community partnerships, capacity building, volunteerism and community development.

#### Skills and Behaviours

- Are able to implement techniques for group facilitation, networking and partnership building.
- Relate well to all audiences, using language readily understood by all.
- Participate in local initiatives to promote mental health and prevent mental illness, intervene early, foster resilience, develop mental health literacy and build capacity.
- Support peer-led community partnerships and initiatives.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How have you tapped into community goodwill, resourcefulness and creativity to support people's recovery goals and aspirations?
- In what ways have you built partnerships with peer workers and supported local peer leaders in community initiatives?
- In what ways have you collaborated with other networks or groups to provide referral pathways and create reciprocal agreements to improve service access (e.g., housing, income security, employment) that can contribute to recovery outcomes?
- What evidence demonstrates that partnerships and community collaboration is "core business" for recovery and not a discretionary extra?

### Recovery-oriented leadership

- In what ways have you supported peer-led community partnerships and community coalition initiatives?
- How do you encourage staff to become active members in local interagency networks and acknowledge and reward their role in community partnerships?
- How have you increased the opportunities for interaction with the community and encouraged volunteers? Do your physical environment and facilities encourage this?
- What have you done to present positive mental health perspectives at community events and ensure organizational visibility at important and locally valued activities?
- How do you promote positive working relationships with local media organizations?
- How do you seek to collaborate across organizations to facilitate access to services and reduce barriers in information sharing and assessment across services?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Collaborate with national, provincial and regional initiatives to promote fairness and equity and the creation of healthy communities; regularly share news and updates with staff about these initiatives.
- Release staff to participate in mental health awareness and education campaigns; support people with lived experience to provide leadership in these activities.
- Strengthen opportunities for intersectoral collaboration, philanthropy and volunteerism, and for providing field experience for trainees and policymakers.

## RESOURCE MATERIALS

- Addiction and Mental Health Collaborative Project Steering Committee. (2014). Collaboration for addiction and mental health care: Best advice. Ottawa, ON: Canadian Centre on Substance Abuse. Retrieved from <http://www.ccsa.ca/Resource%20Library/CCSA-Collaboration-Addiction-Mental-Health-Best-Advice-Report-2014-en.pdf>
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## CHAPTER 4

# Responding to the Diverse Needs of Everyone Living in Canada

The diversity of Canada's population is a source of great strength that enriches our common culture, enlarges our social fabric and contributes to our shared understanding of mental health and mental illness. This diversity is multi-faceted and complex. It embraces the rich traditions, histories, cultural practices and spiritual beliefs that have been contributed by Canada's Indigenous peoples and by people from around the world. It refers to the diverse needs that arise from people's evolution across the lifespan, different abilities, socioeconomic status, sexual orientation, the experience of racism and other forms of discrimination and spiritual or religious beliefs. Ignoring this diversity of needs and experience can hinder access to services and contribute to disparities in health outcomes.

### RESPECTING THE DIVERSITY OF PEOPLE'S NEEDS

Recovery-oriented practice is grounded in principles that encourage and enable respect for diversity and are fully congruent with practices that are culturally responsive, safe and competent and can meet the needs of immigrants, refugees and people from ethnocultural and racialized groups.<sup>1</sup> To varying degrees, the principles that inform a recovery orientation—such as fostering hope, enabling choice, encouraging responsibility and promoting dignity and respect—apply to people of all ages (taking into account their developmental stage) and to meeting the needs of lesbian, gay, bisexual, transgender, transsexual and queer (LGBTQ) people.<sup>2</sup>

Recovery-oriented practice takes a holistic approach to health, values the role of family and community and listens for, understands and responds to the multiple, complex and intersecting influences that impact everyone's mental health and well-being. It does not prescribe a single path to recovery and can adjust to the differing values placed on individual autonomy, family unity and community cohesion within different traditions, cultures and contexts. Recovery-oriented practice acknowledges that, for many people, drawing on religious beliefs and spiritual practices can help overcome the sense of despair that can initially accompany mental health problems and illnesses, while enabling people to make sense of their experience and find a deeper meaning, greater purpose and renewed hope.<sup>3</sup>

Not every service provider will be able to know all things about all cultures or all dimensions of diversity. Rather, the starting point for recovery-oriented practice involves embracing a general approach based on respect for, and interest in, the diversity of people's needs and designed to build on their existing strengths. At the same time, in responding to the shared needs that can arise from a common background or set of experiences, one must always guard against stereotyping. Although two individuals may share a common cultural heritage, they may also be very different in other ways (age, gender, sexual orientation, religious or spiritual beliefs). We are all multifaceted individuals, and our individual identities are shaped by the many intersecting dimensions of our lives.

The experience of multiple, intersecting forms of discrimination based on factors such as race, age, gender, sexual orientation and social status can deepen a sense of marginalization and have a compound effect on mental health and well-being.<sup>4</sup> Inclusive and culturally responsive services promote practices that recognize and help counteract all forms of discrimination and address the structural barriers that can limit access to appropriate programs, treatments, services and supports for people from diverse backgrounds.<sup>5</sup>

Creating inclusive services that are able to meet diverse needs can be advanced through collaborative partnerships with community leaders that offer opportunities for mutual learning. Such partnerships strengthen community capacity and expand access to services through shared programming and reciprocal service agreements.

**This chapter outlines how recovery-oriented practice addresses needs arising from three dimensions of diversity:**

- Adapting recovery-oriented practice across the lifespan.
- Meeting the needs of immigrant, refugee, ethnocultural and racialized communities.
- Addressing differences relating to gender and sexual orientation.

## **ACROSS THE LIFESPAN**

It is necessary to adapt the way in which recovery principles are applied to reflect the realities of people's backgrounds, contexts and changing objectives as they move across the lifespan. The term recovery, for example, can be taken to imply a process of recovering a sense of self and capacities that were lost – a concept that is most applicable to midlife adult populations. The objectives for infants, children, youth and seniors cannot be exactly the same.

Recovery-oriented practice is grounded in principles that encourage and enable respect for diversity

The recovery goal for infants, children and youth involves helping them develop their identity throughout the various developmental stages, attaining their best possible cognitive and mental functioning and retaining mental well-being into adulthood. Infants, children and youth are not “little adults,” and their symptoms of mental health problems and illnesses present very differently from those of adults. Because infants, children and youth are in the process of forming an identity as they grow up, their presentation must be considered in relation to each specific stage of development.

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**It is necessary to adapt the way in which recovery principles are applied to reflect the realities of people’s backgrounds, contexts and changing objectives as they move across the lifespan.**

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Recovery-oriented approaches with infants and children draw on perspectives of growth, health and well-being related to development, resilience and supportive family systems. Recovery-oriented practice and service delivery with infants and children occur in collaboration and partnership with a wide range of services, including childcare, education and recreation. Recovery approaches with adolescents and young people focus on prevention, early intervention, achieving developmental goals, building resilience and enhancing well-being. An integrated approach across mental health and allied service systems is required to provide flexible and individually tailored connections between child-, adolescent- and adult-focused services, both

hospital-based and in the community, and to ensure seamless continuity of care during developmental transition points. For those whose illness starts early in life, the same values and principles need to guide their care throughout their lifespan.<sup>6</sup>

## **RECOVERY SUPPORTS DIGNITY, CONNECTION AND CHOICE**

Older adults face numerous challenges to their ability to live independently with safety and dignity. These include physical limitations, chronic illness and dementia and neurocognitive changes. However, it cannot be assumed that age and cognitive impairment are linked, or that the presence of a mental health problem or illness is inextricably tied to cognitive decline. The recovery goal for older adults at every stage of the aging process is to ensure that they are supported in maintaining physical autonomy, privacy and dignity and have the greatest possible control over decision-making. Recovery-oriented practice supports older adults in maintaining contact with family, sustaining social connections and actively participating in valued roles within their community of choice.

As people living with mental health problems age, they may face the additional challenge of losing the support of family caregivers as their parents age, or encounter difficulty accessing housing or long-term care facilities. Recovery-oriented practice seeks to ensure that older adults, including those who experience a late onset of illness, have timely access to the resources they need to address mental health problems and illnesses that may emerge as they pass through important transitions associated with aging – such as retirement, alterations in income level, physical decline and changing social support networks, including spousal bereavement and increased social isolation.

People's ability to participate actively in decision-making will vary. For example, family members or guardians will be the primary decision-makers for young children or for older adults whose ability to make decisions for themselves may be compromised by a mental health problem or illness. Sometimes, in the absence of any better option – as when people temporarily lose their ability to look after themselves – caregivers and providers will need to take over. The use of Advanced Care Directives can help people retain decision-making control, define health care treatment goals and assign a substitute decision-maker to ensure their wishes are followed.

### **IMMIGRANT, REFUGEE, ETHNOCULTURAL AND RACIALIZED COMMUNITIES**

People who are immigrants, refugees, members of ethnocultural groups or likely to be racialized (that is, to have others make assumptions about them based on perceptions about race) face particular challenges that put their mental health at greater risk. Many from these communities have difficulty getting a job, finding employment that matches their level of skill and education, earning a decent income or obtaining adequate housing.<sup>7</sup>

While they make up a large part of Canada's population, too many people from the immigrant, refugee, ethnocultural and racialized (IRER) communities face significant barriers to seeking or obtaining help. People from diverse backgrounds can have different values and traditions that inform approaches to health. People sometimes experience and describe mental health problems and illnesses differently, which may be challenging for service providers who do not share the same background. For some, the importance placed on promoting autonomy and self-direction within recovery-oriented practice may appear

to be in tension with their own emphasis on family and community connections.<sup>8</sup>

Culturally safe, responsive and competent services provide an environment in which people are able to express themselves and deal with problems without fear of judgment. The need for cultural responsiveness and safety draws attention to issues of power and discrimination that can contribute to poorer health outcomes for some groups and that may diminish the quality of care they receive. It also points to the importance of providers reflecting on their own background and possible biases.

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**Culturally safe, responsive and competent services provide an environment in which people are able to express themselves and deal with problems without fear of judgment.**

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Providing responsive recovery-oriented service can be strengthened by ongoing collaboration with community leaders and organizations to build trust and deepen mutual understanding. Recovery-oriented practice supports communities to develop their own priorities, strengthen existing social networks and address all the factors that impact mental health. Expanding treatments and supports that are linguistically accessible, responsive and attuned to culture, experience and beliefs will improve recovery.<sup>9</sup>

### **GENDER AND SEXUAL ORIENTATION**

Mental health problems and illnesses affect men and women differently and at different stages in life. For example, women are more likely than men to experience anxiety and depression, including depression following the



birth of a child. Men are more likely to experience psychotic illness, usually at a younger age.<sup>10</sup> Girls and women attempt suicide at higher rates, but men and boys (particularly older men) die by suicide more often.<sup>11</sup>

The different ways that gender makes a person vulnerable to mental health problems and illnesses mean that the impact of gender needs to be considered across the spectrum of mental health activities, including in prevention and early intervention efforts. Recovery-oriented services need to be alert to systemic disadvantage and barriers to service that may be related to gender roles, stereotyping and discrimination. Key risk factors for women are often interrelated: women have more caregiving responsibilities, endure higher rates of poverty and are more likely to suffer domestic violence and abuse. Childhood sexual abuse is linked to mental health problems and illnesses later in life for both girls and boys, but girls are more likely to be abused. Factors that threaten a sense of success and achievement, such as job loss, have a particular impact on men. Men may be less likely to acknowledge emotional problems. They may believe that men should handle their issues alone, and thus may delay seeking help. In addition, men do not always present signs and symptoms in ways that are easily recognized by service providers.

Stigma and discrimination on the basis of sexual orientation have an impact on the mental health and well-being of lesbian, gay, bisexual, two-spirited, queer, transgender and transsexual (LGBTQ) people. Sexual and physical assault and bullying are factors that increase the risk of suicide for this population. Risks for LGBTQ youth can be reduced by an accepting family and connection with other LGBTQ youth. Older LGBTQ people may be reluctant to access mental health

services because of past negative experiences with the service system, including prejudice, discrimination and lack of knowledge about their needs.<sup>12</sup>

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### **The different ways that gender makes a person vulnerable to mental health problems and illnesses mean that the impact of gender needs to be considered across the spectrum of mental health activities**

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Lesbian, gay, bisexual, two-spirited, transgender and transsexual people are helped in their recovery by their families, by educational institutions and workplaces, by their friends and partners and by mainstream services and community-specific support and community groups. Building collaborative partnerships with LGBTQ health and community resources can provide positive education and increase accessibility to the full range of services. The recovery concepts of self-determination, self-management, personal growth, empowerment, choice and meaningful social engagement are consistent with affirmative practice and with the processes of coming out.<sup>13</sup>



## ENDNOTES FOR CHAPTER 4

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- 1 The Ontario Human Rights Commission describes communities facing racism as “racialized.” Race is a social construct and it is now generally recognized that notions of race are primarily centred on social processes that seek to construct differences among groups with the effect of marginalizing some in society. The Report (1995) of the Commission on Systemic Racism in the Ontario Criminal Justice System defined racialization “as the process by which societies construct races as real, different and unequal in ways that matter to economic, political and social life.”
- 2 For definitions of LGBTQ refer to: Barbara, A. M. (2007). Asking the right questions 2: Talking about sexual orientation and gender identity in mental health, counselling, and addiction settings. Toronto, ON: Centre for Addiction and Mental Health. Retrieved from [http://www.camhx.ca/Publications/Resources\\_for\\_Professionals/ARQ2/arq2.pdf](http://www.camhx.ca/Publications/Resources_for_Professionals/ARQ2/arq2.pdf)
- 3 Macnaughton, E. (Ed.). (2001). Spirituality and recovery [special issue]. Visions: BC’s Mental Health Journal, no. 12. Retrieved from [http://2010.cmha.bc.ca/files/visions\\_spirituality.pdf](http://2010.cmha.bc.ca/files/visions_spirituality.pdf)
- 4 Weisser, J., Morrow, M., & Jamer, B. (2011). A critical exploration of social inequities in the mental health recovery literature.
- 5 Kirmayer, L. J., Fung, K., Rousseau, C., Lo, H.-T., Menzies, P., Guzder, J., Ganesan, S., Andermann, L., & McKenzie, K. (2012). Guidelines for training in cultural psychiatry. Canadian Psychiatric Association position paper. Retrieved from [http://www.academia.edu/2824551/Guidelines\\_for\\_Training\\_in\\_Cultural\\_Psychiatry](http://www.academia.edu/2824551/Guidelines_for_Training_in_Cultural_Psychiatry)
- 6 Simonds, L. M., Pons, R. A., Stone, N. J., Warren, F., & John, M. (2013). Adolescents with anxiety and depression: Is social recovery relevant? *Clinical Psychology and Psychotherapy*, 21(4), 289–298. doi: 10.1002/cpp.1841
- 7 Canadian Collaborative Mental Health Initiative. (2006). Establishing collaborative initiatives between mental health and primary care services for ethnocultural populations: A companion to the CCMHI planning and implementation toolkit for health care providers and planners. Mississauga, ON: Author. Retrieved from [http://www.shared-care.ca/files/EN\\_CompanionToolkitforEthnocultural.pdf](http://www.shared-care.ca/files/EN_CompanionToolkitforEthnocultural.pdf)
- 8 Sadavoy, J., Meier, R., & Ong, A. Y. M. (2004). Barriers to access to mental health services for ethnic seniors: The Toronto study. *Canadian Journal of Psychiatry*, 49(3), 192–199.
- 9 Hansson, E., Tuck, A., Lurie, S., & McKenzie, K. (2010). Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and options for service improvement. Calgary, AB: Mental Health Commission of Canada, Task Group of the Services Systems Advisory Committee. Retrieved from [https://www.mentalhealth-commission.ca/English/system/files/private/Diversity\\_Issues\\_Options\\_Report\\_ENG\\_0.pdf](https://www.mentalhealth-commission.ca/English/system/files/private/Diversity_Issues_Options_Report_ENG_0.pdf)
- 10 Abel, K. M., Drake, R., & Goldstein, J. M. (2010). Sex differences in schizophrenia. *International Review of Psychiatry*, 22(5), 417–428. doi: 10.3109/09540261.2010.515205
- 11 World Health Organization. (2002). Gender and mental health. Geneva, Switzerland: Author. Retrieved from [http://www.who.int/gender/other\\_health/en/genderMH.pdf](http://www.who.int/gender/other_health/en/genderMH.pdf)
- 12 Kidd, S. A., Veltman, A., Gately, C., Chan, J., & Cohen, J. N. (2011). Lesbian, gay, and transgender persons with severe mental illness: Negotiating wellness in the context of multiple sources of stigma. *American Journal of Psychiatric Rehabilitation*, 14(1), 13–39. doi: 10.1080/15487768.2011.546277
- 13 Lucksted, A. (2004). Lesbian, gay, bisexual, and transgender people receiving services in the public mental health system: Raising issues. *Journal of Gay & Lesbian Psychotherapy*, 8(3–4), 25–42. doi: 10.1300/J236v08n03\_03

# Responsive to the Diverse Needs of Everyone Living in Canada

**Recovery-oriented practices are responsive to people at different stages of life, from diverse backgrounds and sexual orientations, with different abilities, of all religious beliefs and spiritual practices, language groups and communities.**

## CORE PRINCIPLES

- » The starting point for recovery-oriented practice is to embrace a general approach that is based on a respect for, and interest in, the diversity of people's needs and that builds on their existing strengths.
- » Recovery-oriented practices acknowledge that not all groups have equal access to mental health services, supports and treatments.
- » Services respect and are responsive to people at different stages of life, from diverse backgrounds and sexual orientations, of all religious beliefs and spiritual practices, language groups and communities, and who live with physical disabilities.
- » Recovery-oriented services address and seek to overcome the adverse impacts on mental health and well-being of disparities relating to the social determinants of health.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Embrace, value and celebrate diversity as a strength.
- Recognize and acknowledge experiences of all forms of discrimination.
- Are willing to work with people from disadvantaged or marginalized communities to address barriers that can prevent them from accessing the resources they need on their journeys of recovery.
- Respect and accommodate diverse views on mental health problems and illnesses, well-being, treatment and services, and recognize that there are many pathways of recovery.
- Acknowledge personal beliefs as valid and relevant to mental health, and recognize that people express their personal identity differently and have many ways of relating to others, including family, community and society.

### Knowledge

- Know that differing values are placed on individual autonomy, family unity and community cohesion within different traditions, cultures and contexts.
- Understand the stages of human development and their implications for recovery approaches across the life span.
- Understand the importance of cultural responsiveness, safety and competence for mental health practice and service delivery.
- Appreciate the connection between physical and mental health and understand the particular needs of people living with physical disability.
- Recognize the range of factors that influence people's expectations for safety and services.

### Skills and Behaviours

- Use language and approaches that demonstrate sensitivity when working with people and families from a diverse range of backgrounds and experience.
- Proactively seek information from people about their preferences, expectations and needs, and use that information to develop appropriate responses.
- Collaborate with people from diverse communities to identify their needs and shape programs and services.
- Support people to identify and practice spiritual activities they find helpful and that contribute to their mental health and well-being.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How do your own values, assumptions and worldview shape your approach to others and influence your practice?
- What resources can you access when in doubt about aspects of diversity, and how have you used these to better individualize approaches within your practice?
- How have you modified your approaches to deliver developmentally appropriate responses and attend to needs for safety, accommodating for age, development stage, physical disability, gender and cultural traditions?
- Throughout their contact with services, how do you provide opportunities for people to share their preferences, expectations and needs?
- How do you include family recovery approaches, support people in fulfilling important social roles and link with naturally occurring supports in responding to the diverse needs of communities?

### Recovery-oriented leadership

- How is access to diversity and cultural support services made available when required?
- How have you facilitated access to knowledge about diversity from people with lived experience of mental health issues? How have you included people with diverse perspectives in developing organizational policy, programs and service improvements?
- What forums and community opportunities have been created to establish shared understanding and different perspectives of mental health, including opportunities for children, adolescents and seniors?
- What partnerships have been formed with organizations and support services, specifically those reaching diverse communities?
- How have you made available training resources and supports for developing competence in addressing diversity?
- What systems are in place to identify and monitor the changing needs of local population groups?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Undertake an environmental scan to map the diversity of your community and build knowledge of existing resources.
- Increase the use of technology to facilitate responsiveness and access to service for rural and remote communities.
- Establish training and service delivery networks to increase exchange opportunities that can help build cultural competence.

## RESOURCE MATERIALS

### Across the Lifespan

- Scottish Recovery Network. (2014). Neither seen nor heard: What about recovery for children and young people? Retrieved from <http://www.scottishrecovery.net/Latest-News/neither-seen-nor-heard-what-about-recovery-for-children-and-young-people.html>
- Spenser, H., Ritchie, B., Kondra, P., & Mills, B. (n.d.). Child & youth mental health toolkits. Hamilton, ON: Collaborative Mental Health Care. Retrieved from <http://www.shared-care.ca/toolkits>

### Sexual orientation

- Kidd, S. A., Veltman, A., Gately, C., Chan, J., & Cohen, J. N. (2011). Lesbian, gay, and transgender persons with severe mental illness: Negotiating wellness in the context of multiple sources of stigma. *American Journal of Psychiatric Rehabilitation*, 14(1), 13–39. doi: 10.1080/15487768.2011.546277
- Lucksted, A. (2004). Lesbian, gay, bisexual, and transgender people receiving services in the public mental health system: Raising issues. *Journal of Gay & Lesbian Psychotherapy*, 8(3–4), 25–42. doi: 10.1300/J236v08n03\_03

### Cultural diversity

- Jacobson, N., Farah, D., & Toronto Recovery and Cultural Diversity Community of Practice. (2010). Recovery through the lens of cultural diversity. Toronto, ON: Community Resource Connections of Toronto, Centre for Addiction and Mental Health, & Wellesley Institute. Retrieved from <http://www.wellesleyinstitute.com/wp-content/uploads/2010/07/RTLCD-report-jul0410.pdf>
- Kirmayer, L. J., Fung, K., Rousseau, C., Lo, H.-T., Menzies, P., Guzder, J., Ganesan, S., Andermann, L., & McKenzie, K. (2012). Guidelines for training in cultural psychiatry. Canadian Psychiatric Association position paper. Retrieved from [http://www.academia.edu/2824551/Guidelines\\_for\\_Training\\_in\\_Cultural\\_Psychiatry](http://www.academia.edu/2824551/Guidelines_for_Training_in_Cultural_Psychiatry)

### Spirituality

- Macnaughton, E. (Ed.). (2001). Spirituality and recovery [special issue]. *Visions: BC's Mental Health Journal*, no. 12. Retrieved from [http://2010.cmha.bc.ca/files/visions\\_spirituality.pdf](http://2010.cmha.bc.ca/files/visions_spirituality.pdf)

# Responsive to Needs across the Lifespan

## CORE PRINCIPLES

- » Recovery-oriented mental health services are responsive and adapted to a person's age and phase of development.
- » Recovery-oriented practice and person-centred philosophies are complementary, strength-based approaches central to supporting people at every stage of life.
- » Recovery-oriented practice works to give purpose to life and enhance quality of life, fostering hope and strengthening resilience for people of all ages.
- » The involvement of family members is adapted to the age and development of the person receiving services.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Embrace, value and celebrate diversity as a strength.
- Accept people for who they are, regardless of age, and treat them with respect.
- Emphasize resilience and the unique developmental aspects of a recovery process for youth.
- Appreciate people's life accomplishments, respect them for their continuing role and contributions to family, friends, community and society and treat them as worthy human beings and full members of society.
- Recognize that ageism – the prejudice or discrimination against or in favour of any age group – is a form of discrimination that contributes to disregarding the views of young people and the social exclusion of seniors.

### Knowledge

- Understand how mental health problems and illnesses, and their associated risk factors, may manifest differently across the age span.
- Recognize that recovery-oriented approaches with children and youth draw on perspectives of growth, health and well-being related to social, emotional, cognitive and physical development.
- Understand basic neuroscience and the long-term impact of adverse childhood experiences and trauma on mental health in later life.
- Know how to connect with the inherent resilience of young people, support the development of their capacities and help them to become socially, morally, emotionally, physically and cognitively competent.
- Understand that mental illness should not be considered an inevitable consequence of aging and that such misperceptions discourage people from seeking help.
- Know how to engage and support caregivers in enhancing recovery in age appropriate ways.
- Recognize the interrelationships between many physical conditions and changes to mental health and behaviour.
- Recognize that the physical and social structures of neighbourhoods or communities can protect older adults from the risks of loneliness and social isolation and that services such as home support and transportation have an impact on the social participation, security, independence and overall health and well-being of older adults.

### Skills and Behaviours

- Encourage and value youth and seniors' perspectives, and ensure their meaningful participation in decision-making.
- Support young people to maximise learning opportunities as they increasingly assume control over decision-making.
- Work to ensure seamless continuity of care during developmental transition points, in particular when youth move to adult mental health services and when older adults require specialist geriatric care.
- Encourage social participation and relationships with others for people of all ages.
- Facilitate an environment in which seniors are provided with the required information, options and supports to make real choices, in keeping with their capacities.
- Provide opportunities for recreation, physical activity and fitness for people at all stages of life.
- Assist older adults to be in control of their own lives, do as much for themselves as possible and make their own choices wherever feasible.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How does your assessment process provide opportunities for people to share information about their needs and expectations related to age, development, gender, sex identity, sexual orientation and spirituality?

## REFLECTIVE PRACTICE QUESTIONS (Continued)

### Recovery-oriented practice (Continued)

- What opportunities have you included to assist families to participate, and how have you helped them to feel comfortable in the service environment?
- When families are impacted by the experience of mental illness of a loved one, what resources have been made available to support family healing, especially for children and, where relevant, for adolescents? Has guidance and support also been offered for siblings?
- How do you support adult children taking over caregiver responsibility and decision-making for their parents?
- How have you adapted interactions and activities to ensure age-appropriate communication and interventions?
- What adjustments in programming and the physical environment have you made to ensure safe participation opportunities for all, including children and young people?
- How have you optimized the use of appropriate technology, in particular for youth and older adults?

### Recovery-oriented leadership

- How do you invite and incorporate input from people with lived experience to ensure responsiveness to age, gender and diversity in organisational policy, practice and service improvements?
- What processes have been established for systematically identifying training needs and routinely offering appropriate age, gender and diversity competency development and training?
- How have regular reviews of practice and documentation been instituted to encourage staff and volunteers to embrace age-sensitive and safe practice?
- How do you convey a positive approach toward the unique needs of older adults with or at risk of mental illness, including by ensuring access to clinical and ethical consultations, adequate supervision and mentoring, as well as through the provision of sufficient resources?
- What service partnerships have been arranged to access specialized services for children and youth and geriatric services for older adults?
- As you critically review your organization's work to address stigma and discrimination, how representative of the community and the lifespan are the stories, celebrations and events?
- How have you advocated for age- and development-appropriate appropriate services and specialized space?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Establish youth, older-adult and intergenerational councils to promote intergenerational learning and enhance engagement with service planning and delivery.
- Partner with school leaders to develop prevention, early identification and mental health promotion strategies and help people stay in school.
- Partner with age-related community networks to identify needs, undertake community development and advocacy campaigns and develop specialized programming and social media tools.
- Expand the availability of peer specialists, and showcase recovery among children, youth and older adults.
- Establish partnerships among mental health services, family practitioners, community nursing, aged-care services, accommodation and residential facilities, disability support, home and community care, substance abuse services and other community support services.
- Assist long-term care facilities and services for older adults to recognize and become more responsive to the needs of people with mental health problems.

## RESOURCE MATERIALS

### Children and youth:

- Cavanaugh, D., Goldman, S., Friesen, B., Bender, C., & Le, L. (2009). Designing a recovery-oriented care model for adolescents and transition age youth with substance use or co-occurring mental health disorders. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. Retrieved from [http://gucchdtacenter.georgetown.edu/resources/Recovery\\_Report\\_Adolescents\\_FINAL.pdf](http://gucchdtacenter.georgetown.edu/resources/Recovery_Report_Adolescents_FINAL.pdf)
- Family Service Thames Valley. (n.d.). mindyourmind. An online portal focused on youth mental health developed in collaboration with youth with experiential expertise. London, ON: Author. Retrieved from <http://www.mindyourmind.ca/>
- Institute of Families. (2014). Creating a culture of feedback: Feedback informed child and youth mental health care. Retrieved from <http://www.instituteoffamilies.ca/sites/default/files/publications/Feedback%20Informed%20Mental%20Health-%20%20GFSE.pdf>
- Institute of Families. (2014). May 7, 2014 Preliminary consensus statements: Urgency, action, role modeling and caring adults. Vancouver, BC: Author. Retrieved from [http://www.familysmart.ca/sites/default/files/Preliminary%20Consensus%20Statements%20-%20May%207%202014%20%282%29\\_0.pdf](http://www.familysmart.ca/sites/default/files/Preliminary%20Consensus%20Statements%20-%20May%207%202014%20%282%29_0.pdf)

### Seniors

- MacCourt, P. (2008). Promoting seniors' well-being: A seniors' mental health policy lens toolkit. Victoria, BC: British Columbia Psychogeriatric Association. [http://www.mentalhealthcommission.ca/English/system/files/private/Seniors\\_Seniors\\_Mental\\_Health\\_Policy\\_Lens\\_Toolkit\\_ENG\\_0.pdf](http://www.mentalhealthcommission.ca/English/system/files/private/Seniors_Seniors_Mental_Health_Policy_Lens_Toolkit_ENG_0.pdf)
- MacCourt, P., Wilson, K., & Tourigny-Rivard, M-F. (2011). Guidelines for comprehensive mental health services for older adults in Canada. Calgary, AB: Mental Health Commission of Canada. Retrieved from: [https://www.mentalhealthcommission.ca/English/system/files/private/document/mhcc\\_seniors\\_guidelines.pdf](https://www.mentalhealthcommission.ca/English/system/files/private/document/mhcc_seniors_guidelines.pdf)

# Responsive to the Needs of Immigrants, Refugees, Ethnocultural and Racialized (IRER) Communities

## CORE PRINCIPLES

- » Recovery is a process that occurs within a web of relations, including the individual, family and community and is contextualized by culture, language, experience of racism and other forms of discrimination, history of migration and the variable impact of the social determinants of health.
- » Responsiveness to the needs of immigrant, refugee, ethnocultural and racialized (IRER) communities requires capacity-building at all levels – systems, organizations and practice.
- » Responsive, recovery-oriented approaches require that practitioners be aware of their own ethnocultural identity, the potential for discrimination within the system and the diverse ways in which mental health, illness and recovery are experienced.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Appreciate the importance of reflecting upon one's own identity and background and relationship to people from other backgrounds and experiences.
- Remain open to others' perspectives of mental health, illness and recovery and tolerant of differences in opinions, experiences and beliefs that shape responses and behaviours.
- Value a support system that enables people from IRER backgrounds to know and exercise their human and legal rights, free from trauma, harassment and discrimination.
- Recognize the value of respectful curiosity and the importance of continuous learning about various cultures and diversity.

### Knowledge

- Understand how assumptions about people from IRER backgrounds and their experiences may impact responsiveness.
- Have knowledge of local IRER communities and local community supports and resources available.
- Understand and respond to the impact of the social determinants of health on mental health and well-being.
- Appreciate the possible impacts of migration, seeking refuge, trauma and separation.
- Recognize cultural differences in expressions of distress, symptom presentation and models of health and illness.
- Are mindful that racism, discrimination and barriers to access can increase health disparities and impede people from IRER backgrounds from exercising their rights and getting the help they need.

### Skills and Behaviours

- Demonstrate compassion and respect for people from IRER backgrounds.
- Actively explore how people from IRER backgrounds and their families understand mental health, illness, trauma and recovery.
- Utilize interpreters, cultural brokers, settlement workers and faith leaders to support a person's recovery plans.
- Provide orientation to services in safe and comfortable spaces.
- Provide information needed to make decisions about mental health care, including written information in easy-to-read language, and where necessary in multiple languages and/or via interpretation.
- Engage with people in the context of their families and important relationships, and explore the implications of experiences such as loss, separation, violence and trauma for recovery.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How have you applied culturally responsive practice to all those seeking support whose background is different from your own?
- How does the recovery plan incorporate provision for people's cultural and religious beliefs and faith traditions?
- How does your practice involve and support family members and other relevant people from IRER communities?

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### Recovery-oriented leadership

- What processes and service initiatives have you put in place to become a culturally responsive and diverse organization (e.g., language policies, cultural diversity plans, data collection/analysis related to local populations and needs)?
- What specific interventions do you use to address discrimination, harassment and bullying?
- Has an organization-wide cultural responsiveness plan been developed? How are you advancing its implementation?
- How do you work with the community and local decision-makers to understand the diversity of needs in your community, to champion issues relevant to them and promote equity and access to services?
- How have you used health equity impact assessments to evaluate effectiveness of the recovery approach with diverse populations?
- What resources have been made available to assist practitioners to work effectively with interpreters, participate in training, and have appropriate resources and materials to support responsive services, including sufficient time to engage families, caregivers and cultural and spiritual leaders?
- How do you participate in community cultural events and celebrations to support positive relationships and shared understanding of mental health issues?

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## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Establish workforce positions or shared networks to build capacity to address the specific needs of the local IRER population (e.g., bilingual workers, cultural liaison workers, immigrant and refugee peer workers, cultural champions).
- Partner with ethnically specific community networks to undertake community development initiatives, advocacy campaigns and specialized programming.
- Subscribe to multicultural communications and training offerings, and make these available to staff.

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## RESOURCE MATERIALS

- Beiser, M. (2009). Resettling refugees and safeguarding their mental health: Lessons learned from the Canadian Refugee Resettlement Project. *Transcultural Psychiatry*, 46(4), 539–583.
- Dunn, J. R., & Dyck, I. (2000). Social determinants of health in Canada's immigrant population: Results from the National Population Health Survey. *Social Science & Medicine*, 51(11), 1573–1593.
- Hansson, E., Tuck, A., Lurie, S., & McKenzie, K. (2010). Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: Issues and options for service improvement. Calgary, AB: Mental Health Commission of Canada, Task Group of the Services Systems Advisory Committee. Retrieved from [https://www.mentalhealthcommission.ca/English/system/files/private/Diversity\\_Issues\\_Options\\_Report\\_ENG\\_0.pdf](https://www.mentalhealthcommission.ca/English/system/files/private/Diversity_Issues_Options_Report_ENG_0.pdf)



# Responsive to Gender Differences and to the Needs of Lesbian, Gay, Bisexual, Two-Spirited, Transgendered, and Transsexual People, their Families of Choice and Communities

## CORE PRINCIPLES

- » Recovery-oriented practice recognizes and affirms diversity in sexuality, sex and gender.
- » Gender-sensitive care recognises that women and men may experience mental health problems and illnesses differently and considers gender sensitivity and safety in service design, workforce development, policies and procedures.
- » Recovery-oriented practice recognizes the negative impact of discrimination, stigma and phobia on the well-being of lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people and recognize that these populations are potentially at high risk.
- » Services uphold people's physical, sexual and emotional safety at all times, ensure safe and welcoming environments and services free from discrimination.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Affirm diversity in sexuality, sex and gender.
- Consider people in the context of their gender, gender identity and sexual preferences, as well as the range of other factors that interact with gender.
- Are able to reflect on the impact of their own gender on the provision of gender-sensitive care.
- Respect transsexual and other people's right to choose their gender and gender norms.

### Knowledge

- Know current trends in service provision of gender-sensitive care and in service provision for lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people.
- Consider gender, gender identity and sexuality in relation to people's identity, experiences, safety, resilience, vulnerability and well-being.
- Understand that men and women are sometimes predisposed to different physical health issues and can be impacted differently by some medications.
- Know the cultures, identities, language and common experiences of discrimination for lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people.
- Recognize that trauma and abuse can have complex and enduring effects on people, that it can be understood to be gendered, both in terms of the prevalence of particular types of trauma, and acknowledge the high prevalence of experiences of assault and abuse amongst people accessing mental health services.
- Be familiar with local and on-line community-specific support groups and advocacy organizations on gender-based issues and for lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people.
- Consider culturally responsive practice in engaging with men and women from diverse backgrounds who may have differing understandings of gender, gender identity and sexual identity and are aware of the different manifestations of gender-based power relationships.
- Recognize the multiple layers of stigma and discrimination that may be experienced by lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people who also have a disability, are from culturally or linguistically diverse backgrounds, or identify as Indigenous peoples.

### Skills and Behaviours

- Ensure practice is tailored and responsive to gender differences, sexual orientation and individual needs.
- Promote sensitivity and responsiveness to issues associated with gender and sexual identity in developing policies, procedures and programs.
- Offer equitable access and inclusive service to eliminate discrimination against lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people.



## MENTAL HEALTH PRACTITIONERS AND PROVIDERS (Continued)

### Skills and Behaviours (Continued)

- Establish rapport using gender-neutral and inclusive language and the person's preferred pronoun.
- Critically analyze and engage in discussion about prevailing cultural assumptions, beliefs and values about gender roles and sexuality.
- Advocate for and support people's self-advocacy and choice with regard to their sexuality and gender norms.
- Explore the range and impact of family responses to issues relating to sexual orientation (e.g., secrecy, isolation, support) and acknowledge and draw on a person's key sources of personal support, including their partner or close friends.
- Seek out and embrace training in cultural safety, cultural competency and diversity.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How does your language, tone, and environment of practice demonstrate understanding of the fear of discrimination experienced by many lesbian, gay, bisexual, two-spirited, transgendered, transsexual and intersex people?
- How have you demonstrated sensitivity in your language, tone and practice and incorporated experiential knowledge to prevent discrimination?
- How does your practice incorporate consultation with the service recipient to reflect how they would like their personal information to be recorded, used and shared?
- How is respect and tolerance for other's choices evident in your engagement with them, particularly when your personal situation may be different from theirs?

### Recovery-oriented leadership

- How do you provide a safe and welcoming environment, including for example visible signals affirming responsiveness to gender and sexual orientation?
- What partnerships have been formed with organizations and support services specifically reaching lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people in order to inform people of support and social opportunities?
- Have you critically examined documentation and processes such as intake and incident forms as well as feedback mechanisms to ensure appropriate options are available to reinforce inclusiveness and respect for gender difference and sexual orientation?
- What avenues are available to proactively incorporate responsiveness to the lived experience of lesbian, gay, bisexual, two-spirited, transgendered, and transsexual people in organizational policy and practice?
- How do data collection and information systems include information about diverse sexuality, sex and gender that is relevant to improving responsiveness?
- How have you promoted acceptance of sexual diversity, redressed discrimination and normalized expression of diverse sexuality and gender identification?
- What resources are made available for staff and volunteers for training and development related to gender sensitivity and sexual orientation?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Develop programming and initiatives to enhance safety that acknowledge gender-specific experiences.
- Use research and evidence to help improve practice, service delivery and outcomes for LGBTQ people and their families.
- Establish links and share expertise with community-specific support groups, organizations and practitioners who welcome LGBTQ people.

## RESOURCE MATERIALS

- Barbara, A. M. (2007). Asking the right questions 2: Talking about sexual orientation and gender identity in mental health, counselling, and addiction settings. Toronto, ON: Centre for Addiction and Mental Health. Retrieved from [http://www.camh.ca/Publications/Resources\\_for\\_Professionals/ARQ2/arq2.pdf](http://www.camh.ca/Publications/Resources_for_Professionals/ARQ2/arq2.pdf)
- Egale Canada Human Rights Trust. National charity promoting LGBT human rights through research, education and community engagement. See <http://egale.ca/>
- Parents, Families and Friends of Lesbians and Gays (PFLAG). (2009, September 4). Rachel Maddow loves the PFLAG pride parade contingent [blog post]. Retrieved from <http://blog.pflag.org/2009/09/rachel-maddow-loves-pflag-pride-parade.html>
- Parents, Families and Friends of Lesbians and Gays (PFLAG) Canada. (2011). Helpful links for healthcare providers. Retrieved from <http://www.pflagcanada.ca/en/links-e.php?audience=clinicians>
- Zwiers, A. (2009). LGBT people and mental health: Healing the wounds of prejudice. *Visions: BC's Mental Health and Addictions Journal*, 6(2), 10–11. Retrieved from <http://www.heretohelp.bc.ca/visions/lgbt-vol6/lgbt-people-and-mental-health>

## CHAPTER 5

# Working with First Nations, Inuit and Métis

There are three key points that are important for mental health practitioners to take into account so that they can best facilitate recovery-oriented services for First Nations, Inuit and Métis:

- First, in many ways, the increasing adoption of recovery principles in the mental health system can be seen as an overdue embrace by mainstream culture of long-held Indigenous understandings of wellness.
- Second, supporting recovery for First Nations, Inuit and Métis means understanding the impact of colonization across generations.
- Third, the context for recovery for First Nations, Inuit and Métis is shaped by their distinct cultures, rights and circumstances, wherever they live, including in urban settings.

As was the case with Strategic Direction 5 of the Mental Health Strategy for Canada,<sup>1</sup> this chapter was developed through a process of engagement with the Assembly of First Nations, Inuit Tapiriit Kanatami, Métis National Council, the Congress of Aboriginal Peoples, and the National Association of Friendship Centres, drawing on policy documents and research that has been done through engagement with Elders and communities wherever possible.<sup>2</sup>

First Nations, Inuit and Métis cultures are distinct from one another and also encompass considerable diversity within each population as well as regional and local specificity. Indigenous people embrace a range of beliefs

and values that can draw from a variety of traditional and Western sources. At the same time, there are also many shared principles with respect to understanding wellness. Many of these principles, such as promoting self-determination and dignity, adopting a holistic and strengths-based approach, fostering hope and purpose and sustaining meaningful relationships, are also the foundation of a recovery orientation as outlined throughout this document.

In an Indigenous context, self-determination is an essential component both for achieving a people's inherent right to self-government and for realizing each person's right to pursue their own journey with dignity. A holistic approach is often expressed through a balance of physical, emotional, mental and spiritual wellness, accompanied by an understanding of the impact of all the social determinants of health, just as a recovery orientation considers all of the dimensions of a person's life. Nurturing hope means encouraging a positive outlook and a focus on strengths and resilience even in the face of challenges, as well as valuing the future of Indigenous children and youth. Having purpose is also a key element of mental wellness, much as recovery emphasizes the importance of building a life of meaning. Relationships with family and community as well as with the land hold a central place in First Nations, Inuit and Métis understandings of wellness. This focus on relationships has also contributed to the way in which recovery is understood in these Guidelines: that everyone's journey of recovery takes place in the context of their lives.

This common ground between recovery principles and shared Indigenous understandings of wellness provides many rich opportunities for learning and for strengthening mental health policy and practice. At the same time, mental health practitioners must understand how recovery for Indigenous peoples is uniquely shaped by Canada's history of colonization. Policies such as residential schools seriously damaged the fabric of First Nations, Inuit and Métis cultures, resulting in a wide range of complex health and social issues that have passed from generation to generation. Residential schools also left a legacy of deep divisions in Canadian society. These divisions are reflected in the work of the Truth and Reconciliation Commission.

Discrimination and racism continue to affect Indigenous people today, finding expression not only in individual behaviour but also in ways that are ingrained within systems and institutions. We can see evidence of this in the stubborn persistence of stereotypes and racist attitudes, and also in high rates of incarceration, large numbers of children in care and high rates of violence against Indigenous women and girls. As well, intergenerational trauma and relatively young populations combine to make the mental wellness of First Nations, Inuit and Métis children and youth a particularly significant concern.

Issues relating to geography also have an important bearing on the work of recovery-oriented practitioners helping to address needs for these populations. First Nations, Inuit and Métis live in highly diverse geographic regions. Overall, 56 per cent of people who identify themselves as Aboriginal live in urban areas (although the percentage is much lower for Inuit and higher for Métis). The rest are spread across hundreds of reserves, hamlets, settlements and other rural communities from coast to coast to coast. Isolation, disputes over

## **FIRST NATIONS, INUIT AND MÉTIS UNDERSTANDINGS OF WELLNESS**

For First Nations, mental wellness is a balance of the mental, physical, spiritual, and emotional. This balance is enriched as individuals have: hope for their future and those of their families that is grounded in a sense of identity, unique Indigenous values, and having a belief in spirit; a sense of belonging and connectedness to their families, to community and creation and it is through these relationships that an attitude towards living life is nurtured; a sense of meaning and an understanding of how their lives and those of their families and community are part of creation and a rich history; and finally purpose in their daily lives whether it is through education, employment, care-giving activities, or cultural ways of being and doing. (NWATM – Copyright 2015, National Native Addictions Partnership Foundation.)

For Inuit, mental wellness is defined as self-esteem and personal dignity flowing from the presence of harmonious physical, emotional, mental and spiritual wellness and cultural identity. According to the Inuit vision for mental wellness, Inuit will have: ample opportunities for positive self-expression; the best of contemporary and traditional ways of life and the life skills to thrive in their environment; and socio-economic conditions that promote mental wellness. Ultimately, Inuit will live in a society in which each person has a valued purpose and role and is a contributing and necessary member of the community. (Alianait Mental Wellness Action Plan, 2007, pp. 1, 11)

Métis understand the environment in terms of sacred relationships that link such things as language, tradition and land in order to foster community spiritual, physical, intellectual and emotional health. (Changing Directions, Changing Lives, 2012, p. 102) Métis Elders tell us that Métis health and well-being is dependent on the land and water as well as a wide range of social, cultural, political and economic influences; all of which inform Métis traditional health knowledge. (Métis Centre, National Aboriginal Health Organization In the Words of our Ancestors: Métis Health and Healing, 2008, p. 7)

Cultural safety is grounded in Indigenous knowledge and experience, and is based on the recognition of cultural diversity and the influence that social inequalities and imbalances of power have on relationships between providers and service users.

**Changing Directions, Changing Lives, 2012, p. 97**

Cultural safety extends beyond cultural awareness and sensitivity within services and includes reflecting on cultural, historical and structural differences and power relationships within the care that is provided. It involves a process of ongoing self-reflection and organizational growth for service providers and the system as a whole to respond effectively to First Nations.

**Honouring our Strengths, 2011, p. 8**

which level of government has jurisdiction over which kind of services for which population group and lack of capacity can make access to treatment and services especially challenging. This means that Indigenous people's ability to access the full range of services, treatments and supports can be severely limited. Nonetheless, we must strive collectively to ensure that everyone has the opportunity to choose the combination of Western and traditional/cultural services that best meets their needs, while respecting their understanding of culture as the foundation of wellness.

Recovery-oriented mental health practitioners have the opportunity and responsibility to understand both the similarities and differences between a recovery orientation and the shared Indigenous values and experiences outlined above. Recovery-oriented services for Indigenous people must be not only trauma-informed but culturally safe (see sidebar) and provided as close to home as possible. Recovery-oriented mental health systems must balance a focus on supporting those already experiencing a mental health problem or illness with efforts to promote mental well-being and prevent problems from arising, particularly among children and youth. Recovery-oriented practice in the Indigenous context also needs to acknowledge the similarities and differences between recovery in the mental health context and the particular meaning of recovery in the very powerful and longstanding Indigenous addictions movement. In the addictions movement, recovery can be associated with both abstinence and harm reduction, as well as with the life-long process of sustaining wellness by reconnecting to culture, strengthening identity and focusing on strengths. Further, addictions and mental health are often integrated under the more holistic term mental wellness in the Indigenous context.

Just as important is the need to recognize and become knowledgeable about the distinct cultures, rights and circumstances of First Nations, Inuit and Métis, as well as urban Aboriginal populations. The following brief overviews have been adapted from Strategic Direction 5 of the *Mental Health Strategy for Canada*.

## FIRST NATIONS OVERVIEW

First Nations rights have been acknowledged through a variety of means: treaties, legislation dating back to the Constitution Act of 1867, self-government and land-claims agreements and court decisions. One quarter of First Nations are not Registered Indians under the Indian Act and do not have access to most federal health benefits.

First Nations are highly diverse, with more than 60 languages and more than 600 bands across the country. Even with this level of diversity, First Nations' ways of life have traditionally been based upon values that include recognizing the importance of spirituality, culture and relationship with the land. Key concepts in First Nations' worldviews include: the spirit, the circle, harmony and balance, regarding all living things as other-than-human beings with whom it is necessary to have a relationship, caring, promoting strengths, connection to the Earth, the path of life as a continuum and language as the voice of culture.<sup>3</sup> Historically, the role played by every person within the community was valued at each stage of life, with Elders and cultural practitioners having community-based sanction for supporting mental wellness.

The cultures and way of life of First Nations that had been evolving were nearly eradicated through the process of colonization. Forced attendance and widespread abuse at Indian residential schools, in conjunction with sweeping apprehensions and adoptions

commonly known as the "Sixties Scoop," continued to erode the mental health landscape for many First Nations,<sup>4</sup> which had already been damaged by colonial processes and assimilation practices.<sup>5</sup> The impact of these experiences across generations has contributed to high rates of substance use and mental health problems, suicide, incarceration, and family and lateral violence. Many First Nations communities also experience high rates of poverty, shortages of adequate housing, unsafe drinking water, food insecurity, and a lack of educational, employment and economic opportunities, all of which undermine health and well-being.

First Nations continue to encounter many challenges in obtaining timely access to mental wellness services, particularly in northern, rural and remote communities. Even when First Nations communities do have the financial resources to offer services, they often have difficulty in recruiting and retaining qualified service providers<sup>6</sup> as well as service providers who have some level of cultural competence and openness to working alongside cultural practitioners. Better support for current and future service providers of First Nations origin will strengthen service delivery over the long term. At the same time, all service providers must be trained to practise in collaborative ways that are culturally safe and effective.

First Nations recognize that in order to bring about change, healing from this historical trauma must occur. They have established initiatives at the national, regional and community levels to address gaps and fragmentation in the continuum of mental wellness services and have insisted on the importance of recognizing communities as their own best resource and drawing on traditional and cultural knowledge. For example, the "Culture as Intervention" research project is strength-

ening the evidence base for cultural interventions. In general, it is critically important to approach First Nations communities with recognition of their inherent strengths.

## **INUIT OVERVIEW**

Inuit rights have been acknowledged through a mix of legislation, self-government and land-claims agreements for each of the four Inuit regions – Inuvialuit in the Northwest Territories, Nunavik in northern Quebec, Nunatsiavut in northern Labrador and Nunavut.

Living on the land, Inuit have worked together to survive. This has shaped a worldview that is focused on strengths. Inuit embrace a holistic approach to mental wellness, defined as “self-esteem and personal dignity flowing from the presence of harmonious physical, emotional, mental, spiritual wellness and cultural identity.”<sup>7</sup>

The Inuit experience of colonization and contact with Europeans occurred relatively recently in the history of Canada. Many older Inuit, particularly those from Nunavut and Nunavik, grew up living on the land year-round, until their families began to rely more on trading or were pushed to settle in communities.<sup>8</sup> Inuit attended either residential schools or day schools, with children housed in residences and hostels, boarded with families or sent away to the south. Inuit children experienced abuse and loss of their culture and language.<sup>9</sup> Other traumatic experiences included the forced relocation of communities, famine, disease and the mass killing of sled dogs.

A disruption of culture, language and way of life ensued, with dramatic and negative consequences for mental health and well-being. Many Inuit today continue to live a traditional life and speak a traditional language, with some still being unilingual. At the same time, across the Inuit regions many also experience

high levels of suicide, addictions, abuse, violence and depression.<sup>10</sup> Addressing the social determinants of health is a key priority for Inuit as communities experience high rates of unemployment, lack of education, inadequate and overcrowded housing conditions and scarcity of healthy food.<sup>11</sup>

Traditional and cultural practices focus on promoting well-being, enabling people to support one another and draw on community strengths, and taking people out on the land to learn about the traditional Inuit way of life. The availability of land-based programs varies from region to region, as does the degree of integration with clinical mental health services. At the same time, high staff turnover and insufficient funding mean that there is often a lack of basic mental health services, with many Inuit having to travel outside of their communities for care. More Inuit need opportunities for education and training in mental wellness, both to build local capacity and to improve access to services in Inuit languages. Non-Inuit mental health practitioners require more training in cultural competency and cultural safety so that they can deliver services in a manner that respects and understands Inuit culture and the role of Elders and recognizes the importance of nonverbal communication.

## **MÉTIS OVERVIEW**

The distinct and unique culture, history, rights and circumstances of Métis people are not well understood in Canada. Métis are descendants of European fur traders and Indian women. Distinct Métis communities developed along the fur trade routes and across the northwest, and continue to exist today. More than 450,000 people reported they were Métis in the 2011 census, with 85 per cent living in the “Métis homeland” (western Canada and Ontario).



Even before Canada became a country in 1867, Métis culture had emerged with its own traditions, language (Michif), way of life, collective consciousness and sense of nationhood. Métis understand the environment in terms of sacred relationships that link such things as language, tradition and land to foster community spiritual, physical, intellectual and emotional health.<sup>12</sup>

For generations, and in different ways in different regions, Métis people have been reluctant to acknowledge their Métis ancestry openly. The aftermath of the Métis struggle to exercise their rights and the execution of their leader Louis Riel in 1885, the lack of respect for Métis land rights and the negative experiences of many Métis children in residential schools, day schools and the mainstream school system (even to this day) have provided powerful disincentives to doing so.<sup>13</sup> Many Métis have been caught between two worlds and fully accepted in neither, with consequences for identity and mental well-being.

More research, supported by stable, multi-year funding, is needed on the intergenerational impact of colonization and its effects on the mental health needs of Métis people today. What is known is that Métis experience many risk factors for mental health problems and illnesses, such as overcrowded housing, substance abuse, family violence, involvement in the criminal justice system and children in care. In 2008 in British Columbia, 9 per cent of Métis youth reported extreme levels of despair, 24 per cent reported having been physically abused and 16 per cent reported seriously thinking about killing themselves.<sup>14</sup> Amongst Métis in Manitoba a recent study found a higher prevalence of depression (22.0% vs. 20.3%), anxiety disorders (9.3% vs. 8.0%) and substance abuse (13.8% vs. 10.5%) compared to all other Manitobans.<sup>15</sup>

“ I have been working in recovery for years with people on mental health on an individual level, but there is recovery at a bigger level as well. There needs to be a sharing of power and resources, and the respect for where people come from. For the aboriginal communities, they need to be the drivers. ”

**Holding Hope in our Hearts,  
2011, Participant, Yellowknife, p. 26**

Métis-specific prevention programs for youth are a key priority for Métis.

It was only in 1982 that the federal government recognized Métis in the Constitution as one of three distinct Aboriginal groups,<sup>16</sup> and Canadian courts are increasingly recognizing Métis rights. Nonetheless, Métis people have no access to specific federally funded mental health and addictions programs. They continue to fall under provincial and territorial jurisdiction, where gaps in Métis-specific programs and services often remain. Some Métis, particularly those living close to reserves, may face the difficult choice of seeking Registered Indian status to qualify for federal benefits, a choice that can sometimes divide families and communities as well as having an impact on individual identity. At the same time, more Métis are reconnecting with their culture, working together to improve their health and well-being and expanding their role in health and social services.

## URBAN ABORIGINAL OVERVIEW

As noted above, the 2011 census shows that more than 56 per cent of Indigenous people live in urban areas. In urban centres there is a strong sense of community that draws First Nations, Inuit, and Métis people together, both collectively and within their own cultures. Some people are firmly rooted in urban areas, and others move back and forth between urban centres and home communities.

The reasons for moving from smaller communities to larger cities and towns will be familiar to anyone in Canada who has made a similar choice: better access to economic opportunities and employment, better access to health and other services, and in some cases the chance to leave a bad situation. For many, this choice does lead to improvements in key protective factors for mental health, such as better access to education and employment.

Amongst Métis in Manitoba a recent study found higher prevalence of depression (22.0% vs. 20.3%), anxiety disorders (9.3% vs. 8.0%) and substance abuse (13.8% vs. 10.5%) compared to all other Manitobans.<sup>17</sup>

Unfortunately, a substantial portion of First Nations, Inuit and Métis living in both urban and rural centres continue to live in poverty.<sup>18</sup> Even within larger urban centres, they continue to face problems with access to services, such as long waiting lists, lack of transportation and federal-provincial jurisdictional issues. For example, First Nations, Inuit and Métis living in urban centres have varying degrees of access to federally-funded mental health crisis counselling. In addition, lack of awareness and understanding amongst service providers of cultural differences impacts those receiving services. The mental health of First Nations, Inuit and Métis in urban centres has also been marked by the effects of the process of colonization as well as the impact of intergenerational trauma.

It is important to increase access to a full continuum of mental health services, treatments and supports, with a strong focus on preventative services, particularly for youth. Services must be culturally safe, and First Nations, Inuit and Métis people living in urban areas should be encouraged and supported to pursue careers in mental health. Increased capacity is needed to deliver services through both mainstream and First Nations, Inuit and Métis organizations, especially since these are often underresourced. In particular, more capacity is needed to deliver specialized services that integrate traditional and cultural with mainstream approaches and can address complex issues.



## ENDNOTES FOR CHAPTER 5

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- 1 “Work with First Nations, Inuit, and Métis to address their distinct mental health needs, acknowledging their unique circumstances, rights, and cultures.” Mental Health Commission of Canada. (2012). *Changing Directions, Changing Lives*, p. 96.
- 2 This Chapter provides only a brief overview of a number of very complex issues. Readers are encouraged to seek out additional information, starting with the resources section of the Guideline Table at the end of the Chapter.
- 3 Elder Jim Dumont, National Native Addictions Partnership Foundation, *Honouring our Strengths: Indigenous Culture as Intervention in Addictions Treatment Project*. (2014). Definition of Culture. Muskoday, SK: Author. Retrieved from <http://www.addictionresearchchair.ca/wp-content/uploads/2012/04/Definition-of-culture.pdf>
- 4 Canada, Royal Commission on Aboriginal Peoples. (1996). *People to people, nation to nation: Highlights from the report of the Royal Commission on Aboriginal Peoples*. Retrieved from <http://www.aadnc-aandc.gc.ca/eng/1100100014597/1100100014637#chp4>
- 5 Wesley-Esquimaux, C. C., & Smolewski, M. (2004). *Historic trauma and Aboriginal healing*. Ottawa, ON: Aboriginal Healing Foundation. Retrieved from: <http://www.ahf.ca/downloads/historic-trauma.pdf>
- 6 Mussell, B., Adler, M., Hanson, G., White, J., & Smye, V. (2011). *Holding hope in our hearts: Relational practice and ethical engagement in mental health and addictions*. Calgary, AB: Mental Health Commission of Canada. Retrieved from [http://www.mentalhealthcommission.ca/English/system/files/private/document/FNIM\\_Holding\\_Hope\\_In\\_Our\\_Hearts\\_ENG.pdf](http://www.mentalhealthcommission.ca/English/system/files/private/document/FNIM_Holding_Hope_In_Our_Hearts_ENG.pdf)
- 7 Alianait Inuit-Specific Mental Wellness Task Group. (2007). *Alianait mental wellness action plan*. Ottawa, ON: Inuit Tapiriit Kanatami. Retrieved from <http://www.itk.ca/publication/alianait-inuit-mental-wellness-action-plan>.
- 8 Pauktuutit Inuit Women of Canada. (2007). *Sivumuapallianiq: Journey forward: National Inuit Residential Schools healing strategy*. Ottawa, ON: Author.
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- 10 Ibid.
- 11 Inuit Tapiriit Kanatami. (2004). *Backgrounder on Inuit health*. Ottawa, ON: Author.
- 12 Métis National Environment Committee. (2011). *Métis traditional knowledge*. Ottawa, ON: Métis National Council. Retrieved from <http://www.metisnation.ca/wp-content/uploads/2011/05/Metis-Traditional-Knowledge.pdf>
- 13 Teillet, J. (2013). *Métis law in Canada (rev. ed.)*. Toronto, ON: Pape Salter Teillet. Retrieved from <http://www.pstlaw.ca/resources/Metis-Law-in-Canada-2013.pdf>
- 14 Tsuruda, S., Smith, A., Poon, C., Hoogeveen, C., Saewyc, E., & McCreary Centre Society. (2012). *Métis youth health in BC*. Vancouver, BC: McCreary Centre Society. Retrieved from [http://www.mcs.bc.ca/pdf/Sept\\_2012\\_brief\\_report.pdf](http://www.mcs.bc.ca/pdf/Sept_2012_brief_report.pdf)
- 15 Sanguins, J., Bartlett, J., Carter, S., Hoepfner, N., Mehta, P., & Bassily, M. (2013). *Depression, anxiety disorders, and related health care utilization in the Manitoba Métis population*. Winnipeg, MB: Manitoba Métis Federation.
- 16 Teillet, J. (2013). *Métis Law in Canada*.
- 17 Environics Institute. (2010). *Urban Aboriginal peoples study: Main report*. Toronto, ON: Author. Retrieved from [http://uaps.ca/wp-content/uploads/2010/03/UAPS-Main-Report\\_Dec.pdf](http://uaps.ca/wp-content/uploads/2010/03/UAPS-Main-Report_Dec.pdf)
- 18 Aboriginal Affairs and Northern Development Canada. (2014). *Urban Aboriginal peoples*. Retrieved from <http://www.aadnc-aandc.gc.ca/eng/1100100014265/1369225120949>

## Working with First Nations, Inuit and Métis

**Recovery-oriented practice learns from Indigenous understandings of wellness, and works with First Nations, Inuit and Métis to support recovery in the context of distinct cultures, rights and circumstances.**

### CORE PRINCIPLES

- » Distinct First Nations, Inuit and Métis cultures, with all of their variations at the regional and community level, provide the context for recovery.
- » Recovery-oriented practice must be holistic, strengths-based and culturally safe, and promote hope, belonging, meaning and purpose.
- » Family, community and the broader social determinants of health all have an impact on wellness and recovery.
- » Supporting self-determination and fostering choice from a full continuum of mainstream, cultural and traditional practices is necessary to promote recovery.
- » People's needs must always be addressed first; jurisdictional issues must not get in the way and are to be resolved once people are safe and healthy.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### VALUES AND ATTITUDES

- Exercise cultural humility; know their own values and how their professional ethics are similar or different from First Nations, Inuit and Métis cultures.
- Respect and seek to learn from and about First Nations, Inuit and Métis cultures and experiences.
- Acknowledge and honour the expertise of Elders, traditional healers, cultural practitioners and community members regarding First Nations, Inuit and Métis mental wellness.
- Commit to providing culturally safe practices, the safety of which is determined by the person receiving the services; such practices must recognize the influence of social inequalities and imbalances of power on the relationship between service providers and users.
- Are willing to challenge personal attitudes and behaviours that may inadvertently contribute to racism and discrimination.
- Support self-determination and service delivery by Indigenous people for Indigenous people.

#### KNOWLEDGE: First Nations

- Understand that First Nations' rights stem from a mix of longstanding treaties and legislation, self-government, land claims agreements and evolving court decisions.
- Are familiar with the core concepts from First Nations cultures, including a spirit-centred worldview, connection to land/creation, connection to ancestors along the path of life continuum and language as the "voice" of culture.
- Understand the key role played by Elders and traditional healers in supporting mental wellness.
- Recognize the importance of community wellness in supporting recovery for individuals.
- Understand the intergenerational impact of colonialism and assimilation policies, such as Indian residential schools and the "Sixties Scoop," on the mental wellness of First Nations.
- Know how poverty, housing shortages, food insecurity and limited educational and employment opportunities undermine the health and well-being of First Nations.

#### KNOWLEDGE: Inuit

- Know that Inuit rights have been established through a mix of legislation and land-claims agreements.
- Understand the importance of adopting a holistic approach, promoting well-being, drawing on community strengths and taking people out on the land.
- Are familiar with local tradition and cultural practices.
- Understand the relatively recent and traumatic Inuit experience of colonization, including rapid loss of language and culture, forced relocation and forced attendance in residential schools.
- Understand the challenges Inuit face in securing adequate housing, food and employment, as well as access to basic mental health services.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS (Continued)

### KNOWLEDGE: Métis

- Understand that a distinct Métis culture emerged among communities that developed along fur trade routes prior to Confederation in 1867.
- Understand how colonization, discrimination and disregard for Métis rights resulted in generations of Métis not openly acknowledging their ancestry.
- Know that the federal government only recognized Métis as a distinct Aboriginal group in 1982, and that Métis do not receive federal funding for specific mental health programs.
- Know that significant gaps in knowledge about Métis mental health needs and gaps in Métis-specific services remain.
- Understand that prevention programs for Métis youth constitute a Métis priority.

### KNOWLEDGE: Urban Aboriginal

- Know that 56 per cent of Indigenous people live in urban areas, where many continue to live in poverty.
- Understand that First Nations, Inuit and Métis in urban centres have also been affected by the process of colonization and the impact of intergenerational trauma.
- Understand that jurisdictional issues result in varying degrees of access to provincially- and federally-funded mental health services for First Nations, Inuit and Métis in urban centres.
- Understand that the lack of access to culturally-safe mental health services that respect the cultural diversity among First Nations, Inuit and Métis constitutes an important challenge in urban areas.

### SKILLS AND BEHAVIOURS

- Reflect critically on their own cultural biases, prejudices and privileges as mental health practitioners, and on the impact of colonization.
- Support action on social determinants of health such as poverty, critical shortages in access to mental health services and lack of access to adequate housing, food and water.
- Provide safe and respectful spaces for people who have experienced trauma and intergenerational trauma.
- Work in collaboration with Elders, traditional practitioners, families and communities, while also being sensitive to privacy and confidentiality issues in small communities.
- Work to address racism and discrimination that continue to have an impact on Indigenous people's wellness, whether they are expressed through individual behaviour or manifest within systems and institutions.

## REFLECTIVE PRACTICE QUESTIONS

### RECOVERY-ORIENTED PRACTICE

- In what ways have you systematically collaborated with First Nations, Inuit and Métis traditional and cultural practitioners and Elders and included them in the delivery of services?
- What have you done to strengthen your knowledge about the rights, cultures and circumstances of First Nations, Inuit and Métis?
- How have you reflected critically on the power imbalances and social inequalities that may exist between yourself as a service provider and those who use your services, as part of a commitment to providing culturally safe practice?
- To what extent has your practice been influenced by an understanding of how recovery for Indigenous peoples is defined by culture and uniquely shaped by Canada's history of colonization?
- How have you worked to strengthen collaborative partnerships between sectors such as health, social services, education, employment, housing and justice to mitigate complex challenges faced by Indigenous people?
- How do you work from a strengths-based approach that promotes resiliency?

**RECOVERY-ORIENTED LEADERSHIP**

- What are the visible signs of a culturally safe and welcoming environment in your organization?
- How have you ensured appropriate ongoing training in cultural safety for staff?
- In what ways is Indigenous knowledge valued alongside mainstream mental health knowledge in your organization and incorporated into the way it works, in particular by creating space for cultural practice?
- How does your organization work in collaboration with First Nations, Inuit and Métis to support their self-determination, including governance over service delivery?
- How does your organization work with others to address discrimination and increase equity in other sectors such as health, education, child welfare, employment, housing and justice?
- How does your organization support improved access to effective mental health care for Indigenous people, wherever they live?
- Does your organization put meeting people's needs first and then address jurisdictional issues once people are safe and healthy?

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**OPPORTUNITIES OVERALL**

- Advocate for all levels of government to work together to improve mental wellness for all Indigenous people, including preventing violence against Indigenous women and girls.
- Support the work of the Truth and Reconciliation Commission.
- Seek out training in cultural safety and cultural competence.

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**OPPORTUNITIES: First Nations**

- Learn about and build on lessons learned from the B.C. First Nations Health Authority regarding self-governance and cross-jurisdictional collaboration.
- Integrate the findings from the "Culture as Intervention" research project into mental health practice, specifically by examining how your services contribute to measures of hope, belonging, meaning and purpose.
- Support the establishment of a full continuum of mental wellness services by and for First Nations.

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**OPPORTUNITIES: Inuit**

- Support the establishment of a full continuum of mental wellness services by and for Inuit, at the national, regional and community levels.
- Support the development and implementation of a national Inuit suicide prevention strategy.

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**OPPORTUNITIES: Métis**

- Strengthen and draw on existing Métis research capacity to guide the development of a full continuum of mental wellness services by and for Métis.
- Over the long term, support policy changes that stem from the growing recognition of Métis rights and jurisdiction by the courts.

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**OPPORTUNITIES: Urban Aboriginal**

- Support the development of an urban Ab original mental health strategy, guided by data and community-driven research.
- Support and strengthen mental health services delivered in the urban environment by First Nation, Inuit and Metis.

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## CHAPTER 6

# Recovery is About Transforming Services and Systems

This chapter looks at the implications of adopting a recovery orientation for organizations delivering mental health services and the systems that support them. It examines four key dimensions that are central to ensuring that a recovery orientation permeates all the activities of each organization and is embraced by all members of its staff, management and leadership. While the chapter focuses on what organizations can do, the issues addressed are relevant to individual service providers regardless of where they work.

Supporting recovery cannot be reduced to a single program, model or service element. It involves reflecting on the way we think about mental health problems and considering the implications for the relationship between providers and those who seek access to supports and services. It entails reviewing how services are organized, how they connect to the broader community and who is involved in delivering services.

**The four Guidelines in this chapter treat the following:**

- Implanting a recovery vision and culture across the organization
- Acknowledging, valuing and learning from experiential knowledge
- Building recovery-promoting service partnerships, and
- Developing a recovery-oriented workforce.

Achieving a fully integrated recovery-oriented mental health system is an ongoing process that will take time to implement. Recovery is a journey not only for people living

with mental health problems and illnesses and their families but for everyone involved in providing support and service. Irrespective of the type of service, service location, population served or professional roles, a recovery orientation provides a lens for assessing what individuals and organizations are doing. Champions – within organizations from top to bottom, from amongst people seeking support and their families, volunteers, advocates, policymakers and funders – are needed to help accelerate the uptake of recovery. The commitment to recovery needs to find expression in everything an organization does.

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**Recovery is fostered when providers apply their knowledge, skills and expertise in ways that assist people to become actively involved in their own care, at their own pace, and work with them so that they increasingly take personal responsibility for their recovery.**

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Services that are recovery-oriented view people living with mental health problems and illnesses as having fundamental aspirations, hopes, and needs that are similar to those of all people. Recovery-oriented services do not prescribe a predetermined definition of “normalcy,” or attempt to “fix” others. Adopting a recovery-oriented approach builds upon the belief that people will recover, and that people are able to

identify what it is that they need. Recovery-oriented services are there to support and encourage people so that they have the opportunity to make decisions and find their own path of recovery.

Recovery-oriented services require clear organizational leadership and direction to ensure that all aspects of practice communicates hopefulness, and all services and staff interactions are person-centred, flexible and responsive to the self-defined recovery goals of each person. Recovery is fostered when providers apply their knowledge, skills and expertise in ways that assist people to become actively involved in their own care, at their own pace, and work with them so that they increasingly take personal responsibility for their recovery.

Recovery-oriented practice works collaboratively to enhance symptom management,

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### **Recovery-oriented practice demonstrates a willingness to embrace each person as a co-creator in the development of responsive person-centred programming**

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assesses risk so that the opportunity for personal growth is balanced against considerations of safety and addresses ethical issues that arise whenever involuntary treatment may be required. Providers do not relinquish their professional accountability, but seek to empower people and their supporters by providing information and acting as a “coach” in shared decision-making rather than as an “expert” who directs care. A recovery orientation is compatible with the application of existing criteria for assessing professional liability in all care settings, including inpatient

and emergency services. These include: consideration of relevant professional standards of practice; ensuring the comprehensiveness of decision-making; and making sure that a person’s wishes are reflected and their role in directing their own care has been taken into account.

### **PROMOTING FULL CITIZENSHIP**

Key to recovery-oriented practice are efforts to remove barriers to social inclusion and support for people to live fully engaged lives within their communities. Participation as full and equal citizens in meaningful social and economic roles is not seen as something reserved for when people “get well,” but rather as a fundamental pathway to recovery. Promoting recovery shifts the focus of service beyond exclusively managing symptoms to supporting positive evolution in all aspects of people’s lives – social, psychological, cultural, sexual and spiritual. Recovery-oriented practice strives to ensure that people have choice in accessing a full range of service options, including specialized psychiatric services, psychosocial rehabilitation, cognitive and behavioral therapies, substance abuse treatment and trained peer support workers. Psychosocial rehabilitation, for example, is an evidence-based practice that uses tools recognized for promoting recovery that should be made available as early as possible.

### **COMMITMENT TO LEARN FROM PEOPLE WITH LIVED EXPERIENCE**

A fundamental shift implied by recovery-oriented practice involves seeing a person and their family not as the “object” of service but as a collaborative “partner” in a journey of recovery. The knowledge people gain through their experience, as well as the expertise of local peer and family organizations, play a critical role in improving services. These contribute systematically to designing, deliv-



ering and organizing services. Recovery-oriented practice demonstrates a willingness to embrace each person as a co-creator in the development of responsive person-centred programming, including peer-led services. The inclusion of experiential wisdom can influence team and corporate culture and better enable them to reflect local needs and innovate using local resources.<sup>1</sup> Participatory research that is peer-led and includes people with lived experience in defining research priorities and developing research protocols<sup>2</sup> can contribute to identifying the best means to enhance recovery.

## WORKFORCE DEVELOPMENT

Implementing a recovery orientation requires an ongoing review of the composition, recruitment and training of the mental health workforce as well as consideration of the ways in which success is measured. Recovery-oriented practice involves building interdisciplinary teams that incorporate the skills of all professional disciplines and value their knowledge and skills equally. Consideration needs to be given to how best to balance psychiatric and medical services with psychological, cognitive behavioural, psychosocial rehabilitation and alternative approaches to care. Building a recovery-oriented workforce requires actively increasing the number of people with lived experience and family members of those with lived experience at every level of each organization, and employing peer support workers across mental health services.<sup>3</sup> Recovery-oriented practice honours the diversity of perspectives and draws from a wide range of fields of study, including ethics and spiritual care. The specialized skills of psychosocial rehabilitation practitioners can help strengthen recovery-oriented practices across disciplines.

## WORKPLACE MENTAL HEALTH

A psychologically healthy workplace supports the mental health needs of staff, helps keep staff engaged and productive and contributes to better services.<sup>4</sup> Having a greater ability to cope, acquiring a sense of purpose and meaning, sharing in decision-making and finding fulfilment are as important for service providers as they are for the people with whom they work. Changing organizational culture and adopting recovery-oriented practices can enhance job satisfaction and reduce risk of compassion fatigue, emotional exhaustion and burnout.<sup>5</sup>

There are already many people with lived experience active in mental health services – at all levels of organizations – who continue to keep this identity secret because they fear discrimination or have been discouraged by professional regulation and training from

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**Irrespective of the type of service, service location, population served or professional roles, a recovery orientation provides a lens for assessing what individuals and organizations are doing.**

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drawing on the value of their own recovery journey. Recovery-oriented practice, on the other hand, sees lived experience as a positive attribute and not as a liability. Creating a recovery culture encourages staff to use their own experiential knowledge, where appropriate, to inspire hope and model recovery. Disclosure is a useful tool within the therapeutic environment that can contribute to an organizational culture founded upon a sense of shared purpose.



Staff and volunteers need to be recruited to reflect the diversity of the community, as well as for their recovery-oriented skills, knowledge and attitudes and for their personal attributes that inspire trust, instill hope, encourage autonomy and value partnership. People with lived experience must be actively engaged in shaping human resource practices, contributing to the revision of role descriptions, guiding recruitment processes, participating in hiring and orientation and informing and delivering ongoing training. The creation of workforce and professional development plans in partnership with those with lived experience and their families will help ensure that the education and tools provided to staff and volunteers strengthens recovery-oriented practice.

## PRIMARY HEALTH CARE AND COLLABORATIVE MENTAL HEALTH CARE

Family physicians and other primary health care providers are usually the first and often the only point of contact for people living with mental health problems and illnesses.<sup>7</sup> In most cases, people are comfortable talking about their mental health and feel the level of care provided by physicians is sufficient in meeting their emotional and psychological needs.<sup>8</sup>

However, many physicians report having insufficient knowledge and training in assessing and treating mental illnesses and report difficulty in accessing specialized psychiatric assessment services. At the same time, people living with serious mental illness are not getting the physical health care they need and are dying significantly younger than other Canadians.<sup>9,10</sup>

Creating primary care collaborative practices and interdisciplinary teams improves mental health care, helps link people to specialized services and builds capacity for early intervention and comprehensive and holistic care. Collaborative care and recovery-oriented practices share common practices, including:

- Adopting a client-centred approach built on communication, respect and trust
- Including people as partners in their own care
- Affirming a person's right to choose treatments and supports
- Adopting a holistic approach to mind and body care
- Acknowledging the importance of family and community support
- Shaping support to the context and culture in which care takes place
- Facilitating seamless and timely access to community supports
- Applying evidence-informed best practices
- Committing to address stigma and discrimination

The Canadian Collaborative Mental Health Initiative has created an extensive evidence-based toolkit to promote this approach.

## **RECOVERY-PROMOTING SERVICE PARTNERSHIPS**

Most of a person's recovery journey occurs outside mental health services, in large part at home where people may be supported by natural networks of family, friends and neighbours, and in the places people work, learn, play or engage in cultural or spiritual pursuits. This means that there is a broad range of groups, supports and services that are in a position to contribute to recovery, and building partnerships with them is core to recovery-oriented practices. Identifying, linking to and creating reciprocal service agreements with non-mental health community resources (including housing, employment, primary health care, transportation, sports, recreation and childcare services) help to facilitate holistic and comprehensive care.

For most people, family physicians are the first point of contact for addressing mental health problems. Creating recovery-oriented collaborative care teams and service partnerships between mental health services and general practitioners can help improve care for both physical and mental health concerns. Accessing mental health services in rural and remote communities presents considerable challenges, and new technological approaches, funding models and service partnerships will be needed to expand access. By applying principles of partnership and community development, service partnerships and alliances can also help in advocating for action on social and economic factors important to the mental health and well-being of individuals, families and communities.<sup>6</sup>

## ENDNOTES FOR CHAPTER 6

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## Recovery Vision, Commitment and Culture

**A recovery orientation permeates the vision, mission and culture throughout organizations delivering mental health services.**

### CORE PRINCIPLES

- » The organization's mission and vision identify supporting recovery as the core business of mental health services and the primary goal of mental health practice.
- » The organization's vision and values reflect a belief in each person's ability to exercise their capacities, make decisions and recover.
- » The physical, social and cultural aspects of the service environment embody humanistic practices and inspire hope and optimism.
- » Service delivery is driven by the organization's mission, vision, values and leadership philosophy.
- » All staff are engaged in implementing the organization's commitment to recovery.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Recognize that promoting recovery is their primary work, not an optional addition or supplementary goal.
- Commit to learning from people with lived experience of mental health problems and illnesses about how the service can best support their recovery efforts.
- Acknowledge the importance of being inclusive and of seeking to maximize opportunities for people to exercise self-direction and take responsibility for their own recovery.

#### Knowledge

- Keep up to date on emerging best practices related to supporting recovery.
- Know ways to maximize a person's ability to make decisions and exercise control over their recovery journey.
- Are able to access tools, resources and training to support recovery-oriented cultural change.

#### Skills and Behaviours

- Champion the promotion of recovery values and principles in the organization's mission, vision and strategic plan, as well as in its promotional material, teaching resources and website.
- Embed recovery principles, values and language in assessment tools, recovery plans, progress and service reports and correspondence.
- Incorporate recovery principles in recruitment, supervision, appraisal, audit and planning materials, as well as in operational policies and procedures.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How does your individual approach to practice align with the organization's vision for its core business and its service delivery goals?
- What examples illustrate your ongoing efforts to create a recovery-oriented culture in the service setting?
- How have you helped to celebrate the success of practice teams in strengthening the implementation of a recovery orientation?
- In what ways have you shared information, research and resources that help to embed recovery-oriented principles and practices in the organization?

### Recovery-oriented leadership

- How does the organization demonstrate the fundamentals of recovery-oriented principles in board and leadership selection, staff induction, community involvement and interaction with the media?
- Critically examine the organization's mission, vision and values statements—how well are they aligned with recovery goals?
- Have you reviewed the time and resources that have been allocated to implementing and sustaining recovery-oriented service delivery?
- What are the systemic barriers that impact your organization and the steps you take to remove or limit their impact?
- What further steps could you take to advance a recovery orientation in service delivery?
- How do you encourage workplaces that are safe, healthy, supportive, nurturing and recovery-enhancing?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Participate in leadership forums and communities of practice that can expand the organization's opportunities to advance recovery.
- Demonstrate to accrediting and regulatory bodies the importance of a recovery vision, commitment and culture and advocate for their inclusion in standards and competencies.
- Conduct a public audit of mission, vision and values against recovery elements and best practices.

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# Acknowledging, Valuing and Learning from People's Experiential Knowledge and from Families, Staff and Communities

**Recovery-oriented mental health services value, respect and draw upon the experiential knowledge of people with mental health problems, their families and friends, as well as staff and the local community.**

## CORE PRINCIPLES

- » The experiential knowledge of people living with mental health problems and illnesses, their families and friends, staff and the community is invited and respected.
- » Recovery-oriented mental health services provide meaningful roles and positions for people with lived experience of mental health problems.
- » The organizational culture supports staff to draw on their lived experience when responding to people who use their services.

## MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

### Values and Attitudes

- Are open and enthusiastic to learn from, and be changed or challenged by, people with lived experience of recovery, whether they are accessing the service, part of the organization's workforce or members of the community.
- Seek out sources of experiential knowledge from outside the organization, such as advocacy groups and committees of people with lived experience, mutual help groups and peer supporters, as well as feedback from consultations, service evaluations and participatory research.
- Advocate for inclusion, equity and robust processes to enable participation by people with lived experience.

### Knowledge

- Understand the importance of participation by people with lived experience and the processes to achieve it, and know how to adapt these processes to different settings, including child and youth services, services for seniors and forensic or compulsory settings.
- Appreciate the contribution of experiential knowledge to optimizing service direction and the exercise of choice that is appropriate for various ages and settings.
- Know how to encourage equitable hiring that will build a suitably qualified and credentialed workforce with lived experience of mental health problems, illnesses and recovery, and that will recognize discriminatory recruitment practices.
- Know workplace standards for accessibility and psychological safety, as well as relevant rights legislation.

### Skills and Behaviours

- Seek and actively use information and feedback from people with lived experience of mental health problems and their families, individually and through the collective voice of their associations, to innovate and improve services.
- Incorporate into practice knowledge gained from research and from working with people with lived experience about what assists in recovery.
- Provide opportunities for people in recovery to learn from the peer workforce, for example through peer mentors, coaching or peer training opportunities.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- What have you observed about how the effective disclosure and sharing of lived experience can help to promote recovery-oriented practice?
- How do you combine experiential knowledge and professional expertise to create a collaborative body of knowledge and foster the co-creation of programming?
- How have you championed peer-run services and programs and integrated these services with your practice to promote recovery?

### Recovery-oriented leadership

- How have you supported staff to reflect upon their own experience with mental health problems, and what have you done to encourage the appropriate use of their experiential knowledge?
- How do you seek and obtain the views of people with lived experience, and how do you use this information to shape services and programming?
- Critically examine your organization's position statements, professional development opportunities, approach to funding and management supports – how have you attended to integrating peer support workers and others with lived experience within your service setting?
- How do decision-making processes provide for involvement of people accessing mental health services and people with lived experience of recovery?
- Are the planning, evaluation and review mechanisms within your organization or service inclusive of people with lived experience of recovery?
- What safe places are provided for peers to meet, gather and organize peer-designed and peer-run activities, campaigns and services?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Provide education and training programs conducted by peers and people in recovery for all staff, across all professions and at all levels; plan opportunities for staff and people with lived experience to learn together, and schedule time for training.
- Promote research and evaluation activity that involves peers and people in recovery; incorporate findings in service improvements and standards of practice.
- Initiate new peer-run service models and programming, creating partnerships of people with lived experience, families, caregivers and service providers.
- Establish connections with family and peer associations, and structure ways for staff and service providers to benefit from their expertise.

## RESOURCE MATERIALS

- Canadian Coalition of Alternative Mental Health Resources. (n.d.). Ratified position papers [consumer-developed]. St. Catharines, ON: Author. Retrieved from <http://ccamhr.ca/positions.html>
- Centre for Addiction and Mental Health. (2015, February 9). From surviving to advising [blog post]. Describes an innovative program of matching fourth year psychiatric residents with people with lived experience who mentor them in engagement, respect and recovery. Retrieved from <http://camhblog.com/2015/02/09/from-surviving-to-advising/#more-1467>
- in2mentalhealth. (2012). Empowerment, identity and hope: Recovery and peer/user-led models in global mental health. <http://in2mentalhealth.com/2012/09/03/empowerment-identity-and-hope-recovery-and-peeruser-led-models-in-global-mental-health/>
- Ontario Council of Alternative Businesses. (n.d.). Voices from the street. A speakers bureau consisting of individuals who have had direct experience with homelessness, poverty, and/or mental health issues. Retrieved from <http://www.ocab.ca/voices.htm>
- PeerZone. (n.d.). Leading our recovery. A consumer-defined resource list. Retrieved from <http://www.peerzone.info/leading-our-recovery#resources>
- Wardipedia. A collection of ideas, examples, information and research about therapeutic mental health inpatient care. See <http://www.wardipedia.org/>

## Recovery-Promoting Service Partnerships

**A recovery-oriented mental health service establishes partnerships with other organizations both within and outside the mental health sector.**

### CORE PRINCIPLES

- » Many services and supports outside the mental health system play an important role in promoting recovery and well-being and are needed in order to connect people with their communities, traditions and cultures.
- » Partnerships increase the efficiency of the mental health system by making the best use of complementary resources.
- » Mental health practitioners work through sound partnerships that facilitate access to locally available services and resources.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Look beyond the mental health setting to identify opportunities for service partnerships.
- Welcome initiatives for new service pathways.
- Acknowledge that strong service partnerships facilitate holistic and comprehensive care.
- Recognize and value the expertise and contribution of other disciplines, other services and other sectors.
- Respect partnering agencies and their staff as equals.

#### Knowledge

- Understand that the expertise and knowledge required to promote recovery comes from both within and beyond mental health services.
- Maintain up-to-date knowledge of local services, resources, referral and access points and processes.
- Are aware of community resources that offer supports related to housing, economic need, employment, transportation, and social and recreational opportunities.
- Have knowledge of the best emerging evidence in service coordination and partnership development, as well as of partnership analysis tools that enable the measurement, monitoring and strengthening of alliances.

#### Skills and Behaviours

- Invest time, staff, materials, resources, and make facilities available to enable service partnerships.
- Make supporting recovery the shared goal of service partnerships.
- Promote the development of self-management plans, advanced care directives and substitute decision-makers to facilitate choice and decision-making by the person experiencing mental health problems and smooth transitions among partnering agencies.
- Ensure a common understanding of respective roles, responsibilities and expectations by all parties in service partnerships.



## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How do you routinely and systematically draw on the strengths, knowledge, expertise and resources of other services to support and enhance achieving recovery goals?
- Do you dedicate time and resources to building effective service coordination and positive relationships with other services and within the team?
- How do you decide on the services and agencies you are referring to or recommending?

### Recovery-oriented leadership

- Is a commitment to proficiency in recovery-oriented practice and service delivery included in your position statements and in the service agreements and contracts that you use?
- Review sample partnership agreements and shared services arrangements – are the administrative, communication and decision-making structures easy to use, accessible, and grounded in recovery principles?
- How do you access experiential knowledge in establishing supportive, responsive, person-centered service partnerships?
- How do you encourage and reward collaborative action by staff as well as reciprocity between agencies?
- What mechanisms have you used to work with others such as regulatory groups, funders or community leaders to promote expanded opportunities for partnerships?
- How do ongoing improvement and quality initiatives ensure that best practice processes for coordination and collaboration are in place (e.g., referral pathways, service conferencing, shared care, joint discharge planning, client directives)?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Standardize common processes across agencies, including protocols, referral processes, service standards, data collection and reporting.
- Establish ways to facilitate the use of Advanced Care Directives and common approaches to promoting a recovery orientation across jurisdictions and sectors.
- Participate in multisectoral planning networks, and advocate for inclusion; keep staff and volunteers updated on these system-wide initiatives.
- Subscribe to and circulate newsletters produced by community organizations and people with lived experience.
- Establish multisectoral local communities of practice with shared goals of advancing recovery approaches, equity and inclusion.

## RESOURCE MATERIALS

- Annapolis Valley Health. (2013). Healthy & flourishing communities. Retrieved from <http://www.avdha.nshealth.ca/mental-health-addiction-services/flourishing-communities/healthy-flourishing-communities>
- Heffernan, J. & Pilkington, P. (2011). Supported employment for persons with mental illness: Systematic review of the effectiveness of individual placement and support in the UK. *Journal of Mental Health*, 20(4), 368–380. doi: 10.3109/09638237.2011.556159
- Heyland, M., Emery, C., & Shattell, M. (2013). The Living Room, a community crisis respite program: Offering people in crisis an alternative to emergency departments. *Global Journal of Community Psychology Practice*, 4(3), 1–8. Retrieved from <http://www.gjcpp.org/pdfs/2013-007-final-20130930.pdf>
- Mitchell, S. (2014). Ontario's Minding Our Bodies initiative: Partnering locally and provincially to promote mental and physical health. *Visions: BC's Mental Health and Addictions Journal*, 10(2), 24. Retrieved from <http://www.heretohelp.bc.ca/visions/mind-body-connection-vol10/ontarios-minding-our-bodies-initiative#sthash.TiRfv34i.dpuf>
- Vasilevska, B., Madan, A., & Simich, L. (2010). Refugee mental health: Promising practices and partnership building resources. Toronto, ON: Centre for Addiction and Mental Health. Retrieved from [http://wiki.settlementatwork.org/w/uploads/Refugee\\_Mental\\_Health\\_Promising\\_practices\\_guide.pdf](http://wiki.settlementatwork.org/w/uploads/Refugee_Mental_Health_Promising_practices_guide.pdf)

## Workforce Development and Planning

**Recovery-oriented mental health services prioritize building a workforce that is knowledgeable, compassionate, collaborative, skilled and diverse; that integrates experiential knowledge; and that is committed to supporting recovery first and foremost.**

### CORE PRINCIPLES

- » Recovery-oriented organizations require a workforce that is knowledgeable, compassionate, collaborative, skilled and diverse.
- » Recovery-oriented organizations value and respect experiential knowledge and see having it as a positive attribute.
- » The organization's professional development and continuous improvement processes include ongoing learning and skill development and encourage reflection on how to strengthen recovery-based practice.
- » Recovery-oriented organizations strive to be mentally healthy and psychologically safe workplaces.

### MENTAL HEALTH PRACTITIONERS AND PROVIDERS...

#### Values and Attitudes

- Are open to changing, developing and embracing new work practices.
- Commit to learning and continuous improvement.
- Welcome the contribution of experiential knowledge to strengthening compassionate, person-centered ways of working.
- Embrace building a workforce with more professionals who have lived experience of mental health problems and value peer-specific work roles.
- Are generous and collaborative in sharing resources and building knowledge.
- Respect the dignity of risk and approach positive risk-taking as an opportunity for success.

#### Knowledge

- Know how the core elements of a recovery orientation can be practiced in any mental health setting and how this orientation can be applied with diverse populations.
- Seek knowledge in a wide range of fields to support recovery-oriented learning and development.
- Understand the evidence base for work practices that strengthen the implementation of a recovery orientation.
- Are knowledgeable about psychosocial rehabilitation practices, values and competencies and their role in promoting personal recovery.
- Know the relevant legislation and requirements regarding safety and the rationale for when coercive interventions may be required.
- Are knowledgeable about the range of options for treatment, therapy and other supports and how best to help manage symptoms.
- Have clarity about professional practice standards and accountabilities.
- Understand the factors that contribute to workplace mental health and psychological safety and their impact on the therapeutic alliance.

#### Skills and Behaviours

- Demonstrate proficiency in assessing the recovery orientation of the organization.
- Collaborate with people with lived experience when formulating plans for training and development.
- Encourage and equip teams to strengthen the application of a recovery orientation across different settings and with various and diverse populations.
- Work with psychosocial rehabilitation specialists who provide specialized services and support adoption of recovery practices across disciplines and services.
- Develop a plan and infrastructure to support staff development and staff retention within a supportive, healthy and nurturing workplace.
- Contribute to service innovation at all levels of the organization, and invite people seeking support, families and other community partners to participate in developing services and training staff.
- Engage regularly in reflective practice to continually increase knowledge, examine their own work, mindsets and habits, and make progress in supporting recovery.

## REFLECTIVE PRACTICE QUESTIONS

### Recovery-oriented practice

- How have you incorporated peer support as a discipline that contributes skills and expertise to mental health services? Do you have paid peer support positions?
- Have you learned from the wisdom and experience of others in the areas of supervision, mentoring and coaching?
- How do you utilize resources such as training programs, ethics consultation or peer discussion to help address conflicts, challenging situations or dynamic tension that you encounter in your work?

### Recovery-oriented leadership

- How do your recruitment procedures promote the selection of staff with the appropriate values, attitudes and knowledge, drawn both from lived experience and academic or professional education, to support recovery processes?
- What actions in the organization have helped to build a culturally competent and diverse workforce?
- How do your staff recruitment, training, development and supervision practices reflect and encourage a focus on strengths and positive outcomes rather than on deficits?
- How does the performance management system assess progress made by members of staff in supporting recovery?
- How have you validated the indicators used in staff and service evaluations and ensured they are relevant and meaningful to people seeking support and their families?
- What have you done to reward leadership—at all levels and positions—that is strong, committed and inspires the application of recovery-oriented principles and values?
- Are people with lived experience of mental health challenges and recovery valued and integrated throughout the organization, from direct service provision to governance?
- In what ways do you assess and promote mental health in the workplace?

## OPPORTUNITIES FOR LEADERS AND MANAGERS

- Initiate learning circles and communities of practice for applying recovery in life and at work; include a broad diversity of perspectives, i.e., IRER, LGBTQ, families, older adults and youth.
- Seek multi-agency partnerships and promote multisite studies to encourage collaborative learning and research; share evaluation methods and findings.
- Create a local workforce/human resources strategy and action plan that integrates experiential knowledge and includes explicit expectations consistent with supporting recovery.
- Work with funders, labour and professional groups, academic institutions, policymakers and regulatory bodies to enable the alignment of workforce strategies (including the recruitment, training and hiring of people with lived experience and peer specialists) so that whole jurisdictions are able to advance recovery.

## RESOURCE MATERIALS

- Adams, E., & Bateman, J. (2008). Mental health recovery: Philosophy into practice: A workforce development guide. Rozelle, NSW, Australia: Mental Health Coordinating Council. Retrieved from <http://www.mhcc.org.au/media/10405/wfdg-intro.pdf>
- Boston University, Center for Psychiatric Rehabilitation. (n.d.). Principled leadership in mental health systems. Boston, MA: Author. Retrieved from <http://cpr.bu.edu/resources/newsletter/principled-leadership-mental-health-systems>
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- Canadian Patient Safety Institute. (2012). Mental health modules. Retrieved from <http://www.patientsafetyinstitute.ca/English/education/PatientSafetyEducationProject/PatientSafetyEducationCurriculum/MentalHealthModules/Pages/default.aspx>
- Lyon, A. R., Stirman, S. W., Kerns, S. E., & Bruns, E. J. (2011). Developing the mental health workforce: review and application of training approaches from multiple disciplines. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(4), 238–253. doi: 10.1007/s10488-010-0331-y
- Psychosocial Rehabilitation / Réadaptation Psychosociale (PSR/RPS) Canada. (2013). Competencies of practice for Canadian recovery-orientated psychosocial rehabilitation practitioners. Bradford, ON: Author. Retrieved from <http://www.psrrpcanada.ca/index.php?src=gendocs&ref=competencies&category=Main>

# Getting Started

## AND MEASURING PROGRESS

These Guidelines have been developed in order to provide a detailed reference guide for answering the question “What does recovery look like in practice?” They seek to address the need identified by stakeholders for greater commonality of language and shared understanding of recovery principles in order to facilitate discussion and accelerate the adoption of recovery practices across Canada.

Building recovery-oriented services is a journey of partnership that involves everyone from people in recovery, their families and caregivers, to direct care staff, office staff and professionals, team managers, key leaders and volunteers. While many, such as psychosocial rehabilitation specialists, have long embraced a recovery orientation, making the shift towards a recovery approach across services and systems will take time. Advancing recovery-oriented practices has significant implications for the design and operation of services, and provinces, regions, organizations and individual practitioners will necessarily move forward at their own pace.

Organizational commitment and leadership is required to champion change and to guide the modification of policies and practice. Fostering continuous quality improvement and strengthening the evidence base to support recovery-oriented practice will require ongoing evaluation of the multiple and complex dimensions of recovery-oriented practice at a system, service, program and individual practice level.<sup>1</sup>

Practitioners can draw on a growing number of tools available to measure recovery values, beliefs and supportive relationships,<sup>2</sup> including tools to measure a person’s experience of hope and optimism, connectedness, personal identity, empowerment and the presence of meaning and purpose in their lives.<sup>3</sup> Evaluation measures are also available to gauge recovery outcomes on a broad range of quality-of-life dimensions, including employment, income, social relationships, community involvement, protection of rights and active citizen participation.<sup>4</sup> As well, it is possible to evaluate the quality of support provided by recovery-oriented services using measures of respect, safety, trust and inclusion.<sup>5</sup>

These Guidelines offer an additional resource that will strengthen existing measures for evaluating progress and also contribute to creating tools that will assess the degree of social inclusion and protection of rights, as well as the extent to which recovery has been adapted to Canada’s specific service approaches and to the mental health needs of its diverse population. This process will be accelerated by creating collaborative partnerships amongst people who are “experts by experience,” service providers, program managers and researchers with skills in evaluation.<sup>6</sup>

## POSSIBLE STEPS FOR GETTING STARTED...

Everyone has a role to play in making recovery work and in doing their part to help transform services. There is no single way or easy formula to implement recovery, and each person and organization will start their journey at a different place, depending of their needs and circumstances. The following suggestions are not an exhaustive list of things one must do, nor is it intended to be linear in application. However, the following ten points are drawn from recognized ways to move policy into practice.

### 1 Build knowledge of recovery-oriented practice

Creating a common language and shared understanding of recovery and what recovery-oriented practice looks like are foundational steps for developing a plan of action.

**a) Share these Recovery-Oriented Practice Guidelines for Canada throughout your organization and network. Consider:**

- Hosting a meeting to discuss the recovery guidelines.
- Offering cross-discipline “lunch and learn” sessions about recovery for people with lived experience.
- Inviting peer support workers to speak about the role of peer support and its benefits.
- Holding research rounds on emerging evidence on recovery practice.
- Supporting the development of ongoing communities of practice.

**b) Learn from others and share innovations:**

- Invite providers from your community or region who have been working to develop recovery-oriented practice to share their experience.
- Read 100 Ways To Promote Recovery (<http://www.rethink.org/about-us/commissioning-us/100-ways-to-support-recovery>)
- Join Star Wards – simple ways to improve in-patient services (<http://www.starwards.org.uk/>)
- Engage with others through the Recovery Collaborative Spaces

### 2 Build leadership

Implementing a recovery approach requires leadership at all levels of an organization. Support from senior management and at the governance level furnishes a mandate to act and reinforces accountability for action.

- Encourage the Board of Directors and senior management to incorporate recovery principles into mission, vision and values statements.
- Sign the Recovery Declaration as an individual and organization; post your certificate publicly.
- Host governance dialogues amongst partners and with your stakeholder groups in order to understand their needs and learn how to work collaboratively to advance recovery-oriented service development.

### 3 Identify recovery champions

Champions who promote the shift to a recovery approach can be key to inspiring change and building momentum amongst their peers, whether people with lived experience and family members, particular groups of providers or categories of people within each organization. They can provide a clear and compelling vision for the benefits of adopting a recovery orientation and demonstrate recovery-oriented values and behaviours in practice.

- Develop a strategy for identifying recovery champions within your organization and from the broader community.
- Identify, honour and celebrate successes, and acknowledge and reward leadership.

### 4 Conduct a situational assessment

Moving forward depends on having a good understanding of the nature of one's practice or service, the extent to which it may already have moved in a recovery-oriented direction and the resources available to support further change. There are already many practitioners, programs and organizations that are delivering essential elements of recovery practice. Identifying organizational and practice strengths helps build confidence and creates a sense of momentum.

- Use reflective practice and leadership questions contained in these Guidelines to help assess current practices.
- Engage people using services and families to evaluate progress.
- Use regular “walkabouts” by leaders and managers, case conferences, town hall meetings, etc. to gain knowledge of organizational strengths and reinforce engagement.

### 5 Commit to action

It is important to make a conscious and deliberate decision to reorient towards recovery and to examine and review all processes and practices. This is a challenging step in transforming policies, practice, services and systems, and has an impact on all parts of the organization or service.

- Examine and review all parts of the organization and make the commitment to take action.
- Create ongoing opportunities for discussion by drawing together staff, people with lived experience, family members and caregivers.
- Identify common ground and build agreement for action.
- Consider what can be done within existing structures and resources and where new investments can be reallocated or leveraged to advance action.
- Schedule regular and frequent check-ins to sustain this commitment to action.

## **6 Develop implementation plans**

Change happens at multiple levels simultaneously, and systematic planning can enable core recovery values, principles and practices to be reflected across all program, policy and service elements. For example, the Guidelines can help to develop organizational, service and/or program goals for:

- Promoting individual recovery.
- Engaging people with lived experience and families within services.
- Creating a human resources and training plan.
- Ensuring that people's rights are respected and promoted.
- Developing a recovery-oriented approach to risk management.
- Aligning practice for each professional discipline with a recovery approach.

## **7 Obtain management support**

Implementing change is enhanced when management provides coherent direction for meeting specific targets, and everyone's lines of responsibility and accountability are clear.

- Identify lead accountability and authority for each component of the plan, a clear reporting structure and effective communications tools.
- Find visible ways to promote and recognize commitment to recovery practice.

## **8 Develop an evaluation plan**

Recovery-oriented practice requires new ways of measuring impact, based on criteria that reflect important recovery program outcomes and the attainment of personal recovery goals. An evaluation plan could establish ways to:

- Measure each individual's progress in attaining personal recovery goals, including improving quality of life and participation in meaningful roles in the community.
- Measure professional practice improvements in adopting recovery values such as respect, engagement and choice.
- Monitor the organization's attainment of milestones, benchmarks and continuous quality improvement.

## **9 Use research and build evidence on recovery practices**

Recovery-oriented practices draw upon evidence-informed practices from a broad range of disciplines and practice approaches.

- Review the research and references included in these guidelines to deepen your understanding of recovery.
- Encourage reciprocal learning and resource sharing within your network.
- Invite people with lived experience and families to be involved in designing and co-creating research.
- Explore the Recovery Inventory, which contains more than 1,000 documents recommended as valued resources by your peers, and help build the Inventory by submitting additional resources.

## 10 Engage in multi-stakeholder planning

Recovery-oriented practice is enhanced by cross-sector planning, strong agreements to knit services together and coordinated action to address the structural barriers that limit opportunity.

- Identify community partners who can support recovery.
- Look for ways to initiate collaborative partnerships and coordinated planning efforts that include government policy planners, nongovernmental organizations, community agencies, people with lived experience and family caregivers.
- Build political will by inviting elected representatives to your setting, and provide them with information about recovery and the importance of system-wide collaboration.
- Identify opportunities for joint planning and coordinated action across ministries that impact mental health and well-being.

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2 Sklar, M., Groessl, E. J., O'Connell, M., Davidson, L., & Aarons, G. A. (2013). Instruments for measuring mental health recovery: A systematic review. *Clinical Psychology Review*, 33(8), 1082-1095. doi: 10.1016/j.cpr.2013.08.002

3 Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry*, 199, 445-452. doi: 10.1192/bjp.bp.110.083733

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6 University of Edinburgh, University of Strathclyde, & Swansea University. (n.d.) Meaningful and Measurable: Personal outcomes: A collaborative action research project. Retrieved from <http://meaningfulandmeasurable.wordpress.com/>



# Conclusion

The path through these Guidelines began with a chapter on the importance of hope to people's recovery. The preceding pages illustrate the significant progress that has been made in the last decade in defining what it means to practise in a way that supports recovery. This should also make us hopeful about our collective ability to bring into being a truly recovery-oriented mental health system. Yet there is clearly still much to do before this new “paradigm” becomes the lived reality for everyone confronting a mental health challenge in our country.

Recovery-oriented mental health practice supports people to define their goals, exercise their capacities and use their strengths to attain their potential. Recovery-oriented practice acknowledges that each person's journey is both unique and complex, and assists people in maximizing their ability to direct and manage it themselves. As we have seen, recognizing the individual nature of this process does not imply that it takes place in a vacuum. Recovery can benefit from many sources and types of support. It is not dependent on any one setting or single type of intervention. It is very promising that this message is spreading.

It is also encouraging to see a growing appreciation that mental health and well-being matters not just for individuals but for families, communities and the whole of society. As such, mental health must continue to be a public priority; embracing a recovery orientation can help make it so. The values and principles that drive a recovery orientation also reflect many key collective aspirations we share as a society – enabling everyone to enjoy the best possible health and well-being; ensuring that people, in all their diversity, are able to take advantage of fulfilling and satisfying opportunities; and being vigilant to promote justice, fairness and freedom, including from all forms of discrimination.

While the Commission has served as catalyst, facilitator and publisher of these guidelines, they were only made possible through the input of many; the Commission gratefully recognizes these contributions. It will now take a sustained effort by ever-growing numbers of people, at every level of the system and society, to sustain the momentum and put the approach contained in the Guidelines into practice. All who have had input, and all who recognize the importance of mental health and well-being, must join in the work ahead. There are many ways to contribute: engage in collaborative action, and help to build communities of practice to implement the Guidelines; advocate and provide the leadership that will ensure the journey continues; and celebrate and share the existing achievements that point to even greater possibilities ahead.

These Guidelines are a valuable resource; it is people who can make a recovery-oriented system a reality.



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## Physicians' Alliance against Euthanasia

### **1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Physicians' Alliance against Euthanasia has been actively involved in the debate around "medical assistance in dying" (MAID) since 2012. The Alliance has a membership of 1123 physicians who have signed our Declaration on optimal end of life care without euthanasia.

Hard evidence regarding MAID in the three groups under consideration is very scarce, since it is legal only in a few countries and the numbers are small. There may not be powerful evidence of harm, but this cannot be taken as proof there is no harm. Moreover, it is essentially impossible to demonstrate a lack of coercion or harm to individual patients.

The members of our Alliance have a collective clinical experience of many years, caring for patients of all ages and social conditions. Our experience may not be quantifiable but is nonetheless very important. We have seen the ambivalence of death wishes; we have seen them evaporate with adequate treatment and social support; we have seen the relief when a suicide attempt fails. We have seen patients who fear burdening their families but might never say so. We have seen abused elders protecting their abuser, who may also be their only source of support.

In every group of persons for whom MAID is permitted there will be errors, emotional appeals and manipulation of information, leading to the death of people who would not have chosen it in a different social and political context, including some who did not in fact choose it. We urge you to consider not only how such extensions can be made "safely", but firstly whether they should be made at all. Complete safety is impossible. The unjust death of even one Canadian is too great a price to pay for the so-called liberty of choosing to die at a difficult moment.

The three extensions being contemplated all raise serious concerns regarding consent.

The "mature minor" concept has come under considerable criticism. Medical and neuropsychological findings indicate that a young person's judgment is not mature until well into adulthood. There is no clear correlation between an adolescent's intellectual ability to assess risk and that adolescent's effective executive capacity to make mature judgments in matters that involve risk. Thus, an adolescent might be able to explain perfectly the risks and benefits associated with the decision being considered, but unable to judge adequately how to apply this knowledge. Far from favouring the opening of access to "medical aid in dying" to adolescents, we propose greater scrutiny of such choices made by young adults, up to the age of at least 21 and perhaps 25.

The proposal to permit MAID for suffering due to mental illness strikes at the heart of suicide prevention strategies. It may be virtually impossible in suicidal patients with mental illness to distinguish between so-called "rational suicide" and suicidality as a symptom of their illness. The role of the physician and of the community suicide prevention worker is to protect the suicidal patient, a task which would be rendered impossible by legal MAID for such patients. To tell a patient that one is willing to consider MAID should a therapeutic intervention fail would undermine the therapeutic process from the beginning. The simple fact of MAID being legal could have the same effect, as the patient would know he or she could seek it elsewhere. The role of transference and counter-transference in every clinician-patient encounter (which may touch on the doctor's own fears of loneliness, dependence, illness, and handicap), has not been

sufficiently considered.

Waiting times for mental health services can be up to a year, and patients suffering from complex disorders may not, even then, see a psychiatrist who has the necessary expertise. Diagnostic inaccuracies can make it appear that a patient's suffering is irremediable when there are therapeutic options that have not been tried.

The proposal to permit MAID by advance request for persons incapable of decision-making is a response to fear of hypothetical future suffering. Our major concerns regarding this possibility include the questionable validity of written advance directives at all, the lack of concurrent consent at the time of death, and the danger of elder abuse.

Many experts consider that advance directives, even for medical treatment decisions, "promise more control over future care than is possible". The notion of choosing, when one is well, to have one's life terminated upon reaching a certain condition is different not in degree, but in kind, from one that authorizes limiting life support in the event of critical or terminal illness. Such a directive denies the person the right to change his or her mind. It requires the physician to directly cause the death of someone who is not asking to die. It binds the incapable person to a decision made at a moment in the past, despite the fact that he or she is still conscious and may have very different wishes from those expressed while still legally capable. Persons with dementia often rate their quality of life as better than their caregivers rate it. In the Netherlands euthanasia is permitted by advance directive but remains very controversial and rarely done, primarily because of the impossibility of knowing the patient's current wishes.

The risk of elder abuse is ever-present. Even when older persons are cognitively intact, more so when cognitively impaired, there is a situation of dependency and a power imbalance between the older person and the caregiver. Even well-intentioned families may give a subtle message that they find the person's care burdensome. When caregivers are abusive this can lead to undue influence to sign legal documents, such as a will or protection mandate (durable power of attorney) in favour of the abuser. Private care for a dependent older person is expensive and can rapidly deplete the expected inheritance of the next generation. Advance directives authorizing death would provide a new and more definitive tool for greedy heirs.

We urge the Government to maintain the safeguards contained in the current law, protecting children and people with mental illness or cognitive disorders.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

The text in Question 1 is a summary of the Physicians' Alliance against Euthanasia Position Statement on medical assistance in dying requests by "mature minors", advance requests, and requests where mental illness is the sole underlying medical condition.

Please find attached the full Statement, as well as the following documents:

1. Physicians' Alliance against Euthanasia Declaration in French and English. This is our founding document.

2. American Academy of Pediatrics, Informed Consent in Decision-Making in Pediatric Practice, 2016.

3. American Psychiatric Association, Position Statement on Medical Euthanasia, 2016.

4. Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper, September 2017.

Other references and links are listed in our Position Statement and can be found online, free or through academic institutions subscribing to the journals referenced.

***We affirm that:***

1. Patients at the end of life should receive diligent and competent care to relieve their pain and suffering. The physician has the obligation to use all the means available to achieve this end.
2. If a patient refuses treatment or requests its withdrawal, his or her wishes must be respected.
3. Modern palliative care skills, drugs and technology permit adequate symptom control for all terminally ill patients. These methods should be universally accessible.
4. A physician who is caring for a dying patient, and who cannot adequately control the person's symptoms, should have access to the necessary expertise and support to be able to do so.
5. When suffering remains uncontrolled by state-of-the-art palliative care, individually adjusted sedation to a point of comfort may be used. In this, as in all palliative care, the goal remains optimal quality of life.
6. To provoke death voluntarily, by lethal injection or any other method, cannot be considered under any circumstance as "medical care", and is contrary to medical ethics. It is never necessary to kill a patient in order to end his or her suffering. The 2400-year-old Hippocratic tradition was a major advance in civilization. It forbids euthanasia and mandates the protection of the weak and the maintenance of trust between the physician and the patient. It calls on physicians and other health professionals to use their knowledge and skills to heal the sick, creating a climate of mutual solidarity. It is ironic that the accepted standards of this ancient code of conduct, written at a time when the means of countering end of life suffering were very limited, might be considered inadequate in this age of refined capacity to control symptoms.
7. We must learn from the negative experiences of countries that have legalized euthanasia. Decriminalization often causes more problems than it is claimed to solve; those documented in the medical and legal literature include:
  - High rates of euthanasia without consent;
  - The impossibility of ensuring adequate reporting and respect for safeguards;
  - A loss of trust in the physician-patient relationship;
  - Conflicts within medical teams and within patients' families.
8. Medical licensing bodies must continue to fulfil their role as protectors of the public and of life, and support physicians in their efforts to improve the quality and accessibility of care of the dying, thus allowing all patients to receive excellent symptom relief throughout their illness and at the time of death.



**Soigner Toujours**

***Donner la mort jamais***

## **Manifeste**

### **Nous affirmons que:**

1. La personne en fin de vie doit bénéficier de soins médicaux diligents et compétents pour le soulagement de la douleur, des malaises et de la souffrance qu'elle éprouve et dont elle souhaite être libérée. Le médecin a l'obligation de déployer à sa demande tous les moyens que lui offre sa profession pour arriver à cette fin.
2. Les volontés du malade qui refuse ou qui veut interrompre des traitements doivent toujours être respectées.
3. Les moyens évolués et modernes de l'approche palliative et les outils thérapeutiques disponibles permettent à toute personne d'être bien soulagée en fin de vie: ces moyens doivent devenir accessibles sur l'ensemble du territoire.
4. Le médecin qui se voit confronté à une situation où une personne sous ses soins, évoluant vers la fin de sa vie, est mal soulagée en dépit de ses meilleures interventions, doit pouvoir obtenir l'aide d'un collègue ou d'une ressource experte en soins palliatifs en vue de mettre en œuvre des moyens alternatifs visant à soulager le malade de façon optimale.
5. Dans les situations où le malade demeure aux prises avec une souffrance mal contrôlée par les meilleurs outils de la médecine palliative, la sédation est une option utile. Titrée jusqu'à l'atteinte du confort du malade, son but est le maintien de sa qualité de vie, comme pour les autres moyens de la médecine palliative.
6. L'acte de provoquer volontairement et directement la mort d'un patient par injection létale ou tout autre moyen ne peut en aucune circonstance être considéré comme un «soin» et est contraire au Code de déontologie du médecin. Tuer la personne qui souffre, même avec la plus grande compassion, n'est pas un soin. Il n'est jamais nécessaire de provoquer la mort d'un patient pour mettre un terme à ses souffrances. La tradition hippocratique vieille de 2400 ans qui interdit l'euthanasie est un critère de civilisation. Elle a pour objectif la protection des faibles, et le maintien du lien de confiance dans la relation médecin-patient. Elle interpelle le médecin, les autres soignants et les proches à travailler avec science et ingéniosité à réconforter et à soulager les malades en créant un climat de solidarité mutuelle. L'interdit de l'euthanasie a été sagement codifié il y a 2400 ans en dépit du fait que c'était à une époque de moyens limités pour soulager le malade; il est ironique de le voir contesté de nos jours, dans un monde médical pourvu d'autant de moyens.
7. L'introduction de l'euthanasie ou du suicide assisté doit aussi être rejetée à cause de l'expérience des pays qui ont commis l'imprudence de les dépénaliser. Elle engendre souvent des problèmes plus graves que ceux qu'on prétendait vouloir régler. Parmi ceux documentés dans la littérature médicale on retrouve:
  - Des taux élevés d'euthanasies sans consentement
  - L'impossibilité de faire respecter les balises instaurées et la procédure de déclaration des euthanasies
  - Des effets dommageables sur la relation médecin-patient
  - Des conflits au sein des équipes soignantes et des familles
8. Les Collèges des médecins doivent continuer d'assumer leur rôle de protection du public et de la vie et appuyer les médecins dans leur quête d'une médecine palliative de qualité et accessible, qui permettra à tout patient d'être bien soulagé durant sa maladie et en fin de vie.



## **Position Statement on medical assistance in dying requests by “mature minors”, advance requests, and requests where mental illness is the sole underlying medical condition**

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**October 6, 2017**

The *Physicians' Alliance against Euthanasia* has been a major participant in the debate around what is now called “medical assistance in dying” (MAID) since 2012, and many of our individual members long before that. The *Alliance* has a membership of 1123 physicians,<sup>i</sup> all of whom have signed our *Declaration*<sup>ii</sup> on optimal end of life care without euthanasia. Although we oppose all euthanasia on medical and philosophical grounds, we understand that the mandate of the present Panel is not to reopen the debate that took place before Bill C-14 was adopted, but rather to consider the advisability of extending MAID to new groups of Canadians.

It must be acknowledged by all those taking part in the present discussion that no one comes to the table without a preconceived position, or “bias”, for or against MAID. One either considers it such a great benefit to those who choose it that the risk of premature death of others must be accepted, though minimized, or one considers every deliberate premature death a harm to be avoided. Those who claim to be neutral on this point are deceiving themselves and others. The recent change in the leadership of the *Working Group on Advance Requests* indicates to us that one “bias” is seen as acceptable by decision-makers while the other is not.

This situation should be kept in mind by all committee members throughout their study of evidence for or against the three extensions of the law now being contemplated. The evidence chosen will reflect the position of the parties presenting it. In fact hard evidence is very scarce, since we are essentially in uncharted territory: MAID for the situations now being considered is legal only in a few countries and the numbers are small. There may not be powerful evidence of harm from laws permitting MAID in vulnerable populations such as those we are contemplating, but this cannot be taken as proof there is no harm. Moreover, it is essentially impossible to demonstrate a lack of coercion or harm to individual patients.

Some have attempted to demonstrate that “vulnerable groups” are not over-represented among people who die by euthanasia or assisted suicide,<sup>iii</sup> but the socioeconomic categories used, such as women, racial minorities and people of low educational or economic status, are of little relevance in this context.<sup>iv</sup> The physician members of our *Alliance* have a collective clinical experience of many



years of caring for patients of all ages and social conditions. Our experience may not be quantifiable but is nonetheless very important. We have seen the ambivalence of death wishes; we have seen them evaporate with adequate treatment and social support; we have seen the relief when a suicide attempt fails.<sup>v</sup> We have seen patients who fear burdening their families but might never say so. We have seen abused elders protecting their abuser, who may also be their only source of support. A brief patient case history by the Canadian palliative care pioneer Dr. Balfour Mount, of a successful professional man who had terminal cancer,<sup>vi</sup> illustrates the fact that vulnerability can be found in the most surprising places.

In the very tendentious debate that took place before the adoption of the law, arguments in favour of euthanasia used dramatic stories of extreme suffering, leading the public and many politicians to believe that MAID would only be applied in similar cases. Subsequent events have indicated the contrary, with people being euthanized for painful arthritis,<sup>vii</sup> treatable psychiatric illness<sup>viii</sup> and fear of losing autonomy.<sup>ix</sup> The rhetoric has shifted from euthanasia as a rare exception to promotion of death as a solution for suffering of all kinds. The “reasonably foreseeable death” criterion is already being flaunted,<sup>x</sup> and two cases presently before the courts may lead to its removal from the law.<sup>xi xii</sup>

We urge all members of the *CCA Expert Panel on Medical Assistance in Dying* to remain fully aware that, in every group of persons for whom MAID is permitted, there will be errors, emotional appeals and manipulation of information, leading to the death of people who would not have chosen it in a different social and political context, including some who did not in fact choose it. We urge you to consider not only **how** such extensions can be made “safely”, but firstly **whether** they should be made at all. Complete safety is impossible, as we have learned in the past year. We believe that the unjust death of even one Canadian is too great a price to pay for the so-called liberty of choosing to die at a difficult moment.

The three extensions being contemplated all raise serious concerns regarding consent. Adolescents’ capacity to consent is not yet fully developed, that of suicidal mentally ill persons is altered by disease, and for patients who have lost capacity, prior consent before their illness is insufficient. For such a grave decision as death we must hold ourselves to a high standard in order to protect every Canadian from premature death.

### **Requests by “mature minors”**

Arguments in favour of extending current legislation on MAID to “mature minors” are based on a perceived unfairness in permitting the “benefit” of a premature death to those over 18 years of age, while denying it to younger persons. Ages of majority vary and cannot be supposed to reflect the most recent findings of neuroscience regarding brain development. It is still 21 years in some U.S. states, and the drinking age is 21 across the U.S. Nor can the early death of a young person, especially if the *apparently* free and informed decision is driven by immature neurodevelopment, be considered a benefit in any way.

The concept of “mature minor” is a legal construct, not a medical concept, and has come under considerable criticism in the literature.<sup>xiii xiv</sup> Recent medical and neuropsychological findings indicate, on the contrary, that a young person’s judgment is not mature until well into adulthood, leading to considerable controversy in this area. Indeed, in criminal law, the trend seems to have reversed, tending toward decreased criminal responsibility of adolescent offenders, based on the immaturity of their still-developing brain.<sup>xv</sup>

For consent to health care, according to the Canadian Medical Protective Association (CMPA), “*The legal age of majority has become largely irrelevant...*”<sup>xvi</sup>, and a child’s maturity and capacity to consent take precedence. With regards to licensure for driving, however, the tendency now is toward increased caution with young drivers, lengthening the process of obtaining a license and restricting the circumstances in which the teenager is permitted to drive.<sup>xvii</sup>

A decision to choose death is distinct from all the above decisions, and there is little or no data on which to rely. It is unique in that there is no going back, and different in kind even from a decision to withdraw or withhold medical treatment.

It is now well known that adolescents do not have fully developed brains until the mid-twenties. According to Cherry (2013),<sup>xviii</sup> “*the empirical outcomes data as well as the anatomical and physiological data support the conclusion that there is no clear correlation between an adolescent’s intellectual ability to assess risk and that adolescent’s effective executive capacity to make mature judgments in matters that involve risk.*” Thus, an adolescent might be able to explain perfectly the risks and benefits associated with the decision being considered, but still be unable to judge adequately how to apply this theoretical knowledge. This flies in the face of the recommendation of the CMPA and other authorities, that the ability of a child to “teach back” the relevant information is sufficient to determine his or her capacity to make a decision.

A 2016 report of the American Academy of Pediatrics states: “*Newer insight into brain structure and function now makes the determination of which minors possess the maturity for decision-making much less clear-cut... Although the size of the brain nearly reaches its adult size in early childhood, we know... that much of the brain has continued dynamic changes in gray matter volume and myelination into the third decade of life. The prefrontal cortex, where many executive functions are coordinated, including the balancing of risks and rewards, is among the last areas of the brain to mature, with these functions continuing to develop and mature into young adulthood.*

*Neuropsychological research to link adolescent behaviors such as sensation seeking and risk taking to brain structure and function is ongoing... One theory is that adolescents have a dual-systems model of decision-making. A “socioemotional” system located in the limbic and paralimbic brain regions is believed to develop around puberty, with increased dopaminergic activity, and manifests as reward-seeking behavior. The “cognitive control” system, which promotes self-regulation and impulse control, is in the prefrontal cortices and gradually develops into the third decade of life. This temporal imbalance or gap between the 2 systems can lead to the risky behavior seen in adolescence and has been analogized to starting a car engine without the benefit of a skilled driver.”*<sup>xix</sup>

An example from the practice of one of us (RH) is a 16 year old adolescent named Myriam (not her real name) who came to the office depressed because she had failed an examination and her boyfriend had recently broken off their relationship. Myriam could only see blackness all around her. She lost interest in her other friends and in activities which formerly gave her pleasure. She no longer wished to go to school. Clearly she was depressed. Some months later, after psychotherapy and medication, Myriam was full of life and enthusiasm.

Far from favouring the opening of access to “medical aid in dying” to adolescents, we propose greater scrutiny of such choices made by young adults, up to the age of at least 21 and perhaps 25. Any limit on the “choice” of these individuals is well compensated for by decreasing the risk of the untimely and ill-chosen death of a young person, which is a tragedy for all concerned.

### **Requests where mental illness is the sole underlying condition**

Suicide is a critical public health issue in Canada. It is currently the 9<sup>th</sup> most frequent cause of death, and rates are increasing.<sup>xx</sup> The website of the Canadian Association for Suicide Prevention refers to suicide as “*a permanent solution to a temporary problem*”,<sup>xxi</sup> and advises that “*If you are unable to think of solutions other than suicide, it is not that solutions don’t exist, only that you are currently unable to see them.*”<sup>xxii</sup> The proposal to permit MAID for suffering due to mental illness strikes at the heart of suicide prevention strategies, both in community settings and in psychiatric practice. For this and other reasons the American Psychiatric Association published in December 2016 a position statement that “*a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death.*”<sup>xxiii</sup>

Whether or not one believes that suicide can at times be a rational act rather than a symptom of mental illness, in the presence of such illness it may be virtually impossible to make the distinction. The role of the physician is to protect the suicidal patient, by removing the lethal means,<sup>xxiv</sup> or when necessary, by confining the patient in hospital against his or her will. Similarly, a community worker in suicide prevention must convince the person not to take action and to seek psychiatric help.

Legal MAID for persons with psychiatric illness would make this work impossible. We have already seen the dilemma played out in Québec: in the first months after the euthanasia law was adopted, the *Collège des médecins du Québec* saw the need to publish guidelines<sup>xxv</sup> on the approach to patients brought to hospital after a drug overdose, as some doctors were refraining from treating them, considering the suicidal act to be an expression of treatment refusal.

A suicidal patient is often reluctant to engage in therapy, tending to migrate toward the preferred option of death. Therefore, to tell a patient that one is willing to consider a MAID request, should a therapeutic intervention fail, would undermine the therapeutic process from the beginning.<sup>xxvi</sup> Similarly, the simple fact of MAID being legal could have the same effect, as the patient would know he or she could seek it elsewhere if the specific doctor were unwilling to provide it. The role of transference and counter-transference in every clinician–patient encounter and “*the risk that the*

*psychiatrist may identify too much with the patient and his or her situation (which may be connected to the doctor's own fears of loneliness, dependence, illness, and handicap)..."<sup>xxvii</sup>* has not been sufficiently considered.

Access to mental health services is another important consideration. In Canada waiting times can be from several months to a year,<sup>xxviii</sup> and patients suffering from complex disorders may not, even then, see a psychiatrist who has the expertise necessary to offer effective treatment. Diagnostic inaccuracies can make it appear that a patient's suffering is irremediable when there are therapeutic options that have not been tried.

The fact that suicide is not illegal does not imply a duty to provide the means to commit suicide. The medical profession, and psychiatrists in particular, must reject MAID for their patients, as it will undermine the care of their most vulnerable patients by its contradictory message and by removing the tools needed to treat their illness.

### **Advance requests**

The proposal to permit MAID by advance request for persons incapable of decision-making is a response, not to present suffering, but to fear of hypothetical future suffering. Our major concerns regarding this possibility include the questionable validity of written advance directives as a decision-making tool, the lack of concurrent consent at the time of death, and the very real danger of elder abuse.

Despite the early popularity of advance written directives for medical decisions in the event of future loss of decision-making capacity, it is not clear that they are a useful tool when used alone. Most research on their efficacy has focused on intermediate outcomes such as completion of an advance directive or occurrence of end-of-life discussions, rather than on the concordance between preferences for care and delivered care.<sup>xxix</sup> Concerns about the applicability of written directives include difficulty envisaging future events while well, and the impossibility of foreseeing all possible medical scenarios. Many have concluded that such documents "promise more control over future care than is possible".<sup>xxx</sup> Widely-used education tools now tend to emphasize reflection and discussion over completion of a written document.<sup>xxxi</sup>

The notion of choosing, when one is well, to have one's life terminated upon reaching a certain degree of loss of autonomy or incapacity has become popular but is fraught with ethical concerns. Such a directive is different not in degree, but in kind, from one that authorizes limiting life support in the event of critical or terminal illness, which is simply a choice to allow the illness to run its natural course.

In the case of cognitive disorders, the directive denies the person the right to change his or her mind. It requires the physician to directly cause the death of someone who is not asking to die, as illustrated by the recent case in the Netherlands of a woman who was sedated, restrained and euthanized against her will in obedience to such a directive.<sup>xxxii</sup> It binds the incapable person to a decision made at a moment in the past, despite the fact that he or she is still conscious and able to

interact and enjoy life, and may have a very different outlook on life and different wishes from those expressed while still legally capable. Persons with dementia often rate their quality of life as better than their caregivers rate it.<sup>xxxiii</sup> There is no reason not to respect the wishes of an incapable person as long as they are not harmful to that person.<sup>xxxiv</sup>

In the Netherlands euthanasia is permitted by advance directive but remains very controversial and rarely done, primarily because of the impossibility of knowing the patient's current wishes.<sup>xxxv</sup> In 2017 a group of Dutch doctors spoke out against the practice: "*Our moral reluctance to end the life of a defenseless human being is too big*", they wrote. Some physicians specialized in euthanasia were among the signatories.<sup>xxxvi</sup>

Dutch academic Boris Brummans wrote in his 2007 article *Death by Document*<sup>xxxvii</sup> of his father's euthanasia death through an advance directive: "*Although the euthanasia was meant to liberate my dad from the conventional constraints of suicide, its textual, declarative form turned him into a prisoner of himself... By signing the euthanasia declaration... my father created a persona of, and for, himself that transcended space and time, based on the person he thought he would be. On what were these thoughts based? Hollow images of a self not yet lived; meager ideas about a life not yet fleshed out.*"

There are further concerns if the directive is written at the time of diagnosis. A diagnosis of dementia – as of any other serious illness – is a major life crisis. Those of us who have been through even lesser crises know that our judgment is not at its best when flooded with overwhelming emotions, fears and questions. Most would be sensible enough to defer life-changing decisions until we are calm enough to think clearly. But for the person diagnosed with dementia the clock is ticking and the advance directive must be signed before decision-making capacity is lost.

Finally, the risk of elder abuse is ever-present.<sup>xxxviii</sup> Even cognitively intact older persons are often dependent on the younger generation, emotionally as well as for help in maintaining their autonomy and navigating a world that has changed since their time. Early, unrecognized cognitive impairment increases the dependency and the power imbalance. Even well-intentioned families may give a subtle message that the older person's care is burdensome to them. When the caregivers are abusive this power differential can lead to an undue influence to sign legal documents, such as a will or protection mandate (durable power of attorney) in favour of the abuser.<sup>xxxix xl</sup> One of us (CF) has extensive clinical experience with such situations and has often testified at court hearings in favour of patients, including the woman whose story was told in a 2016 Montreal Gazette article.<sup>xli</sup> Private residential or home care for a dependent older person is expensive and can rapidly deplete the expected inheritance of the next generation. Advance directives authorizing death would provide a new and more definitive tool for greedy heirs.<sup>xlii</sup>

## **Conclusion:**

Canada is one of only a handful of countries where actively ending the life of a sick person is permitted by law. The World Medical Association <sup>xliii</sup> and the near-totality of national medical associations oppose euthanasia. For our country to have taken this step despite full awareness of Canadians' inadequate access to palliative care and pain medicine was ill-advised to say the least. To extend hastened death to people who are not imminently dying, and who may not be fully able to consent to it, while mental health care is inaccessible and elder abuse is rampant, would be the summit of heedlessness and disregard for the well-being of our citizens. We make our own the position expressed in September 2017 by the American College of Physicians: *"The ACP does not support the legalization of physician-assisted suicide, the practice of which raises ethical, clinical, and other concerns. The ACP and its members, including those who might lawfully participate in the practice, should ensure that all patients can rely on high-quality care through to the end of life, with prevention or relief of suffering insofar as possible, a commitment to human dignity and management of pain and other symptoms, and support for families. Physicians and patients must continue to search together for answers to the challenges posed by living with serious illness before death."* <sup>xliv</sup>

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For the **Physicians' Alliance against Euthanasia**

<https://collectifmedecins.org/en/>

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<sup>i</sup> <https://collectifmedecins.org/en/declaration/signatories/>

<sup>ii</sup> <https://collectifmedecins.org/en/declaration/>

<sup>iii</sup> Battin MP, van der Heide A, Ganzini L, *et al.* Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *Journal of Medical Ethics* 2007;**33**: 591-597.

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## APA Official Actions

### Position Statement on Medical Euthanasia

Approved by the Board of Trustees, December 2016

Approved by the Assembly, November 2016

“Policy documents are approved by the APA Assembly and Board of Trustees. . . These are . . . position statements that define APA official policy on specific subjects. . .” – *APA Operations Manual*

**POSITION:**

**The American Psychiatric Association, in concert with the American Medical Association’s position on Medical Euthanasia, holds that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death.**

**Authors:**

The Joint Reference Committee, stemming from an action paper from the Assembly.



# Informed Consent in Decision-Making in Pediatric Practice

Aviva L. Katz, MD, FAAP, Sally A. Webb, MD, FAAP, COMMITTEE ON BIOETHICS

Informed consent should be seen as an essential part of health care practice; parental permission and childhood assent is an active process that engages patients, both adults and children, in their health care. Pediatric practice is unique in that developmental maturation allows, over time, for increasing inclusion of the child's and adolescent's opinion in medical decision-making in clinical practice and research. This technical report, which accompanies the policy statement "Informed Consent in Decision-Making in Pediatric Practice" was written to provide a broader background on the nature of informed consent, surrogate decision-making in pediatric practice, information on child and adolescent decision-making, and special issues in adolescent informed consent, assent, and refusal. It is anticipated that this information will help provide support for the recommendations included in the policy statement.

Since the publication of previous American Academy of Pediatrics (AAP) statements on informed consent in 1976<sup>1</sup> and 1995,<sup>2</sup> obtaining informed permission from parents or legal guardians before medical interventions on pediatric patients is now standard within our medical and legal culture. The 1995 statement also championed, as pediatrician William Bartholome stated, "the experience, perspective and power of children" in the collaboration between pediatricians, their patients, and parents and remains an essential guide for modern ethical pediatric practice.<sup>2</sup> As recommended in the 1995 publication, the revised policy statement<sup>3</sup> affirms that patients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable.

Although some aspects of decision-making in pediatrics are evolving in response to changes in information technology, scientific discoveries, and legal rulings, recent reports have noted that change can be slow. Despite the long-standing stance of the AAP that older children and adolescents should be involved in the medical decision-making and consent process, there still has not been widespread understanding and endorsement among practitioners of the concept of pediatric assent or refusal.<sup>4-6</sup>

## abstract

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The discordance between current clinical practice and previously published guidance may reflect the gradual evolution of change within the culture of medicine or perhaps suggests a need to build on the discussion of informed consent, assent, and refusal for children and adolescents. The purpose of this technical report is to provide a firm grounding of the concept of informed consent, addressing both the legal and philosophical roots, to provide information on a variety of standards applicable for decision-making by surrogates for pediatric patients and to discuss how issues of assent, refusal, and consent affect the care of children and adolescents in a variety of clinical and research settings.

For purposes of this report, we will define and use the following terms: a pediatric patient or a minor who has not reached the legal age of majority (in most states, 18 years of age) is a patient younger than 18 years; an adolescent refers to a person in the transition between childhood and adulthood, classically defined as 13 to 18 years of age; a child refers to a person from the ages of 1 through 12 years; and an infant refers to a person in the first year of life.

## HISTORY AND NATURE OF INFORMED CONSENT

The current concept of informed consent in medical practice has roots within both ethical theory and law. The support for informed consent in ethical theory is most commonly found in the concept of autonomy, the right of an autonomous agent to make decisions as guided by his or her own reason.<sup>7</sup> As a brief description, informed consent incorporates 2 duties: disclosing information to patients and their surrogates and obtaining legal authorization before undertaking any interventions. The historical shift in US medical practice from paternalism to respect for individual

autonomy was shaped by events in the 20th century, such as the distrust of the medical profession after the Nuremberg trial of Nazi doctors, widespread publicity regarding research ethics violations, the turbulence of the civil rights and women's rights movements, and the long-standing American characteristic of individualism. This long-standing American emphasis on individualism correlated with an increased interest in and attention to the issue of informed consent.<sup>8,9</sup>

Autonomy (from the ancient Greek *autos* [self] and *nomos* [rule or law]) can be seen as derived from Kantian moral philosophy, with key elements of liberty, the capacity to live life according to your own reasons and motives, and agency, the rational capacity for intentional action. A formulation of Kant's categorical imperative notes that we are obliged to act out of fundamental respect for other persons by virtue of their personal autonomy. This imperative forms the moral basis to respect others and ourselves as moral equals and provides moral support for the concept of informed consent. Although many, if not most, patients in pediatric practice lack the agency required to be truly autonomous agents, this framework remains important in providing the background for continued respect of their moral potential.

In pediatrics, the duties to protect and promote health-related interests of the child and adolescent by the physician are also grounded in the fiduciary relationship (to act in the best interest of the patient and subordinating one's own interests) between the physician and patient, but these duties may conflict with the parent's or patient's wishes and set up tensions either within the family or between the family and the physician. Most believe that parents have an ethically parallel fiduciary obligation to protect and promote both the health-related and

the non-health-related interests of their child or adolescent, with the pediatrician and the parents acting as "co-fiduciaries" for health matters.<sup>10</sup> This provides a conceptual framework for moving the discussion from parental rights to parental responsibility when considering pediatric medical decision-making and informed consent.

Appropriate decisional capacity and legal empowerment are the determinants of decision-making authority in medicine. A reliance on individual liberties and autonomy in the pediatric patient is not realistic or legally accepted, so parents or other surrogates provide "informed permission" for diagnosis and treatment, with the assent of the child as developmentally appropriate.<sup>2</sup> However, the goals of the informed consent process (protecting and promoting health-related interests and incorporating the patient and/or the family in health care decision-making) are similar in the pediatric and adult population and are grounded by the same ethical principles of beneficence, justice, and respect for autonomy. As we will discuss further, in pediatric care we often need to expand our understanding of autonomy to recognize the autonomy of the family unit, allowing respect for both the privacy of the family unit, within limits, and parental authority and responsibility for medical decision-making.

Although the requirement of "simple" consent by patients for surgical procedures dates back to 18th-century English law, it was only in the 1950s that the American courts began to develop the doctrine of true "informed" consent from patients through disclosure of facts by physicians. The term "informed consent" is derived from the ruling in *Salgo v Leland Stanford Jr University Board of Trustees* in 1957.<sup>11</sup> This term was adopted verbatim from an *amicus curiae* brief filed by the

American College of Surgeons: "A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent... in discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent."

The judgment in this case identified the need for a full disclosure of the facts necessary to form an informed consent. Later cases (*Mitchell v Robinson*, *Natanson v Kline*)<sup>8,9</sup> shaped our modern understanding of the required elements of disclosure during the consent process by mandating disclosure of risks, the nature of the medical condition, details of the proposed treatment, the probability of success, and possible alternative treatments. The standard of what information must be included in discussions leading to informed consent or informed refusal of treatment has evolved over time and varies somewhat from state to state.<sup>9</sup>

## THE PROCESS OF INFORMED CONSENT

Several different but common standards for the physician's disclosure obligation have emerged. The professional community standard defines adequate disclosure by what the trained and experienced physician tells his or her patient. The objective, reasonable person standard requires the physician to disclose information that a reasonable person in the patient's condition would need and want to know.<sup>9</sup> A small minority of states use the subjective standard of what a particular patient would need to know to make a decision to evaluate the extent of disclosure. Physicians should make substantial efforts to craft disclosures that maximize understanding by all surrogates or patients regardless of developmental maturity, severity of illness,

educational limitations, or language barriers.

Pediatricians should be adept at explaining information to their young patients in an age-appropriate and descriptive manner. This vital skill, if not a standard, enhances the assent and permission process in pediatrics. Although the ability of the child or adolescent to provide assent or consent changes along with cognitive development and maturation, disclosure of the medical condition and the anticipated interventions in a developmentally appropriate manner demonstrates respect for the patient's emerging autonomy and may help enhance cooperation with medical care. The pediatrician and pediatric medical subspecialist should have an understanding of the spectrum of intellectual disability encountered in childhood and adolescence and should be prepared to provide the individualized support needed to maximize understanding of the disease process and therapeutic options.

The content of the informed consent discussion is closely linked with professional experience. Disclosure of risks may differ between physicians in community and academic settings, between younger and older physicians, or among those who perform minimally invasive compared with open procedures.<sup>12</sup> During disclosure to the patient and/or the surrogate regarding treatment options, many believe it is important for the physician to disclose his or her or the facility's own experience with the proposed intervention and periprocedural complications. The issue of disclosure of surgeon-specific outcome data has been addressed recently in the surgical literature.<sup>13,14</sup> Although the potential advantages of this disclosure may include enhanced patient autonomy and understanding during decision-making, some critics contend the accuracy of surgeon-specific performance rates is often illusory because of a variety of

limitations and generally not truly available for thoughtful discussion in the informed consent process.<sup>13</sup> Transparency and honesty in discussing provider experience with patients and families are critical, and there is case law on this issue, with the court finding that, in certain instances, physician-specific data may be material in allowing a fully informed consent.<sup>15</sup>

Although informed consent is usually thought of as linked to surgical or invasive interventions in health care, the same process of disclosure of potential diagnosis, options for evaluation and treatment, likely outcomes, and potential associated risks is also necessary to ensure that medical decision-making for routine or noninvasive clinical treatments is transparent to patients and families.

## SEEKING INFORMED CONSENT

Knowledge about a medical condition is critical to making informed health care decisions by and for adults, adolescents, children, and infants. Informed consent is not satisfied by merely obtaining a signature on a form but is a process of dialog with a patient about a planned course of action. The first part of that dialog is determining whether the patient and/or his or her family/surrogate are capable of understanding the information one discloses. The terms "capacity" and "competence" are frequently blurred in medical discourse. Capacity is a clinical determination that addresses the integrity of mental abilities, and competence is a legal determination that addresses society's interest in restricting decision-making when capacity is in question.<sup>16</sup> Pediatricians can determine whether an adolescent is capable of making health care decisions, and the courts generally determine competence. It is also important to understand that an individual can still have decision-making capacity while

being declared legally incompetent. This situation is typically illustrated when an adult with newly diagnosed dementia is still able to participate and make health care decisions but is incompetent to manage financial affairs, as determined by the courts. It is critical to recognize that capacity is not an all-or-none phenomenon and is relatively task specific.

A patient may have the capacity to participate in certain areas of medical decision-making but may not have the capacity to contribute in more complex discussions, such as end-of-life decision-making. In addition, it is important to recognize that neither capacity nor competence is permanent and may fluctuate over time and should be reassessed over the course of illness, as indicated.

As informed consent and, more recently, assent in pediatrics have evolved over the 50 years since the Salgo case, certain elements of the process listed as follows serve as the framework for conversations with our patients and their families.<sup>2</sup> It is vital that throughout the process, the health care professional understands that providing information and obtaining permission, consent, or assent are 2 different, although linked, functions.

1. Provision of information: patients and their surrogates should be provided explanations, in understandable, developmentally appropriate language, of the nature of their illness or condition; the nature of the proposed diagnostic steps and/or treatments and the probability of their success; the existence and nature of the risks and anticipated benefits involved; and the existence, potential benefits, and risks of potential alternative treatments, including the option of no treatment.
2. The patient's and/or surrogate's understanding of the above information should be assessed.

3. Because decisional capacity is a critical requirement in providing consent, the capacity of the patient and/or surrogate to make the necessary decisions should be assessed (often, assessment of the capacity to make decisions and the understanding of the pertinent medical information occurs simultaneously).

4. There should be assurance, insofar as is possible through ongoing dialog, that the consent is voluntary and that the patient and/or surrogate has the freedom to choose among the medical alternatives without undue influence, coercion, or manipulation. This condition recognizes that we are all subject to subtle pressures in decision-making and that medical decision-making cannot occur in isolation from other concerns and relationships.

The process of informed consent requires participation by the physician or health care provider of record. In teaching hospitals or clinics, it is ethically and legally inappropriate to permit medical students to obtain informed consent from parents or patients without the support and involvement of more senior, knowledgeable staff. Medical students lack the comprehensive medical knowledge required to provide adequate information for a truly informed consent. Junior house staff may also not have sufficient knowledge to satisfy condition number 1 listed above and will need education from more experienced physicians to assist in the dialog with patients and surrogates. Both medical students and junior house staff benefit from opportunities to observe attending physicians engage patients and families in informed consent discussions and may assist in providing initial information to patients and families and by answering questions that fall within their level of understanding.<sup>17,18</sup>

Patient or surrogate comprehension of procedural consent has been reported to be <50% in the adult surgical literature.<sup>19</sup> Similarly, studies of recall and comprehension by parents and pediatric research subjects after informed consent discussions reveal that parents and subjects have far greater understanding of their research rights than the clinical implications of the interventions.<sup>20</sup> New strategies to improve patient literacy and recall during consent are being developed and include multimedia presentations, requirements for "repeat back" elements of the proposed interventions, and trying to increase the time spent in the informed consent discussion.<sup>19,20</sup>

How one shares this information is also crucial to building a successful, trusting relationship with children, adolescents, and their parents/guardians and is critical to achieving the goals of treatment. The event model, in which discrete interventions are seen as a one-shot encounter and patients and their surrogates are left to accept or reject a physician-formulated plan, is inferior to the process model, in which medical decision-making is a longitudinal process over time, with information shared between the physician and the patient/surrogate.<sup>9</sup> This process model, which recognizes that a multitude of decisions are made throughout the medical course as new information emerges, fosters better communication and understanding between clinicians and patients/surrogates. An example of the importance in framing medical decision-making as a longitudinal process that takes shape over time is the care of a critically ill child undergoing resuscitation and stabilization in the ICU. A broad discussion of the many elements that may be required for resuscitation is clearly required, but individualized consent for each element, especially in the likely condensed time frame



is not, as long as there has been an overarching discussion and agreement on the goals of care and an understanding of the likely intensity of interventions required. A more interactive role for the decision-maker and/or patient in informed consent and pediatric assent may improve understanding and ownership of the medical condition and its management and often improves compliance with recommended care.

### **STANDARDS FOR SURROGATE DECISION-MAKING FOR CHILDREN AND ADOLESCENTS**

A deeper understanding of the issue of assent and consent in childhood is facilitated by distancing oneself from the potentially confrontational and legalistic approach of respect for individual autonomy as an overarching principle in pediatrics. A more nuanced approach, incorporating respect for the pediatric patient's medical experience, for family dynamics, and for emerging data on adolescent cognitive development and decision-making, allows for alternative models for both child and surrogate decision-making.

Before discussing models and standards for decision-making in pediatrics, it is helpful to appreciate the complexity of how decisions are made by parents and surrogates. A recent literature review of 55 research articles on the process of treatment decision-making noted that decisions are influenced by such things as provider relationships, previous knowledge, changes in a child's health status, emotions, and faith.<sup>21</sup> Parental distress presents a challenge for good informed decision-making. Parents who receive new diagnoses of cancer or other life-threatening illnesses in their children report burdensome emotional and psychological stress that can interfere with

decision-making.<sup>22-24</sup> Parental coping mechanisms and their perceptions of undue external influence by clinicians or family members on decision-making may result in hostile and uncertain feelings about treatment goals for their seriously ill children.<sup>24</sup> Clinicians should be aware of the effects of stress and uncertainty on autonomous parental decision-making and choose effective communication strategies to limit these negative effects.

When compared with surrogate decision-making that uses substituted judgment for adults who have lost the capacity to make their own medical decisions, surrogate decision-making for infants, children, and adolescents draws from different constructs, such as the best-interest standard, harm principle, constrained parental autonomy, and shared, family-centered decision-making. With substituted judgment, a standard often used in surrogate decision-making for incapacitated adults who previously had the capacity for medical decision-making, surrogates "substitute" their understanding of the patient's known preferences and values in determining goals of treatment. It is important to note that this is an uncommon decision-making model in pediatrics, because most children and many adolescents cannot or have not stated known preferences that are based on their level of understanding and are reflective of core values that an adult with capacity may have had an opportunity to share. In cases in which adolescents, usually those with chronic debilitating diseases, have had the capacity to express wishes about goals of care before deterioration of cognitive function or the onset of overwhelming illness, the substituted judgment standard should be respected by families and the health care team. The opportunity to provide this guidance about their future medical care should be discussed with adolescents during

their ongoing health care in a manner consistent with their cognitive development and maturity.

Parents generally are better situated than others to understand the unique needs of their children and family and make appropriate, caring decisions regarding their children's health care. This parental responsibility for medical decision-making in caring for their child or young adult is not an absolute right, however, because the state also has a societal interest in protecting the child or young adult from harm and can challenge parental authority in situations in which the child or young adult is put at risk (the doctrine of *parens patriae*).

Pediatric health care providers have legal and ethical duties to provide a standard of care that meets the pediatric patient's needs and not necessarily what the parents desire or request. Parental decision-making should primarily be understood as parents' responsibility to support the interests of their child and to preserve family relationships, rather than being focused on their rights to express their own autonomous choices. It is important to note that parental authority regarding medical decision-making for their minor child or young adult who lacks the capacity for medical decision-making is constrained compared with the more robust autonomy in medical decision-making enjoyed by competent adults making decisions regarding their own care. By moving the conversation from parental rights toward parental responsibility, clinicians may help families minimize conflicts encountered in the course of difficult medical decision-making. It is important to recognize that just as there may be conflict between the family and the health care team, there may also be conflict between the patient's parents. Conflict between parents may predate the current health care concern or crisis or may reflect a different understanding of

what medical intervention is in the best interest of their child. These issues must be acknowledged and addressed in the process of medical decision-making for the patient.

Since publication of the 1995 AAP statement, several frameworks providing guidance for pediatric decision-making have emerged in the literature. Historically and legally, medical decision-making in children has centered on the best-interest standard, which directs the surrogate to maximize benefits and minimize harms to the minor and sets a threshold for intervention in cases of abuse and neglect.<sup>25</sup> The focus is on the pediatric patient rather than on the interests of the caregiver and, as philosophers Buchanan and Brock<sup>26</sup> defined it, “acting so as to promote maximally the good of the individual.” Confusion and concern regarding the use of this standard occur if it is interpreted this rigidly, asking the parent to consider the child’s absolute best medical interest in isolation, without considering other interests such as finances or family.<sup>25,27</sup> A broader approach for using the best-interest standard acknowledges the pediatric patient’s emotional, social, and medical concerns along with the interests of the child’s family and strives to maximize benefits and minimize harms within this framework. Best-interest determination in this “ideal” framework may help establish *prima facie*, rather than absolute, duties to children. Another option is to view best interest as a standard of reasonableness wherein the benefit to burden ratio is balanced such that most rational people would agree with the choice of action.<sup>25</sup>

The harm principle may be seen as a more realistic framework to apply in pediatric surrogate medical decision-making, especially when there is a concern about the child’s safety. The goal here is not to identify a single course of action that is in the child’s best interest or represents the

physician’s preferred approach but to identify a harm threshold below which parental decisions will not be tolerated and outside intervention is indicated to protect the child.<sup>27</sup> In addition, when considering intervention, the potential harm to the child by the parental decision must be serious and imminent and a greater threat than the potential harm from state intervention. Diekema<sup>27</sup> stated that if a parental refusal places the child at significant risk of serious harm (eg, refusing a potentially life-saving therapy or a critical therapy of proven efficacy), other questions should be asked to justify state interference: Do the projected benefits of the proposed intervention outweigh the burdens more favorably than the parents’ option? Would another option that is less intrusive to parental autonomy prevent the harm? Can state interference be generalized to all other similar cases? Would the public agree that state interference is reasonable? Proponents of the harm principle note that it is a more appropriate standard for determining when to interfere with parental decisions than the best-interest standard, because parents often make decisions that conflict with a child’s best medical interest, and this situation is generally tolerated within the context of the overall care of the child and family. These concerns would also apply in considering parental decision-making for young adults who lack the capacity to participate in their own medical decision-making.

The model of constrained parental autonomy<sup>28</sup> allows parents, as surrogate decision-makers, to balance the “best interest” of the minor patient with their understanding of the family’s best interests as long as the child’s basic needs, medical and otherwise, are met. Rather than best interests, there is the promotion of basic interests, with medical care as a basic

interest. This model reinforces that a parent’s authority is not absolute but is constrained by their caring and responsibility for the child. An important focus in this model is family autonomy, with the goal of promoting long-term autonomy for the child throughout his or her development within the family setting.

Shared decision-making is a central tenet of the family-centered medical home, especially with respect to children with chronic health conditions. Shared, family-centered decision-making is an increasingly used process for pediatric medical decision-making.<sup>29</sup> This process is dependent on collaborative communication and the exchange of information between the medical team and the family. In addition to the medical team providing information about the patient’s disease process and the risks and benefits of treatment options, it is important for family members to share information regarding their goals and values so that care decisions can meet these needs and address each stakeholder’s perception of the disease process.

## **CULTURAL AND RELIGIOUS INFLUENCE ON DECISION-MAKING**

Medical decision-making in pediatrics is informed by the cultural, social, and religious diversity of physicians, patients, and families. Understanding this tenet and embracing culturally effective pediatric health care may allow for better incorporation of family values in the informed consent process.<sup>30</sup> Occasionally, parental decisions based on culture or religion may conflict with the medical recommendations. Low health literacy in non-English-speaking families can lead to unfavorable health outcomes. The use of appropriately trained interpreters during the informed consent process is vital to obtain

and share relevant information in an easily understandable fashion and to optimize medical treatment of pediatric patients.<sup>30,31</sup>

Other examples of the potential impact of religious and cultural beliefs on medical care include the risk associated with religious-based refusals, such as the refusal of blood transfusions as a life-saving therapy by patients who practice the Jehovah's Witnesses faith, and the refusal to seek medical care when medically necessary, or declining interventions, even in the face of serious illness, by patients who are Christian Scientists. Although adults with the capacity for medical decision-making have the freedom to make decisions that reflect their faith and religious values, even at the risk of serious harm or death, there is clearly a competing state interest in protecting a child from significant risk of serious harm, as noted in the 1944 US Supreme Court ruling *Prince v Massachusetts*.<sup>32</sup> The AAP statement on religious objections to medical care<sup>33</sup> endorses that children, regardless of parental religious beliefs, deserve effective medical treatment when such treatment is not overly burdensome and is likely to prevent substantial harm, serious disability, or death. Clinicians must balance the need to work collaboratively with all parents/families, respecting their culture, religion, and the importance of the family's autonomy and intimacy, with the need to protect children from serious and imminent harm. Clinicians must recognize that failure to provide appropriate care may constitute abuse or neglect, and this situation should not be unreported because of perceived state or federal exemptions for religious groups. This protection is extended until children are able to make such religious decisions for themselves, recognizing that some mature adolescents may either endorse or reject the tenets of their parent's faith over time.

## THE CHILD/ADOLESCENT AS MEDICAL DECISION-MAKER

The value of involving children and adolescents in their own medical decision-making is increasingly recognized around the world.<sup>34–37</sup> The respect owed to pediatric patients as participants in the medical decision-making process is dependent on several factors, including cognitive abilities, maturity of judgment, and the respect owed to a moral agent, which may not all proceed to maturation along the same timeline. Children and adolescents are dependent on their parents for most aspects of their daily life and usually have limited experience with making any medical decisions. Although the child or adolescent should be recognized as a moral being with all of the appropriate dignity and rights, they are more vulnerable decision-makers than adults, in significant part because of both inexperience with decision-making and the slow process of maturation of judgment, as reviewed below.

Developmental research in the 1980s concluded that many minors reach the formal operational stage of cognitive development that allows abstract thinking and the ability to handle complex tasks by midadolescence.<sup>38,39</sup> During that time, the Tennessee Supreme Court, in deciding *Cardwell v Bechtol* in 1987,<sup>40</sup> used the “rule of sevens” to uphold the presumption of decision-making capacity for a 17-year-old girl receiving spinal manipulation. This “rule” stated that no capacity exists for children younger than the age of 7 years, a lack of capacity is presumed but may be rebutted with appropriate evidence between the ages 7 and 14 years, and capacity is presumed but may be rebutted at age 14 years and older. Newer insight into brain structure and function now makes the determination of which minors possess the maturity for decision-making much less clear-cut.

For more than a decade, considerable neurobiological research in animals and humans has focused on the complex interaction of brain development and remodeling with social, emotional, and cognitive processes during adolescence. Although the size of the brain nearly reaches its adult size in early childhood, we know from structural MRI studies that much of the brain has continued dynamic changes in gray matter volume and myelination into the third decade of life.<sup>41–44</sup> The prefrontal cortex, where many executive functions are coordinated, including the balancing of risks and rewards, is among the last areas of the brain to mature, with these functions continuing to develop and mature into young adulthood.

Neuropsychological research to link adolescent behaviors such as sensation seeking and risk taking to brain structure and function is ongoing but still speculative in many areas.<sup>45–47</sup> One theory is that adolescents have a dual-systems model of decision-making.<sup>48,49</sup> A “socioemotional” system located in the limbic and paralimbic brain regions is believed to develop around puberty, with increased dopaminergic activity, and manifests as reward-seeking behavior. The “cognitive control” system, which promotes self-regulation and impulse control, is in the prefrontal cortices and gradually develops into the third decade of life. This temporal imbalance or gap between the 2 systems can lead to the risky behavior seen in adolescence and has been analogized to starting a car engine without the benefit of a skilled driver.<sup>50</sup> Or, in other words, the circuitry of reward-related behavior develops earlier than the control-related brain regions.

Other contributors to the risky choices that some adolescents may make include peer pressure and highly complex or stressful situations. Although pubertal changes



do affect behavior, as has been mentioned, all changes cannot be attributed to “raging hormones.”

On the positive side, late adolescence is also a period during which youth develop a coherent sense of identity, with an increased understanding of their individual beliefs, values, and priorities.<sup>51</sup> The path toward autonomy in the journey from adolescence to adulthood is linked to both intellectual maturity and moral functioning.<sup>52</sup> Early life experiences are paramount in the shaping of moral functioning. With normal development, the integration of emotions, reasoning, and self-reflection with physical and social experiences helps determine the degree of moral intelligence in the transition to adulthood. A coherent sense of identity and stable, deep-seated values are key to making reflective, autonomous decisions required for true informed consent.

Some youth navigate this complex developmental process quite well despite the complex interactions of biology and social context. However, the research to date articulates that, in general, adolescents make decisions differently than adults do, and although they may have cognitive skills, they are more likely to underutilize these skills.<sup>45,53,54</sup> The implications for decision-making by adolescents in stressful health care environments are that they may rely more on their mature limbic system (socioemotional) rather than on the impulse-controlling, less developed prefrontal cognitive system. As clinicians, we should look for evidence of stable, internalized values in adolescent medical decision-making that is reflective of the patient’s cognitive maturation. These values are key to the decision-making process and, in difficult situations, may help provide a foundation in developing goals of care.

Some adolescents and young adults with cognitive impairments and

special health needs may never develop the capacity to allow meaningful participation in medical decision-making. Parents will need to continue to serve as surrogate decision-makers for these patients, even as these adolescents turn 18 years of age and become adults. The legal issues involved in securing guardianship are beyond the scope of this report.

### **ASSENT IN PEDIATRIC DECISION-MAKING**

Pediatric practice is unique in that the developmental maturation of the child allows for increasing longitudinal inclusion of the child’s voice in the decision-making process. Assent from children even as young as 7 years for medical interventions may help them become more involved in their medical care and can foster moral growth and development of autonomy in young patients.<sup>2,55–59</sup> The 1995 AAP statement on informed consent endorses pediatric assent in decision-making. However, the definition and application of assent have lacked consistency in both clinical and research arenas.<sup>55,56</sup> A strict interpretation of assent requires that the child meet all of the elements of an adult informed consent, a requirement that challenges obtaining assent at younger ages. Others seek a developmental approach that would require different levels of understanding from children as they age.<sup>57</sup> At the very least, assent should include the following elements<sup>2</sup>:

1. helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition;
2. telling the patient what he or she can expect with tests and treatments;
3. making a clinical assessment of the patient’s understanding of the situation and the factors

influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy); and

4. soliciting an expression of the patient’s willingness to accept the proposed care.

Note that one should not solicit a child’s assent if the treatment or intervention is required; the patient should be told that fact and should not be deceived. A child is not the final decision-maker, the parent or surrogate is. Many recommended medical interventions come with the likelihood of associated pain, invasive procedures, or at a minimum, inconvenience. Parents should balance the anticipated benefits with the level of burdens and risks of such treatments when making decisions for their children about pursuing therapy. If the likely benefits of treatment in conditions with a good prognosis outweigh the burdens, parents may choose a treatment plan over the objections or dissent of the child. A common example of this situation is an appendectomy for acute appendicitis. Regardless of the child’s degree of participation in and/or disagreement with the care plan, he or she should still be given as much control over the actual treatment as possible: for example, in determining the location for intravenous catheter placement.

Dissent by the pediatric patient should carry increased weight when the proposed intervention is not essential and/or can be deferred without substantial risk or discomfort to the patient or family. A perceived dilemma with assent is that parents and clinicians may resist incorporating assent into their practice when the stakes are too high if the child dissents, as in the case of an appendectomy for acute appendicitis. In 1 recent survey example, the majority of pediatricians would ignore an adolescent’s refusal of treatment when parents are in favor and the prognosis

is good.<sup>4</sup> As stated previously in this report, maintaining honesty in communications with patients and families helps to minimize this concern; information should always be provided in a developmentally appropriate manner, but assent should only be solicited if some element of refusal will be respected. In situations with a poor prognosis and interventions associated with a heavy patient burden, more consideration should be given to the adolescent's opportunity to provide assent or refusal.

Encouraging the patient to actively explore options and take on a greater role in his or her health care may promote empowerment and compliance with a treatment plan.<sup>60</sup> There is core philosophical and developmental support for the notion that we all need the opportunity to make choices to create ourselves as moral agents and create a coherent sense of identity.<sup>61</sup>

### **SPECIAL ISSUES IN ADOLESCENT INFORMED CONSENT/ASSENT/REFUSAL**

There are 3 broad categories of circumstances in which a minor can legally make decisions regarding his or her own health care: exceptions based on specific diagnostic/care categories, the mature minor exception, and legal emancipation.

The legal ability of adolescents to consent for health care needs related to sexual activity, including treatment of sexually transmitted infections (STIs) and provision of contraceptive services, prenatal care, and abortion services, has expanded over the past several decades. This change is not specifically related to an acceptance of the adolescents' abilities in medical decision-making. Rather, this is a public health decision and reflects both the concern that adolescents will not seek care for issues that reflect sexual activity if required to involve their parents for consent and an extension of the broad US

Supreme Court rulings regarding the constitutional right to privacy for all on these matters. It is important for the clinician to note the significant variability between states in how the statutes are worded regarding access for these services. The Guttmacher Institute ([www.guttmacher.org](http://www.guttmacher.org)) is an excellent resource for reviewing state policies on sexual and reproductive health and can be accessed electronically.<sup>62</sup>

Although all states allow access to treatment of STIs, the protection of the adolescent's confidentiality is less widespread. Some states permit the practitioner to disclose information to parents/guardians if they believe it is in the minor's best interest. Many states, insurers, and electronic medical record systems do not make provisions for deferred billing and/or payment for STI services, thus endangering an adolescent's desire for confidentiality. Practitioners are best advised to become familiar with their state statutes and to consider promoting changes in legislation to improve adolescent confidentiality protection where appropriate.<sup>63</sup>

Human papillomavirus (HPV) infection is the most common STI, and several strains of HPV are known to cause cervical cancer, with new data also linking this virus to oral cancers. Primary prevention is available in the form of vaccination, which is recommended for both boys and girls ages 11 through 12 years by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention. It is unknown whether most states will include the HPV primary prevention vaccination in the category of protected STI treatment or general vaccination for which minors may not provide consent.

The majority of states allow some or all adolescents 12 years or older access to contraceptive services and usually do not require parental notification. In contrast,

minor consent to abortion without parental involvement is uncommon: currently, 37 states require parental involvement, although, in general, there is a mechanism by which the minor can petition the court for access to abortion services without parental knowledge or consent.

There is similar variability among the states regarding adolescents' access to mental health and substance abuse prevention and treatment services. The majority of states do allow adolescents to consent to treatment of substance abuse, and importantly, programs receiving federal funding are governed by federal confidentiality regulations that prohibit sharing information regarding treatment without the patient's consent.<sup>64</sup>

The mature minor doctrine recognizes that there is a subset of adolescents who have adequate maturity and capacity to understand and appreciate an intervention's benefits, risks, likelihood of success, and alternatives and can reason and can choose voluntarily. Under the mature minor doctrine, the age, overall maturity, cognitive abilities, and social situation of the minor are considered in a judicial determination, finding that an otherwise legally incompetent minor is sufficiently mature to make a legally binding decision and provide his or her own consent for medical care. In contrast, legally emancipated minor statutes do not address decision-making ability but rather the legal status of the minor. Adolescents who are living separately from their parents and are self-supporting, married, or on active duty with the armed forces are generally considered legally emancipated and competent to make their own decisions and provide consent for medical care.

Although there are significant limitations on adolescents' legal right to consent to their own medical care, all states presume adolescent parents

to be the appropriate surrogate decision-makers for their children and allow them to give informed consent for their child's medical care. This right reflects the adolescent's status as a parent, rather than his or her decision-making capacity as a mature or emancipated minor. There is clearly a significant and concerning paradox encountered in allowing adolescents to take responsibility for complex medical decision-making for their infants and children while, in general, "protecting" adolescents from providing assent and directing their own medical care, even in more controlled, low-risk situations. The case of early adolescent parents of critically ill infants is particularly difficult with regard to consent. These parents, often the mother alone without the involvement or support of the infant's father, are generally charged with the responsibility of making important medical decisions for their infants that they would never be permitted to make for themselves or for other relatives.<sup>65,66</sup>

Although this arrangement meets the legal responsibility of recognizing and respecting the adolescent's status as a parent who has a right and responsibility for decision-making for his or her child, it does not appropriately address the ethical issues raised by young adolescent decision-making nor the physician's ethical responsibility to both the adolescent and his or her child. Adolescent parents are in a very vulnerable situation, facing the need to care for a child while still completing important developmental tasks for themselves. Many pediatricians and neonatologists seek permission from the adolescent parent to involve an adult relative, often the maternal grandparents, in crucial decisions regarding the care of the infant. This adult, selected by the mother as her co-decision-maker, can provide mentoring in shared decision-making to the adolescent

parent and may help safeguard the rights and well-being of the infant. Although not required by law, physicians should provide support for the adolescent mother, as needed, in selecting someone to help her provide informed permission for her infant's care.<sup>65,66</sup>

The informed consent process surrounding relatively higher risk, yet elective procedures, such as pectus excavatum repair and bariatric surgery, highlights the complex issue of adolescent medical decision-making. Surgery to repair pectus excavatum is most commonly undertaken in adolescent patients. The evidence to support significant physiologic improvement in cardiorespiratory function as a result of the surgery is limited, and the most common indication for surgery is distress regarding the appearance of the chest wall. Although the surgery is most often completed in a minimally invasive manner, it is not without the risk of complications, including significant postoperative pain, an extended period postoperatively of limitation of activities, the potential for recurrence of the pectus excavatum appearance, and rarely, the risk of cardiac injury and hemorrhage.<sup>67-69</sup> These can be extremely difficult concerns for the adolescent, especially the younger adolescent to consider and balance, because this deliberation includes the need to consider both acute and long-term risks and benefits. In this situation, the surgeon and the health care team must undertake thoughtful, developmentally appropriate conversations with both the adolescent patient and his or her family to provide the medical information needed to make an informed medical decision. In addition, the surgeon and the health care team must work to elicit from the family, but especially from the adolescent patient, their beliefs and concerns about the surgery and their cognitive understanding

of the associated risks and benefits and how these issues affect their medical decision-making. With this process, which includes input from both the family and the health care team, the adolescent should be able to be supported in making either an informed assent or refusal of the surgical procedure. This procedure provides an excellent example of a situation in which a major medical decision must be made but is best made by carefully supporting the adolescent's opportunity to provide assent or refusal, because only he or she can truly weight the risks and benefits as they apply to him or her. Throughout this process, the surgeon and the health care team must also be aware of balance between coercion by the family or health care team as well as the opportunity to support developmentally appropriate decision-making. A considered refusal of surgery by the adolescent should be respected, given the elective nature of the procedure and the associated postoperative pain and risks. Parental requests for surgical intervention must include the adolescent in the discussion, and the need to include the adolescent and respect his or her concerns must be discussed with the family. The surgeon and the health care team may also find themselves in the situation in which the adolescent is anxious to proceed with surgery, while the family/parents are reticent to provide consent. Continued discussion directed at having all participants clarify their goals for the surgery and their understanding of the risks may allow for a decision that all can respect.

#### **INFORMED REFUSAL OF TREATMENT BY ADOLESCENTS**

Adolescents or older children who have experienced serious and/or chronic illnesses often have an enhanced capacity for decision-making when weighing the benefits and burdens of continued treatment,

especially when the likelihood of a good outcome is low.<sup>70</sup> Refusal of life-sustaining therapy by such an adolescent should be given careful consideration by parents and the health care team. The pediatrician should work with the health care team, patient, and family in a collaborative approach to resolve any conflicts between the parents and adolescent, and the clinicians should generally advocate for the adolescent's wishes if they reflect an ethically acceptable treatment option. When conflicts about the goals of treatment persist, the health care team should enlist the involvement of secondary consultants, an integrated palliative care team, ethics consultation, psychologists, psychiatrists, or chaplains. Seeking legal intervention should be a last resort.

In general, it is also reasonable to respect an adolescent's refusal of nonurgent, non-life-threatening care as long as efforts are directed toward helping the physician and the family understand the basis of the refusal and providing appropriate education for any misconceptions.

Although age provides a clear legal definition of majority, there is still no bright line demarcating when a minor becomes "mature" enough to independently demonstrate the capacity for informed consent or refusal. Courts have weighed in on this issue with a variety of outcomes, detailed below. Recent pressure to generalize functional MRI neurobiological research to individual adolescents to prove criminal culpability is disturbing, because the science still struggles to separate social and environmental influences from biological determinants of behavior.<sup>45</sup>

One of the first mature-minor doctrine cases to rule on whether an adolescent has the right to make decisions about life-sustaining treatments is *In re E.G.* (1989).<sup>71</sup> In this case, the Illinois Supreme

Court ruled that a 17-year-old with leukemia and who was a member of the Jehovah's Witnesses faith was mature and had the right to refuse blood transfusions. Importantly, her mother agreed with her decision. The judges observed that the age of majority "is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood." A second case, *Belcher v Charleston Area Medical Center* (1992),<sup>72</sup> heard by the West Virginia Supreme Court of Appeals, also recognized the mature-minor doctrine and directed physicians to seek input from a mature minor before treatment. In this case, a physician wrote a do-not-resuscitate order for a 17-year-old with muscular dystrophy without discussion with the patient, despite the family's request that he do so. The patient, Larry Belcher, later had a cardiac arrest and died without resuscitation.

Case law continues to evolve on the issue of a minor's right to refuse medical treatment. A recent case<sup>73</sup> involved 13-year-old Daniel Hauser and his mother, Colleen Hauser. Daniel was found to have a very treatable form of Hodgkin lymphoma, with an estimated survival of 80% to 95% after standard chemotherapy and radiation therapy. Despite receiving an initial course of chemotherapy, Daniel and his mother refused further recommended chemotherapy, insisting instead on using "holistic" medicine based on Native American healing practices. One important aspect of this case was Daniel's inability to meet elements of informed assent/consent, because his limited cognitive abilities and illiteracy hampered his ability to comprehend his medical condition and its recommended treatments. A 2009 Minnesota court order in this case considered both a parent's right to raise a child free of interference and the constitutionally protected

right to religious belief but found both less compelling than the state's need to protect the child and to proceed with necessary medical therapy for a treatable, life-threatening illness.

This legal decision is in contrast to previous decisions, such as the case of Dennis Lindberg.<sup>74</sup> Dennis was a 14-year-old with leukemia who practiced the Jehovah's Witnesses faith and was allowed to refuse a blood transfusion after a 2007 court ruling by a Mt Vernon, Washington, judge who found him to be a mature minor. Although Dennis' biological parents objected to this ruling, his long-time guardian, who had raised him in the Jehovah's Witnesses faith, supported his refusal of transfusions. He died within hours of the ruling. In another prominent case in 2006, Abraham Starchild Cherrix, a 16-year-old with lymphoma, successfully deferred standard therapy for his lymphoma, supported by a Virginia court ruling. This ruling centered on the patient's maturity, understanding of his illness, and parental support of his refusal and quickly resulted in Virginia's 2007 "Abraham's Law" that allows adolescents 14 years of age and older a decision-making role in life-threatening conditions.<sup>75</sup>

Despite the legal rulings and ethical guidance, there is still much controversy about informed refusal by adolescents of life-sustaining treatments.<sup>5,76-80</sup> A recent statement from the Confederation of European Specialists in Pediatrics clearly states that pediatric patients may not refuse life-saving treatment.<sup>35</sup> Although the Confederation of European Specialists in Pediatrics references the United Nations Convention of the Rights of the Child, citing article 12, which provides for "the view of the child being given due weight in accordance with the age and maturity of the child," and finds that this clearly applies to medical treatment, they state that the physician has a



duty to act in the best interest of the child.

Many bioethicists support limiting a child's or adolescent's short-term autonomy by overriding a treatment refusal to preserve long-term autonomous choice and an open future.<sup>28,54</sup> Although adolescents may possess the capacity for decision-making, as discussed earlier, it may be limited by lack of perspective or real-life experiences. Some also argue that parental responsibility in promoting and protecting their child's life does not abruptly end when an adolescent has decision-making capacity. They should not cede sole decision-making authority to their minor child.<sup>77</sup> Instead, parental authority and decision-making are constrained to identify and protect the best interests of their child when he or she refuses medical care.

In general, adolescents should not be allowed to refuse life-saving treatment, even when parents agree.<sup>34,54,78</sup> However, in circumstances of a life-limiting terminal illness when only unproven, overly burdensome or likely ineffective treatment options exist, some adolescents may make an informed choice to forgo interventions to address their underlying disease and instead focus on measures that provide comfort and support.

The dilemma of an adolescent treatment refusal is ethically and emotionally challenging. Pediatricians must ascertain the capacity of the minor for decision-making while recognizing that the "science" of that determination is still evolving. The presence of chronic illness can either enhance a child's decisional skills or contribute to regression, emotional immaturity, and anger when facing a choice. The involvement of psychiatric counselors, ethicists, child life specialists, social workers, or other consultants, such as an integrated

palliative care service, may help the patient, family, and clinical team resolve conflict.

### **EMERGENCY EXCEPTIONS TO INFORMED CONSENT**

Parental consent is usually required for the evaluation and medical treatment of pediatric patients. However, there are situations in which children may present with emergency medical conditions and a parent or legal guardian is not available to provide consent. The AAP policy statement "Consent for Emergency Medical Services for Children and Adolescents"<sup>31</sup> recommends that a medical screening examination and appropriate medical stabilization of the pediatric patient with an urgent or emergent condition should never be withheld or delayed because of problems with obtaining consent. Although clinicians, courts, and parents may differ on what constitutes an emergency, this standard should apply when urgent interventions to prevent imminent and significant harm are necessary and when reasonable efforts to find a surrogate are unsuccessful.

Clinicians should also be aware that current federal law, under the Emergency Medical Treatment and Active Labor Act, mandates a medical screening examination and, if indicated, treatment and stabilization of an emergency medical condition, regardless of consent issues, in any hospital that receives federal funding. If an emergency medical condition is not identified with a screening examination, then Emergency Medical Treatment and Active Labor Act regulations no longer apply and the physician should seek proper consent or assent before further nonurgent care is provided.<sup>31</sup>

There also may be situations in which practitioners seek consent by proxy for nonurgent care (eg, a babysitter brings a 6-year-old to the doctor's office). Guidance for clinicians in

this area is found in the AAP policy statement "Consent by Proxy for Nonurgent Pediatric Care."<sup>81</sup>

### **INFORMED CONSENT/ASSENT/REFUSAL IN RESEARCH INVOLVING CHILDREN AND ADOLESCENTS**

The informed consent process for both research and clinical care shares similar ethical foundations and also encounters similar problems in ensuring consistency across institutions and practices. Informed consent and assent obtained from children involved in research are clearly mandated, in contrast to the "recommended" guidance in place in clinical care. This process has been closely scrutinized for >3 decades since the publication of the *Belmont Report* in 1978.<sup>82</sup> Produced by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, the *Belmont Report* formed the basis of much of the work on informed consent in the research setting. Institutional review boards (IRBs) have incorporated the *Belmont Report*, the *Report and Recommendation: Research Involving Children*,<sup>83</sup> the NIH Policy and Guidelines on the Inclusion of Children as Participants in Research Involving Human Subjects,<sup>84</sup> and the appropriate federal guidelines (the "Common Rule" [45 CFR §46, 1991]) into the rules balancing the risk/benefit ratio that guide the review of research protocols including children as research subjects. The informed permission of the child subject's parent(s) must be obtained before enrolling the subject in the research protocol. In a distinction from the usual clinical practice, there are also clear guidelines on the need to obtain assent from the child subject in research and to respect a minor's dissent from study participation, with limited exceptions.

Although assent is mandated, federal guidelines on how to obtain assent

and at what age are not explicit. This situation results in variability in requirements of local IRBs of the age at which assent should be obtained and what elements of the traditional informed consent process are required from children and adolescents.<sup>2,55–59</sup> Although the AAP and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research recommend assent for children >7 years, there is still wide variation in the inclusion of children in the assent process.<sup>85</sup> The ability of the capable mature minor to consent to medical research depends on individual state laws, but generally, risks must be minimal and the research aim should center on a medical condition for which the minor can legally give consent. More detailed information is found in the AAP clinical report “Guidelines for the Ethical Conduct of Studies To Evaluate Drugs in Pediatric Populations.”<sup>86</sup>

Most research into the assent or consent process has occurred in the pediatric oncology population, because up to 80% of pediatric patients with cancer are also enrolled as subjects in clinical research trials. Oncologists may neglect to include adolescents in the decision-making process because of perceived inability of the adolescent to comprehend information when facing a life-threatening situation and the presumed sufficiency of parental permission.<sup>87</sup> Children enrolled in clinical trials very often have limited awareness and appreciation of the research trial, do not recall having a role in deciding whether to enroll, and do not feel free to dissent.<sup>59</sup> Observational studies have noted variations in how often the physician addressed the child versus the parent during the assent/permission discussion.<sup>70,88</sup> Observed decision-making approaches during discussion of enrollment include patient-centered, parent-centered, or joint child-parent decisions. The

latter or partnering approach may be the most successful in meeting the criteria for parental permission and child assent but may not be possible when families or physicians exercise authority over the child. A strong push toward endorsing a developmentally appropriate assent process in research may encourage more joint decision-making.

The IRB can provide a waiver from requiring assent if greater-than-minimal-risk research has the potential for an important direct benefit that is only available in the context of the research or the research carries only minimal risk and could not be carried out without the waiver.<sup>89</sup> This is a critical difference from the child’s input into decision-making in the clinical world.

## CONCLUSIONS

Informed consent should be seen as a constitutive part of health care practice; parental permission and childhood assent is an active process that engages patients, adults, and children in the health care process. Pediatric practice is unique in that developmental maturation of the child allows for increasing longitudinal inclusion of the child’s opinion in medical decision-making in clinical and research practice. Although new research has shown that neurologic maturation continues into the third decade of life, seeking assent from children and adolescents for medical interventions can foster the moral growth and development of autonomy in young patients and is strongly recommended. Surrogate decision-making by parents or guardians for pediatric patients should seek to maximize the benefits for their child by balancing health care needs with social and emotional needs within the context of overall family goals, cultural beliefs, and values. Physicians should recognize that some pediatric patients, especially older adolescents and

those with medical experience because of chronic illness, are minors with enough decision-making capacity, moral intelligence, and judgment to provide true informed consent, or, in non-life-threatening settings, informed refusal, for their proposed care plan. Clinicians have both a moral obligation and a legal responsibility to question and, if necessary, to contest surrogate and/or patient medical decisions that put the patient at significant risk of serious harm. Adolescent treatment refusals remain controversial and are ethically and emotionally challenging for families and clinicians.

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## ABBREVIATIONS

AAP: American Academy of Pediatrics  
HPV: human papillomavirus  
IRB: institutional review board  
STI: sexually transmitted infection

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# Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper

Lois Snyder Sulmasy, JD, and Paul S. Mueller, MD, MPH\*; for the Ethics, Professionalism and Human Rights Committee of the American College of Physicians

Calls to legalize physician-assisted suicide have increased and public interest in the subject has grown in recent years despite ethical prohibitions. Many people have concerns about how they will die and the emphasis by medicine and society on intervention and cure has sometimes come at the expense of good end-of-life care. Some have advocated strongly, on the basis of autonomy, that physician-assisted suicide should be a legal option at the end of life. As a proponent of patient-centered care, the American College of Physicians (ACP) is attentive to all voices, including those who speak of the desire to control when and how life will end. However, the ACP believes that the ethical arguments against legalizing physician-assisted suicide remain the most compelling. On the basis of substantive ethics, clinical practice, policy, and other concerns articulated in this position paper, the ACP does not support legalization of physician-assisted suicide. It is problematic given the nature of the patient-

physician relationship, affects trust in the relationship and in the profession, and fundamentally alters the medical profession's role in society. Furthermore, the principles at stake in this debate also underlie medicine's responsibilities regarding other issues and the physician's duties to provide care based on clinical judgment, evidence, and ethics. Society's focus at the end of life should be on efforts to address suffering and the needs of patients and families, including improving access to effective hospice and palliative care. The ACP remains committed to improving care for patients throughout and at the end of life.

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**H**ow we die, live, and are cared for at the end of life is important, with implications for individuals, their families, and society. The 1997 report *Approaching Death: Improving Care at the End of Life*, by the Institute of Medicine (IOM), documented inadequate end-of-life care in the United States (1). The investigators of SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment; 2000) agreed (2, 3). The emphasis by medicine and society on intervention and cure has sometimes come at the expense of good end-of-life care. Inappropriate treatment at the end of life may be harmful and draining—physically, emotionally, and financially—for patients and their families. Many people have concerns about death. At the end of life, some patients receive unwanted care; others do not receive needed care (4–6). Some end-of-life concerns are outside of medicine's scope and should be addressed in other ways. Although medicine now has an unprecedented capacity to treat illness and ease the dying process, the right care in the right place at the right time has not been achieved.

Medicine and society still struggle with getting it right for all patients. Although progress has been made, the principles and practices of hospice and palliative medicine have not been fully realized (4). Revisiting these issues in 2014, the IOM's *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* reported that challenges remain in

delivering quality end-of-life care to a growing and diverse elderly population, especially with regard to access to care, communication barriers, time pressures, and care coordination (7). Inadequate reimbursement and other disincentives also are barriers to palliative and hospice care.

Hospice and palliative care may ease apprehension about the dying process. Such care requires improving access to, financing of, and training in palliative care; improving hospital, nursing home, and at-home capabilities in delivering care; and encouraging advance care planning and openness to discussions about dying. Of note, 90% of U.S. adults do not know what palliative care is; however, when told the definition, more than 90% say they would want it for themselves or family members if severely ill (4).

Within this context of challenges in providing palliative and hospice care, a few U.S. jurisdictions have legalized physician-assisted suicide. This paper presents the position of the American College of Physicians (ACP) on the topic. The ACP recognizes the range of views on, the depth of feeling about, and the complex-

## See also:

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\* This paper, authored by Lois Snyder Sulmasy, JD, and Paul S. Mueller, MD, MPH, was developed for the Ethics, Professionalism and Human Rights Committee of the American College of Physicians. Individuals who served on the Ethics, Professionalism and Human Rights Committee at the time of the paper's approval were Carrie A. Horwitch, MD, MPH† (Chair); Omar T. Atiq, MD† (Vice Chair); John R. Ball, MD, JD†; Nitin S. Damle, MD, MSt; Pooja Jaleel, BA†; Daniel B. Kimball Jr., MD†; Lisa S. Lehmann, MD, PhD†; Ana María López, MD, MPH†; Paul S. Mueller, MD†; Alexandra Norcott, MD†; Sima Suhas Pendharkar, MD, MPH†; Julie R. Rosenbaum, MD†; Molly B. Southworth, MD, MPH†; and Thomas G. Tape, MD†. Approved by the ACP Board of Regents on 27 March 2017.

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ity of this issue. This executive summary is a synopsis of the ACP's position. See the **Glossary** for definitions and the **Appendix** for the full position paper.

## METHODS

This position paper was developed from September 2015 to March 2017 on behalf of the ACP Ethics, Professionalism and Human Rights Committee (EPHRC). Committee members abide by the ACP's conflict-of-interest policy and procedures ([www.acponline.org/about-acp/who-we-are/acp-conflict-of-interest-policy-and-procedures](http://www.acponline.org/about-acp/who-we-are/acp-conflict-of-interest-policy-and-procedures)), and appointment to and procedures of the EPHRC are governed by the ACP's bylaws ([www.acponline.org/about-acp/who-we-are/acp-bylaws](http://www.acponline.org/about-acp/who-we-are/acp-bylaws)). After an environmental assessment to determine the scope of issues and literature reviews, the EPHRC evaluated and discussed several drafts of the paper; the paper was then reviewed by members of the ACP Board of Governors, Board of Regents, Council of Early Career Physicians, Council of Resident/Fellow Members, Council of Student Members, Council of Subspecialty Societies, Patient Partnership in Healthcare Center and Advisory Board, and other committees and experts. The paper was revised on the basis of comments from the aforementioned groups and individuals, reviewed again by the full leadership, and then revised further. Finally, the ACP Board of Regents reviewed the paper and approved it on 27 March 2017. Financial support for this project is exclusively from the ACP operating budget.

## BACKGROUND AND BRIEF RATIONALE

In 2001, the ACP published a position paper opposing legalization of physician-assisted suicide (8). This issue also has been considered every few years in the *American College of Physicians Ethics Manual*, including the current edition (9). Given recent changes in the legal landscape, public interest in the topic, and continuing barriers to palliative and hospice care, an updated position paper is presented here. Within a framework that considers clinical practice, ethics, law, and policy, this paper provides background, discusses the role of palliative and hospice care, explores the nature of the patient-physician relationship and the distinction between refusal of life-sustaining treatment and physician-assisted suicide, and provides recommendations for responding to patient requests for physician-assisted suicide.

Medical ethics establishes the duties of physicians to patients and society, sometimes to a greater extent than the law (9). Physicians have duties to patients on the basis of the ethical principles of beneficence (that is, acting in the patient's best interest), nonmaleficence (avoiding or minimizing harm), respect for patient autonomy, and promotion of fairness and social justice (9). Medical ethics and the law strongly support a patient's right to refuse treatment, including life-sustaining treatment. The intent is to avoid or withdraw treatment that the patient judges to be inconsistent with his or her goals and preferences. Death follows

naturally, after the refusal, as a result of the underlying disease (9).

Ethical arguments in support of physician-assisted suicide highlight the principle of respect for patient autonomy and a broad interpretation of a physician's duty to relieve suffering (10). Proponents view physician-assisted suicide as an act of compassion that respects patient choice and fulfills an obligation of nonabandonment (11). Opponents maintain that the profession's most consistent ethical traditions emphasize care and comfort, that physicians should not participate in intentionally ending a person's life, and that physician-assisted suicide requires physicians to breach specific prohibitions as well as the general duties of beneficence and nonmaleficence. Such breaches are viewed as inconsistent with the physician's role as healer and comforter (12, 13).

Both sides agree that patient autonomy is critical and must be respected, but they also recognize that it is not absolute and must be balanced with other ethical principles (9, 14). To do otherwise jeopardizes the physician's ability to practice high-value care in the best interests of the patient, in a true patient-physician partnership. Only by this balancing of ethical principles can physicians fulfill their duties, including those in more everyday encounters, such as when a physician advises against tests requested by a patient that are not medically indicated, declines to write an illegal prescription, or breaches confidentiality to protect public health. It also undergirds the physician's duty not to engage in futile care (such as care based on requests for nonindicated cardiopulmonary resuscitation or end-of-life treatment of brain-dead patients under an expansive view of patient autonomy). Physicians are members of a profession with ethical responsibilities; they are moral agents, not merely providers of services (15).

The suffering of dying patients may be great and is caused by somatic symptoms, such as pain and nausea; psychological conditions, such as depression and anxiety; interpersonal suffering due to dependency or unresolved conflict; or existential suffering based in hopelessness, indignity, or the belief that one's life has ended in a biographical sense but has not yet ended biologically. For some patients, a sense of control over the manner and timing of death brings comfort. However, is it reasonable to ask medicine to relieve all human suffering? Just as medicine cannot eliminate death, medicine cannot relieve all human suffering. Both proponents and opponents of physician-assisted suicide wish to alleviate suffering of dying patients, and physicians have an ethical duty to provide competent palliative and hospice care (9). However, is physician-assisted suicide a type of control over suffering and the dying process that is within the goals and scope of medicine?

Balancing respect for patient autonomy against other principles reflects ethical arguments about the nature of the patient-physician relationship—a relationship that is inherently unequal because of power differentials and the vulnerability of illness—physicians' duties, and the role of the medical profession in society. A fuller consideration of this ethical balance, intent and

### Glossary

*Suicide*: The act of killing oneself intentionally.

*Physician-assisted suicide*: Physician participation in advising or providing, but not directly administering, the means or information enabling a person to intentionally end his or her life (e.g., ingesting a lethal dose of medication prescribed for that purpose).

*Euthanasia*: The act of intentionally ending a life to relieve pain or other suffering (e.g., lethal injection performed by a physician).

causation in acts near the end of life, medicalization versus personalization of death, and the ethics and implications of physician-assisted suicide are presented in the Appendix.

### POSITION STATEMENT

The ACP affirms a professional responsibility to improve the care of dying patients and their families.

The ACP does not support the legalization of physician-assisted suicide, the practice of which raises ethical, clinical, and other concerns. The ACP and its members, including those who might lawfully participate in the practice, should ensure that all patients can rely on high-quality care through to the end of life, with prevention or relief of suffering insofar as possible, a commitment to human dignity and management of pain and other symptoms, and support for families. Physicians and patients must continue to search together for answers to the challenges posed by living with serious illness before death (9).

### CONCLUSION

Society's goal should be to make dying less, not more, medical. Physician-assisted suicide is neither a therapy nor a solution to difficult questions raised at the end of life. On the basis of substantive ethics, clinical practice, policy, and other concerns, the ACP does not support legalization of physician-assisted suicide. This practice is problematic given the nature of the patient-physician relationship, affects trust in that relationship as well as in the profession, and fundamentally alters the medical profession's role in society. Furthermore, the principles at stake in this debate also underlie medicine's responsibilities on other issues and the physician's duty to provide care based on clinical judgment, evidence, and ethics. Control over the manner and timing of a person's death has not been and should not be a goal of medicine. However, through high-quality care, effective communication, compassionate support, and the right resources, physicians can help patients control many aspects of how they live out life's last chapter.

From the American College of Physicians, Philadelphia, Pennsylvania.

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**APPENDIX AND EXPANDED RATIONALE: ETHICS AND THE LEGALIZATION OF PHYSICIAN-ASSISTED SUICIDE—AN AMERICAN COLLEGE OF PHYSICIANS POSITION PAPER**

**Framing the Issues: Care Near the End of Life**

We all will die. How we die—and live at the end of life—is important, with implications for individuals, their families, and society. How we are cared for at the end of life matters.

The groundbreaking 1997 report *Approaching Death: Improving Care at the End of Life*, by the IOM, documented inadequate end-of-life care in the United States (1). In 2000, the SUPPORT investigators agreed (2, 3). Although the cultural norm of fighting disease aggressively is the right approach in many cases, the emphasis by medicine, as well as society, on intervention and cure sometimes comes at the expense of good end-of-life care. Inappropriate treatment at the end of life may be harmful and draining—physically, emotionally, and financially—for patients and their families. Many of us have concerns or apprehensions about how we will die. Indeed, some patients receive unwanted care at the end of life, whereas others do not receive the care they need (4–6). Although medicine now has an unprecedented capacity to treat illness and ease the dying process, the right care in the right place at the right time has not been achieved.

Medicine and society still struggle to get it right for all patients. Although progress has been made, the principles and practices of hospice and palliative medicine have not been fully realized (4). Revisiting these issues in 2014, the IOM report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* found that challenges remain in delivering quality end-of-life care to a growing and diverse elderly population, especially regarding access to care, communication barriers, time pressures, and care coordination (7). Inadequate reimbursement and other

**Appendix Table.** U.S. Jurisdictions Where Physician-Assisted Suicide Is Legal

Where	When	How
Oregon	1997	Voter-approved ballot initiative
Washington	2008	Voter-approved ballot initiative
Montana	2009	Court decision*
Vermont	2013	Legislation
California	2015	Legislation
Colorado	2016	Voter-approved ballot initiative
District of Columbia	2016	Legislation

\* A patient's request for physician-assisted suicide can be an affirmative defense for a physician who participates.

disincentives also create barriers to palliative and hospice care.

Wide agreement exists that hospice and palliative care may ease apprehension about the dying process. Such care requires improving access to, financing of, and training in palliative care; improving hospital, nursing home, and at-home capabilities in delivering care; and encouraging advance care planning and openness to discussions about dying. Of note, 90% of U.S. adults do not know what palliative care is, but when told the definition, more than 90% say they would want it for themselves or family members if severely ill (4).

Access to state-of-the-art symptom control remains limited for all dying patients. Of particular concern, evidence of ethnic and racial disparities in access, outcomes, and communication is increasing (5, 6). Many patients fear they will not receive appropriate end-of-life care when they need it. Others are concerned about being a financial, physical, or other burden on their family, losing autonomy or control, or being placed in a long-term care facility. Some are alone or lonely; loneliness has a mortality risk similar to that of cigarette smoking, yet its health implications are underappreciated (16). Many persons approaching death are clinically depressed or have other psychiatric comorbid conditions, and some contemplate suicide (17, 18). According to Wilson and colleagues, “the expression of a desire for death by a terminally ill patient should raise a suspicion about mental health problems; by itself, however, it is not definitively diagnostic of one” (17). This desire fluctuates over time (19, 20) and may be related to inadequate symptom management. Medicine can and should ameliorate many of these problems; some, however, are outside the scope or goals of medicine and should be addressed in other ways.

As challenges in providing palliative and hospice care continue, a few jurisdictions have legalized physician-assisted suicide (see the **Glossary** for definitions and the **Appendix Table** for U.S. jurisdictions with physician-assisted suicide laws). The ACP recognizes the range of views, depth of feeling, and complexity of the issue of physician-assisted suicide.

## Revisiting Physician-Assisted Suicide

In 2001, the ACP published a position paper opposing legalization of physician-assisted suicide (8). The issue also has been considered every few years in the *American College of Physicians Ethics Manual*, including the current edition (9). Given recent changes in the legal landscape, public interest in the topic, and continuing barriers to palliative and hospice care, an updated position paper is presented here. Within a framework that considers clinical practice, ethics, law, and policy, this paper provides background, discusses the role of palliative and hospice care, explores the nature of the patient-physician relationship and the distinction between refusal of life-sustaining treatment and physician-assisted suicide, and provides recommendations for responding to patient requests for physician-assisted suicide.

## The Context

Physician-assisted suicide is medical help with a patient's intentional act to end his or her own life (for example, an individual taking a lethal dose of medication prescribed by a physician for that purpose). It is ethically, legally, and clinically different from patient refusal of life-sustaining treatment through the withdrawal or withholding of treatment. Physician-assisted suicide also differs from euthanasia, an act in which a physician intentionally terminates the life of a patient (such as by lethal injection), the purpose of which is to relieve pain or other suffering (8). Dictionaries define suicide as intentionally ending one's own life. Despite cultural and historical connotations, the term is neither disparaging nor a judgment. Terms for physician-assisted suicide, such as aid in dying, medical aid in dying, physician-assisted death, and hastened death, lump categories of action together, obscuring the ethics of what is at stake and making meaningful debate difficult; therefore, clarity of language is important.

Although suicide and attempted suicide have been decriminalized in the United States, assisting a suicide remains a statutory offense in most states. Euthanasia is illegal everywhere in the United States. In New Mexico, a lower-court decision authorized physician-assisted suicide, but it was struck down; like all appellate courts, the New Mexico Supreme Court ruled that there is no right to physician-assisted suicide. Elsewhere in the world, in 2015, the Parliament of the United Kingdom voted down a physician-assisted suicide bill, 330 to 118, and Canada legalized both physician-assisted suicide and euthanasia. In 2016, the Parliament of South Australia rejected a bill on euthanasia. Physician-assisted suicide and euthanasia are legal in the Netherlands, Belgium, and Luxembourg; euthanasia is legal in Colombia; and Switzerland has decriminalized assisted suicide.

## Principles of Medical Ethics and Arguments, Pro and Con

Medical ethics establishes the duties of physicians to patients and society, sometimes to a greater extent than the law (9). Physicians have duties to patients based on the ethical principles of beneficence (acting in the patient's best interest), nonmaleficence (avoiding or minimizing harm), respect for patient autonomy, and promotion of fairness and social justice (9). Medical ethics and the law strongly support a patient's right to refuse treatment, including life-sustaining treatment. The intent is to avoid or withdraw treatment that the patient considers unduly burdensome and inconsistent with his or her health goals and preferences. Death follows naturally after the refusal, due to the underlying disease (9).

Ethical arguments in support of physician-assisted suicide highlight the principle of respect for patient autonomy and a broad interpretation of a physician's duty to relieve suffering. The decision to intentionally end one's life is regarded as intensely private and therefore should not be prohibited (10). Seeking physician-assisted suicide is most frequently associated with concerns about loss of autonomy and control, decreasing ability to participate in enjoyable activities, and loss of dignity, rather than pain or other symptoms (21, 22). For persons who seek this type of control, palliative and hospice care are not the issue—they often are already receiving those services. In Oregon, the state with the most experience, 1327 persons have obtained prescriptions for lethal doses of medications under the law since 1997; 859 died after taking the medication. Of 105 deaths during 2014, 68% occurred in persons older than 65 years, 95% were white, 56% were men, 48% were persons with a baccalaureate degree or higher, and 69% had cancer (21). More recent justifications present physician-assisted suicide as a personal choice, avoiding discussion of important medical ethics considerations (11).

Proponents of physician-assisted suicide view it as an act of compassion that respects patient choice and fulfills an obligation of nonabandonment (11). In support of legalization, they also argue that some patients receiving a lethal prescription ultimately do not use it. In addition, some maintain that physician-assisted suicide already occurs where it is illegal (23), so legalization would result in standardization, transparency, and monitoring.

Opponents maintain that the profession's most consistent ethical traditions emphasize care and comfort and that physicians should not participate in intentionally ending a person's life (12). Physician-assisted suicide requires physicians to breach specific prohibitions as well as the general duties of beneficence and nonmaleficence. Such breaches are viewed as inconsistent with the physician's role as healer and comforter



(13). Pronouncements against physician-assisted suicide date back to Hippocrates.

Opponents agree that patient autonomy is critical and must be respected but recognize that it is not absolute and must be balanced with other ethical principles (9, 14). To do otherwise jeopardizes the physician's ability to practice high-value care in the best interests of the patient, in a true patient-physician partnership. Only by such a balance of ethical principles can physicians fulfill their duties, including those in more everyday encounters, such as when a physician advises against tests requested by a patient that are not medically indicated, declines to write illegal prescriptions, or breaches confidentiality to protect public health. It also undergirds the duty that physicians not engage in futile care (for example, care based on requests for nonindicated cardiopulmonary resuscitation or end-of-life treatment of brain-dead patients under an expansive view of patient autonomy). Physicians are members of a profession with ethical responsibilities; they are moral agents, not merely providers of services (15).

Death certificate requirements under physician-assisted suicide laws ask physicians to list the cause of death as the underlying illness, not the new pathology caused by ingestion of a lethal dose of medicine (24), which seems inconsistent with the physician's duty of honesty. Moreover, although individual physicians may decline to participate, conscientious objection to physician-assisted suicide does not address the fundamental ethical objections to it.

The suffering of dying patients may be great; it is caused by somatic symptoms, such as pain and nausea; psychological conditions, such as depression and anxiety; interpersonal suffering due to dependency or unresolved conflict; or existential suffering based in hopelessness, indignity, or the belief that one's life has ended in a biographical sense but has not yet ended biologically. For some patients, a sense of control over the manner and timing of death brings comfort. However, is it reasonable to ask medicine to relieve all human suffering? Just as medicine cannot eliminate death, medicine cannot relieve all human suffering; attempting to do so ultimately leads to bad medical care (25). Good medicine demands compassion for the dying, but compassion also needs reason (26). Both proponents and opponents wish to alleviate suffering of dying patients, and physicians have an ethical duty to provide competent palliative and hospice care (9). However, is physician-assisted suicide a type of control over suffering and the dying process that is within the goals and scope of medicine?

Balancing respect for patient autonomy against other ethical principles reflects arguments about the nature of the patient-physician relationship, physicians' duties, and the role of the medical profession in soci-

ety. In fact, one may argue that making physicians arbiters of assisted suicide is a return to paternalism and not a power physicians should want (27), that "the legalization of physician-assisted suicide does not empower patients; it empowers physicians" (28).

Legalization of physician-assisted suicide also raises social justice issues. Society and the medical profession have duties to safeguard the patient-physician relationship and human dignity. These duties apply especially to the most vulnerable members of society: the sick, the elderly, children, the disabled, the poor, minorities, and others. Some individuals might view themselves as unproductive or burdensome and, on that basis, as candidates for assisted suicide, especially if a physician raises it or validates a request. Physician-assisted suicide laws have been associated with a 6% increase in total suicides (15% in those older than 65 years) in the states where physician-assisted suicide is legal, controlling for state-specific time trends (29, 30). Although a recent study did not find vulnerable groups being pressured to accept physician-assisted suicide, it did raise questions about a lack of data on complications and on how many physicians may have assisted without reporting (31). Vulnerable communities and individuals raise strong concerns that legalization leads to attitudinal changes, subtle biases about quality of life, and judgments that some lives are not worth living (32, 33). National disability groups are opposed to physician-assisted suicide (32, 34). One article reported various opinions among focus group participants (35). Finally, advocating for physician-assisted suicide where there is no general right to health care and access to hospice and palliative care services is limited, especially in an era of health care cost containment, is ironic (8).

## **Ethics and the Nature of the Patient–Physician Relationship**

The ACP's main concerns in this debate are ethical ones. The patient-physician relationship is inherently unequal. Physicians have specialized medical knowledge, training, experience, and prescribing powers that patients do not. Illness makes patients vulnerable (including physicians who are patients [36, 37]). Patients disrobe, are examined, and disclose intimate information to their physicians. The physician must earn the patient's trust, preserve his or her confidentiality, and act as a fiduciary. Physicians publicly profess that they will act for the benefit of their patients, putting patients' welfare and best interests first and helping them cope with illness, disability, suffering, and death. The physician has a duty to respect the dignity and the cultural and spiritual uniqueness and traditions of every patient (9).

Physician-assisted suicide and euthanasia were common during the time of Hippocrates, leading to

their specific prohibition in the Hippocratic Oath (38). Together with the prohibition of sexual relationships between physicians and patients and the duty to maintain patient confidentiality, the Oath provides a context for a therapeutic alliance to prevent the exploitation of patient relationships.

The Hippocratic Oath, of course, is not followed word for word today; however, it has been analyzed and applied over time in light of its fundamental principles. Acting in the best interests of the patient and recognizing the special nature of the patient-physician relationship, principles and prohibitions set ethical boundaries to prevent misunderstandings and misuse of medical authority. These boundaries encourage patients to be open and honest regarding intimate health matters in a safe space, in the context of a trusted relationship.

Physicians can influence patients, even in ways physicians may not appreciate. Patients seeking physician-assisted suicide may seek validation to end their lives. Indeed, studies have shown that socially isolated, vulnerable persons seek social support and contact through visits with their physicians (16). Physicians may influence patients based on their own fears of death and disability (39). Evidence also suggests that many physicians who participate in physician-assisted suicide are adversely affected by the experience (40). Some commentators question whether assisted suicide needs to be physician assisted and whether others might provide assistance instead (41).

### **The Ethics of Refusal of Treatment and Providing Symptom Control: A Closer Look at Intent and Causation**

For decades, the consensus has been that after a careful weighing of patient autonomy, beneficence, nonmaleficence, and societal interests, a patient may forgo life-sustaining treatment. Although Hippocratic writings explicitly proscribe euthanasia and physician-assisted suicide, they deem treatment abatement ethically appropriate in patients who are "overmastered by disease" (42). Although some lower courts have questioned the importance of this distinction (43), the U.S. Supreme Court has distinguished the refusal of treatment from suicide (44, 45). Withdrawal of treatment based on patient wishes respects the patient's bodily integrity and right to be free of unwanted treatment. Physician-assisted suicide and euthanasia are interventions done with the intent to end the patient's life (46, 47). This distinction is ethically and legally important (9).

Some argue that withdrawing treatment on the basis of patient wishes—an omission, such as forgoing a mechanical ventilator in a patient with respiratory failure—and prescribing a lethal dose of medicine for the patient's use—a commission—are equivalent, because

they both are acts that lead to the patient's death. However, commission (doing something) versus omission (not doing something) is not alone determinative. Withdrawing ventilator support is an act, but the act merely removes an intervention that prevented a preexisting illness from running its course. The aim of the act is not to terminate the patient's life (47). Intent and causation are critical factors in distinguishing physician-assisted suicide from withdrawal of life-sustaining treatment.

Death may be accelerated if a patient requests withdrawal of a life-sustaining treatment and that request is carried out. However, the patient could have refused the treatment when it was originally offered; therefore, he or she may request its withdrawal after it is started. If not for the intervention to which the patient consented, death would have occurred as a result of the underlying disease. As the International Association for Hospice and Palliative Care, citing the European Association for Palliative Care, stated, "Withholding or withdrawing ineffective, futile, burdensome, and unnecessary life-prolonging procedures or treatments does not constitute euthanasia or PAS [physician-assisted suicide] because it is not intended to hasten death, but rather indicate the acceptance of death as a natural consequence of the underlying disease progression" (48).

The intent of treatment refusal is freedom from an unwanted intervention. A natural death follows due to the underlying disease (in fact, imposing unwanted treatment is a bodily invasion and is considered unethical and an illegal battery). In contrast, if a person disconnects a ventilator without patient consent and the patient subsequently dies, that person has acted wrongly. In both instances, the patient dies after withdrawal of life-sustaining treatment, but in very different ways under ethics and the law. Death by medication overdose is not a natural death due to an underlying medical condition.

Research advances have introduced new life-sustaining technologies into clinical practice. For example, many patients have life-sustaining devices, such as pacemakers, implantable cardioverter-defibrillators, and ventricular assist devices. Physicians inevitably encounter patients whose underlying disease no longer is being treated effectively by the device or who have a terminal illness the device cannot treat (such as cancer). Desiring a natural death, patients or their surrogates may request withdrawal of therapies delivered by these devices. In these situations, the death that follows is due to the underlying heart disease or other comorbid conditions (49, 50). Physicians should honor these requests. However, without a firm line drawn between withdrawal of life-sustaining treatment and physician-assisted suicide, or because of confusion between the two, some physicians might consider discontinuation of these therapies as intentional killing and refuse to im-

plement such requests. Patients and families often, but not always, see the line.

Intent and causation also are critical factors in providing pain or symptom relief. Competent provision of symptom control is an ethical duty (9). Patients often fear the prospect of unrelieved pain. Some physicians withhold pain medication because of ungrounded concerns that higher doses may accelerate death through respiratory suppression or that the patient may become addicted to the medication. Appropriate pain relief, however, rarely results in either (51, 52), and patients and families need to understand this (52). Under the rule of double effect, strong ethical support exists for increasing pain medication for terminally ill patients if the intent is to relieve pain, even if it might shorten life (9, 53, 54).

The rule of double effect holds that an action undertaken with the intent of achieving a benefit is morally acceptable even if it has a harmful side effect, provided that the harmful side effect is not intended, the side effect is not the cause of the benefit, and the benefit outweighs the harm. Vigorous management of pain and symptoms, such as dyspnea and nausea, at the end of life is ethical, even if the risk for shortening life is foreseeable, if the intent is to relieve those symptoms. The beneficial effects are pain and symptom control; the rare but potential harmful effect is respiratory suppression, but it is not intended. If the intent was to cause death, or to cause death to relieve pain, it would not be permissible. Likewise, it would not be in keeping with the rule of double effect to use pain control to "treat" loneliness, depression, being tired of living, or existential suffering.

### **Law and Ethics: U.S. Supreme Court Decisions on Assisted Suicide**

Although the language of rights is sometimes invoked, there is no right to physician-assisted suicide in the United States. In fact, in landmark decisions, the U.S. Supreme Court overruled 2 lower courts that had found a constitutional right (45, 55). The lower-court rulings differed in important ways. In *Compassion in Dying v. Washington* (56), the U.S. Court of Appeals for the Ninth Circuit had held that persons have a right to choose how and when they die. As applied to the limited circumstance of the competent, terminally ill adult who wants a physician's prescription for a lethal dose of medication, the Washington State criminal statute banning physician-assisted suicide was found unconstitutional as a violation of the Due Process Clause of the 14th Amendment, which says a state may not "deprive any person of life, liberty, or property without due process of law."

In contrast, in *Quill v. Vacco* (43), the U.S. Court of Appeals for the Second Circuit specifically declined to "identify a new fundamental right." It said a New York

law was unconstitutional on much narrower grounds, as a violation of the Equal Protection Clause of the 14th Amendment, because competent patients at the end of life were being treated differently: Some patients could refuse life-sustaining treatment and thereby accelerate death, but others were prohibited from seeking prescriptions from physicians to hasten death. The Equal Protection Clause says that no state shall "deny to any person within its jurisdiction the equal protection of the laws."

The U.S. Supreme Court found both lower-court decisions unpersuasive. Instead, it found refusal of treatment and physician-assisted suicide to be very different. Refusal of treatment, the Court concluded, means being free of the bodily invasion of unwanted medical treatment—a right to be left alone, not a right to something. This is a "negative right"—a form of right of which Americans have many—and differs from a positive right to secure assistance to kill oneself and control the manner and timing of death. Lending support to the rule of double effect, Justice Sandra Day O'Connor pointed out in her concurring opinion that vigorous pain control for the dying is ethical and available: "... a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death." This would include what some refer to as palliative sedation or terminal sedation, although a more accurate term would be double-effect sedation.

The U.S. Supreme Court ruled that there is no constitutional right to assisted suicide and that states may prohibit it. However, the Court also left open the possibility that individual states could legalize it.

### **Slippery Slopes**

Although the ACP's fundamental concerns are based on ethical principles, research suggests that a "slippery slope" exists in jurisdictions where physician-assisted suicide and euthanasia are legal. In the Netherlands, requests are granted for patients whose "medical condition" is categorized as "tired of living." Many patients report "loneliness" and "psychological suffering" as symptoms (57). One study found that persons receiving euthanasia or physician-assisted suicide in the Netherlands for psychiatric disorders were mostly women with complex and chronic psychiatric, medical, and psychosocial histories, and disagreement about patient eligibility among physicians was not unusual (58, 59). In Oregon, referrals for psychiatric evaluations have been infrequent (60); in 2014, only 3 of 105 persons who died under the law were referred for formal psychiatric or psychological evaluation. In a study from Belgium, death by euthanasia increased from 2% in 2007 to 5% in 2013. Similarly, approvals of euthanasia

requests increased from 55% in 2007 to 77% in 2013 (61). An editorial said these trends were “worrisome” and “require that [the slippery-slope concern] be taken very seriously” (62).

A recent review found that safeguards and controls in jurisdictions where physician-assisted suicide and euthanasia are legal are not always followed (63), and concerns have been raised about underreporting (31). Subtle long-term changes in attitudes are difficult to detect. For example, although only a small number of persons have requested physician-assisted suicide in Oregon, as noted earlier, questions arise regarding whether that fact lessens these and other concerns.

Limiting physician-assisted suicide to the terminally ill is said to be a safeguard, but prognostication raises practical concerns. Laws such as Oregon's require a consultation from a second physician to confirm the diagnosis and prognosis. However, predicting how long a terminally ill patient will live or to what extent cognitive capacity will be impaired by disease or injury often is difficult. In addition, many patients do not have longstanding relationships with physicians who know them well. Furthermore, current safeguards are likely to be challenged. Restricting physician-assisted suicide to terminally ill adults with decision-making capacity raises legal concerns about arbitrary discrimination (64). Fairness, it may be argued, would require granting access to decisionally incapable and non-terminally ill persons. Also, because some patients cannot take pills, arbitrary discrimination could be asserted, unless the practice is broadened from physician-assisted suicide to euthanasia.

### **Dying Well: Moving From Medicalization to Personalization of Death**

Is a medicalized death a good death? Have we already gone too far down a path in which dying patients receive unwanted technology in the intensive care unit while their family members are regarded as “visitors”? Is the solution medicalization of death through medication overdose? Physician-assisted suicide is not a therapy. It runs counter to the goal of the patient rights movement to empower patients to experience a more natural death.

Medicalizing death does not address the needs of dying patients and their families. What is needed is care that emphasizes *caring* in the last phase of life, facilitating a natural dying process, and humanizing institutions that are used only when those settings are unavoidable. The 3 Wishes Project shows how even simple, nontechnologic approaches in the hospital intensive care unit can improve care, ease dying, enhance dignity, and give voice to patients and families while deepening the sense of vocation among clinicians (65). The 3 Wishes researchers said the project

... aimed to integrate palliative care and spiritual care into critical care practice. Eliciting and honoring wishes fostered a community of caring, promoting patient- and family-centeredness as a core component of palliative care. It encouraged the verbalization and realization of unmet spiritual needs, whether secular or faith-based. Our findings underscore the drive that we all have to search for meaning, memories, and closure in anticipation of death while helping to create preparedness, comfort, and connections during the dying process (65).

In “A Modern *Ars Moriendi*,” a physician recounts the death of her rancher father, noting the challenges they faced trying to refuse hospital treatment. Ultimately, his wishes were met by going home and changing the “focus from life-prolonging technology to life-enriching community” (66). Earlier hospice care, avoiding the intensive care unit in the last month of life, and experiencing death at home are associated with family perceptions of better care for cancer patients (67). Studies have found regional variations in end-of-life care, with “little relationship to patient preference,” but some evidence of lower-intensity care when the primary care physician is more involved in care (68). Longitudinal relationships should be valued and supported by health care systems and payers.

Home is where most patients want to die (69), and even the discontinuation of ventilators (70) or implantable cardiac devices (71) can be done compassionately and effectively at home with hospice care. This approach is more patient centered and a better use of resources when hospital care is not truly necessary. This is the control the medical profession can and should give patients and their families. Dying well requires science and an art of caring for the dying.

### **Medicine's Role in a Societal Decision**

The ACP recognizes that some patient cases will be medically and ethically challenging, that autonomy-based arguments in support of legalization of physician-assisted suicide are compelling, and that some might find physician-assisted suicide justifiable in rare circumstances. Patients have the ultimate authority over their lives, but whether physicians should assist them in carrying out suicide is another matter.

Despite changes in the legal and political landscape, the ethical arguments against legalization of physician-assisted suicide remain the most compelling. We are mindful that ethics is not merely a matter for a vote. Majority support of a practice does not make it ethical. Medical history provides several cautionary examples of laws and practices in the United States (such as racial segregation of hospital wards) that were widely endorsed but very problematic.



Furthermore, the ACP does not believe neutrality on this controversial issue is appropriate. The medical profession should not be neutral regarding matters of medical ethics (9). The ACP is not neutral on practices that affect the patient-physician relationship and trust in the profession, such as laws that restrict or mandate discussions with, or certain recommendations for, patients. According to the *American College of Physicians Ethics Manual*, physicians have a duty to come forward, to "clearly articulate the ethical principles that guide their behavior in clinical care, research, and teaching, or as citizens or collectively as members of the profession. It is crucial that a responsible physician perspective be heard as societal decisions are made" (9).

A few patients want to control the timing and manner of death; many more are fearful of what living the last phase of life with serious illness will be like. To the extent that the debate about legalizing physician-assisted suicide is a dilemma because of the failings of medicine to adequately provide comfort and good care to dying patients, medicine should do better. Legalized physician-assisted suicide medicalizes suicide (72). Physician-assisted suicide is not a private act but a social one, with effects on family, community, and society.

### **Responding to Patient Requests for Assisted Suicide**

Etymologically, to be compassionate means to "suffer with" another person; remaining with a dying patient is the essence of nonabandonment (73). When the patient's suffering is interpersonal, existential, or spiritual, care coordination is necessary, and the roles of the physician are to remain present; provide compassionate care; and enlist the support of social workers, psychologists, hospice volunteers, chaplains, and family in addressing sources of suffering that are beyond the scope of medical care.

Regardless of jurisdiction, physicians may encounter patients who request physician-assisted suicide (or express fear of suffering with death). Patient concerns and reasons for the request should be discussed thoroughly. As for all patients nearing the end of life, the physician should:

1. Be present (74), listening to the patient and keeping dialogue open, exploring the reasons for the request, trying to understand its meaning and seeking alternative solutions where possible.

2. Affirm that he or she will care for and not abandon the patient, accompanying and advising the patient through the journey of end-of-life care (studies suggest "the desire to hasten death is future focused and appears to be related to fear of distress and not coping, rather than with current levels of distress or coping ability" [75]).

3. Discuss patient goals of care and the nature of curative and comfort care, explaining a both/and approach to disease-oriented and palliative care as well as an either/or approach and asking, for example, how do you hope I can help you?

4. Facilitate advance care planning and an understanding of surrogate decision making, as desired by the patient.

5. Ensure that the patient is fully informed of the right to refuse treatments and what that entails.

6. Discontinue or do not start medications and interventions that interfere with the patient's values, goals, and preferences.

7. Assess and treat the patient's pain and other distressing physical and psychological symptoms.

8. Assess and optimize patient function through a whole-patient focus.

9. Coordinate, as desired by the patient, the efforts of other members of the health care team, and use community-based resources to address financial, emotional, and spiritual burdens on the patient and family.

10. Prepare the patient and family for what they can expect as illness progresses, addressing uncertainty together and ensuring that the patient and family have informed expectations, including, for example, an understanding that advanced illness often entails a natural loss of appetite and thirst.

11. Regularly assess the patient's status and decision-making capacity.

12. Arrange hospice care at home if that is the patient's preference, being cognizant that palliative and hospice care expertise should be used as early as is indicated. Many patients in the United States receive such care too late or not at all.

Requests for physician-assisted suicide are unlikely to persist when compassionate supportive care is provided (76, 77). However, providing this care may be challenging, especially in today's time-pressured health care environment. It requires us to reflect and act on "... the original purpose of physicians' work: to witness others' suffering and provide comfort and care ... the privilege at the heart of the medical profession" (78).

Physicians should consult with colleagues in caring for the patient and family but also seek support for themselves. According to Kearney and colleagues, "Self-care is an essential part of the therapeutic mandate" (79). Collegial support also reinforces better care of the patient and family. Describing a phone conversation with a colleague about the shared care of a patient, a physician reflects that it was, "A call whose sole but worthy purpose was to say, 'I feel powerless, and I know you do, too, so let's talk this over.'" Yet, it "... allowed two physicians to share ... and reconcile to the inevitable. All too often, we announce our triumphs but camouflage our losses, as if the death of a patient rep-

resents a personal failure. In hindsight, acknowledging the impending loss enabled appropriate palliation for the patient and timely pastoral care for her husband . . . " (80).

The need to ensure the central role of families in care; provision of consistent, high-quality care; and education, training, and support of physicians were identified as overarching themes in a series of reports on end-of-life care recently issued by the British Medical Association (81). The British Medical Association and Australian Medical Association both reaffirmed opposition to legalization of physician-assisted suicide and euthanasia in 2016.

## Conclusion

The art of medicine is arguably most needed as patients live out the last phase of life. Society's goal should be to make dying less, not more, medical. The ACP affirms a professional responsibility to improve the care of dying patients and their families.

The ACP does not support the legalization of physician-assisted suicide, the practice of which raises ethical, clinical, and other concerns. The ACP and its members, including those who might lawfully participate in the practice, should ensure that all persons can rely on high-quality care through to the end of life, with prevention or relief of suffering insofar as possible, a commitment to human dignity and the management of pain and other symptoms, and support for family. Physicians and patients must continue to search together for answers to the challenges posed by living with serious illness before death (9).

Control over the manner and timing of a person's death has not been and should not be a goal of medicine. However, through high-quality care, effective communication, compassionate support, and the right resources, physicians can help patients control many aspects of how they live out life's last chapter. Throughout patients' lives, including as they face death, medicine must strive to give patients the care, respect, and comfort they deserve.

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**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The major concern REAL Women of Canada has in regard to the three issues under discussion, is the excessive vulnerability of these groups under the assisted suicide legislation. There are no safeguards by which their lives can be protected under such legislation.

Our concern has been exacerbated by the study released in the Netherlands regarding the application of the euthanasia law there. Data from the 2015 study concerning end of life decisions has revealed that 431 terminations of life were carried out without consent. (1)

This was an increase from 310 in the previous 2010 report.

Mental illness is treatable. No one's life should be terminated for this reason. A person with mental illness is not properly able to decide on the termination of his/her life. The position paper published by the Canadian Mental Health Association (CMHA) dated August 2017 rejects assisted suicide for reasons of mental illness. It recommends instead the development of a National Suicide Strategy. We support this recommendation. (2)

A further difficulty arises in how "mentally ill" is defined. The expression "mental illness" is a broad category that includes different psychiatric disorders such as schizophrenia, bi-polar disorder, obsessive-compulsive disorder, and clinical depression, to name a few.

While these disorders are different as to their symptoms and how they are treated, they share one vital characteristic: there is a disconnect between what the person's mind says is true and what is actually true. This distortion renders the notion of consent to be untenable in case of mental illness.

Dr. Boudewijn Chabot, a psychiatrist for the elderly, researcher of self-chosen death, and an early champion of the legislation for euthanasia in the Netherlands, recently expressed his concerns about the rate at which assisted suicide is taking place in demented and chronic psychiatric patients claiming that the law is not safeguarding the rights of such individuals. (3)

A person with mental illness, who has been involuntarily hospitalized, cannot give a proper consent. His life may be imperiled when his life is balanced by health care officials according to the financial cost of maintaining that life. The Canadian Medical Association Journal (CMAJ) published the Cost analysis of medical assistance in dying in Canada, January 23 2017 (4)

Children as mature minors: Who is to determine whether a minor is "mature"? Certainly, hopefully, not the physician who would administer the lethal injection. The problem in determining the "maturity" of an adolescent, is that adolescence is a time of exceptional turbulence, experienced by individuals who have barely experienced life. This does not place them in a good position to decide on the termination of their life.

To permit a "mature" adolescent to determine the end of his/her life is to lack an understanding of the vulnerability of such young persons and their susceptibility to be influenced by others. They have not lived long enough to acquire the knowledge to weigh the credibility of the arguments for or against assisted suicide and to understand the value of their own life, not just for themselves personally, but for others as well.

Suicide is now the second leading cause of death among adolescents and young adults. It is not helpful, therefore, that the law permitting assisted suicide, which has normalized suicide as a valid alternative to the problems of life, should apply to adolescents. (5)

Advance consent: This is also a troublesome option. An individual signs an advance consent, in



anticipation of future suffering which he wishes to avoid, but which event may never occur. The advance consent renders that person vulnerable under his power of attorney who will be able to authorize death even though the incapacitated person at that point is content (satisfied) with his/her life.

It is also a concern that in the absence of a power of attorney the question arises as to who will be making the decision to end that life? In whose interest would that decision be made? Would it be that of the incapacitated person, or will it be in the interest of those caring for him?

Further, suffering is not always present in dementia and Alzheimer patients as this depends on the stages of the disease. The presence of these illnesses should not be a reason to terminate that life. The “quality of life” of an individual is difficult to evaluate by another. If a termination under an advance consent does occur, the reason for termination may be actually contrary to the wishes of that individual at that time. For these reasons, it is understandable that the Alzheimer’s Society has rejected assisted suicide under advance directive. (6)

There are other dark clouds hanging over the three issues. One is the situation that has occurred in Belgium where organ transplants can be authorized by those individuals who agree to terminate their life. Organ transplant can create intense pressure on those individuals who may be persuaded that their choice to die would be beneficial to others. It also may be a persuasive reason for the individual to make the decision to terminate a life, even if that individual is satisfied with his life but is pressured to believe that his death would contribute to others by providing his organs for them.

If MAID is extended to the three conditions being addressed, then it will be easy to further extend it for any other conditions.

Eventually, MAID will be declared a constitutional right and anyone who wishes to apply may do so, without requiring any reasons.

In summary, REAL Women of Canada is entirely opposed to extending access to assisted suicide to the mentally ill, “mature” adolescents, or by way of an extended directive.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

(1) Statistics Netherlands, Deaths by medical end-of-life decision; age, cause of death  
<http://statline.cbs.nl/Statweb/publication/?DM=SLLEN&PA=81655ENG&D1=a&D2=a&D3=a&D4=I&LA=EN&VW=T>

(2) Canadian Mental Health Association, Opposed Euthanizing Mentally Ill Patients September 7, 2017  
<http://cmha.ca/wp-content/uploads/2017/09/CMHA-Position-Paper-on-Medical-Assistance-in-Dying-FINAL.pdf>

(3) NRC Handelsblad, June 16 2017, Worrying cultural change around the self-chosen death  
<https://trudolemmens.wordpress.com/2017/06/19/the-euthanasia-genie-is-out-of-the-bottle-by-boudewijn-chabot-translation/>

(4) The Canadian Medical Association Journal (CMAJ) published the Cost analysis of medical assistance in dying in Canada, January 23, 2017

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5250515/>

(5) Canadian Mental Health Association, Suicide and Youth  
[http://toronto.cmha.ca/mental\\_health/youth-and-suicide/#.WbrSvdVSypo](http://toronto.cmha.ca/mental_health/youth-and-suicide/#.WbrSvdVSypo)

(6) Alzheimer Society of Canada, Medical Assistance in Dying Position Paper March 16, 2017  
[http://www.alzheimer.ca/~media/Files/national/Media-centre/asc\\_position\\_03152016\\_MAID\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Media-centre/asc_position_03152016_MAID_e.pdf)

## Deaths by medical end-of-life decision; age, cause of death


May 24 2017 | [more info](#)

← Change selection

		Subjects ☑	Total deaths	Without end-of-life decision			With end-of-life decision				Withholding medic.treatm.hastening death		Explicit intention of hastening death			
				Total without end-of-life decision	Sudden and unexpected death	Not sudden and unexpected death	Total with end- of-life decision	Withhold.medic.treatm.possible hastenl..	Intensifying measures, possible hasten..	Intensifying measures, partly intendin..		Total explicit intention of hastening ..	Euthanasia	Assisted suicide	Ending of life without explicit request	
Periods ↕	Cause of death ↔	Age ↕	number													
2015	Total causes of death	Total age	147 134	61 607	24 542	37 066	85 527	7 437	50 911	1 712	18 213	7 254	6 672	150	431	
		0 years	561	195	85	111	366	52	96	10	208	0	0	0	0	
		1 to 17 years	296	153	110	43	143	10	85	10	38	0	0	0	0	
		17 to 65 years	22 166	11 378	6 577	4 801	10 788	797	6 515	379	1 459	1 638	1 544	13	81	
		65 to 80 years	44 866	18 611	7 965	10 646	26 255	2 237	14 605	416	5 998	2 999	2 764	86	149	
		80 years or older	79 245	31 269	9 805	21 464	47 976	4 340	29 610	898	10 511	2 617	2 365	52	201	
	Congenital anomalies (age zero)	Total age	163	30	0	30	133	16	28	10	79	0	0	0	0	
		0 years	163	30	0	30	133	16	28	10	79	0	0	0	0	
		1 to 17 years														
		17 to 65 years														
		65 to 80 years														
		80 years or older														
	Other/unknown causes of death (age zero)	Total age	398	165	85	81	233	36	68	0	129	0	0	0	0	
		0 years	398	165	85	81	233	36	68	0	129	0	0	0	0	
		1 to 17 years														
		17 to 65 years														
		65 to 80 years														
		80 years or older														
	Malignant neoplasms (>0 years)	Total age	44 155	12 392	1 449	10 943	31 762	1 793	20 747	838	3 735	4 649	4 419	77	153	
		0 years														
		1 to 17 years	100	18	0	18	83	0	54	10	19	0	0	0	0	
		17 to 65 years	10 623	2 945	479	2 465	7 678	353	5 134	241	667	1 283	1 201	13	69	
		65 to 80 years	19 461	5 697	590	5 107	13 764	817	8 785	283	1 698	2 181	2 091	45	45	
		80 years or older	13 971	3 733	380	3 353	10 238	623	6 775	304	1 351	1 185	1 127	19	39	
	Diseases circulatory syst.excl.CVA (>0..	Total age	29 679	18 218	10 556	7 662	11 461	1 370	6 402	146	3 206	337	310	17	10	
		0 years														
		1 to 17 years	7	0	0	0	7	0	7	0	0	0	0	0	0	
		17 to 65 years	2 767	2 342	1 807	535	425	43	222	0	148	12	7	0	5	
		65 to 80 years	8 056	5 965	4 471	1 494	2 090	365	833	28	763	101	86	10	5	

	Diseases respiratory system (>0 years)	80 years or older	18 849	9 911	4 278	5 633	8 938	962	5 340	118	2 294	224	217	7	0
		Total age	12 766	5 497	2 089	3 408	7 269	471	4 266	151	1 904	477	477	0	0
		0 years													
		1 to 17 years	4	0	0	0	4	0	4	0	0	0	0	0	0
		17 to 65 years	1 453	712	499	213	742	93	364	73	181	31	31	0	0
		65 to 80 years	3 906	1 769	871	898	2 138	136	1 242	0	559	201	201	0	0
	Diseases nervous syst.incl.CVA (>0 yrs)	80 years or older	7 402	3 016	719	2 298	4 386	243	2 655	79	1 164	245	245	0	0
		Total age	17 211	6 267	1 800	4 467	10 944	1 126	5 959	120	3 053	686	580	7	99
		0 years													
		1 to 17 years	40	20	20	0	20	0	16	0	4	0	0	0	0
		17 to 65 years	1 336	521	365	156	814	146	217	0	246	205	205	0	0
		65 to 80 years	4 367	1 629	320	1 310	2 739	291	1 319	0	827	302	195	7	99
	Suicide (>0 years)	80 years or older	11 469	4 097	1 095	3 002	7 372	689	4 408	120	1 976	179	179	0	0
		Total age	1 871	1 831	1 641	190	41	4	0	0	32	5	0	5	0
		0 years													
		1 to 17 years	30	30	28	2	0	0	0	0	0	0	0	0	0
		17 to 65 years	1 482	1 457	1 300	157	25	4	0	0	21	0	0	0	0
		65 to 80 years	281	265	248	17	16	0	0	0	11	5	0	5	0
		80 years or older	78	78	65	13	0	0	0	0	0	0	0	0	0

	Other/unknown causes of death (>0 years)	80 years or older	78	78	65	13	0	0	0	0	0	0	0	0	0
		Total age	40 891	17 207	6 922	10 285	23 685	2 621	13 441	448	6 075	1 100	886	45	170
		0 years													
		1 to 17 years	114	85	62	23	29	10	4	0	15	0	0	0	0
		17 to 65 years	4 506	3 401	2 126	1 275	1 105	159	578	65	196	107	99	0	7
		65 to 80 years	8 794	3 286	1 466	1 820	5 507	629	2 425	105	2 139	209	190	19	0
		80 years or older	27 477	10 435	3 269	7 166	17 042	1 823	10 433	277	3 725	784	596	26	162



# Canadian Mental Health Association's Position Paper on **Medical Assistance in Dying (MAiD)**

AUGUST 2017



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# The Canadian Context - Overview of Bill C-14

On April 14, 2016, Bill C-14 (the Bill) received first reading in the House of Commons of Canada and was formally passed into law on May 30, 2016. The Bill primarily sets out to decriminalize medical assistance in dying (MAiD) by amending portions of the Criminal Code that otherwise prohibit it. Additionally, it addresses eligibility and procedural elements of MAiD. The Bill follows the Supreme Court of Canada 2015 decision in *Canada v. Carter*, which legalized MAiD in Canada by striking down the Criminal Code provisions associated with the act.

Beyond providing detailed eligibility criteria, the Bill is most notable for its definition of ‘grievous and irremediable’ medical condition that includes a “reasonably foreseeable natural death”. The Bill aims to maintain the Criminal Code’s prohibition of assisted suicide, while creating an exemption for MAiD so as to protect medical practitioners. The counselling or assistance of suicide remains against the law in any circumstance outside of MAiD. Importantly, criminal sanctions are outlined for medical or nurse practitioners that do not comply with the procedural requirements set out in the Bill, acting as a key safeguard for ensuring the responsible implementation of this legislation. The Bill will amend the *Criminal Code of Canada*, the *Pension Act*, the *Corrections and Conditional Release Act*, and the *Canadian Forces Members and Veterans Re-establishment and Compensation Act*.

Bill C-14 does not, however, explicitly include mental illnesses in the eligibility criteria. The Bill provides a narrow definition of a ‘grievous and irremediable’ medical condition:

(s.241)

## Grievous and irremediable medical condition

A person has a grievous and irremediable medical condition if

- A. they have a serious and incurable illness, disease or disability;
- B. they are in an advanced state of irreversible decline in capability;
- C. that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- D. their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The first criterion uses the word ‘incurable’, which could easily exclude most mental illnesses based on the availability of treatment and recovery-based philosophies of mental health agencies such as CMHA. Subsection (b) requires a ‘state of irreversible decline in capacity’, which would also likely exclude mental illnesses, as they often fluctuate in symptoms and are remediable with appropriate treatment. Finally, Subsection (d) requires that a natural death be reasonably foreseeable, subsequently setting a very high threshold that will not likely be met solely on the basis of a mental illness.

In legalizing physician-assisted dying in the *Carter* decision, the Supreme Court indicated that its intention was to address a very small number of eligible patients. The Supreme Court found that there was no evidence to show that physician-assisted dying had negatively impacted vulnerable populations in other jurisdictions where it is legal, nor was there an increased risk of people with disabilities wanting to access it. The ruling allows for competent adults living with a “grievous and irremediable medical condition that causes enduring and intolerable suffering” to end their

life with the assistance of a physician. The Supreme Court did not, however, define “grievous and irremediable,” raising the questions of whether or not mental illnesses and addictions can be defined that way and what the implications of doing so would be in this context.

End-of-life care is a relevant issue to all Canadians, meaning that the regulation of this new law must adequately address the needs and well being of a diverse and complex population. The questions surrounding mental health are complex ones, requiring careful navigation in order to properly address people living with mental health conditions. While there may be some question as to whether mental illnesses can be included in the term “grievous and irremediable medical condition,” it is our position that the Supreme Court of Canada specifically distinguished their ruling from the laws of other countries such as Belgium which includes “euthanasia for minors or persons with psychiatric disorders or minor medical conditions” (para. 111 of Carter). This very important distinction attempts to distance Canada’s legal framework on this issue from other nations that have raised controversy due to their broad policies and administration of the practice. Upon comparison of other jurisdictions that allow for psychiatric- Euthanasia/Assisted Suicide, CMHA’s position that mental illness not be included in this definition becomes clear.

## Other Jurisdictions – A Case Review of the Netherlands and Belgium

As Canada continues to debate the particularities of the legalization of MAiD, it is important to look towards our international neighbours who have forged the way before us. Beyond Canada, euthanasia or assisted suicide (EAS)<sup>1</sup> is now legal in some form in Belgium, the Netherlands, Switzerland, Luxembourg, and several American states.<sup>1</sup> In regards to this report, however, it is essential to analyze the countries that have legalized EAS for non-terminally ill patients suffering *solely* from mental illnesses. Here, we will assess this practice in the Netherlands and Belgium, focusing on data from two specific studies that analyzed cases of psychiatric EAS within their respective countries.

The Netherlands (NL) and Belgium (BE) have constructed a set of “due care” criteria that must be met for EAS to be legally performed. The most striking difference between their standards and the Canadian law is that death need not be foreseeable to perform EAS in the Dutch and Belgian cases, hence why psychiatric- EAS may be performed. Tinne Smets et al. have organized the Dutch and Belgian substantive and procedural requirements as follows:<sup>2</sup>

- The patient’s request must be voluntary and well considered; it must be repeated, and may not be the result of any external pressure (BE/NL).
- The patient must be in a medically futile state of constant and unbearable physical or psychological suffering, which cannot be alleviated, resulting from a serious and incurable condition caused by illness or accident (BE).
- The patient’s suffering must be lasting and unbearable (NL).
- The physician must inform the patient about his/ her health condition and prospects (BE/ NL).
- The physician must terminate life in a medically and technically appropriate way (NL).

<sup>1</sup> Note: EAS is the term used interchangeably in the Belgium and the Netherlands context, while in Canada MAiD is used; however, both terms are referencing physician-assisted death.

- The treating physician must consult another physician before proceeding (BE/ NL).
- The physician must notify the case of euthanasia for review (BE/ NL).

Beyond these official, legislative similarities, it is important to highlight the social, normative similarities as well. In both countries, psychiatric-EAS appears to be on the rise—Since 2006 it has increased by an average of 15% a year, nearly three times the 2002 figure [meaning] that today about one in 25 deaths in the Netherlands is the result of psychiatric-EAS.<sup>8</sup> Similarly, a Belgian statistic claims that, since 2002, the number of EAS reported deaths has increased each year, “rising from 742 in 2004/2005 to 2086 in 2010/2011,” although it should be noted that this may also reflect better reporting.<sup>9</sup> The social normalization of this practice is alarming upon realization of the systemic flaws highlighted by the Belgian and Dutch studies that analyzed psychiatric EAS cases in both countries.

Through a comparison of the two studies conducted by Lieve Thienpont et al. (2015) in Belgium and Scott Kim et al. in the Netherlands, some issues with EAS reporting become clear. The Belgium study analyzed 100 cases of EAS requests, procedures and outcomes between 2007 and 2011, while the Dutch study compared 66 cases of *completed* EAS cases between 2011-2014. While the Dutch study is null here as all procedures were completed, the Belgian study highlights important findings in psychiatric EAS—mentally ill patients have a high likelihood of *changing their minds*. Out of the 48 patients who were approved for EAS, 11 (excluding 1 patient who postponed due to imprisonment) either postponed or cancelled their procedures.<sup>10</sup> Additionally, of the 52 patients who were not accepted, 38 withdrew their requests before a decision was made.<sup>11</sup> Therefore, 48% of patients (38 withdrew + 10 who postponed) in this study changed their minds. This is a concerning statistic as it reveals the high likelihood that, with more time and support, a patient requesting psychiatric EAS may retract their decisions. Follow up data collected a year later further supports this claim: Of the 57 patients who were still alive (35 died by EAS, 6 by suicide, 2 by other health issues), only 9 patients still had EAS requests being processed.<sup>12</sup> Meanwhile, in the remaining 48 patients, “their requests were on hold because they were managing with regular, occasional or no therapy”.<sup>13</sup> These patients who were successfully coping and functioning, just one year later, may have otherwise already died due to the practice of psychiatric EAS. Most patients suffering with depression or other psychiatric disorders may struggle to find coping techniques for long periods of their lives; however, our position is that death need not be the solution. This study suggests evidence of this, highlighting that psychiatric EAS requests may be part of the natural symptoms of many mental illnesses, particularly depression. In fact, “depression is more influential on the desire to hasten death than physical pain”.<sup>14</sup> And, where a desire to die is often part of a patient’s disorder, “the competence of [a] decision and the intractability of their suffering are much more difficult to assess”.<sup>15</sup> It is difficult to justify supporting a “wish to die” if that wish is a known symptom of a patient’s mental illness and if said symptoms are treatable.

CMHA also notes the changing social norms in Belgium and the Netherlands surrounding this issue. The increases in requests of psychiatric-EAS may be attributed to “continuing attitudinal and cultural shifts; values of autonomy and self-determination have become more prominent, and acceptance of euthanasia continues to increase in the population at large”.<sup>16</sup> After the Dutch data revealed that 20% of patients had never had psychiatric hospitalization, that there was a high ratio of women to men (2.3 to 1), and that social isolation and or loneliness was a key observation in 56% of the reports,<sup>17</sup> a red flag was raised: psychiatric-EAS may intersect with larger social issues. We must be careful to avoid the use of psychiatric-EAS as a “substitute for effective psychosocial intervention and support”.<sup>18</sup> However, while psychiatric-EAS may be on the rise, it still remains an unfavourable option to the majority of the population. A Dutch survey (2012) revealed that a minority of healthcare professionals (35-36%) and the general public (28%) agreed with providing EAS to patients with chronic depression.<sup>19</sup>



Upon analysis, it is clear that the existing state policies on psychiatric-EAS in Belgium and the Netherlands allow for substantial gaps in their standards and compliance mechanisms. The Dutch and Belgian data validates CMHA's position that psychiatric-EAS does not have a place in the current Canadian context.



## Canadian Mental Health Association (CMHA) – Our Vision, Mission and Values

Founded in 1918, the Canadian Mental Health Association (CMHA) is the most established, most extensive community mental health organization in Canada. Through a presence in hundreds of neighbourhoods across every province, CMHA provides advocacy and resources that help to prevent mental health problems and illnesses, support recovery and resilience, and enable all Canadians to flourish and thrive.

Visit the CMHA website at [www.cmha.ca](http://www.cmha.ca).

# Mental Health and Recovery

Mental health affects us all and mental health conditions may occur across the life span, regardless of gender, race, sexual orientation or other social factors. For numerous reasons CMHA believes that psychiatric-MAiD should remain illegal, the most important of which is the core belief that any such mental health condition is treatable, recovery is always possible, and that in order to be inclusive, a society must support people with mental illnesses and addictions.

## i. Belief in Recovery

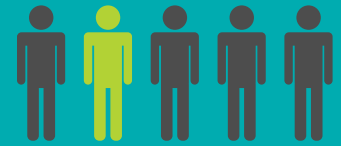
Recovery is the process by which people with lived experience of mental health and addictions issues gain control, meaning and purpose in their lives. Recovery is a unique, personal experience, involving different paths for different people. For some, recovery may mean the complete absence of the symptoms of a mental illness while, for others, recovery entails developing effective coping strategies for ongoing symptoms in an effort to maintain an active, full life within the community.<sup>23</sup>

Many mental health and addictions services and supports now promote recovery-oriented philosophies in their practices. Growing evidence shows that people can and do improve and recover from mental illness and addictions, effectively renouncing the outdated medical assumptions that mental illnesses only worsen over time. Now, new and more effective medical, social and community services and supports have been developed and implemented with the goal of recovery at the forefront.

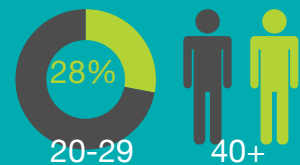
Recovery involves changes in the way individuals with mental health and addictions conditions think, act and feel about themselves and their lives. It also requires changes in the ways services are funded and organized, mental health professionals are trained, and success is measured. Recovery is about transforming the mental health and addictions system so that it truly puts the person at the centre.

## ii. Loss of Hope

It is important to discuss the potentially negative impact of a psychiatrist's or medical practitioner's approval of MAiD for their patient. Presenting MAiD as a viable option may "reinforce loss of hope and demoralization"<sup>24</sup> in struggling patients. It is argued that, "by answering a death request of a psychiatric patient positively, a central therapeutic element in the doctor-patient relationship, namely the instrument of hope, is removed".<sup>25</sup> Also related is the argument that these discussions "about the possibility of (assisted suicide) between doctor and patient may reinforce feelings of desperation and demoralization in the patient". The doctor-patient relationship is of key importance as patients often look to their doctors for answers. If the doctor—the patient's advisor and power figure—agrees or supports the



One in five Canadians experiences a mental health issue in any given year.<sup>20</sup> Currently, more than 6.7 million people are living with a mental health condition in Canada.<sup>21</sup>



More than 28% of people aged 20-29 experience a mental illness in a given year, and by the time people reach 40 years of age, 1 in 2 people in Canada will have had or have a mental illness.<sup>22</sup>

wish to die for reasons of mental illness, it is an indirect admission that the patient will never recover and that they cannot recover from their mental health condition. As CMHA firmly believes in recovery and the treatment of mental illnesses and addictions provided the proper supports and resources, this “loss of hope” is considered very detrimental.

### iii. Non-discrimination

CMHA supports that non-discrimination between mental illness and physical illness be upheld. If a patient with a reasonably foreseeable natural death *a/so* has a mental illness, that mental illness should not preclude them from being able to access MAiD. Whether or not the patient was afflicted by a mental illness before or after the physical illness, in an effort to prevent discriminatory practises in public health, the physical illness must take precedence if it meets the eligibility criteria as put forth by bill C-14.

## Our Position

As a recovery-oriented organization, CMHA does not believe that mental illnesses are irremediable, though they may be grievous or unbearable.

We recognize that people with mental illnesses can experience unbearable psychological suffering as a result of their illness, but there is always the hope of recovery.

CMHA’s position on medical assistance in dying in Canada, is that people with a mental health problem or illness should be assisted to live and thrive.

# Recommendations

As a recovery-oriented organization, CMHA makes the following recommendations to the Government of Canada:

## 1. Support Recovery

CMHA believes that every person living with mental health and addictions issues must be actively supported in their journey of recovery. With the right supports and resources, research suggests that recovery is possible regardless of the mental health diagnosis.<sup>26</sup> Recovery-oriented practice, or one that places the patient at the centre of care, is essential for a high performing mental health and addictions system in Canada.

## 2. Continue to invest in community mental health and addictions services and supports

We need governments to ensure there is access to a full continuum of mental health services and supports for all Canadians, in all communities across Canada. Although there have been significant new investments in mental health and addictions, Canada still lags behind all of the other G7 countries. Before we assist people in dying, we should assist people to live and thrive – this starts with making sure that all Canadians have equitable access to mental health and addiction services. The overall well-being and resilience of Canadians with lived experience of mental health issues will improve if their basic needs for income security, affordable and safe housing options, and opportunities to secure supported employment are met; and if a range of community-based, traditional and/or alternative mental health and addictions services and supports are available to them.

### Equity

- » It is well established that some groups (or populations) in society experience social and economic disadvantage – inequities – due to the unequal distribution of power, wealth and resources. The social determinants of health both determine and deepen inequities.
- » Marginalized groups are more likely to experience poor mental health and in some cases, mental health conditions. In addition, marginalized groups have decreased access to the social determinants of health that are essential for recovery and positive mental health.
- » Our marginalized communities are at a greater disadvantage in terms of access to care compared to non-marginalized groups. The principles of equitable provision must inform our mental health and addictions system.

## 3. Develop a national suicide prevention strategy

Though Canada has a national mental health strategy, *Changing Directions, Changing Lives: the Mental Health Strategy for Canada*<sup>27</sup>, we currently lack a comprehensive suicide prevention strategy. A national strategy for suicide prevention is necessary to coordinate the existing suicide prevention efforts currently underway in provinces and territories across Canada, and to bring evidence-informed practices for suicide prevention to every community in our country. CMHA recommends that a national suicide prevention strategy be developed to promote mental health recovery for all Canadians.

#### **4. Invest in research to accurately predict and understand the course of illness in mental health and substance use**

Our understanding of mental health and addictions issues and our implementation of practises/solutions, are quite underwhelming. There is a shortcoming here that needs to be addressed and we encourage investment in research to better understand these issues.

*Approved by the Canadian Mental Health Association National Board of Directors, August 2017*



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## End Notes

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2017



## Worrying cultural change around the self-chosen death

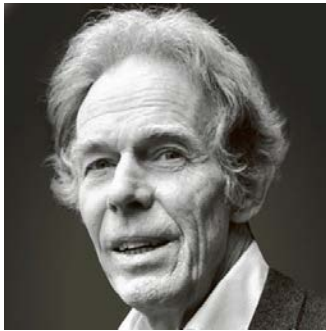
Message for the format table. The Euthanasia Law does not provide protection to people with dementia and psychiatric problems, says *Boudewijn Chabot*. "Noiselessly, the foundation of the law is eradicated."

June 16, 2017

<https://www.nrc.nl/nieuws/2017/06/16/de-euthanasiegeest-is-uit-de-fles-11123806-a1563406>

NRC Handelsblad June 16 2017

About twenty years ago I was in the courtroom at the Supreme Court. I had given a fatal drink to a fifty-year-old, physically healthy social worker ten years before the Euthanasia Act. The judgment: 'guilty without punishment'. I struggled - and struggle - for self-determination. However, I am now worried about the rate at which euthanasia is taking place in demented and chronic psychiatric patients.



**Boudewijn Chabot** is a psychiatrist for the elderly and researcher of the chosen life end.

Recently, the third evaluation of the Euthanasia Act, which came into force in 2002, appeared. And like the previous times, the tone was positive. "The goals of the law have been realized. All actors are content about the content and functioning of the law. "That sounds good, but it is not. Because behind this satisfaction, problems that the researchers do not nominate.

To understand what has gone wrong, the reader must know the three most important cautionary requirements in the law. There must be a voluntary and deliberate request; 2. unbearable and futile suffering; 3. There is no other reasonable solution than euthanasia.

The second and third requirements are closely linked to each other because if another solution, such as specialist palliative care, indicates, suffering is not clear. If the patient refuses that option, the physician will not be convinced of an "unbearable" suffering and will not provide euthanasia.

At least as important is what is *not* in the law. There is no physical disease and the doctor need not have a treatment relationship with the patient. Many doctors and citizens thought this was the case. But such constraints are deliberately omitted to leave room for the development of concepts such as 'unbearable and futile suffering'.

In the last ten years, the number of reports of euthanasia increased from two thousand to six thousand per year. Citizens ask more often, doctors are willing to do so and consultants who help the doctors give more green light. The review committee found in only 6 of the 6,091 (0.16 percent) cases in 2016.

All of this indicates a culture cover around the self-chosen death under the wings of the doctor. Apparently doctors give ear to the increasing demand for euthanasia in all kinds of nasty diseases, especially in cancer. This increase in itself does not disturb me - even if the number of tens of thousands passes over a few years.

What worries me is the increase in the number of times euthanasia was given to dementia, from 12 in 2009 to 141 in 2016, and to chronic psychiatric patients, from 0 to 60. That number is small, you will say. But note the rapid increase of brain diseases such as dementia and chronic psychiatric diseases. More than one hundred thousand patients suffer and their disease almost never cures. In these groups, the financial expense of the care has affected the quality of life. You can stumble across the fact that all this causes the number of euthanasia cases to rise.

Strikingly, doctors of the Levenseinde Clinic Foundation do euthanasia in these patients, while basically they never treat patients for their illness. By 2015, a quarter of euthanasia was awarded by these doctors, in 2016 it was raised to one third. By 2015, doctors of the Levensindeck clinic performed 60 percent of euthanasia in chronic psychiatric patients, in 2016 it increased to 75 percent (46 out of 60 people).

Nevertheless, there is some realization that something went wrong, because the review committee has recently been strengthened with a few specialists in the field of parental medicine and psychiatry. However, their vote will be lost in the choir of the forty five commissioners who have made the current 'jurisprudence'.

These figures can not be found in the annual report of the commission or in the researchers' tables. The fact that a total of sixty times euthanasia has been granted to psychiatric patients in 2016 is reflected in the annual report of the review committee. But it does not say that this request has been awarded 46 times by a physician at the Levenseinde Clinic. That number should be found in the annual report of the Levenseinde Clinic. Is this fog coincidental?

#### Cornerstone of the law

Is there a further brake on this development? Not by the review committee - which can not be returned to her 'case law'. Already in 2012, at the second law assessment, it became apparent that there is never a discussion within the review committee about whether or not the requirement of futile and unbearable suffering has been met. The committee members found this difficult to judge, as was already apparent from the previous bill: "If the notifying physician and the consultant found the suffering to be unbearable, who are we here to talk about?"

The interpretation of this cornerstone of the law already reflected what a doctor and consultant accept as unbearable and futile suffering.

This also shows from the reviews. In 2016, the committee only ruled in 1 of the 201 cases of euthanasia in dementia and psychiatry that the judgment was inconvenient because the requirement of "unbearable suffering" was not met. What problem does the test solve, which costs about four million euros annually? The researchers do not answer this question.

Ever moving to a nursing home or treatment with another medicine was a "reasonable alternative" for euthanasia. At least it had to be tried. Many doctors now accept that a patient can refuse a reasonable alternative without endangering euthanasia. This brake has also disappeared.

In the Chabot judgment, the Supreme Council had still made "exceptional great caution" in psychiatric patients a prerequisite. Those words are worn out, because now a reasonable alternative to death can be refused and the euthanasia of the commission still gets the stamp carefully. This has been the case for many years, as also in the previous law evaluation, the majority of the review committee did not find that doctors easily accept that patients refuse a reasonable other solution.

*Within the Levenseinde Clinic, a group culture has emerged in which euthanasia is considered to be beneficial work*

Ethicus Govert den Hartogh, who has been in the review committee for many years, has identified this crazy process of endurance: "The patient suffers unbearably when he says he is unbearable and an

alternative is not a reasonable alternative if the patient rejects it. In fact, those requirements add little more to the demand of a voluntary and thoughtful request. "

The erosion of beautiful words reminds us of the abortion law. In order to get abortion, the woman had to be in an "emergency" state. Soon every woman knew that she got what she wanted if she waited early and any other abortion solution. The Dutch legislature has been more creative in the field of moral ground, with big words that, after some time, lost their stakes. Consider the "sustainable disruption" that was required for divorce.

Doing that legal term does not have to be a problem. Sometimes this leads to an amendment of the law, such as with sustained disruption. Sometimes we also accept that the core concept in the law has been eradicated in favor of self-determination, such as in abortion. The problem is, however, that the euthanasia's euthanasia committee in its annual reports continues to speak of "unbearable and futile suffering," as if those words still really add great weight.

However, the researchers are seeing the increasing importance of self-determination, but not the utter meaning of the two other legal requirements. Noiselessly, the foundation of the law is eradicated.

The doctors who work in the Levenseinde clinic are considered a "forefront" and call the clinic an 'expertise center'. Unfortunately, there is little expertise in palliative treatments for the simple reason that a patient rejects treatment that is accepted as an expression of self-determination.

By 2016, about 40 physicians who worked part-time at the Levenseinde Clinic performed 498 times euthanasia. On average, this amounts to 12 times euthanasia per doctor, each month one. Within the clinic, a group culture has emerged in which euthanasia is considered to be beneficial, especially in severe dementia and chronic psychiatric patients. The fact that the Levenseindekliniek also rejects many requests does not matter. The clinic also reports many people who do not even qualify for euthanasia.

[What happens to doctors for whom a deadly injection becomes monthly routine?](#)

[TWEET](#)

What happens to doctors for whom a deadly injection becomes monthly routine? They are not missing out on good intentions, but do they realize that they blow a fire that could be a fire by waking up the deaths of vulnerable people who are still trying to live with their disabilities?

The Levenseindekliniek now employs active psychiatrists. She justifies this by pointing to the long waiting list. Their task: lifting outrageous and unbearable suffering from psychiatric patients by giving euthanasia. Every time the clinic comes into the news, a wave of 'treated' depressed patients is reported to rarely treated well. Because chronic psychiatry has become a diagnostic recipe company through cuts, good treatment is scarce.

The newly recruited psychiatrists need no treatment relationship with the patient. That has accepted the review committee in case of serious physical illnesses. Now she has also applied this to non-cure brain diseases - without discussing it with the psychiatric professional group.

*Since chronic psychiatry has become a diagnostic recipe company through cuts, good treatment is scarce*

That has been a hasty step. Without a treatment relationship, most psychiatrists can not reliably determine whether a death wish is the most important, sustainable desire. Even with a treatment relationship it remains difficult. But a psychiatrist of the clinic without treatment relationship can do that in less than ten 'in-depth' conversations? Well ...

In dementia there is another bottleneck. The Euthanasia Act has added that a written declaration of wisdom can replace the oral request, while the other diligence requirements remain consistent.

According to Ethics Den Hartogh, this means that in case of a malicious demented patient, two of the three legal requirements expire - try to demand a well-considered request and the requirement of reasonable alternatives - because they are not applicable.

Remaining the requirement that there should be unbearable and futile suffering. But unbearable suffering is often difficult in advanced dementia, as five professors of senior medicine recently said in *NRC*. The personal discoloration of 'suffering' in dementia plays a major role.

Also read the line of opinion that she wrote at the time: [No, do not secretly commit euthanasia](#) .

However, that uncertainty for the review committee does not appear to be a problem. If a physician and a specialist prescribe parenting medicine that a person with dementia suffers unbearably, the commission once asks a question, but does not make it difficult.

Due to the erosion of "unbearable suffering" and the equality of written wisdom with an oral request, the door for euthanasia has been widely opened in severe dementia.

Then, in serious dementia, there is one more formidable obstacle: how do you kill someone who does not work because he has no realization of what will happen? Already in 2012, *NRC* described how it went into its work. A spouse carried a drowsiness to his demented woman in the porridge before the GP came with the deadly syringe. At the time, the review committee did not mention anything about this assistance. Even in later cases of euthanasia with advanced dementia, she mentioned the precise execution.

In 2016 three cases of euthanasia were reported in deep-demented individuals who could not confirm their death wish. One of the three has been assessed by the commission as being inadequate; Her wisdom was acceptable for different interpretations. Also the execution was careless; The doctor had first done a sleeping in the coffee. When the patient was on bed and was given a high dose, she got up with fright and had to be held by family. The doctor stated that she had been consciously gone.

For example, a doctor can kill someone secretly because after sleep you can not resist. If necessary, physical coercion is used. A large group of doctors called that "secretly" and left in a page-sized ad, including in *NRC*, society knowing this will not.

Also read the pamphlet of the 220 doctors: [Doctors: Dementists can get too easy euthanasia](#) .

History repeats itself

In the third assessment of the law, the remarkable use of a deadly drug in deep dementia is this remarkable sentence: "In these cases, this can be inherent in the nature of the situation and has not been previously identified."

Immediate administration of medication has previously occurred, but was never mentioned in an annual report. That's strange because the commission of doctors queries relatively frequently about the medications administered and rejects the rejection of the euthanasia directive relatively often as incorrectly. In a deeply demented person, it is morally problematic: how do you kill someone who does not understand that he will be killed? Concern about the exact implementation seems to be far from the transparency expected by the doctors' committee.

Investigators condemn this as being "inherent in the nature of the situation". When it comes to killing a defenseless human being, everything that is "inherent in the situation" should be completely clear in the judgment and the annual report. The review committee lacks transparency for five years now. And the researchers iron this fold smoothly.

Should the Public Prosecutor's Office lean back after fifteen years now, take his responsibility and submit the case to the court? When the review committee earlier assessed euthanasia on all three legal requirements, the OM did not follow.

In case of serious dementia, the following legal questions can only be answered by the Supreme Court: May people be killed secretly? Is not that a form of compulsion because possible resistance is eliminated here? Precisely in the euthanasia of a defenseless man, any shame of coercion must be avoided.

The OM can set up a cassation in the interests of the woman who was still scared. Then it submits the matter directly to the Supreme Court. I think it's likely that it will lean back. In that case, specialists in veterinary medicine who are very interested in clarity about this legal question may appeal to the court of law against the decision not to prosecute.

History repeats itself by legislation of moral hot hanging guns. Self-determination around the end of life is as important to many citizens as for abortion. It is therefore not surprising that the first diligence requirement, a voluntary and considered request, has gained importance. And that this requirement has pushed the other two diligence requirements to the margin. What is astonishing is that the smoke curtain continues to grow around 'unbearable and futile suffering' in the third law assessment by the researchers.

Where did the Euthanasia Law go wrong? The euthanasia practice goes hand in hand because the legal requirements that physicians with physically ill citizens can reasonably get out of control can be applied without limitation to vulnerable patients with incurable brain diseases. In psychiatry, an essential limitation disappeared when no treatment relationship was found for euthanasia. In case of dementia, such a restriction disappeared by making the written declaration of wisdom equal to a current oral request. And finally, it was a good thing when the review committee found that wilson-conquered people were secretly killed.

I do not see how to get the mind back in the bottle. It would be a lot if we acknowledge he's out of it.

# Cost analysis of medical assistance in dying in Canada

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## ABSTRACT

**BACKGROUND:** The legalization of medical assistance in dying will affect health care spending in Canada. Our aim was to determine the potential costs and savings associated with the implementation of medical assistance in dying.

**METHODS:** Using published data from the Netherlands and Belgium, where medically assisted death is legal, we estimated that medical assistance in dying will account for 1%–4% of all deaths; 80% of patients will have cancer; 50% of patients will be aged 60–80 years; 55% will be men; 60% of patients will have their lives shortened by 1 month; and 40% of patients will have

their lives shortened by 1 week. We combined current mortality data for the Canadian population with recent end-of-life cost data to calculate a predicted range of savings associated with the implementation of medical assistance in dying. We also estimated the direct costs associated with offering medically assisted death, including physician consultations and drug costs.

**RESULTS:** Medical assistance in dying could reduce annual health care spending across Canada by between \$34.7 million and \$138.8 million, exceeding the \$1.5–\$14.8 million in direct costs associated with its implementation. In sensitiv-

ity analyses, we noted that even if the potential savings are overestimated and costs underestimated, the implementation of medical assistance in dying will likely remain at least cost neutral.

**INTERPRETATION:** Providing medical assistance in dying in Canada should not result in any excess financial burden to the health care system, and could result in substantial savings. Additional data on patients who choose medical assistance in dying in Canada should be collected to enable more precise estimates of the impact of medically assisted death on health care spending and to enable further economic evaluation.

The Criminal Code of Canada's prohibitions on medical assistance in dying have been lifted.<sup>1</sup> The logistics of offering medical assistance in dying to Canadians need to be formalized, and the consequences of this practice need to be anticipated. As with any new medical intervention, understanding the clinical and costing implications of medical assistance in dying is important.

Health care costs increase substantially among patients nearing the end of life, accounting for a disproportionate amount of health care spending. For example, in Manitoba, more than 20% of health care costs are attributable to patients within the 6 months before dying, despite their representing only 1% of the population.<sup>2</sup> Furthermore, as death approaches, health care costs increase dramatically in the final months.<sup>3,4</sup> Patients who choose medical assistance in dying may forego this resource-intensive period.

In a 1998 special article in *The New England Journal of Medicine*, Emanuel and Battin predicted that legalizing medical assistance in dying in the United States would save hundreds of millions of health care dollars per year;<sup>5</sup> a similar model can be applied to Canada. Here, we combine data on the use of medical assistance in dying from countries where it is legal with Canadian-specific end-

of-life cost data to estimate the effect of this intervention on health care costs in Canada.

## Methods

Emanuel and Battin's model relies on 3 main factors to estimate cost savings from medical assistance in dying: the number of patients expected to choose the intervention; the effect of the intervention on life expectancy; and the total health care costs associated with end-of-life care.<sup>5</sup> We updated their model to include more recent and detailed demographic estimates of the patients who may choose medical assistance in dying, including age, sex and underlying diagnosis, in addition to Canadian-specific cost data.

## Proportion of deaths due to medical assistance in dying and patient demographics

Between 1990 and 2012, medical assistance in dying accounted for an estimated 1.8%–3.3% of total deaths in the Netherlands, with a trend for an increase in rates over the last 25 years.<sup>6,7</sup> In Belgium, medical assistance in dying has accounted for between

0.3% and 4.6% of all deaths, with the highest rates documented in the most recent 2013 survey.<sup>8,9</sup> Based on these numbers, we estimated that medical assistance in dying will eventually play a role in 1%–4% of all deaths in Canada.

Several individual studies, in addition to a recent systematic review, have shown that medical assistance in dying is most commonly chosen by men, by patients in their 7th and 8th decade of life and by patients with cancer.<sup>6,10,11</sup> Based on these previous data, we assumed that 55% of patients choosing the intervention will be male, that 50% of patients will be aged 60–79 years, 30% will be aged 18–59 years and 20% will be 80 years and older, and that 80% of patients will have cancer.

### Impact on life expectancy

A 2010 physician survey from the Netherlands estimated that 40% of cases of medical assistance in dying were associated with a reduction in life expectancy of less than 1 week, and 60% were associated with a reduction of more than 1 week (no upper time limit provided).<sup>6</sup> Thus, we predicted that about 40% of Canadians who choose medical assistance in dying will have their lives shortened by 1 week, and 60% of patients will have their lives shortened by 1 month.

### Cost of end-of-life care

With the collaboration of the authors (and after ethics approval), previously published costing data from the province of Ontario<sup>3</sup> were reanalyzed into the relevant subgroups for our model. Briefly, total health care costs for all decedents in Ontario between Apr. 1, 2010, and Mar. 31, 2013 ( $n = 264\,755$ ), were measured using administrative data. These costs were calculated at an individual patient level on a cumulative daily basis, which allowed for weekly and monthly costs preceding death to be determined. Costs included those associated with acute care (emergency department visits and hospital admissions), outpatient care (physician billing, outpatient clinics [including dialysis and cancer care], laboratory services and select drug or device expenses) and continuing care (long-term care, complex continuing care, rehabilitation and home care). Additional details are available in the original publication.<sup>3</sup>

We excluded deaths from “external causes” (accident, poisoning, assault, drowning, and complications of medical care, as defined by International Statistical Classification of Diseases and Related Health Problems, 10th revision [ICD-10], codes). Patients were considered to have cancer if they had 1 hospital admission with a discharge diagnosis or 2 outpatient visits with an ICD-10 billing code of neoplasm in their final 2 years of life. We created subgroups according to sex and age, as defined previously, and calculated the average total cost of health care use in the final month and final week of life for each subgroup.

### Estimating potential savings associated with medical assistance in dying

We assumed 268 056 total deaths annually in Canada based on Statistics Canada figures for the period July 1, 2014, to June 30, 2015.<sup>12</sup> We ran 4 iterations of our model in which medical assistance in dying accounted for 1%, 2%, 3% and 4% of total deaths.

We used the total number of cases to derive the number of patients in each subgroup using the assumptions described previously.

We then multiplied the number of cases in each subgroup by the mean total cost of either the final week or final month of life associated with that subgroup. We combined the total cost associated with each subgroup to estimate the potential cost savings in a given year associated with medical assistance in dying.

### Effect on costs with the assumption that patients selected palliative care

Our base-case model uses mean costs for all decedent subgroups, which can be interpreted as the cost associated with standard end-of-life care across a variety of scenarios and patient wishes. It is possible that patients who request medical assistance in dying would choose a less aggressive palliative care approach. Because a previous review suggested that palliative care reduces end-of-life health care costs by 40%–70% compared with standard care,<sup>13</sup> we conducted 2 additional analyses in which we reduced the cost of care preceding death by 40% and 70%.

### Additional sensitivity analyses

We conducted additional sensitivity analyses using our base-case analysis (assuming 1% of decedents select medical assistance in dying) varying our assumptions regarding sex, age group, cancer status and effect on life expectancy. The variations we modelled included 30%–70% of cases involving male patients, 50%–100% of cases involving cancer patients, equal division of cases among the 3 age groups, and plausible variations in the proportion of patients who may have their life expectancy reduced by 1 month as opposed to 1 week.

### Estimating the costs associated with implementing medical assistance in dying

There is no standardized approach to medical assistance in dying yet in Canada, and each case will have unique patient and provider elements, which makes estimating the costs associated with this service difficult. Acknowledging this, we estimated the direct costs of offering medical assistance in dying within a fee-for-service setting, understanding that there will have to be 2 independent assessments for patient eligibility,<sup>14</sup> and that medications chosen by the physician involved will be administered at a separate visit after being prepared by a pharmacy. Therefore, each case will include at least 2 physician claims for a consultation, 1 claim for a follow-up visit where the medication is administered, the cost of the drugs in addition to pharmacy preparation time and 1 claim for completion of the death certificate. To keep costs consistent and comparable with our end-of-life costing analysis, we used Ontario physician fees in our calculations.<sup>15</sup> Although there is no standard drug regimen for medical assistance in dying across Canada, we had confidential access to the drug regimens suggested in Alberta (including an anxiolytic, local anesthetic, sedative and paralytic), as well as the associated costs. Costs for these alternate regimens varied between \$25 and \$326 per case. We assumed



an additional \$30 of pharmacist time (about 30 min of time to prepare and dispense the drugs based on a mean pharmacist wage of \$60/h, including benefits<sup>16</sup>).

We created 2 base-case scenarios, a low-cost scenario in which the assessments are performed by primary care physicians and the least costly drug regimen is used, and a high-cost scenario in which the assessments are done by specialists and the most costly drug regimen is used (Table 1). In addition, there will be patients who request medical assistance in dying and incur the 2 assessment fees but do not complete the process, either being denied, retracting their request or dying from their disease. In the Netherlands, data from a single centre suggests 25% of requests for medical assistance in dying are ultimately granted,<sup>17</sup> whereas this proportion is more than 75% in Belgium.<sup>18</sup> We chose a conservative estimate that 33% of requests in Canada will be granted, meaning for every patient receiving medical assistance in dying, we added the cost of 2 additional patients who underwent assessment only.

## Results

Table 2 shows the mean health care spending in the final week and final month of life that was used to calculate potential cost savings for each subgroup. The potential cost of implementing medical assistance in dying, and the estimated savings in end-of-life care associated with the intervention, are shown in Table 3. Assuming a low-cost scenario and standard end-of-life care (i.e., base-case analysis), we expect that net health care costs would be reduced by \$33.2 million per year if 1% of deaths are due to medical assistance in dying. When end-of-life costs were reduced by 40% and 70% with the assumption that a palliative approach would have been chosen, net cost savings are reduced to \$19.3 million and \$8.9 million, respectively (Table 3). As noted within Table 3, overall health care costs are lower across all scenarios considered, even when higher drug and physician costs are assumed.

Varying the sex, cancer status and age group of the patients across plausible ranges had little effect on the projected savings, whereas varying the estimated effect on life expectancy had a larger impact on projected savings. For example, if 80% of patients have their lives shortened by 1 month (rather than 1 wk), there would be an additional \$5.7 million in health care savings, whereas if 80% of patients have their life expectancy shortened by only 1 week, the projected savings would be reduced by \$11.3 million, or more than 30%.

**Table 1: Inputs used to calculate the costs associated with implementing medical assistance in dying in Canada**

Input*	Cost, \$
<b>Low-cost scenario</b>	
Primary care physician assessment	77.20
Primary care physician follow-up visit	38.35
Medications	25.40
Pharmacist time	30.00
Completion of death certificate	20.60
Total for completed case	268.75
Total for assessed case	154.40
<b>High-cost scenario</b>	
Internal medicine specialist assessment	157.00
Internal medicine follow-up visit	61.25
Medications	326.00
Pharmacist time	30.00
Completion of death certificate	20.60
Total for completed case	751.85
Total for assessed case	314.00
*Costs based on Ontario Schedule of Benefits, <sup>15</sup> with the exception of medication costs, which are based on Alberta protocols. <sup>16</sup>	

**Table 2: Expected number of cases of medical assistance in dying and associated health care spending in the final week and month of life among men and women with and without cancer\***

Age, yr	Expected death within 1 wk				Expected death within 1 mo			
	Men		Women		Men		Women	
	No.	Mean cost, \$	No.	Mean cost, \$	No.	Mean cost, \$	No.	Mean cost, \$
<b>With cancer (n = 4289)</b>								
18–59	283	7430	232	6897	425	19 958	347	19 115
60–79	472	6880	386	6420	708	17 996	579	17 608
≥ 80	188	5725	154	4980	283	14 846	232	13 236
<b>Without cancer (n = 1072)</b>								
18–59	71	7090	58	8293	106	14 673	87	18 063
60–79	118	7144	97	7080	177	16 470	145	16 450
≥ 80	47	5264	39	4065	71	12 861	58	10 253
*Numbers were derived with the assumption that medical assistance in dying would account for 2% of total deaths in Canada (n = 268 056 from July 1, 2014, to June 30, 2015) and that 80% of patients would have cancer. The sum of numbers in each subgroup may be greater than the total because of rounding.								

## Interpretation

If Canadians adopt medical assistance in dying in a manner and extent similar to those of the Netherlands and Belgium, we can expect a reduction in health care spending in the range of tens of millions of dollars per year. Our analyses suggest that the savings will almost certainly exceed the costs associated with offering medical assistance in dying to patients across the country, and that the inclusion of medical assistance in dying in the services covered by universal health care will not increase health care spending, but rather will release funds to be reinvested elsewhere. We are not suggesting medical assistance in dying as a measure to cut costs. At an individual level, neither patients nor physicians should consider costs when making the very personal decision to request, or provide, this intervention.

## Strengths and limitations

We used comprehensive Canadian-specific cost data, provided a range of potential savings based on projected uptake of medical assistance in dying across the country, used more detailed subgroupings to create case estimates than in a previously published American model,<sup>5</sup> and performed extensive sensitivity analyses. We provided a preliminary estimate of the direct costs of medical assistance in dying in Canada, including the costs of requests that are not ultimately granted.

The main limitation of our model was using data from the Netherlands and Belgium to build our case estimates. In Canada, only competent adults aged 18 years and older whose “natural death has become reasonably foreseeable” will be eligible for medical assistance in dying,<sup>14</sup> whereas in the Netherlands and Belgium, there are provisions to allow medical assistance in dying for patients with nonterminal diseases, minors and patients with dementia.<sup>19,20</sup> Therefore, we may have overestimated the propor-

tion of total deaths due to medical assistance in dying by using statistics from countries with more liberal policies. We did, however, provide a range of estimates to account for this possibility.

Our cost data were specific to the province of Ontario, and may not represent end-of-life spending in all Canadian provinces.<sup>3</sup> However, these are the most comprehensive data available on end-of-life health care costs in Canada, including costs across a broader range of services (such as outpatient visits and diagnostic investigations) than previous reports.<sup>2,4</sup> In addition, these cost data are recent and therefore more likely to reflect current fee schedules and current standards of care at the end-of-life, including new treatments. Finally, the costs were calculated on a daily basis, allowing for the use of weekly and monthly subtotals, which were crucial to our model.

It should be noted that our estimates regarding the effect of medical assistance in dying on life expectancy were taken from a single physician survey.<sup>6</sup> Because our sensitivity analyses found this variable to have a considerable effect on our results, determining how to accurately measure and report this information for Canadian cases will be important for future cost analyses.

Our estimates of the costs associated with offering medical assistance in dying were based on a very simple model, which predominantly used Ontario-level costs for consistency. This analysis should be updated if and when unique billing codes for the consultations and delivery of medical assistance in dying are developed. We did not account for additional potential costs, such as coordination services. In Alberta, there is a medical assistance in dying coordination team with several full-time employees who respond to patient or provider inquiries and assist in liaising patients with willing providers. These are fixed costs, and do not necessarily vary with the number of cases, but could be substantial if every province adopts this approach. Administrative costs associated with creating an oversight body or reporting mechanism, as suggested by the

**Table 3: Estimated health care costs and savings associated with medical assistance in dying in Canada**

Cost and savings	% of total deaths due to medical assistance in dying (n)			
	1% (2681), \$	2% (5361), \$	3% (8042), \$	4% (10722), \$
<b>Gross savings</b>				
Base-case: mean end-of-life costs	34 706 110	69 412 219	104 118 329	138 824 438
Palliative care scenario: 40% reduction in end-of-life costs	20 823 666	41 647 331	62 470 997	83 294 662
Palliative care scenario: 70% reduction in end-of-life costs	10 411 833	20 823 666	31 235 499	41 647 331
<b>Cost of providing medical assistance in dying</b>				
Low-cost scenario	1 548 412	3 096 246	4 644 657	6 192 491
High-cost scenario	3 699 378	7 397 376	11 096 754	14 794 752
<b>Net savings</b>				
Base-case — low-cost scenario	33 157 698	66 315 974	99 473 671	132 631 947
Base-case — high-cost scenario	31 006 732	62 014 843	93 021 575	124 029 686
Palliative 40% reduction in end of life cost — low-cost scenario	19 275 254	38 551 085	57 826 340	77 102 171
Palliative 40% reduction in end of life cost — high-cost scenario	17 124 288	34 249 955	51 374 243	68 499 910
Palliative 70% reduction in end of life cost — low-cost scenario	8 863 421	17 727 420	26 590 842	35 454 840
Palliative 70% reduction in end of life cost — high-cost scenario	6 712 455	13 426 290	20 138 745	26 852 579

Canadian Medical Association,<sup>21</sup> were also not accounted for. Nevertheless, even if these costs were included, it is likely that the implementation of medical assistance in dying would be cost neutral or result in cost savings.

Finally, our analysis is only a cost analysis and it does not consider the clinical effects of medical assistance in dying on patients at the end of life. Patient-level research that explores the reasons why Canadians choose medical assistance in dying, the value they assign to their suffering versus death and other aspects of their experience will need to be done before true economic evaluation of medical assistance in dying in terms of cost-effectiveness and utility can be done.

## Conclusion

Our analysis suggests that the provision of medical assistance in dying in Canada will be cost neutral or result in a reduction in total health care costs, although the true effect on health care costs will not be certain until we determine who the typical Canadian patient requesting the intervention is and how its practice is implemented across the country. Our study highlights the need to prospectively collect certain data to accurately measure the effect of this new policy on health care spending, namely the total number of patients, in addition to demographics, underlying diagnosis and estimated effect on life expectancy.

The implementation of medical assistance in dying is a major event in Canadian history. Anticipating, measuring and responding to the broad range of effects that may result from this decision should be considered the responsibility of physicians, politicians and policy-makers alike.

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**Contributors:** Aaron Trachtenberg developed the study idea, conducted all analyses, wrote the initial draft and provided critical revisions. Braden Manns provided key inputs into the protocol, supervised analyses and provided key revisions to the study protocol. Aaron Trachtenberg and Braden Manns read and approved the final manuscript and agreed to act as guarantors of the work.

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Canadian Mental  
Health Association  
Toronto

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# Suicide and Youth

Youth are among the highest risk populations for suicide. In Canada, suicide accounts for 24 percent of all deaths among 15-24 year olds and 16 percent among 16-44 year olds. Suicide is the second leading cause of death for Canadians between the ages of 10 and 24.

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Adolescence is a time of dramatic change. The journey from child to adult can be complex and challenging. Young people often feel tremendous pressure to succeed at school, at home and in social groups. At the same time, they may lack the life experience that lets them know that difficult situations will not last forever. Mental health problems commonly associated with adults, such as depression, also affect young people. Any one of these factors, or a combination, may become such a source of pain that they seek relief in suicide. Suicide is the second leading cause of death among young people after motor vehicle accidents. Yet people are often reluctant to discuss it. This is partly due to the stigma, guilt or shame that surrounds suicide. People are often uncomfortable discussing it. Unfortunately, this tradition of silence perpetuates harmful myths and attitudes. It can also prevent people from talking openly about the pain they feel or the help they need.

Suicide can appear to be an impulsive act. But it's a complicated process, and a person may think about it for some time before taking action. It's estimated that 8 out of 10 people who attempt suicide or die by suicide hinted about or made some mention of their plans. Often, those warning signs are directed at a friend.

Recognizing the warning signs is one thing; knowing what to do with that information is another. Suicide was a taboo subject for a very long time. Even talking about it is still difficult for most people. But being able to talk about suicide can help save a life. Learning about suicide is the first step in the communication process. Suicide is about escape. Someone who thinks seriously about suicide is experiencing pain that is so crushing, they feel that only death will stop it.

## Some myths about suicide

**Myth:** Young people rarely think about suicide.

**Reality:** Teens and suicide are more closely linked than adults might expect. In a survey of 15,000 grade 7 to 12 students in British Columbia, 34% knew of someone who had attempted or died by suicide; 16% had seriously considered suicide; 14% had made a suicide plan; 7% had made an attempt and 2% had required medical attention due to an attempt.

**Myth:** Talking about suicide will give a young person the idea, or permission, to consider suicide as a solution to their problems.

**Reality:** Talking calmly about suicide, without showing fear or making judgments, can bring relief to someone who is feeling terribly isolated. A willingness to listen shows sincere concern; encouraging someone to speak about their suicidal feelings can reduce the risk of an attempt.

**Myth:** Suicide is sudden and unpredictable.

**Reality:** Suicide is most often a process, not an event. Eight out of ten people who die by suicide gave some, or even many, indications of their intentions.

**Myth:** Suicidal youth are only seeking attention or trying to manipulate others.

**Reality:** Efforts to manipulate or grab attention are always a cause for concern. It is difficult to determine if a youth is at risk of suicide. All suicide threats must be taken seriously.

**Myth:** Suicidal people are determined to die.

**Reality:** Suicidal youth are in pain. They don't necessarily want to die; they want their pain to end. If their ability to cope is stretched to the limit, or if problems occur together with a mental illness, it can seem that death is the only way to make the pain stop.

**Myth:** A suicidal person will always be at risk.

**Reality:** Most people feel suicidal at some time in their lives. The overwhelming desire to escape from pain can be relieved when the problem or pressure is relieved. Learning effective coping techniques to deal with stressful situations can help.

## What are the signs

Most people who consider suicide are not determined to die. They are undecided about whether to live or die, so they may take risks and leave it to someone else to save them. Warning signs may be their way of asking for help or revealing the seriousness of their situation. Warning signs can be very subtle. They can also be as obvious as someone saying, 'You won't be seeing me any more.'

Here are some common warning signs:

- sudden change in behaviour (for better or worse)
- withdrawal from friends and activities,
- lack of interest
- increased use of alcohol and other drugs
- recent loss of a friend, family member or parent, especially if they died by suicide
- conflicting feelings or a sense of shame about being gay or straight
- mood swings, emotional outbursts, high level of irritability or aggression
- feelings of hopelessness
- preoccupation with death, giving away valued possessions
- talk of suicide: eg. 'no one cares if I live or die'
- making a plan or increased risk taking
- writing or drawing about suicide (in a diary, for example)
- 'hero worship' of people who have died by suicide

Remember, there is no ultimate list of warning signs. It may be right to be concerned about someone simply because their behaviour is out of character. Sudden shifts in a person's attitude or actions can alert friends to potential problems.

## What can you do

The only person who can stop a person from considering suicide is the suicidal person. But you can help them to reconsider and seek other solutions. The most important thing is to listen. Take your friend seriously.

People who share their suicide plans often demand secrecy from their friends. But they're usually hoping that their friend will stop them by getting help. When a life is at risk, requests for confidentiality must be ignored.

Don't be afraid to be the first to mention suicide. Talking about suicide openly does not increase the risk. Ask if your friend is suicidal. Bringing the subject into the open can bring relief.

You can help by:

- really listening, without judging not challenging, or becoming angry and shocked
- finding ways to break through the silence and secrecy
- asking if they have plans or have made prior attempts
- helping them find ways to lessen their pain
- helping them see positive possibilities in their future
- guiding them to other sources of help as soon as possible, such as a counsellor or other trusted adult, or community crisis lines listed in your telephone book

No one can solve another person's problems. But sympathy and support can help; knowing that someone else has faced similar tough times and survived can help a suicidal person see a light at the end of a very dark tunnel.

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Comments are closed.

# Société Alzheimer Society

## C A N A D A

### MEDICAL ASSISTANCE IN DYING

#### Position statement

#### Background Information

Dementia is a progressive disease that will eventually lead to death. Because dementia is very different than other life-limiting illnesses, the needs of people with dementia at the end of life are unique and require special considerations.

Due to the progressive, degenerative nature of dementia, people with the disease will eventually become unable to make decisions about treatment and their own care. Family members and health care professionals often have to make difficult decisions on behalf of the person with dementia. People with dementia should make their wishes known to their family members (or a substitute decision maker in some provinces) when they are still capable. A written advance care plan can guide families when the person with dementia is no longer able to express their wishes for health and personal care decisions.

#### What is medical assistance in dying?

Medical assistance in dying (MAID) is the administration by health care teams (physicians, nurses, pharmacists and other health care professionals) of medications or substances to end the life of a person, at her/his request, in order to relieve suffering by hastening death. *(Other terms used include physician-assisted death, physician-assisted dying, physician-assisted suicide, physician-hastened death, etc.)*

#### What is the issue?

The significant outcome of the Supreme Court decision of February 6, 2015 is that physician-assisted dying will no longer be considered murder under the Criminal Code of Canada. This means that a competent adult with *enduring and intolerable suffering* can request MAID by clearly consenting to terminate her/his life.

#### Capacity and consent

While a person with dementia will not be deemed incapable to make decisions for herself immediately at the time of diagnosis, due to the progressive nature of dementia, specific skills will be lost during the course of the disease, including the capacity to consent to treatment including MAID. Therefore, a diagnosis of dementia does not render someone immediately incapable.



To consent - in this instance, to MAID - the person needs to be capable of retaining and understanding new information, analyzing the information and making an informed decision. Consent must be clearly expressed and voluntary - at the time that medical assistance in dying is provided - and the person's ability to make decisions must be carefully assessed to ensure that she/he is able to understand the information provided and the consequences of making a decision to end their life.

All of these abilities (i.e. retaining, understanding and analyzing information and making informed decisions) may be impaired in people with dementia and consent will not be possible at the time of medical assistance in dying or throughout the mandated period of reflection (during which a person can withdraw her/his consent).

Consequently, the law does not consider people with dementia competent to make a decision to end their life, at the end of their life. Furthermore, the Alzheimer Society believes that if a person is not deemed competent, then she/he is extremely vulnerable and the risk of abuse is simply too great.

## **Our position:**

Given the progressive nature of dementia, wishes, values and beliefs may change, skills are lost and the ability to make decisions is greatly reduced. MAID should only be possible when a person is deemed competent at the time of MAID.

However the Special Joint Committee On Physician-Assisted Dying (Parliament of Canada) has recommended "that the permission to use advance requests for MAID be allowed any time after one is diagnosed with a condition that is reasonably likely to cause loss of competence or after a diagnosis of a grievous or irremediable condition but before the suffering becomes intolerable"<sup>1</sup>.

The Alzheimer Society of Canada believes that because we cannot predict future suffering, providing **advance consent**<sup>2</sup> for MAID should not be possible for people with dementia. The Alzheimer Society believes that people with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life. People with dementia do not have the **capacity to make an informed decision and consent** to end their life at the later stages of the disease.

In view of this position, the Alzheimer Society of Canada:

- Aims to reduce the stigma and stereotypes around Alzheimer's disease and other dementias, stressing that living a satisfying life doesn't end with a diagnosis and that it is possible to continue to live well with the disease.

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<sup>1</sup> Medical Assistance in Dying: A Patient-Centred Approach - Report of the Special Joint Committee on Physician-Assisted Dying available at <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&DocId=8120006&File=18>

<sup>2</sup> In this case, provide consent for assisted death in prediction of grievous and irremediable suffering due to life-limiting illnesses - Advance consent often requires a mandated "period of reflection" that allows patients several opportunities to withdraw their consent, which is different than consent in the here and now.



# Société Alzheimer Society

## C A N A D A

- Urges those who develop the new legislation to take into account the complex circumstances and vulnerability of people with dementia and limit the harm and risk that MAID could represent.
- Urges people with dementia to make their wishes for their future care known, preferably through **advance care planning**<sup>3</sup>, as soon as possible after diagnosis. It's important that families plan together while the person with dementia is able to fully participate in decision-making about their care to ensure the best possible **quality of life**.
- Calls for improved **quality hospice palliative care** that is available to all Canadians with dementia as they near the end of their life. The right to access quality palliative care will help minimize unnecessary suffering and improve the **quality of dying** for people with life-limiting illnesses.

### Additional resources:

- *A dignified death for dementia patients: Who makes that call?* André Picard, The Globe and Mail, published February 16, 2016; available at <http://www.theglobeandmail.com/opinion/a-dignified-death-for-dementia-patients-who-makes-that-call/article28760956/>
- *Life goes on after diagnosis of Alzheimer's*, Jim Mann, Vancouver Sun, February 12, 2016; available at <http://www.vancouversun.com/opinion/letters/gravitational+waves+link+discovery/11720885/story.html>

For more information on advance care planning:

- Planning for the future, Alzheimer Society of Canada, available at <http://www.alzheimer.ca/en/Living-with-dementia/Planning-for-the-future>.
- Speak Up Campaign on advance care planning in Canada, available at <http://www.advancecareplanning.ca/>

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<sup>3</sup> Advance care planning: is the process of planning for a person's future health-care where the person has conversations with close family and friends about their values and beliefs.

Right to Die Society of Canada

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Regarding Mental Illness, I have already alerted you to an article by me which was published in the Journal of Ethics in Mental Health, in May (Special Issue on MAID)

Regarding Advance Directives, I will be sending you my/our submission by e-mail (it is a bit longer than 1000 words so might not fit onto this form)

Regarding Mature Minors, I will be sending the submission by e-mail (it is shorter than 1000 words but still might not fit because I have written a fair number of words already)

Regarding "my/our": Tomorrow I will be sending the three submissions to RTDSC members (both paid and honorary) for whom I have a current e-mail address, inviting them to add comments or make additions. If someone wishes to be known as a dissenter I will pass that information on to you, but most of the members like the way I think and write. Also, most RTDSC members who are vigorous and "wired" are also members of Dying With Dignity, and that group has invited its members to make submissions.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Some material like this is referenced in the three items referred to above.

# Advance Directives

Right to Die Society of Canada (Ruth von Fuchs, President)

- 1) What are the objectives (including for whom and for when)?**
- 2) What are the obstacles?**
- 3) What are some ways in which the obstacles can be dealt with?**

## **1) What are the objectives?**

### **For whom?**

The "owner" of a life usually wants it to continue as long as it is mainly pleasant, but stop when the pleasantness ends. Relatives and friends tend to feel the same, though they are less well equipped to make judgments about pleasantness. Management personnel in care facilities have a financial interest in residents' longevity, and they may have a lower standard about pleasantness, contenting themselves with an absence of obvious displeasure, even if that absence depends largely on drugs.

### **For when?**

In an advance directive, writers are concerned with future pleasantness or unpleasantness. They may list particular types of unpleasantness known to be common in advanced dementia (such as sorrow, bewilderment, fear, and guilt). They may consider unpleasantness for their loved ones as well as for themselves, e.g. by stipulating that their life should not extend into a time when they can no longer recognize family members.

In addition to future miseries, however, people can suffer in the present because of a possible future situation which may or may not involve distress at that time. They may worry about a situation in which they are different but in ways that do not necessarily indicate suffering.

One of my uncles was a brilliant university professor and a gentle person whose hobby was painting landscapes, but he developed dementia and became subject to rages so extreme that he had to be institutionalized. In one of these rages he tried to push a little old lady through a plate glass window. (Presumably his sedation level was immediately adjusted upwards.) His son, a cousin with whom I was quite close when I was a child, is having his prime-of-life years blighted by the fear of being similarly betrayed by his nervous system. Many other Canadians, with or without a genetic connection to a dementia victim, are equally anxious.

## **2) What are the obstacles?**

Anxiety on this subject is fuelled largely by our country's present demand that all life-ending actions be performed or requested by the owner of the life, and at a time when that person is fully competent.

Regarding action by the owner of the life: it is sometimes claimed that there is no need to permit advance requests for MAID because if we get diagnosed with dementia we can always end our

life ourselves. After all, the condition does develop slowly, and it usually does not strike until we have had at least five or six decades of good life, so maybe we should not be greedy. There are people who would not mind having a do-it-yourself death (I am one such person, and Gillian Bennett was another). But many difficulties currently stand in the way.

The fastest and most graceful method, a powerful anti-emetic followed by the drinking of a pentobarbital solution, is problematical in many ways. The smallest danger is losing several hundred dollars, if the supplier you try turns out to be a scammer; the worst danger is having police break down your door and ransack your house in a "wellness check", having been alerted by an international police agency that found your e-mail order. There are several non-pentobarbital methods (see the books listed under **Resources** on [righttodie.ca](http://righttodie.ca)) but many people find them rather taxing and/or deficient in gracefulness.

Regarding action by a doctor or a nurse practitioner: these people appreciate the reassurance they receive when a person states that MAID is still wanted. They do regret that the present law occasionally leads someone to forego pain-relieving drugs in order to keep their mind clear enough to provide the required confirmation on D-day, but most professionals are likely still content with the power to shorten the required waiting period in cases where the person is at risk for losing competence. I suspect that almost all of them would draw back from ending the life of an unconscious person, or – worse yet – a conscious person who appeared happy.

Apart from the obstacle created by the current-and-competent affirmation requirement, there can be psychological obstacles (within someone's relatives, for instance) and what might be called systemic obstacles (within institutions and the incentive structures that govern them).

A young woman who phoned me told this story: her grandmother had always been a very proud and meticulous person. After she went grey she dyed her hair black, and she always wore heels when she went outside the house. Following a major but non-fatal stroke she was reduced to lying on her back in hospital and seemed to most observers to be very unhappy. When her daughter and granddaughter came to visit she would fix her eyes on them and weep copiously. The grand-daughter was sure she was pleading to be released but the daughter said "They're tears of joy".

As has already been mentioned, the continuing life of an institution resident is a matter of financial stability for that institution. Probably no employee or shareholder of the institution consciously thinks of things this way, but their actions (and inactions) are shaped by the situation.

### **3) What are some ways in which the obstacles can be dealt with?**

The problems with self-deliverance may take time to resolve. Pentobarbital is effectively unavailable through legitimate channels, having been priced at \$23,000 per dose. Some people have suggested that we could get a compounding pharmacy to produce pentobarbital for use by those who meet the requirements of the MAID law, but this may not be as simple as it sounds.

In the meantime, perhaps approved candidates could be given a prescription for DDMP (diazepam, digoxin, morphine and propranolol), the second secobarbital substitute to be developed in the USA. (Secobarbital's price was raised to \$3000, enough to make the drug unacceptable to many insurers and unaffordable to most patients.)

The problems with life-ending actions/inactions by outsiders have been tackled by some people in their Living Will. My own directive has the following post-script:

"The above characterizations [*personal traits which caregivers and substitute decision-makers should be mindful of, such as my being a proud person and a public-spirited person*] refer to "the real me". If I am somehow overtaken by dementia before I can escape, and I begin to look happy being someone quite different from the real me (e.g. slovenly, or selfish), you are to consider that this new person is an impostor and has no credibility. Do not let her betray the real me. Withhold or withdraw all life-support from her, but protect her from suffering while she dies, through continuous deep sedation if necessary."

American legal scholar Norman L. Cantor recently revised his Living Will to include these passages:

"I wish to die upon reaching a degree of permanent mental dysfunction that I deem to be intolerably demeaning. For me, this means mental deterioration to a point when I can no longer read and understand written material such as a newspaper or financial records such as a checkbook . . . it is critical to shape the post-mortem recollections of my loved ones and to preserve the lifetime image as a vital, critically thinking individual that I have strived to cultivate. In addition, it is important to me to avoid being an emotional, physical or financial burden on my family and friends, even if they would willingly assume such burdens. I fully understand that my determination to avoid prolonged, progressive debilitation could prompt my demise even though I might appear content in my debilitated condition."

[*Changing the Paradigm of Advance Directives to Avoid Prolonged ...*

[blogs.harvard.edu/billofhealth/2017/.../changing-the-paradigm-of-advance-directives/](https://blogs.harvard.edu/billofhealth/2017/.../changing-the-paradigm-of-advance-directives/)

*Posted on April 20, 2017 by Norman Cantor*]

These two efforts address the apparent-happiness situation, which is more problematic than the obvious-distress situation. But even with that situation, medical personnel may say "If the person does not ask for death, then I am doing what a veterinarian does." I respond "Is that so bad?" Personally, I would be happy to have my relatives and caregivers look after a dog-like or cat-like me with the same empathy and concern I have finally learned to practise with my pets. We fear abuses, but they are rare, and we should not let our policies be distorted by excessive cynicism.

Hesitation about providing MAID to a demented person could perhaps be reduced by including a video component in one's advance directive. The prospective provider could then see the face of the real/former self, alert and passionately pleading for the power to drain the glass of life, instead of the current face, which might be contorted or drug-glazed.

It would be wise for people to use a standardized form, or at least receive editorial guidance (e.g. from a specialist social worker or from a right-to-die consultant). A Dutch dementia patient who was at the centre of a troubling case in January 2017 had written in her directive that she would like euthanasia "when I myself find it the right time". Since she was almost certainly never going to find any such thing, once her dementia had progressed, her unfortunate wording damaged the credibility of the whole document. Medical staff in her facility had to determine "the right time" on her behalf, from her mood and her behaviour (she became angry and fearful, and wandered the corridors at night).

The person's relatives could help too, if we amended the law to allow MAID requests from substitute decision-makers. (See my comment about excessive cynicism, above.)

## **Mature Minors**

Right to Die Society of Canada (Ruth von Fuchs, President)

**1) What are the objectives?**

**2) What are the obstacles?**

**3) What are some ways in which the obstacles can be dealt with?**

**1) What are the objectives?**

Young people who are suffering intractably want release by death, just like older people whose suffering cannot be adequately relieved by available and acceptable therapies.

**2) What are the obstacles?**

**a)** Since young people have a relatively small database of life experiences, there is a concern that they may not have sufficient perspective on their situation, and thus be deficient in decision-making capacity.

**b)** Since young bodies are more resilient than old bodies, there is a hope that recovery may occur after enough time goes by, even if doctors are generally pessimistic.

**c)** Young people are the vehicles through which the genes of our species go forward into the future. Evolution has designed us to be strongly supportive – sometimes even cruelly demanding – about their remaining alive. In its issue for February 3 2000, the *New England Journal of Medicine* reported a study on the types of care given to children who are terminally ill with cancer. The authors wrote "For most children with cancer, the primary goal of treatment is to achieve a cure. Considerations of the toxicity of therapy, the quality of life, and growth and development are usually secondary to this goal . . . Children who die of cancer receive aggressive treatment at the end of life. Many have substantial suffering in the last month of life."

**3) What are some ways in which the obstacles can be dealt with?**

**a)** Medical records (and perhaps also diaries kept by the young people or their parents) could be consulted to reveal the duration and the severity of the suffering. If both were comparable to what would make an older person eligible for MAID, the young person could be accepted. When something is sufficiently major, "perspective" is immaterial. The magnitude of the torment becomes the qualifying factor.

b) There may be data on recovery rates by patients whose age and diagnosis are similar to those of the applicant. A policy could be established that a recovery rate below X% would permit the provision of MAID.

c) Awareness is the best antidote to the subconscious biases and assumptions that have been bred into us over the millenia. When we find ourselves exclaiming "But you're so young!" we should take a step back and imagine how we would view the situation if age were taken out of the equation.

## **Addendum:**

### **Immature Minors, or "If we don't give them death, what do we give them instead?"**

So far in our history, unacceptable MAID candidates have usually just been put back onto the shelf and told to carry on as they were -- experiencing severe pain or other kinds of distress, and being denied relief that could have been provided by some existing treatments because those treatments might have increased the risk of death (this was how we handled Tracy Latimer, for instance). But this is very similar to the approach that skilled torturers use with their "patients". Great care is always taken to stop just short of causing death.

We could at least allow children to try any drugs or procedures that might decrease their suffering, even if there was a fairly high attendant risk that death would be hastened. Adults are allowed to take such chances if they wish, and barring children seems like punishing them for their youth. They have not signed a duty-to-live contract with the universe, any more than adults have. They just have the misfortune to awaken "protective" feelings in others, because they are the leading edge with respect to the perpetuation of our species.

As an aside, I note that such feelings are even stronger in a child's parents than they are in other people, the genes in question being rather largely those of the parents. Fortunately most parents rise above the selfishness that biology tempts them towards. But we should remember the temptation before we automatically reach for "parental consent" as the best danger-reducing policy to use with decision-making by minors.

# REFLECTION

## MAID and Mental Illness: Critical Thoughts, Constructive Thoughts

Ruth von Fuchs  
President, Right to Die Society of Canada  
Toronto, Canada

The current law on Medical Assistance In Dying (MAID) says that as long as a mental illness is the sole source of a person's suffering, MAID will not be provided. I believe the policy is extreme and needs refinement. To support my belief, and to suggest some revisions, I make the following points:

### **(1) A mental illness does not automatically deprive someone of capacity for making the MAID decision that is right for them.**

Writing in *Health Ethics Today* (24:1, August 2016, pp. 6-8), Navjeet Gill and Paul Byrne assert, "Mentally ill patients ... may have the capacity to make end of life decisions. ... A thorough capacity assessment done by a professional is key to determining whether or not a patient's decision is truly their own and in line with their beliefs and values."

Indeed, if a revised law meant that MAID was no longer out of the question, that fact alone could improve patients' decision-making ability. Currently they are often weighed down by a feeling of "foreverness", brought on by the knowledge that they may have to suffer through several decades until bodily breakdown occurs, when in some cases they have already endured many years of torment. A high degree of desperation often results, greatly impairing their capacity for making wise decisions.

To prevent the foreverness feeling and the resulting desperation, we could establish an evidence-based protocol such as one that said patients would be accepted for MAID if they had:

- a) endured 5 or more years of treatment without adequate improvement, and/or
- b) tried more than 6 different drugs/therapies without adequate improvement, and/or
- c) received a standard course of treatment from 3 or more different professionals without adequate improvement.

The patient would be the one to decide what did or did not constitute adequate improvement.

The numbers might need adjusting, in the light of experience. For instance, if it turned out that many patients were suiciding violently after only 3 years of treatment, the first number could be revised downward.



It is important to remember that capacity has domains or spheres – someone can be incompetent to make decisions in Domain A but quite competent to make decisions in Domain B. For instance, patients may be incompetent to make judgments about which treatment is most likely to help them, but quite competent to assess the net value of a given course of treatment (improvement, if any, versus side effects or other "downsides"). And the patient is probably the best-qualified person in the world to answer the question, "Can I bear any more of life like the one I am having, which seems to be the only kind I can have?"

**(2) With a mental illness, irremediability (the first variable noted by the Supreme Court) is different from what it is with a physical illness.**

With a grievous physical illness, it usually means you will be afflicted with death. With a grievous mental illness, it currently means you will be afflicted with life. You will remain available to have increasingly unpromising therapies tried on you, suffering physically from side effects and psychologically from repeated disappointments.

Although "irremediable" is the word used by the Supreme Court, the words "intractable" and "refractory" are more common in the world of medicine, along with the phrase "treatment futility". In a 2010 paper, psychiatrist Justine Dembo writes, "I would ask ... whether acknowledging futility could ever be helpful for the patient, for the physician, and for the therapeutic alliance, and whether refusing to acknowledge futility could ever be harmful." (Journal of Ethics in Mental Health 5(1) Nov. 2010)

If a psychiatric patient who seems to have arrived at the treatment-futility stage expresses interest in MAID, it may happen occasionally that their doctor will feel able to designate them as meeting the requirements (assuming there is no longer an absolute exclusion of people whose suffering stems solely from a condition labelled as mental). But doing this would often be hard on the doctor – it would feel like saying, "I was not good enough at my job."

One solution could be to have a doctors' college or other group set up committees of experts in the various mental diseases which frequently lead to MAID requests. The experts would prepare an outline of what they considered to be a minimal standard treatment regimen. If the patient's records were checked against this, and passed muster, the patient would be accepted for MAID.

Another solution would be to set ceilings for treatment variables such as length of time or number of drugs, as was suggested under Point 1 above.

In acknowledging that an exit was among the possibilities, and need not be avoided at all costs, psychiatrists could re-conceptualize their role as that of "decision-making coach". (Probably most marriage counselors no longer consider that their goal is to prevent divorce; instead they see their role as helping the couple make the decision that is best in their case.)

As long as death remains "the thought which must not be thunk", patients will tend to keep quiet about the fact that they are interested in it. They will see the doctor as a potential jailer, if they consider hospitalization to be a dreadful fate, as many of them do. Once MAID

is put on the table, they can start to see the doctor as a partner, working with them on making the most important decision they will ever make.

One area in which useful data could be gathered by a helping professional is what might be called the graphing of the patient's symptoms. Some mental illnesses, notably bipolar disorder, involve fluctuation in the type or the intensity of the suffering. Ideally, patients would keep a diary in which they recorded a "score" (e.g. from 1 to 10 or from -5 to +5) for their depression or whatever, several times each day. But many disorders make the person too scattered to be methodical about such a project. Someone from their coaching staff could phone them at regular intervals and get a reading to enter into the log (even a "no answer" or a busy signal might be worth recording). The information thus gathered would be helpful in evaluating treatments. It could also help reveal the periodicity of the patient's condition. Then, if MAID is eventually settled on as the best option, it could be scheduled for the phase the patient wanted – perhaps at a time which is likely to be near the end of an "up" phase, or perhaps at a different time.

### **(3) Intolerability (the second criterion suggested by the Supreme Court) has more scope to develop with a mental illness than it does with a physical illness.**

Many mental-illness patients suffer through decades of torment. Even if they have had interludes of relative wellness, the recurring nature of their attacks has made peace and hopefulness impossible. They feel like a mouse being killed by a cat. Eventually the distress caused by this vulnerability may accumulate to the extent that during their next interval of calmness they apply for MAID.

Risk-benefit analysis, common in the world of public policy, is useful here. There is a real risk that exhausted and desperate patients will make their exit alone and in a violent way. Often the alternatives to be compared are not death versus life, but solitary and painful death versus gentle death which can truly benefit the patients and those who love them.

However, patients themselves may want to do some analysis. What if they want to compare the benefits of death with the benefits of continued life? Of course, the comparison could not involve real death, which is permanent. But for the sake of stretching our minds a little, let us imagine that we offer them a simulation. They would be given continuous deep sedation, along with technology to take care of nutrition and elimination, for a week or whatever other interval would be safe for their bodies. They would agree to make a film record of their pre-sleep thoughts and feelings, then another one upon regaining consciousness, responding to open-ended questions such as, "How did you feel when you woke up?" Some patients might discover that they felt relieved, but others might feel bitter disappointment. This information would be quite valuable both to the patients and to their caregivers. And we would be doing error prevention in the proper way: saving people only from acts which would be mistakes by their own standards, not from acts which would be mistakes solely by the standards of outsiders. Just a little creative thinking...

## **(4) Moving from what the Court said to what it did not say, the phrase used was "medical condition", not "physical condition".**

Even if the Court had said "physical condition", mental illnesses would have been included – they stem from structural and electrochemical abnormalities in the brain – but many readers would have taken the wording to exclude mental illnesses.

The kingdom of mental illness has fuzzy boundaries. One border is with neurological conditions such as Parkinson's disease, which are treated by neurologists and whose most prominent symptoms are sensory/motor. However, patients may also develop disorders of thoughts and feelings, often considered the hallmark of psychiatric diseases.

The other neighbour is psychological disorders, which are treated by psychotherapists and whose difference from psychiatric disorders is a matter of degree – they are not quite severe enough to interfere drastically with a person's ability to manage everyday life, whereas psychiatric disorders are.

The fuzzy-borders problem, and the matter-of-degree problem, create difficulties for lawmakers' assumption that "mental illness" can always be delineated with clarity and certainty. To the extent that its delineation may sometimes be difficult, it is poorly qualified to be the basis for a major legal distinction, as it tries to be in the current version of C-14.

The problem is not even delineation, sometimes. Real mistakes can occur. For instance, a person experiencing a cardiovascular event such as atrial fibrillation or a transient ischemic attack may get diagnosed (at least fleetingly, e.g. in an emergency room) with panic disorder, one of the many psychiatric diseases currently identified by symptoms alone. Once a notation about a psychiatric condition has been made in a person's file, there may be difficulties for that person if at some future time an application for MAID is filed. Even if the law disqualifies only applicants whose desire for death stems solely from a mental condition (as the current law does), adjudicators who get a "whiff" of mental illness could well be put off, and be inclined to reject the person's application.

A final problem is that psychiatry as a specialty appears to suffer occasionally from what could be called growing pains (to be charitable) or immaturity (to be less charitable). Sometimes the discipline looks like rather a frail reed to bear responsibility for such a sweeping disenfranchisement as the current C-14 entrusts to it

As an example of what many people would call immaturity, consider the usual response when psychiatric patients feel pain – not just sorrow or tension or fear, but actual throbbing or stabbing or burning pain. Their doctors often resort to discounting the patient's experiences, if no explanation or cure is obvious to them, labelling the pain with minimizing terms such as "psychogenic" or "somatoform". They may deny that they are calling the pain unreal, but to most laypeople (probably including the patient) the word psychogenic means "imaginary". The term somatoform is even worse. It suggests that although the pain feels as if it is in the patient's body, it really isn't, and the patient just doesn't have the wit to grasp the fact. (So as to avoid being purely negative, I offer a substitute label: "rogue pain". This

term too casts aspersions, but it casts them on the pain, not on the patient.)

**(5) Continuing with things the Court did not say, in this case probably because they thought it would be assumed: access to MAID must be governed by the Charter of Rights and Freedoms.**

The Charter says that people must not be discriminated against because of things they have no control over, such as their gender or their age or their ethnicity.

In most cases people also have no control over what diseases they develop. There is often a large genetic component in illnesses, including refractory mental illnesses. Victims ask, "Conceived without our consent, saddled with genes we did not choose, situated within communities that are still a long way from being able to nurture and protect every one of their members, how can we possibly have a duty to live? And how can our fellow citizens have a right to make us act as if we do?" American state lawmakers were the first to claim this right, when they said people had to wait until they were only six months away from death. Then Quebec legislators followed suit by inserting "en fin de vie" ("at the end of life") into the original Bill 52. And now Canadian federal legislators have effectively copied the Americans, though without the same degree of numerical precision.

Some people have been dealt a very bad hand. Since they did not join the game voluntarily – indeed none of us did – they should not be punished for their misfortune. And continued life, rather than death, is what constitutes punishment in their case.

The BC Civil Liberties Association is preparing a court challenge to C-14, stating that the present version violates the Charter by giving preference to people with fast-moving conditions such as cancer and doing disservice to people diagnosed with slow-moving conditions which can cause great suffering over a period of years, long before death is "reasonably foreseeable". A similar injustice occurs when people with a mental-illness diagnosis are barred from receiving MAID. Diagnosis should not be grounds for discrimination.

Supporters of discrimination against mental patients may say it is a necessary protection. But although these patients can sometimes benefit from a temporary withdrawal of their civil rights, a permanent abrogation enshrined in law is excessive.

**(6) Parliamentarians, including the Minister who has been the most strenuous defender of C-14 as currently written (Jody Wilson-Raybould), like to note that Courts make judgments, but laws are made by Parliament.**

In the Carter decision the Supreme Court made what could be termed a recommendation for a law governing MAID. Their thinking was shaped by the voluminous research and testimony they had received, and indirectly by the even-more voluminous research and testimony which had been reviewed by Justice Lynn Smith in B.C., whose decision the SCC was considering. It is doubtful that Wilson-Raybould has been informed by materials of

comparable quantity and quality. News reports from June 1 of 2016 suggest that she was moved quite substantially by a desire to avoid having Canada's policy be "the broadest in the world".

But many Canadians would not share her fear of that.

**Acknowledgements:** none

**Competing Interests:** none

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## Additional Comments:

### (1) Advance Directives

An AD is prepared by an individual while competent on the basis of certain values that are integral to the self-perception and identity of that person. The AD is prepared in anticipation of the eventuality that s/he will not be competent (lack capacity) to communicate or insist on these values being followed.

The fact that someone has lost capacity/competence does not, legally, ethically or logically entail that the individual has lost the right to informed consent that all persons possess. It merely means that the individual cannot exercise that right on her own behalf. This is what underlies the ethics and the law of substitute decision-making.

Further, both in ethics and in law, substitute decision-makers have an obligation to make decisions in accordance with the wishes of the now-incompetent person in accordance with the values that the now-incompetent person expressed while competent.

An AD is just such an indication of the competently held values of the now-incompetent person. Therefore to refuse to follow advance directives not only violates the ethics of substitute decision making, it also violates the right of autonomy of persons as persons. The legal case that reflected this very clearly—i.e., that ADs are binding even when following them will result in the demise of the individual in question—was *Malette v. Shulman* (Ont. C.A.), 1990 CanLII 6868 (ON CA)

### (2) Mature Minors

While at first glance the exclusion of Minors per se from access to MAiD is eminently defensible, closer consideration shows it to be highly questionable from both an ethical and a legal perspective.

The underlying principle of this exclusion cannot be the notion that life, and in particular young life, should be protected at all cost. This would be to ignore the fact that some life is nothing but suffering for the individual who lives that life. This fact is part of the rationale that legitimates a decision in favour of MAiD for adults.

To exclude Minors from access to MAiD is to say either that Minors cannot suffer because they have not reached a statutorily defined age, or that the suffering of Minors requires less care and respect than that of adults. The first of these is demonstrably false; to advance the second is to adopt an ethical perspective that denies full-fledged and ethically relevant personhood to individuals simply because of their age. Given the

Universal Declaration of Human Rights, which stipulates that all persons are equal as persons, this is ethically indefensible. As an aside, it should be noted that this protective and exclusionary approach to Minors is not in fact followed in health care, where it is considered perfectly appropriate to withhold treatment from extremely disabled newborns who suffer from irremediable and incurable conditions, and to make for a comfortable and pain free death by the administration of appropriate narcotic analgesics.

As to the exclusion of Mature Minors, not only do the preceding considerations apply in their case as well, but there is the additional factor that, as the term 'Mature' indicates, they are considered to have capacity to make decisions on their own behalf. That is, in fact, how they live – and are accepted as living in legal terms in contemporary society. This consideration ethically entitles them to have their wishes as respected as those of any other competent person.

Nor is this merely an ethical consideration: it is reflected in the Supreme Court of Canada judgment in the case of *A.C. v. Manitoba (A.C. v. Manitoba (Director of Child and Family Services))*, 2009 SCC 30, [2009] 2 S.C.R. 181) which stipulates that the test for decision making authority in health care for Minors is not age but capacity.

One might also point to the Canadian Charter of Rights and Freedom which, at s. 15, stipulates that any public policy that discriminates solely on the basis of age is unconstitutional. The current Act does just that. Hence it is unconstitutional. Nor is it saved by s. 1 of the Charter because, as the Oakes test mandates, it does not meet the criterion that it is demonstrably necessary to discriminate in this fashion for a free and democratic society because there are no other means of ensuring the otherwise legitimate aim. There are other means – as is pointed out in *A.C. v. Manitoba*: a test for capacity will ensure that the Mature Minor has sufficient understanding and capacity to avoid an otherwise uncalled for and unjustified decision in favour of termination of life.

Salvation Army

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*



## **The Salvation Army in Canada Submission to the Council of Canadian Academies' Expert Panel on Medical Assistance in Dying**

October 2017

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The Salvation Army in Canada has more than 100 years of experience working with the country's most vulnerable and marginalized people. We strive to provide the highest standard of professional care to individuals, where every person is cared for unconditionally and without discrimination. Many of the 1.9 million people in Canada we served last year live with complex mental-health conditions. As a result, our submission today focuses on instances of medical assistance in dying (MAiD) where mental illness is the sole underlying medical condition.

The Salvation Army believes that MAiD should not be made available where mental illness is the sole underlying medical condition. "The sanctity of life is one of our most fundamental societal values"<sup>i</sup> and we submit expansion of the MAiD criteria would challenge this principle.

### **Mental Illness in Canada**

In today's society, mental illness is one of the most significant barriers to well-being. The Salvation Army has witnessed the life-saving and life-changing impact mental-health supports and programs can make on the lives on individuals and their families. We remain committed to addressing and supporting those who are struggling with mental-health issues, ensuring there is always hope.

In any given year, 1 in 5 Canadians live with mental illness and/or substance-use disorders.<sup>ii</sup> Further, statistics indicate that suicide is the second leading cause of death among Canadians aged 15 to 34.<sup>iii</sup> Despite the fact that 20% of people in Canada will experience mental illness, access to mental-health services is a significant problem. Access to services is impacted by numerous barriers: stigma, poverty, lack of integration between mental-health and health services, shortage of mental-health professionals, regional disparities, and cross-cultural diversity.<sup>iv</sup>

### **Experience in Other Jurisdictions**

The Salvation Army is moved by the evidence and experience of other jurisdictions that legalized euthanasia and assisted death in recent years, particularly the Netherlands and Belgium. In both countries, euthanasia and assisted death, where mental illness is the sole driving cause, appear to be on the rise. Since 2006, these services have increased in The Netherlands by an average of 15%.<sup>v</sup> While this may reflect better reporting by medical professionals, statistics are similar in Belgium where the number of reported deaths rose from 742 in 2004/2005 to 2,086 in 2010/2011.<sup>vi</sup>

### **Our Position**

The Salvation Army strongly supports the recommendations put forward by the Canadian Mental Health Association.<sup>vii</sup> In addition, we submit the following regarding requests for MAiD where mental illness is the sole underlying medical condition:

1. Availability of Treatment

Across the country, significant barriers exist for thousands of people seeking mental-illness treatments and services. Salvation Army ministry units witness individuals' daily struggles to access appropriate mental-illness treatment and services. Individuals and their families must often navigate multiple levels of bureaucracy to locate appropriate services and treatment.

In addition, suicide today, especially among youth, is a significant public health issue, with far reaching social, emotional, and economic consequences. Yet access to services, especially in remote communities, remains limited at best. Ongoing significant investment in mental health treatment and services across the country is needed before any discussion about the expansion of eligibility criteria for MAiD.

2. Faith in Recovery

The Salvation Army has journeyed with thousands of people on their paths to recovery. Recovery from mental illness is deeply personal, unique and may involve many different treatments and services. Recovery also means different things to different people—for some it will mean complete elimination of symptoms while for others it may involve the use of coping mechanisms for ongoing symptoms that enable them to lead fulfilling lives in their communities.

Studies indicate that, with the right supports and resources, recovery is possible regardless of the mental-health diagnoses.<sup>viii</sup> We submit that allowing MAiD in cases where mental illness is the sole underlying condition will undermine the belief that recovery is possible.

3. Importance of Hope

Our brand promise, "Giving Hope Today," has been at the heart of The Salvation Army's mission in Canada for over 130 years. The Salvation Army has observed the power of hope in guiding people through their experiences with mental-health and substance-use concerns.

We believe that presenting MAiD as an option for those experiencing mental illness weakens a physician or mental health professional's ability to provide care and hope.

The Salvation Army contends that the right treatment and services can lead to restored hope, healing and new life, and that restored relationships are preventative factors against suicidal behaviour.

## **Recommendations**

The Salvation Army has assisted countless Canadians in their recovery from mental illness and substance-use disorders. In doing so, we have witnessed the power of hope, faith in recovery, and the efficacy of mental-health supports and treatment. We are deeply concerned at the prospect of expanding MAiD criteria to include mental illness and put forward the following alternatives:

1. Focus on Recovery

The Salvation Army believes that every person living with mental-health and/or substance-use concerns must be actively supported on their journey to recovery. Where mental illness is the sole underlying cause for requesting MAiD, alternative recovery methods should be explored instead.

2. Investment in Community Mental-Health and Substance-Use Disorder Services and Supports

The Salvation Army calls for a greater Investment in community mental health and substance use disorder services and supports. Barriers to service access are a significant issue across the country. Although many are working to reduce the stigma associated with mental illness, the demand for services vastly outweighs their availability.

The Salvation Army submits that the expansion of MAiD to include vulnerable persons, especially those experiencing mental illness, challenges sanctity of life, one of the core and fundamental values of Canadian society.

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<sup>i</sup> *Carter v. Canada (Attorney General)* 2015 SCC 5 at 63

<sup>ii</sup> Smetanin, P., Stiff, D., Briante, C., Adair, C.E., Ahmad, S. and Khan, M. The Life and Economic Impact of Major Mental Illnesses in Canada: 2011 to 2041. RiskAnalytica, on behalf of the Mental Health Commission of Canada 2011.

<sup>iii</sup> Navaneelan T (2017). Suicide rates: An overview. Statistics Canada. Accessible at [www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm](http://www.statcan.gc.ca/pub/82-624-x/2012001/article/11696-eng.htm).

<sup>iv</sup> Canadian Mental Health Association. "Access to Services" [www.cmha.ca](http://www.cmha.ca).

<sup>v</sup> Theo A. Boer. "Euthanasia in the Netherlands: An Eyewitness Report," *Human Life Review* 41 (2015), p. 61.

<sup>vi</sup> Thienpont L, Verhofstadt M, Van Loon T, et al "Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study" *BMJ Open* 2015, p. 3

<sup>vii</sup> CMHA National. "Canadian Mental Health Association's position paper on medical assistance in dying (MAiD)." August 2017

<sup>viii</sup> Mike Slade and Eleanor Longden. "Empirical evidence about recovery and mental health," *BMC Psychiatry* 15 (2015), p. 285.

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The main issues and concerns listed below are broken down into two groups: considerations that are specific to providing MAID in a paediatric setting, and considerations relating to providing MAID more generally. Both these general and paediatric-specific concerns are important to our organization.

**Concerns Regarding Requests for MAID in Paediatric Settings**

a) Issue of providing MAID within a framework of Child and Family-Centered Care, which locates the child at the center of clinical concern and understands the family as central to the wellbeing of the child.

Example:

- How should MAID be discussed with the paediatric patient? With parents; without parents; before a discussion with parents; after a discussion with parents?
- Should any part of the approach be standardized for all MAID cases or follow practice consistent with discussing other end of life options for mature minors?
- How should healthcare providers respond when a mature minor requests MAID but their parents have clearly expressed their opposition to this request? Does MAID warrant any distinct approaches to protecting the patient's right to privacy and confidentiality?
- Should MAID requests and administration be kept confidential from parents and other family members if the capable patient indicates they do not want family members involved?

b) Issue of the practice of MAID within organizations providing paediatric care and committed to suicide prevention initiatives for young people.

Example:

- Should self-administration of MAID become an option in paediatric institutions or is practitioner administration preferable in order to avoid being misinterpreted as contradicting anti-suicide initiatives?
- Should paediatric institutions provide proactive education on why/ how MAID and suicide are different?

c) Issue of drug protocols.

Example:

- Are current drug protocols physiologically appropriate for young bodies? Would alternative protocols need to be designed? If so, by whom?
- Does evidence exist to guide paediatric-specific protocols?

d) Issue of terminology. If MAID access is extended to "mature minors", the terminology used should be consistent with respect for persons in this category.

Considerations:

- The term "Mature Minors" may be interpreted as demeaning/ dismissive to young people in this category. An alternative may be, simply, "capable patients."
- Has the CCA found any research that asks young people this question directly? If so, what

language do they prefer?

e) Issue of justification for restricting who is eligible for MAID if MAID should not become available for mature minors.

If MAID remains inaccessible to capable young people who are under the age of 18, health care providers and paediatric patients need a rationale that is consistent with frameworks already in place for end of life decision making of young people (see item a in response to prompt 2 below).

- If steps are put in place to alleviate the suffering of adults in situations where palliative care is felt to be insufficient, health care providers and paediatric patients will need a clear rationale for the ethical defense of failing to provide access for capable young people and, perhaps down the road, incapable young people.

#### Concerns Regarding Requests for MAID in General

f) Issue of providing MAID in multicultural settings.

Considerations:

- Respecting cultural diversity while ensuring the patient's physical and mental wellbeing.
- What aspects of MAID administration can be adjusted to accommodate the plurality of meaning systems, traditions, and rituals surrounding end of life, death and dying?
- What aspects of MAID administration must not be modified?

g) Issue of providing MAID in a way that reduces social stigma while ensuring practitioner safety.

Considerations:

- Being secretive about MAID (on an institutional and practitioner level) fosters social stigma. Taking institutional and social response to treating HIV/AIDS as an example, should paediatric health care settings be open about providing MAID in order to normalize the procedure and reduce stigma?
- Being open about providing MAID (on an institutional and practitioner level) may endanger MAID providers. Taking institutional and social response to providing abortions as an example, should there be higher level of provider anonymity to protect MAID providers?
- How should these competing concerns be balanced?

h) Issue of the duty to inform. Should MAID conversations begin with patient request or with the duty of practitioners to inform patients (when medically appropriate) of all available treatment options?

Considerations:

- Patients who are not already informed about the existence of MAID will not be in a position to request it. This is most likely to be a problem for patients who are socially marginalized in other ways (linguistically, economically, etc).
- Care must be taken to ensure patients do not feel pressured to pursue MAID by their health care providers.
- Capable patients must be fully informed of all medically appropriate treatment options in order for them to make an autonomous decision about which course of action they wish to pursue.

This is foundational to informed consent.

- If there is a positive duty to inform medically appropriate patients about the existence of MAID, should capable paediatric patients be informed about MAID when they are alone or in the presence/ company of their caregivers?

i) Issue of providing MAID in a way that is consistent with distributive justice/ and ethical resource allocation.

Example:

- Should institutions admit patients solely for MAID when this is a procedure that can be safely and effectively carried out in community settings?
- Will institutions that decide to provide MAID accept transfers from outside of their catchment for the sole purpose of MAID?

j) Issue of Nurse Practitioners prescribing MAID.

Now that Nurse Practitioners can prescribe controlled substances in Ontario, they can be considered primaries for MAID.

- Could the NP be listed as the Most Responsible Practitioner (MRP) or would they need to get admitting privileges to serve in this capacity?
- Would a medical directive be required for the NP to complete the MAID pharmacy order set?
- Are there any issues with NPs completing the death certificate?

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

a) The capacity to make health care decisions is not linked to age in Ontario.

- In jurisdictions where decisions are made based on capacity rather than age, capable young people can make medical decisions that will result in their death.
- Ontario's Health Care Consent Act (HCCA) allows capable patients to stop or discontinue life sustaining treatment
- The HCCA currently allows capable patients to refuse interventions even when those interventions are life sustaining.
- If MAID is to be treated differently than all other medical decisions in jurisdictions where capacity is not linked to age, the Canadian government should provide a clear justification why. (See item 1(i), above)

b) There are practitioners in paediatric health care settings such as The Hospital for Sick Children (SickKids) who would be willing to perform MAID when all necessary criteria are met.

- A policy for managing MAID requests by patients who are over the age of 18 is currently being developed at SickKids. As part of this policy, an internal MAID resource group will be formed consisting of practitioners who are willing to provide MAID. This group will also help manage conscious objections as well as MAID referral, assessment and provision. Members of the policy working group are confident that there will be sufficient MAID practitioners to meet the demand, which is anticipated to be very small.

c) Is organ donation medically viable following MAID? Is it ethically appropriate to offer? If so, when should this offer be introduced?

- Ontario currently offers organ donation as an option to capable patients of any age. Ontario supports advanced directive organ donation for patients who are 16 or over, and allows living donation for people who are 16 or over.
- This age limit on advanced directive organ donation has been imposed based on the Trillium Gift of Life Network Act [Ontario] RSO 1990, Chapter H.20, Part 1, Sect. 3 (1) [Internet]. Toronto, ON: Government of Ontario; 1990.
- Organ donation following MAID has been performed in other jurisdictions (Belgium and the Netherlands). The Canadian Society of Transplantation is in the process of authoring a guidance document on organ donation after MAID.

d) Some clinicians have communicated that they foresee clinical scenarios in which it may, potentially, be medically appropriate to offer MAID to patients who are not yet and may never become capable.

- For example: Under present legislation, withdrawal of life support may be offered for a child born with devastating deficits. However it is recognized that it may take some time for the child to die after withdrawal. While for some parents, this time with their child is seen as a “gift”, even though the child may show no signs of consciousness, for other parents this period of waiting for death only adds to their suffering. When the outcome is certain death and the time leading up to that death only creates more suffering for the family with no apparent benefit to the family, some clinicians feel that it would be reasonable to find a means to bring about the death more quickly and predictably.
- We appreciate that this concern might be outside the scope of the CCA’s work on Mature Minors, but we raise it here in the hopes of raising awareness about this clinical reality.

e) Social Environment, Young People, and MAID

- Young people are embedded within dense relational systems. In person and, increasingly, online interactions with family members, friends, siblings, and other actors in the social world shape the way young people understand themselves and make decisions.
- Given the heightened controversy, consequence, and finality of MAID, eligibility assessments for young people should be particularly attuned to the various types of social pressures that young people may face.
- It may even be appropriate to create internal consistency in capacity assessment by having a specialized professional team within the larger health care organization that can assesses young people’s capacity in these circumstances.

f) Hospital Capacity and Ensuring Geographic Availability.

- Our organization would like to emphasize the importance of ensuring geographic availability across the province and across the country. This is critical in order to reduce the burden of patient and family travel and to minimize the chances of families needing to interact with unfamiliar care providers at such a critical time.
- Our organization is concerned about undue burden (physical, emotional, psychological) on practitioners if our organization were to become the only mature minor MAID referral site in the province.

**Submission to the Council of Canadian Academies on behalf of the  
MAID Working Group at The Hospital for Sick Children  
Sept 10, 2017**

**Co Chairs: Randi Zlotnik Shaul JD, LLM, PhD, Adam Rapoport MD, FRCPC, MHSc**

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition? [1000 word maximum]**

The main issues and concerns listed below are broken down into two groups: considerations that are specific to providing MAID in a paediatric setting, and considerations relating to providing MAID more generally. Both these general and paediatric-specific concerns are important to our organization.

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  - The HCCA currently allows capable patients to refuse interventions even when those interventions are life sustaining.
- If MAID is to be treated differently than all other medical decisions in jurisdictions where capacity is not linked to age, the Canadian government should provide a clear justification why. (See item 1(i), above)

b) There are practitioners in paediatric health care settings such as The Hospital for Sick Children (SickKids) who would be willing to provide MAID when all necessary criteria are met.

- A policy for managing MAID requests by patients who are over the age of 18 is currently being developed at SickKids. As part of this policy, an internal MAID resource group will be formed consisting of practitioners who are willing to provide MAID. This group will also help manage conscientious objections as well as MAID referral, assessment and provision. Members of the policy working group are confident that there will be sufficient MAID practitioners to meet the demand, which is anticipated to be very small.

c) Is organ donation medically viable following MAID? Is it ethically appropriate to offer? If so, when should this offer be introduced?

- Ontario currently offers organ donation as an option to capable patients of any age. Ontario supports advanced directive organ donation for patients who are 16 or over, and allows living donation for people who are 16 or over.

- This age limit on advanced directive organ donation has been imposed based on the Trillium Gift of Life Network Act [Ontario] RSO 1990, Chapter H.20, Part 1, Sect. 3 (1) [Internet]. Toronto, ON: Government of Ontario; 1990.
- Organ donation following MAID has been performed in other jurisdictions (Belgium and the Netherlands). The Canadian Society of Transplantation is in the process of authoring a guidance document on organ donation after MAID.

d) Some clinicians have communicated that they foresee clinical scenarios in which it may, potentially, be medically appropriate to offer MAID to patients who are not yet and may never become capable.

- For example: Under present legislation, withdrawal of life support may be offered for a child born with devastating deficits. However it is recognized that it may take some time for the child to die after withdrawal. While for some parents, this time with their child is seen as a “gift”, even though the child may show no signs of consciousness, for other parents this period of waiting for death only adds to their suffering. When the outcome is certain death and the time leading up to that death only creates more suffering for the family with no apparent benefit to the family, some clinicians feel that it would be reasonable to find a means to bring about the death more quickly and predictably.
- While this concern may be outside the scope of the CCA’s work on Mature Minors, but it is raised here raise awareness about this clinical reality.

e) Social Environment, Young People, and MAID

- Young people are embedded within dense relational systems. In person and, increasingly, online interactions with family members, friends, siblings, and other actors in the social world shape the way young people understand themselves and make decisions.
- Given the heightened controversy, consequence, and finality of MAID, eligibility assessments for young people should be particularly attuned to the various types of social pressures that young people may face.
  - It may even be appropriate to create internal consistency in capacity assessment by having a specialized professional team within the larger health care organization that can assesses young people’s capacity in these circumstances.

f) Hospital Capacity and Ensuring Geographic Availability.

- It is important to ensure geographic availability of MAID across the province and across the country. This is critical in order to reduce the burden of patient and family travel and to

minimize the chances of families needing to interact with unfamiliar care providers at such a critical time.

- Concern about undue burden (physical, emotional, psychological) on a small group of practitioners if SickKids were to become the only mature minor MAID referral site in the province.

On Behalf of the MAID Working Group at The Hospital for Sick Children, we thank you for considering these issues and concerns as part of your analysis.

Sincerely,

*Randi Zlotnik Shaul*

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MAID Working Group Co-Chair  
Director, Department of Bioethics  
The Hospital for Sick Children



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Adam Rapoport MD, FRCPC, MHSc  
MAID Working Group Co-Chair  
Director, Department of Palliative Care  
The Hospital for Sick Children

Toronto Catholic Doctors Guild

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see the 1000 word attached submission paper. Thank you for the opportunity to comment on the Call for Input.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see the attached list of references.

# Informed Consent

Informed consent is a legal requirement for accepting MAID, however informed consent is not a legal term and is distinct from both decision making capacity and legal competence. There is lack of consensus over whether informed consent reflects true autonomous decision-making (Epstein). The standards for informed consent must be high when the clinical decision has serious consequences. Accepting death from MAID is the gravest possible decision. The more vulnerable the patient group the more necessary it is to ensure informed consent for MAID occurs. **There is already evidence from other jurisdictions that euthanasia does occur without an explicit request from the patient (van der Heide et al.), which is an unacceptable outcome.** As there are no published standards in Canada to aid clinicians in obtaining properly informed consent for MAID, it follows that extending MAID to more vulnerable groups, such as the mentally ill, children, and those no longer able to consent for themselves is unjustifiable.

## 5 Requirements for Informed Consent:

### Voluntarism, Capacity, Disclosure, Understanding, and Decision (Falagas et al)

An informed consent structure to an action such as MAID requires at minimum:

1. a vulnerability assessment (ensures voluntarism and capacity; answers questions of supports, resources, coercion), *particularly for those persons / populations at risk of marginalization*
2. a screen for capacity and if necessary assessment by a forensic psychiatrist or similar expert in capacity, *particularly for mental illness*
3. a palliative care consultation (this is needed to allow the patient to make decisions as free from physical symptoms as possible, as pain affects decision-making)
4. a consultation with a medical expert in their specific condition to properly appreciate the time course, prognosis, and therapies available for their condition (required for understanding and decision). **Failure to provide palliative or specialist consultation constitutes a failure of informed consent and should not be tolerated.**

### Mature Minors

- Decision making capacity (DMC) in children cannot be properly assessed as validated and reliable tools for DMC assessment in children are lacking, especially tools for MAID assessment (Ruhe et al)
- DMC in children / adolescents fluctuates during development. Executive functions are immature even until post-adolescence in some aspects; ability to “future plan” is immature; **reasoning** is affected in adolescents by emotional factors, hormonal changes, and pressures from peers / caregivers / medical providers.
- “Assent” to a proposed treatment is often taken by clinicians as evidence supporting decision making capacity. **Both understanding and reason are required for DMC to be present; assent guarantees neither. Assessment of the child’s “reasoning” during**

**capacity assessment is rarely done.** (Ruhe)

- It is not clear whether capacity to refuse treatment confers the ability to consent to treatment (Ruhe et al). Published arguments for “ages of consent” do not apply to the the decision to undergo MAID and cannot be extended to an action that has irrevocable consequences.

## Advanced Directives

- The exact circumstances a patient will encounter in their medical journey cannot be predicted even by experienced clinicians. **A patient cannot consent in advance to be killed under circumstances with which they have no experience or real understanding.**
- It is also likely that some patients with dementia would be killed who have since withdrawn their “assent” to death, insofar as they are presently contented and have no active wish to die. In medical care, the will of the patient must be operative in treatment decisions even for patients who do not meet tests of legal competence, or else their autonomy is violated. **Allowing advanced directives for death may destroy patient current autonomy.**
- As the future cannot be predicted, advanced directives always require interpretation based on the patient’s values and current situation. Directives for MAID will necessitate a third party’s subjective “interpretation” of the personal subjective suffering of the patient. By definition this determination cannot be made using any objective criteria. The space for medical error and abuse to occur is broad. The current legal framework for the provision of MAID, which is based on subjective suffering, does not allow for adequate protection for patients in the case of advanced directives for MAID.
- The presence of decision making capacity can fluctuate significantly during medical illness. Patients who request death under specific circumstances related to capacity (i.e. progressive dementia) may be prematurely euthanized if acute illness results in temporarily diminished capacity. Furthermore the caregiver will not know whether to treat the patient to restore capacity; withhold treatment which may result in their natural death; or actively euthanize the patient.
- Patients are unwilling to be a burden on others, as evidenced by recent statistics from Washington citing this as a concern for 51% of participants in the Death with Dignity Act who have died. The “obligation to die” will disproportionately burden those with the fewest social and financial resources.

## Mental Health

- Capacity to make treatment decisions may be lacking in persons with psychiatric illness.
- Capacity assessment is difficult and imperfect even when done by experts. 51% of psychiatrists in Oregon were uncertain about their ability to assess a patient’s capacity to make a decision to hasten death. 78% of all respondents thought that a “very



stringent” standard of competence should apply in physician-assisted death even if this meant that some competent patients would be excluded from death. Only 27% believed one psychiatric assessment was sufficient. 59% believed the assessment could only be done by a forensic psychiatrist and only 11% thought any MD could assess. (Ganzini)

- Suicidality can be a presenting feature in a number of mental health illnesses such as depression, bipolar disorder and borderline personality disorder. Acute suicidality is properly interpreted as evidence of a lack of capacity. The response to suicidality is suicide prevention to preserve life; life is the most basic condition of future autonomous choice.
- Our current correctional system does not have adequate capacity to appropriately manage inmates with mental health illness (evidenced by inhumane solitary confinement duration and substandard or inappropriate responses to cries for help a la Ashley Smith). If psychiatric illness is allowed as the sole criteria for MAID, inmates will be disproportionately affected.
- The risk of mistakenly providing MAID to someone lacking capacity due to psychiatric disease is too great an error to accept.
- **It is irresponsible and unjust to expand MAID access to persons with solely psychiatric disease when timely access to appropriate mental health services is so poor.**

*The authors of this submission thank the Council of Canadian Academies for the opportunity to respond to this consultation. We hope that these comments are helpful to you.*

**Children**

1. Coroner's Inquest Touching the Death of Ashley Smith <http://www.csc-scc.gc.ca/publications/005007-9009-eng.shtml>
2. Response to the Coroner's Inquest Touching the Death of Ashley Smith. Ottawa December 2014. <http://www.csc-scc.gc.ca/publications/005007-9011-eng.shtml>  
BMC Pediatr. 2017; 17: 120. Medical decision-making in children and adolescents: developmental and neuroscientific aspects. Petronella Grootens-Wiegers et al. PMCID: PMC5422908

**Mental health**

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2. A Three Year Review of Federal Inmate Suicides (2011-2014). <http://www.oci-bec.gc.ca/cnt/rpt/pdf/oth-aut/oth-aut20140910-eng.pdf>
3. Toward Quality Mental Health Services in Canada. [https://www.sfu.ca/content/dam/sfu/carmha/resources/2017-toward-quality-mh/CARMHA\\_REPORT\\_29\\_Aug\\_Final.pdf](https://www.sfu.ca/content/dam/sfu/carmha/resources/2017-toward-quality-mh/CARMHA_REPORT_29_Aug_Final.pdf)

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7. Seyfried, L, Ryan, KA, Kim, SYH. Assessment of Decision-Making Capacity: Views and Experiences of Consultation Psychiatrists. Psychosomatics. 2013.54:115–123.

8. van der Heide et al. End-of-Life Practices in the Netherlands under the Euthanasia Act. *New England Journal of Medicine*. 2007. 356:1957-1965.

**Advanced directives**

1. <https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2016.PDF>
2. <https://www.ontario.ca/page/find-retirement-home#section-4>
3. Buckley et al, "Predictors of Quality of Life Ratings for Persons with Dementia Simultaneously Reported by Patients and their Caregivers: The Cache County (Utah) Study", *Int Psychogeriatr*. 2012 July ; 24(7): 1094–1102.
4. Canadian Society of Palliative Care Physicians. "Submission to Special Joint Committee on Physician-Assisted Dying." (January 27, 2016) Retrieved from <http://www.cspcp.ca/wp-content/uploads/2014/10/CSPCP-Submission-to-the-Special-Joint-Committee-on-Physician-Assisted-Dying-National-Secretariat.pdf>.>
5. Dourado et al., 2016. Quality of life in mild dementia: patterns of change in self and caregiver ratings over time. *Revista Brasileira de Psiquiatria*. 38:294–300.
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7. Hongisto et al. 2015. Self-Rated and Caregiver-Rated Quality of Life in Alzheimer Disease with a Focus on Evolving Patient Ability to Respond to Questionnaires: 5-Year Prospective ALSOVA Cohort Study. *Am J Geriatr Psychiatry* 23(12): 1280-1289
8. Kouwenhoven, P. et al. 2015. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. *BMC Medical Ethics*. 16:7
9. Parker B, Petrou S, Underwood M, et al. Can care staff accurately assess health-related quality of life of care home residents? A secondary analysis of data from the OPERA trial. *BMJ Open* 2017;7:e012779. doi:10.1136/bmjopen-2016- 012779.

Toujours Vivant – Not Dead Yet

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Please see the 1000 word attached submission paper. Thank you for the opportunity to comment on the Call for Input.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

Please see the attached list of references.

**CALL FOR INPUT: ADDENDUM**  
**CCA Expert Panel on Medical Assistance in Dying in Canada**

*What is the available evidence on, and how does it inform our understanding of, medical assistance in dying (MAID) in the case of mature minors, advance requests, and where mental illness is the sole underlying medical condition, given the clinical, legal, cultural, ethical, and historical context in Canada?*

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition? [1000 word maximum]**

Toujours Vivant-Not Dead Yet (TVNDY) is a non-religious organization by and for people with disabilities and our allies. Our goal is to inform, unify and give voice to the disability rights opposition to assisted suicide, euthanasia, (AS/E) and other life-ending practices that discriminate against disabled people. ([Coleman \(1\)](#)) While not all people with disabilities have a terminal illness, people who are terminally ill also have disabilities; and both groups are targeted by these statutes.

We are concerned about allowing minors access to medical aid in dying (MAID) ([Webcast 17/08/25](#)) because many ill and disabled children grow up in families where non-disabled parents see their lives as burdensome, tragic, a disappointment of parental aspirations, and "not worth living." ([Hasbrouck](#)) Such views are transmitted to and internalized by the child, resulting in low self-esteem which focuses on the disability or illness as the problem, ([Gill \(1\)](#)) rather than societal discrimination. ([Hitselberger](#)) Parents who kill their disabled children are already given more lenient treatment than those who kill non-disabled children, ([Webcast 13/11/01](#)) and parents even order radical surgery for their disabled children to make them easier to care for (e.g. sterilization, the Ashley Treatment). ([NDRN report, McDonald](#)) Ill and Disabled children lack positive role models in popular culture and are usually isolated from other disabled people with a positive self-identity. ([Haynes](#)) In addition, ill and disabled adolescents face the same developmental instability and difficulties as non-disabled teens, ([Ludi](#)) who are at higher risk for suicide; ([Greydanus](#)) why should non-

disabled adolescents benefit from aggressive suicide prevention programs, while ill and disabled children are encouraged and enabled to kill themselves? ([Peace \(1\)](#), [Peace \(2\)](#), [Coleman \(2\)](#)) Indeed, there are many laws and policies restricting adolescents' liberties with the aim of protecting them ([Pothier](#)) from potential self-inflicted harm, such as those forbidding access to tobacco and alcohol, therefore limiting AS/E access to adults would be consonant with existing public policy. ([Canadian Pediatric Society](#))

Advance directives, ([Webcast 17/09/08](#)) even for refusal or withdrawal of treatment, already pose a significant danger to ill and disabled people, ([Manitoba League](#), [Asch](#), [Coleman \(3\)](#)) there is no reason to believe this situation will improve with the advent of advance directives for assisted dying. ([Alzheimer society of Canada](#)) Upon admission to hospital or long-term care, most disabled people are pressured to sign "Do Not Resuscitate" orders ([Kemp](#), [Hershey](#)), or similar advance directives which have a strong bias against life-sustaining treatment. ([Troschuk](#), [Coleman \(4\)](#)) As well, studies have shown that medical personnel tend to over-interpret Medical Orders for Life-Sustaining Treatment as providing for less care than is actually called for. [A study in the Journal of Emergency Medicine \(Mirachi\)](#) contained a survey by researchers from the University of Pittsburgh Medical Center. More than 700 physicians in 34 states responded. Over 50% of physicians interpreted a living will as having a "do not resuscitate" (DNR) order when it did not. About the same percentage over-interpreted DNR orders as meaning no treatment except "comfort care" or "end-of-life" care. ([Webcast: 16/4/1](#)) Nor do advance care planning documents or policies take into account the needs of people who may not be able to orally state their wishes, whether or not they are deemed "incompetent." ([Coleman \(3\)](#)) Provision for other ways to communicate is usually ad-hoc, rather than having Alternative and Augmentative Communication equipment and trained staff on hand to enable a non-verbal person to make their current wishes known. ([Pereira](#), [MyHealth.Alberta.ca](#)) Also, family and medical staff may be unwilling to believe that a person might want to continue living, and ignore a change of heart as a sign of incompetence. ([Webcast: 14/02/07](#)) This reflects the commonly-held view that the quality of life of ill and disabled people is, by definition, lower than that of non-disabled people, despite studies that find disabled people feel they have

a good quality of life. ([Albrecht](#)) The fact is that people usually change their minds about wanting to die once they have adjusted to life with a disability, given services that enable them to remain in their own homes and emotional support to deal with feelings of loss and grief. ([Gill \(1\)](#), [Gill \(2\)](#)) For example in 2010, 32-year-old Dan Eley was on vacation in Colombia when he [broke his neck in a diving accident](#). He became paralyzed from the shoulders down. At first, he wanted to end his life in Switzerland, helped by the non-profit Dignitas. Mr. Eley's mother, Carolyn, agreed, on the condition that [he wait five years](#) before making a final judgment about his quality of life. In 2012, he founded [a non-profit](#) that helps young people in Columbia and the UK access education or employment. Mr. Eley continues to run the organization today.

Aside from the reasons outlined by Dr. Harvey [Chochinov](#), Paul [Applebaum](#) and others, we are concerned that allowing assisted dying solely for mental health reasons ([Webcast 17/09/01, American Psychiatric Association](#)) only codifies specific discrimination against people with psychiatric disabilities. This discrimination already manifests in a lack of parity between physical- and mental-health care; ([Coleridge](#)) where mental health services are so underfunded as to make them inadequate and unavailable to many who need them. ([Mental Health Commission of Canada](#)) This is both a reflection and perpetuation of the stigma associated with psychiatric disability; ([Chochinov](#)) the notion that mental illness is a character flaw that can be overcome with hard work and perseverance. ([Byrne](#)) Mental health treatment has moved away from interactive modalities toward the exclusive use of drug therapies over the past few decades, ([Davis](#)) and those whose needs do not respond to this narrow regime may find themselves abandoned by the system. ([Applebaum, DeRubeis](#)) The experience of the Netherlands and Belgium has shown that the majority of people who are euthanized because of psychiatric disabilities are women, and many were physically and sexually abused ([Webcast: 16/2/19](#)); thus death becomes a second form of victimization when the mental health system gives up on the person, rather than applying vigorous suicide prevention strategies. ([Poole, Moskowitz, Hamilton](#)) The evolution of the practice of euthanizing people with psychiatric disability in Belgium and the Netherlands gives us cause for concern. ([Groenewoud, Kim](#)) We are also worried about research showing that mental health professionals often harbour negative

feelings toward suicidal clients, which could have an adverse effect in the life-or-death equation. [\(Hicks\)](#)

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*\*Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

### **TVNDY webcasts relevant to the proposed areas of MAID expansion**

<b>Date</b>	<b>Topic &amp; link</b>
13/11/01	Euthanasia and Disability: <a href="#">Connection between devaluation of disabled children and euthanasia/assisted suicide</a> (relevant section: 16:12-26:40)
14/02/07	Euthanasia and Disability: BC Court decision in <a href="#">Margot Bentley case</a> – discussion of nonverbal consent/expression of preferences (relevant section: 3:50-11:00)
16/2/19	Euthanasia and Disability: A study of 66 cases of euthanasia for psychiatric reasons in the Netherlands shows <a href="#">70% were women</a> . (relevant section: 10:34-27:00)
16/4/1	Euthanasia and Disability: Discussion of the problems with <a href="#">Medical Orders for Life Sustaining Treatment</a> and advanced directives (relevant section: 4:27- 23:10 - skip the comments on official languages around 19:15 / on institution transfer around 22:45)
17/08/25	Euthanasia and Disability: Discussion of the problems with <a href="#">allowing euthanasia for "mature minors"</a> (relevant section: 1:17-19:22)



17/09/01	Euthanasia and Disability: Discussion of the problems with <a href="#">mental illness as the sole condition for euthanasia eligibility</a> (relevant section: 0:50-20:17)
17/09/08	Euthanasia and Disability: Discussion of the problems with <a href="#">allowing euthanasia in advanced directives</a> (relevant section: 0:36-16:59)

## Studies & Documents

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**Key section:** “The Alzheimer Society of Canada believes that because we cannot predict future suffering, providing advance consent for MAID should not be possible for people with dementia. The Alzheimer Society believes that people with dementia need to be safeguarded as they will be extremely vulnerable at the end of their life. People with dementia do not have the capacity to make an informed decision and consent to end their life at the later stages of the disease.”

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Byrne, Peter, Stigma of mental illness and ways of diminishing it, *Advances in Psychiatric Treatment* Jan 2000, 6 (1) 65-72; DOI: 10.1192/apt.6.1.65, Retrieved August 11, 2017 from <http://apt.rcpsych.org/content/6/1/65>

Canadian Pediatric Society. (2016, February 3). Submission to the Special Joint Committee on Physician-Assisted Dying. Retrieved August 9, 2017, from, [https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8092308/br-external/2016-02-03\\_PDAM\\_brief\\_Cdn\\_Paediatic\\_Society\\_e-e.pdf](https://www.ourcommons.ca/Content/Committee/421/PDAM/Brief/BR8092308/br-external/2016-02-03_PDAM_brief_Cdn_Paediatic_Society_e-e.pdf).

**Key section:** “The CPS believes that while the issues of suffering and autonomy play out in children as well as adults, it is not arbitrary to restrict any first iteration of Canadian Physician Assisted Death legislation to ‘adult’ patients (18 years).”

Chochinov, H. M. (2016, March 28). The Risky Concept Of Mental Illness Assisted Suicide. *Huffington Post*. Retrieved August 9, 2017, from [http://www.huffingtonpost.ca/harvey-max-chochinov/assisted-suicide-mental-illness\\_b\\_9541656.html](http://www.huffingtonpost.ca/harvey-max-chochinov/assisted-suicide-mental-illness_b_9541656.html)

Coleman, D. (1) (2010). Assisted suicide laws create discriminatory double standard for who gets suicide prevention and who gets suicide assistance: Not Dead Yet Responds to Autonomy, Inc. *Disability and Health Journal*, 3(1), 39-50. Retrieved August 9, 2017, from [http://www.disabilityandhealthjnl.com/article/S1936-6574\(09\)00089-2/fulltext](http://www.disabilityandhealthjnl.com/article/S1936-6574(09)00089-2/fulltext)

Coleman, D., (2) Lucas, C., Ne'eman, A., & Wolinsky, E. (2016, August 14). Letter to Wisconsin Department of Children and Families. Retrieved August 9, 2017 from, <http://notdeadyet.org/letter-to-wisconsin-department-of-children-and-families>

**Summary:** A letter from disability advocates Carrie-Ann Lucas, Emily Wolinsky, Diane Coleman, and Ari Ne’eman to the secretary of Wisconsin Department of Children and Families. The letter describes Jerika Bolen's desire to end her life and her disability in detail – including the necessary assistance she was not receiving – and summarizes reasons why authorities should intervene to provide suicide prevention and other life-saving services to Ms. Bolen and her family.

Coleman, D. (3) (2012, May 31.) Disability Perspective on Public Policy in Advance Care Planning. Retrieved August 9, 2017, from <http://notdeadyet.org/disability-perspectives-on-public-policy-in-advance-care-planning>

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**Summary:** This study shows the importance of support from family, friends, and medical professionals when adjusting to a newly-acquired disability or medical condition. It also shows the potential inability of medical professionals to provide sufficient information for informed consent when discussing interventions related to disabilities and life-altering medical conditions.

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**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

**Mature Minors**

UHN has no experience with requests for MAID by mature minors. Although we serve primarily an adult population, ~1% of patients seen annually at UHN are  $\leq 18$ . Among 11,042 patients under 18 seen in out-patient, in-patient, day surgery and emergency department visits at UHN in 2016, no MAID inquiries or requests were made.

**Advance Requests**

Our experience with MAID in the last year has identified many clinical challenges which we believe would be resolved by changing the law to include advance care directives.

**A. Before diagnosis**

Our experience of MAID eligibility assessments has been that patients interested in pursuing MAID are clear about their values and know well in advance the conditions under which they would want to receive MAID. Family members are also usually highly supportive of their loved ones MAID decisions, and would reliably be able to execute patients' wishes for MAID specified in an advanced directive as substitute decision makers (SDMs). This already is permitted and regularly occurs for decisions surrounding resuscitation orders, withdrawal of life support and palliative sedation. Normalization of MAID as an option within clinical care would be facilitated by its inclusion in advance directives, as with all other treatment options in palliative care.

**B. After diagnosis but before the onset of suffering.**

Approximately 15% of patients assessed for MAID have been declined because they were seeking the potential option of MAID in future, while simultaneously pursuing active treatment options. The denial of eligibility for MAID in such cases was often distressing, repeating the loss of control which had initially motivated their MAID request. It is also highly anxiety provoking for patients to know when the right time to apply is because suffering is a fluctuating and subjective state, and disease progression can be both precipitous and unpredictable at the end of life. Particularly with brain disease, patients fear loss of cognitive ability, which occurs on a continuum, and patients are not always able to assess for themselves when this is beginning. It has also been difficult for their physicians to guide patients in this decision, as the subtlety of distinguishing when a patient is requesting MAID in scenario B vs scenario C described below is difficult.

**C. After MAID approval**

The requirement for patients to be competent to provide consent at the time of receiving MAID has been challenging for several reasons. The option of having an SDM execute an advanced directive for a patient assessed and approved for MAID would resolve these difficulties.

Approximately 17% of patients approved for MAID did not receive it in the end because of difficulties determining the right time for intervention. These patients were certain in their intent to die by MAID, were approved on the basis of current psychological suffering related to the anticipation of future deterioration, and were waiting for some indication of imminent decline before determining a date. All were frustrated by the legal requirement to still be cognitively intact prior to administration of MAID as this meant potentially giving up days of competent life. In many cases fear of losing capacity has forced patients to die sooner than they needed to. MAID providers have found it difficult deal with the fact that most patients could have had some



more quality time before their death, but didn't dare risk losing capacity.

A further 14% of patients have waited many months before coming forward for MAID intervention, resulting in the need to repeat their MAID eligibility assessments as advised by the CMPA. This is both burdensome and anxiety-provoking for patients, and resource intensive for the medical system. There is currently no legal or clinical guidance available about next steps for when MAID approvals "expire", causing anxiety and uncertainty for MAID assessors.

Finally, in most cases, patients withhold pain medication, at the expense of increased suffering, to ensure that they retain the mental competence to provide informed consent at the last moment.

### Mental Illness

The MAID program at UHN has been developed and led within the Department of Supportive Care, and a psychiatrist has participated as an eligibility assessor in almost every MAID case at UHN. Based on our experience to date, we do not believe mental illness should be approved as a sole condition underlying a MAID request.

In cases where a mental illness was the sole medical condition, the perception of patients that they had a right to receive MAID was a significant barrier to engaging them in psychiatric care. For example, one patient developed an obsessional and delusional fixation on MAID, refusing psychiatric care and insisting on MAID assessment as her right, despite repeatedly being informed that she would not be found to be eligible. This patient ultimately required psychiatric admission for involuntary treatment. If MAID were permitted solely for mental illness, we believe this scenario would be much more common than the rare patient with psychiatric illness who retains capacity to consent for MAID. This would result in a fruitless resource burden on MAID assessors and a compromise of psychiatric care.

Even among psychiatric patients who retain capacity, the determination that their suffering is truly irremediable may be extremely difficult to ascertain. Another patient with a bipolar depression was admitted following a suicide attempt. This individual regarded psychiatric interventions, including medications and psychotherapy as unacceptable to her. She instead requested MAID and would likely have been capable to make this decision. However many social factors contributed to her decision, including the experience of an unsupportive spouse, and it would have been difficult to establish whether these factors were influencing or coercing the voluntariness of her decision. Such individuals with mental illness are a vulnerable population for whom we believe it would not be possible to clinically determine the irremediability of suffering or voluntariness, regardless of safeguards built into the law.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

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## **Briefing Note: Perceptions of MAiD offered by Partners in Care**

Thirteen former or current patients volunteered to participate in face-to-face individual interviews about their perspectives on Medical Assistance in Dying (MAiD) in order to inform UHN's approach to delivery of this service. The interviews were conducted in May and June of 2016 by members of the UHN Bioethics team and were guided by a conversation template (see Appendix). In total, the Partners in Care spent over twenty hours speaking with us about some of the issues that concern them most regarding MAiD. All of the Partners in Care, with the exception of one, reported that there were some circumstances under which they would consider requesting MAiD.

### **Overarching Themes**

Three broad themes emerged as areas of greatest importance to our Partners in Care:

1. Relationships matter
2. We need to do this well
3. MAiD is not merely a medical procedure

#### **1. Relationships matter**

All of the Patient Partners spoke about the importance of relationships in the context of MAiD. Many expressed a desire that their family members be emotionally and spiritually supported before, during, and after a medically assisted death. Participants also thought it imperative that health care providers (current teams and those who will care for them at the end of their lives) have a 'personal touch'; be consistently and readily available to them; exhibit openness; possess an ability to listen and communicate with honesty and compassion; and be able to establish or build on a foundation of trust.

*"You need a connection; otherwise it's like killing an animal. It is very profound."*

*"It should engage your family. Families can be scorched by the experience and scarred by each other."*

*"The conversations should be with clinicians where there is some kind of 'chemistry' or connection.... the personal is important and with those who know me well"*

*"... Build relationships, trust. Won't do anything without this trust. Without this, it [MAiD] may seem like it's about the burden of resources."*

#### **2. We need to do this well**

Many Patient Partners stressed the importance of "get[ting] this right" given the gravity of the decision and the finality of the intervention. All were insistent that healthcare staff members involved with MAiD be well prepared to assume the responsibilities associated with what they regarded as extraordinarily important work. Participants' concerns were not merely about getting the *technical aspects of the intervention right*; respondents also expected at least some members of their health care team to be *skilled at engaging in conversation* with those seeking information or expressing a desire to explore their options, values, and anxieties in relation to MAiD. Ensuring smooth and person-centered transitions to enable timely conversations and emotional support was considered essential in order to demonstrate respect for patient welfare and to ensure that we provide the highest standard of quality care. Finally, there was an expectation that UHN provide the *right kind of*

information, at the right time, and in the right way. This meant providing general information to the public about MAiD, and more specific information to those who make requests for the intervention. The educational needs that were identified related to the steps involved in the process itself, and what patients and their families might expect once patients have decided to pursue this option (e.g., what are the medications, how they will be delivered, what should the patient do to prepare for the act, where will it take place, how will family and loved ones be supported?). Empowering patients, families, and community members through education and accessible resources was viewed as crucial; participants suggested that information could be provided via a variety of formats (e.g., brochures, videos, posters, web testimonials).

*“I would like to know all my physicians and the assisted dying physician are coordinating with each other ... I would like my regular doctor even if he isn’t doing it to ask me questions...how is it going? Are you happy with the care you are getting?”*

*“Use a person with a lot of experience [in communication]. Language matters.”*

*“It is important that information be available if this is something a patient wants to know about....Keep materials in resource library downtown and we can check it out. All [staff members] have to know how to send patients to the expertise [and information they are seeking].”*

*“There needs to be very specific information about what to expect. Need to set expectations so patients know what to expect and to guide people along as they experience it.”*

### **3. MAiD is not merely a medical procedure**

Nearly all Patient Partners articulated the view that MAiD ought *not* to be regarded in the same matter-of-fact way as any other medical intervention. Participants stressed the very personal nature of the decision, observed that they were not simply concerned about access to a service, and suggested that death is a part of life and legacy-work. Nearly all respondents illustrated the importance of MAiD by offering vignettes drawn from their own illness narratives or by referencing the deaths of their parents or others close to them.

Few Patient Partners expressed strong preferences about the location of death. Many stated that wherever it was to take place, it should be imbued with meaning and allow friends and family to accompany them. For some participants this was seen as the termination of a long and difficult journey and the manner and timing of death was described as an important part of the legacy that they would leave behind. A couple of respondents suggested that they would not request MAiD at home, or another treasured location like a cottage, out of concern that the association with the place would become a burden for loved ones. Another conveyed the view that MAiD is a distinctive process by suggesting that it should not be part of the teaching side of the hospital. This respondent claimed that learners should not be involved because this is an “intimate, personal time” not appropriate to the involvement of “a bunch of people training.”

*“the transition from life to death is very profound. The transition must be smooth. The pull of fear can hurt the soul.”*

*“It would need to be a very personal conversation. It is like deciding to have a child - it’s another big life decision.”*

## **Concluding Remarks**

The UHN Partners in Care provided valuable patient-centred perspectives into how the complex practice of MAiD should be approached at UHN. Their diverse reflections were generous, intimate, and sometimes tearful. We are grateful for the opportunity to spend time with them and to benefit from their hard-won insights.

We recognize that members of the UHN Partners in Care have perspectives that are informed by their own engagement with the health care system. Many participants explicitly referenced their experiences as persons who had endured grave illness, injury, or disability. Those less acquainted with hospitals, or without significant health-related challenges, may have offered very different views. This is a limitation of our findings and we do not claim to have recruited a representative sample. We do, however, believe that the Partners in Care volunteer pool offers us an extraordinary opportunity to access perspectives on MAiD that might otherwise escape the notice of health care professionals and leaders.

It is our hope and theirs that this exercise will assist in UHN's efforts to provide Medical Assistance in Dying in a compassionate and person-centered, as well as technically proficient, manner.

Respectfully submitted,

Ann M Heesters on behalf of

UHN Bioethics

**Summary Table: Overarching Themes**

Theme	Description	Representative Quotes
<b>Relationships Matter</b>	Family members should not be abandoned by the clinical team during the MAiD process; healthcare providers need to respond compassionately and empathically in order to build and sustain trust.	<p><i>“It should engage your family. Families can be scorched by the experience and scarred by each other.”</i></p> <p><i>“You need a connection; otherwise it’s like killing an animal. It is very profound.”</i></p> <p><i>“If you make it about process not people, then you are a cog in the wheel of death ... Build relationships, trust. Won’t do anything without this trust”</i></p>
<b>We need to do this well</b>	This theme highlights importance of the technical, educational, and emotional competencies required to deliver MAiD. The theme also includes person-centred transitions and empowering patients, families, and community members through education and accessible resources in a variety of formats.	<p><i>“I would like to know all my physicians and the assisted dying physician are coordinating with each other... I would like my regular doctor even if he isn’t doing it to ask me questions...how is it going? Are you happy with the care you are getting?”</i></p> <p><i>“Use a person with a lot of experience [in communication]. Language matters.”</i></p> <p><i>“I would want to minimize the hand-offs [transitions] to nurses and then back and forth to doctors and ensure accuracy of the information.”</i></p>
<b>MAiD is not merely a medical procedure</b>	MAiD should <i>not</i> be considered in the same way as any other medical intervention; MAiD is considered more of a personal decision; death is a part of life and legacy-work.	<p><i>“It would need to be a very personal conversation. It is like deciding to have a child - it’s another big life decision.”</i></p> <p><i>[Referencing a person with advanced dementia] “my farewells were a long time ago... What value is there in the pain of this? Lack of connectivity matters... It’s not great pain [I fear] but being a burden to the wonderful people I love.”</i></p>

## Appendix

### MAID Interview Guide

The purpose of this interview is not to debate the morality of MAiD (whether it is right or wrong). We are engaging with you to help us better understand the informational needs of our patients and how the organization can best support patients and their loved ones in navigating MAiD.

Below are some questions for you to think about which will be the basis of our discussion when we meet:

- Can you imagine requesting MAID? If so, under what circumstances might that be?
- With whom on the clinical team would you (or the patients you know) feel most comfortable having a preliminary discussion about MAID?
- What would be important aspects to touch upon in this conversation?
- What conditions would make exploration of these issues most comfortable?
- Do you perceive any barriers to initiating this type of conversation? What might those be?
- How else would you like to learn about MAiD at UHN?
- What information would be *most helpful* for you (patients and families) to understand MAID at UHN?
- If you were to choose MAID, where would you prefer your assisted death to take place?
- UHN has outpatients as well as inpatients. How should resources and information about MAID be made available to patients and family members?
- Who should be the one to give information and answer patients/family members' questions?
- Is there any information that would be less helpful or can you think of an example of how MAID information should *not* be communicated?

**1. What are your organization's main issues concerning requests for MAiD by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

Although the three topics under consideration are challenging for our community, we believe that we have had an unusual opportunity to put them into perspective as bioethicists who engage end-of-life cases across the continuum of care. UHN is a high-volume adult tertiary-care hospital with a world-class cancer centre and several critical care units, but our team members have also supported long-term care facilities, rehabilitation and mental health facilities, and community care access centres. We interact daily with physicians, patients, families and staff and have held frank, intimate conversations about values with these stakeholders. In addition, our team regularly conducts MAiD education sessions, briefings and de-briefs. Our MAiD coordinator has been engaged with nearly every UHN MAiD case.

**Mature Minors**

UHN does not typically serve minors so this question has not yet arisen for us, although we do have specialty services which could receive children who might request MAiD if they were eligible. In Ontario, per HCCA, there is no minimum age for consent to healthcare decisions. Maturity including insight, and abilities for reasoning and judgment, is not solely contingent upon chronological age. Mature minors may be vulnerable to influence, but so too are many older adults, especially those with capacity and minor cognitive deficits. Further, we recognize how some adults may be rendered vulnerable by virtue of interdependent relationships with intimate others. These may be more difficult to navigate than in pediatrics where the instinct to protect a child from suffering (perhaps more easily evoked) might counter instincts to prolong life at the cost of intolerable suffering.

**Mental Illness**

With severe/chronic mental illness, and refractory depression in particular, cases can end in suicide or involve repeated suicide attempts. Depression can have a profoundly negative effect on families that may be unaware of the severity of their loved ones' struggles, until suicide ensues. MAiD may allow a very different outcome. In MAiD cases families are generally involved at the end of life. If due care is exercised, therefore, we see a potential for a less distressing outcome than is customary with this population. Furthermore, the option of MAiD may be comforting for mentally ill patients, who may struggle with loss of control and thoughts of suicide. We recognize that this is a fraught subject for some of our colleagues working in psychiatry, for whom refractory mental illness may seem like a treatment failure, and we do not minimize the challenges associated with efforts to perform effective capacity assessments in the context of illness that results in a variable capacity, or only local capacity, to make treatment decisions. However, the problems that capacity assessments present for the mentally ill arise on a daily basis, and much of the time patients are found capable of directing their own care. This includes cases involving the withdrawal, or refusal, of life-sustaining treatments.

The problems plaguing capacity assessments in healthcare are not unique to MAiD and caution should be taken to ensure that efforts to single out this population are not the result of stigma. Advocates have made great efforts to disrupt the arbitrary distinction between mental and physical illness. For reasons of biology and physiology, as well as history, mental illness (and its associated suffering) may not be taken as seriously as physical illnesses. This has led to gross inequities in funding, treatment, and support relative to the burden of disease. A member of our team has prepared an unpublished survey of literature pertaining to capacity assessment and



we append the reference at the end of this document.

Finally, we recognize that mental illness may make some patients susceptible to manipulation (as, in fact, may any illness). Family, religion, cultural norms may play important roles with respect to illness, and ought to be sensitively addressed. MAiD teams must be able to provide psychosocial support to these patients, and be aware of the complexities of a patient's illness, if they are to optimize their ability to make choices.

Finally, we note that in countries where patients with a sole mental health diagnosis can qualify for assisted dying, it is a rare occurrence. However, creating a dichotomy between physical and mental suffering is dangerous. The healthcare community has been moving in the direction of considering "total pain," and viewing physical and mental suffering as equally valid experiences. One must consider whether the rights of the mentally ill will be violated, if they are denied access to MAiD.

#### Advance requests

Although we support the idea that advance requests for MAiD ought to be permissible under some circumstances we note that the time before a clear diagnosis might present difficulties. Many patients may not yet be able to fully comprehend or imagine their future. Advance requests rely on the assumption that persons can reliably project themselves into the future and know what healthcare decisions they would make should they be unable to speak for themselves. This, however, is a general limitation of advance requests. Many people have not had the lived-experience of a grievous and irremediable medical condition or of intolerable suffering, but a number have been caregivers, friends, or family members of someone who suffered at life's end and will be motivated sufficiently to write an advance request. We do not rule out the possibility that this could be appropriate.

The time after diagnosis is far less problematic - especially once any initial shock has dissipated. Advance requests seem especially meaningful for illnesses where there is no known cure or where decline is predictable: Huntington's, muscular dystrophies, highly malignant cancers with little expectation of remission, Alzheimer's or other dementias, etc. We also recognize that the inability to make an advance request may compel some patients to shorten their lives out of fear that they ultimately may become incapable of making the request. Our staff members have observed first-hand the suffering caused by the legislative requirement that patients retain the capacity to consent at the time that the intervention is delivered. We know that delirium and pain medication can interfere with the ability to consent and this has caused a great deal of needless anxiety and distress; therefore we maintain that retained capacity is not essential after assessment and approval for MAiD.

## **2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAiD as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

#### References:

A. Heesters. Briefing Note to UHN Leadership on Views of Patient Partners on Medical Assistance in Dying. [Unpublished internal document drawing on interviews with thirteen patient partners prior to the enactment of MAiD legislation in Canada].

M. Li, S. Watt, M. Escaf, M. Gardam, A. Heesters, G. O'Leary, G. Rodin. From Legislation to

Implementation: A Hospital-Based Program of Medical Assistance in Dying. *New Eng J Med.*, 376:2082-2088, 2017.

Shanker RR. A Review of the Literature on Capacity Assessment Tools within Mental Health Practice. University of Toronto Joint Centre for Bioethics [Internet] [cited 2017 Oct 4]; Available from: <http://jcb.utoronto.ca/news/documents/JCB-MAID-Briefing-Documents-Review-of-the-Literature.pdf>

**1. What are your organization's main issues concerning requests for MAID by mature minors, advance requests, and/or where mental illness is the sole underlying medical condition?**

The Joint Centre for Bioethics MAID Implementation Task Force, MAID Advance Request Working Group is currently conducting a systematic review of the literature related to; Advance Directives, Advance Requests, Advance Consent, Capacity and Advance Directives, Autonomy, Precedent Autonomy, Concepts of Personhood for those with Dementia or other Cognitive Deficits. Our review will examine the literature related to the history and function of Advance Directives, their utilization, strengths, weaknesses, challenges with interpretation and understanding the meaning of language employed in such directives and possible application to the question of MAID in the Canadian context. Our literature review currently includes more than 140 scholarly, peer reviewed publications. We are using a double blind methodology for the review of the literature, with each reviewer being blind to the comments and classifications of the other reviewer. Our review also includes examining the literature and evidence from jurisdictions outside of Canada that currently permit the use of Advance Directives for the provision of MAID. We have preliminarily identified the following themes and threads running through the literature; concepts of suffering, anticipatory suffering, future suffering, personhood, autonomy, precedent autonomy, capacity, consent, cognitive impairment and personhood and impact of dementia to understandings of self. We will also be undertaking a gap analysis in order to better understand what the evidence and literature do not currently address with relation to the above mentioned themes.

We anticipate completing our work by the end of calendar year 2017 and would respectfully request leave to submit our completed analysis at that time. We wish to be respectful of the time and efforts of the CCA and regret being unable to submit a completed assessment by the requested deadline of September 22, 2017 but we wish to ensure that our analysis is thorough and comprehensive.

**2. Please identify or provide relevant knowledge\* that your organization would like to have considered by the CCA Expert Panel on MAID as it relates to mature minors, advance requests, and/or where mental illness is the sole underlying medical condition. Please provide web links, references, or attachments.**

*\* Relevant knowledge includes but is not limited to the following: studies, surveys, regulations, guidelines, traditional knowledge, practices, and clinical cases.*

N/A