

MEDICAL ASSISTANCE IN DYING IN CANADA: CHOICES FOR CANADIANS

Report of the Special Joint Committee on Medical Assistance in Dying

Hon. Marc Garneau and Hon. Yonah Martin Joint Chairs

FEBRUARY 2023
44th PARLIAMENT, 1st SESSION

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THE SPECIAL JOINT COMMITTEE ON MEDICAL ASSISTANCE IN DYING

has the honour to present its

SECOND REPORT

Pursuant to its Orders of Reference from the Senate on Thursday, March 31, 2022, Wednesday, May 4, 2022, Thursday, September 22, 2022, Thursday, October 6, 2022, and Wednesday, February 1, 2023 and from the House of Commons on Wednesday, March 30, 2022, Monday, May 2, 2022, Thursday, June 23, 2022, and Wednesday, October 5, 2022, the committee has completed its statutory review of the provisions of the *Criminal Code* relating to medical assistance in dying and their application and has agreed to report the following:

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LIST OF ACRONYMS

AMAD Special Joint Committee on Medical Assistance in Dying

(1st Session, 44th Parliament)

CAMAP Canadian Association of MAID Assessors and Providers

MAID medical assistance in dying

MAID MD-SUMC medical assistance in dying where mental disorder is the sole

underlying medical condition

PDAM Special Joint Committee on Physician-Assisted Dying (1st Session,

42nd Parliament)

SUMMARY

In 2014, Quebec enacted its <u>Act respecting end-of-life care</u>, which includes rules relating to "medical aid in dying." In 2015, the Supreme Court of Canada declared in <u>Carter v. Canada (Attorney General)</u> that the sections of the <u>Criminal Code</u> (Code) that prohibited assisted death infringed the <u>Canadian Charter of Rights and Freedoms</u>. In June 2016, <u>Bill C-14</u>, An Act to amend the <u>Criminal Code and to make related amendments to other Acts (medical assistance in dying)</u> received Royal Assent. The amendments to the Code allow a person aged 18 or older who has a grievous and irremediable medical condition and whose natural death is reasonably foreseeable to access medical assistance in dying (MAID), provided that they meet certain additional requirements.

In 2021, the MAID law was revised by Bill C-7, An Act to amend the Criminal Code (medical assistance in dying). Following this change, people who do not have a reasonably foreseeable natural death can apply for MAID. However, the law specifies that you cannot apply for MAID if your sole medical condition is a mental disorder until March 2023. These changes were in response to the decision of the Superior Court of Quebec in *Truchon c. Procureur qénéral du Canada* (*Truchon*). Truchon held that the reasonably foreseeable death requirement under the Code and the end-of-life requirement under Quebec's legislation were contrary to the Charter. With the new amendments, there are two "tracks" for MAID applications: "track one" for people whose natural death is reasonably foreseeable, and "track two" for people whose natural death is not reasonably foreseeable. There is no waiting period for people who apply under track one. People who apply under track two have a 90-day waiting period, which can be waived if someone is going to imminently lose capacity to consent to MAID.

Bill C-7 required that an expert panel look at issues relating to MAID where a mental disorder is the sole underlying medical condition (MAID MD-SUMC). The Expert Panel on MAID and Mental Illness was established in August 2021, and released its <u>Final Report of the Expert Panel on MAID and Mental Illness</u> in May 2022.

Bill C-7 required that a parliamentary committee review the law. Bill C-14 had also required a parliamentary committee review but that review had not taken place before

^{1 &}lt;u>Carter v. Canada (Attorney General)</u>, 2015 SCC 5.

^{2 &}lt;u>Truchon c. Procureur général du Canada</u>, 2019 QCCS 3792.

Bill C-7 was introduced. According to Bill C-7, the review had to include the following five issues:

- the state of palliative care in Canada;
- protections for Canadians with disabilities;
- MAID MD-SUMC;
- MAID for mature minors; and
- advance requests for MAID.

A special committee of the House of Commons and the Senate was established for this purpose (Special Joint Committee on Medical Assistance in Dying), and it started its study of the MAID law in May 2021. However, the study was interrupted by the federal election. The committee started meeting again in April 2022. It released an interim report on MAID MD-SUMC in June 2022, and then continued to hear from witnesses in the fall of 2022.

In total, the committee held 36 meetings and heard from close to 150 witnesses. It also received more than 350 briefs and other correspondence, demonstrating the level of engagement on this issue.

One theme that cuts across many of the topics the committee examined is the importance of MAID training materials for healthcare professionals. These training materials, which are being developed by the Canadian Association of MAID Assessors and Providers, will help standardize approaches to MAID assessments across Canada. The committee also heard that there needs to be better engagement with Indigenous Peoples and communities on MAID, including MAID for mature minors and MAID MD-SUMC, as well as with persons with disabilities.

On the topic of palliative care, the committee heard that not everyone has access to palliative care, and that access can depend on where you live. Witnesses talked about the need for palliative care to be provided earlier and not only at end-of-life.

For persons with disabilities, the committee heard that more financial supports are needed so that persons with disabilities do not live in poverty. Better access to social supports, disability supports and healthcare are also important. Without these, the committee heard that persons with disabilities might see MAID as a way to relieve suffering due to poverty and lack of services. Unless their natural death is reasonably

foreseeable, a person who is applying for MAID on the basis that their disability is a grievous and irremediable medical condition would apply under track two. Much discussion focused on how to balance protecting people who might be vulnerable with allowing MAID for individuals who want to have access to that choice. A bill that will establish a federal disability benefit was introduced in June 2022,³ and in October 2022, the federal government released Canada's Disability Inclusion Action Plan, 2022. In addition to recommending continued support for persons with disabilities, the committee recommends examining the language in the *Criminal Code* MAID provisions to make sure that they do not contribute to stigma.

Access for MAID MD-SUMC was to be permitted as of March 2023. Applying for MAID MD-SUMC would also be under track two. As mentioned above, the committee released an interim report on mental disorder in June 2022 that discusses issues related to MAID MD-SUMC. The committee heard concerns that more time was needed to make sure that standards are in place before someone is able to apply for MAID MD-SUMC. On 15 December 2022, an announcement was made that the federal government would "work with our parliamentary colleagues in the House of Commons and the Senate to negotiate an extension of the March 17, 2023 eligibility date" for MAID MD-SUMC. The committee supports this extension. Bill C-39, An Act to amend An Act to amend the Criminal Code (medical assistance in dying) was introduced in the House of Commons on 2 February 2023 and proposes a one year delay to the date for eligibility for MAID MD-SUMC.

For MAID and mature minors, the committee heard a mix of views about whether MAID should be available to those under the age of 18. Many witnesses believed that age alone does not determine whether someone is capable of consenting to MAID. At the same time, a cautious approach was recommended, especially since there is little evidence from youth themselves on this topic. Most witnesses agreed that if MAID for mature minors were allowed, it should only be under track one (reasonably foreseeable natural death). The committee recommends that mature minors should have access to MAID under track one. The committee also recommends that youth be consulted on the topic of MAID and mature minors.

Finally, the committee heard that there is significant support among Canadians to be able to make an advance request for MAID. A key requirement for MAID is that a person have the capacity to consent to its provision. When someone has a diagnosis that involves the future loss of capacity, such as dementia, an advance request would allow

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Bill C-22, An Act to reduce poverty and to support the financial security of persons with disabilities by establishing the Canada disability benefit and making a consequential amendment to the *Income Tax Act*.

the person to indicate under what conditions they would like MAID to be provided in future. The advance request would have to be made while the person still has capacity. The committee heard details about what the advance request should contain, and that the request should be periodically reviewed. While most of the details relating to advance requests fall to the provinces and territories since they are primarily responsible for healthcare, the *Criminal Code* would still need to be amended to allow advance requests, and the committee supports amending the *Criminal Code* in that manner.

LIST OF RECOMMENDATIONS

As a result of their deliberations committees may make recommendations which they include in their reports for the consideration of the House of Commons or the Government. Recommendations related to this study are listed below.

Recommendation 1

That the Government of Canada, in partnership with provinces and territories,	
continue to facilitate the collaboration of regulatory authorities, medical	
practitioners and nurse practitioners to establish standards for medical	
practitioners and nurse practitioners for the purpose of assessing MAID	
requests, with a view to harmonizing access to MAID across Canada	20

Recommendation 2

That the Government of Canada, through relevant federal departments and in	
collaboration with relevant regulatory authorities, medical practitioners, and	
nurse practitioners, continue to address the quality and standardization of	
MAID assessment and delivery	20

Recommendation 3

That, every six months, Health Canada provide updates to the House of	
Commons Standing Committee on Indigenous and Northern Affairs and the	
Standing Senate Committee on Indigenous Peoples on its engagement with	
First Nations, Inuit and Métis on the subject of MAID.	22

Recommendation 4

Recommendation 5

That the Government of Canada, through Correctional Service Canada, support	
approved track one MAID recipients being able to die outside a prison setting	
only for the event itself and any immediate preparatory palliative care that	
is required	. 24

Recommendation 6

Recommendation 7

That, with the understanding that palliative care is not a prerequisite to access or receive MAID, the Government of Canada work in partnership with the provinces and territories on the following action items:

- a) Continue the National Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada and look into innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with life-limiting illness and their caregivers.
- b) Support the efforts of provinces and territories to develop initiatives aiming to improve home-based palliative care and culturally appropriate palliative care for underserved populations as well as access to this care.
- c) Identify ways to improve access to high-quality, culturally appropriate, palliative and end-of-life care, in a timely manner by:
 - Supporting palliative home care;
 - Supporting specialized paediatric palliative care; and

Supporting access to advance care planning29
Recommendation 8
That the Government of Canada, in collaboration with the provinces and territories, work to develop data systems to collect disaggregated data for Black, Indigenous, racialized, disabled, and 2SLGBTQ+ communities beyond the regulations that went into force January 1, 2023
Recommendation 9
That Health Canada review the Special Access Program, other programs and policies, and relevant laws and regulations to determine whether there are ways to improve access to promising therapies, such as psilocybin, for both research purposes and for individual use as part of palliative care supports 32
Recommendation 10
That the Government of Canada continue to support persons with disabilities by implementing measures to reduce poverty and ensure economic security 40
Recommendation 11
That the Government of Canada, through the Department of Justice, and in consultation with organizations representing persons with disabilities, explore potential amendments to the <i>Criminal Code</i> that would avoid stigmatizing persons with disabilities without restricting their access to MAID. Options considered should include replacing references to "disability" in section 241.2(2) of the <i>Criminal Code</i> , with attention to the potential legal ramifications of such an amendment across Canada
Recommendation 12
That the Government of Canada convene an expert panel to study and report on the needs of persons with disabilities as they relate to MAID, similar to the Expert Panel on MAID and Mental Illness

Recommendation	13
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That, five months prior to the coming into force of eligibility for MAID where a mental disorder is the sole underlying medical condition, a Special Joint Committee on Medical Assistance in Dying be re-established by the House of Commons and the Senate in order to verify the degree of preparedness attained for a safe and adequate application of MAID (in MD-SUMC situations). Following this assessment, the Special Joint Committee will make its final recommendation to the House of Commons and the Senate
Recommendation 14
That the Government of Canada undertake consultations with minors on the topic of MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, within five years of the tabling of this report
Recommendation 15
That the Government of Canada provide funding through Health Canada and other relevant departments for research into the views and experiences of minors with respect to MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, to be completed within five years of the tabling of this report
Recommendation 16
That the Government of Canada amend the eligibility criteria for MAID set out in the <i>Criminal Code</i> to include minors deemed to have the requisite decision-making capacity upon assessment
Recommendation 17
That the Government of Canada restrict MAID for mature minors to those whose natural death is reasonably foreseeable
Recommendation 18
That the Government of Canada work with provinces, territories and First Nations, Inuit and Métis communities and organizations to establish standards for assessing the capacity of mature minors seeking MAID

Recommendation 19
That the Government of Canada establish a requirement that, where appropriate, the parents or guardians of a mature minor be consulted in the course of the assessment process for MAID, but that the will of a minor who is found to have the requisite decision-making capacity ultimately take priority 65
Recommendation 20
That the Government of Canada appoint an independent expert panel to evaluate the <i>Criminal Code</i> provisions relating to MAID for mature minors within five years of the day on which those provisions receive Royal Assent, and that the panel report their findings to Parliament.
Recommendation 21
That the Government of Canada amend the <i>Criminal Code</i> to allow for advance requests following a diagnosis of a serious and incurable medical condition disease, or disorder leading to incapacity
Recommendation 22
That the Government of Canada work with provinces and territories, regulatory authorities, provincial and territorial law societies and stakeholders to adopt the necessary safeguards for advance requests
Recommendation 23
That the Government of Canada work with the provinces and territories and regulatory authorities to develop a framework for interprovincial recognition

of advance requests.......74



INTRODUCTION

For decades, Canadian courts and legislators have grappled with the issue of assisted dying. In 2014, following a years-long consideration of the issue by the legislature and the provincial government, Quebec enacted its <u>Act respecting end-of-life care</u>. Part of this law set out rights with respect to end-of-life care as well as rules relating to "medical aid in dying."

In 2016, in response to the Supreme Court of Canada decision in Carter v. Canada (Attorney General)¹(the Carter decision), the Criminal Code (Code) was amended to allow medical assistance in dying (MAID) for individuals whose natural death is reasonably foreseeable (i.e. "track one"), provided that they meet certain criteria. The law was later amended to allow MAID for individuals whose natural death is not reasonably foreseeable (i.e. "track two"). There is no waiting period for people who apply under track one. People who apply under track two have a 90-day waiting period, which can be waived if someone is going to imminently lose capacity to consent to MAID.²

Who should have access to MAID in Canada is the subject of fierce debate. How can the law protect vulnerable individuals while at the same time respect autonomy and individual choice? How do barriers to accessing healthcare, social and financial supports potentially affect a choice to seek MAID? Was the expansion of MAID beyond those whose natural death is reasonably foreseeable part of a "slippery slope?" These are but a few of the issues that the Special Joint Committee on Medical Assistance in Dying (the committee) has wrestled with over the last nine months as it undertook its review of the MAID law and its application, which included examining the state of palliative care in Canada, protections for Canadians with disabilities, MAID where mental disorder is the sole underlying medical condition (MAID MD-SUMC), MAID for mature minors, and advance requests for MAID.

During the course of its study, the committee heard from close to 150 witnesses and received more than 350 briefs and other correspondence. The considerable interest in the work of this committee speaks volumes about the prominence this issue holds for

¹ Carter v. Canada (Attorney General), 2015 SCC 5.

For a comparison of the requirements for "track one" versus "track two," see Table 1 – Comparison of the Current Safeguards with the Safeguards Provided for in Bill C-7 by Julia Nicol and Marlisa Tiedemann, <u>Legislative Summary of Bill C-7: An Act to amend the Criminal Code (medical assistance in dying)</u>, Publication No. 43-2-C7-E, Library of Parliament, Ottawa, revised 19 April 2021.



Canadians. Witnesses included healthcare practitioners, academics, and lawyers, as well as advocacy and religious organizations. The committee also heard from individuals directly affected by MAID. The committee's sincere appreciation for those who shared such personal experiences, including stories of loss, grief, suffering and vulnerability, cannot be overstated.³

The committee recognizes that for many individuals, the topic of MAID relates to deeply held moral and religious values. Some Canadians believe that MAID is not acceptable under any circumstances, and some Canadians believe that the current eligibility for individuals with disabilities whose natural deaths are not reasonably foreseeable singles them out. However, others believe that the current MAID law continues to exclude individuals who should have access to MAID, in some circumstances infringing their rights under the *Canadian Charter of Rights and Freedoms* (Charter). With that in mind, the committee has thoughtfully considered the issues brought forward by witnesses and in briefs and shares its summary of the debates and its recommendations below.

PARLIAMENTARY AND LEGISLATIVE BACKGROUND

In 2015, the Supreme Court of Canada declared in the <u>Carter</u> decision that sections 241(b) and 14 of the Code, which prohibited assisted death, infringed the section 7 Charter right to life, liberty and security of the person.

In response to that decision, Parliament established the Special Joint Committee on Physician-Assisted Dying (PDAM) to make recommendations "on the framework for a federal response." PDAM tabled its report in February 2016, 4 and soon after, the government introduced Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). The bill received Royal Assent in June 2016, allowing individuals aged 18 or older who have capacity to consent and who have a grievous and irremediable medical condition and whose natural death is reasonably foreseeable to access MAID, provided that certain additional requirements are met.

Bill C-14 required that three key issues that were considered by PDAM—MAID for mature minors, advance requests for MAID, and MAID for individuals where a mental disorder is the sole underlying medical condition (MAID MD-SUMC)—were to be the

3 The briefs are listed on the <u>Special Joint Committee on Medical Assistance in Dying</u>'s website.

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⁴ Parliament of Canada, Special Joint Committee on Physician-Assisted Dying, <u>Medical Assistance in Dying: A Patient-Centred Approach</u>, 1st Session, 42nd Parliament, February 2016.

subject of independent reviews. ⁵ These reviews were carried out by the <u>Council of</u> <u>Canadian Academies</u> and released in 2018. Bill C-14 also required that a parliamentary committee review the law (statutory review) five years after Royal Assent.

The Code provisions related to MAID were amended again in 2021 by <u>Bill C-7</u>, <u>An Act to amend the Criminal Code (medical assistance in dying)</u> to allow individuals with a grievous and irremediable medical condition but whose natural death is not reasonably foreseeable to access MAID. These amendments were in response to the decision of the Superior Court of Quebec in *Truchon c. Procureur général du Canada* (the *Truchon* decision). The *Truchon* decision held that the reasonably foreseeable death requirement under the Code was contrary to the Charter rights to life, liberty and security of the person (section 7) and equality (section 15) and that the end-of-life requirement under Quebec's legislation was also contrary to the right to equality. The infringements were not justified under section 1. Neither the Government of Canada nor the Government of Quebec appealed the decision in *Truchon*.

While Bill C-7 initially excluded eligibility for MAID MD-SUMC, additional amendments to the final version provided that an individual would be able to apply for MAID MD-SUMC as of 17 March 2023. The final version of Bill C-7 also required an independent expert review relating to MAID MD-SUMC.⁷

In addition, as the parliamentary committee statutory review required by Bill C-14 had not yet taken place, section 5 of Bill C-7 required that a joint parliamentary committee be established to review the Code's MAID provisions and their application, as well as "issues relating to mature minors, advance requests, mental illness, the state of palliative care in Canada and the protection of Canadians with disabilities."

The statutory review began in May 2021. However, the committee only held a few meetings due to the dissolution of the 43rd Parliament at the call of the federal election in August 2021. It was re-established in March 2022. The committee released an interim

⁵ Bill C-14, clause 9.1.

^{6 &}lt;u>Truchon c. Procureur général du Canada</u>, 2019 QCCS 3792.

⁷ Bill C-7, clause 3.1(1).



report on MAID MD-SUMC in June 2022,⁸ and the government provided its response to that report in October 2022.⁹

On 15 December 2022, the Honourable David Lametti, Minister of Justice and Attorney General of Canada, the Honourable Jean-Yves Duclos, Minister of Health, and the Honourable Carolyn Bennett, Minister of Mental Health and Addictions and Associate Minister of Health, released a statement indicating that "our government intends to work with our parliamentary colleagues in the House of Commons and the Senate to negotiate an extension of the March 17, 2023 eligibility date," ¹⁰ which is the date on which eligibility for MAID MD-SUMC will be permitted. This extension is supported by witness testimony, and the committee endorses this decision by the ministers. Bill C-39, An Act to amend An Act to amend the Criminal Code (medical assistance in dying) was introduced in the House of Commons on 2 February 2023 and proposes a one year delay to the date for eligibility for MAID MD-SUMC.

SYSTEMIC AND PRACTICAL ISSUES

Who is Accessing MAID?

Dr. James Downar, Critical Care and Palliative Care Physician, told the committee that, for the most part, those who request MAID "almost invariably have excellent access and are receiving palliative care far more than the average population." Dr. James Downar and lawyer Bryan Salte from the College of Physicians and Surgeons of Saskatchewan pointed to evidence suggesting that those who are accessing MAID in Canada are not marginalized individuals. Professor Constance MacIntosh believed that physicians would be able to recognize cases involving social disadvantage or a lack of supports, and may not approve MAID in such cases. According to Jocelyn Downie, University Research Professor, Faculties of Law and Medicine, Dalhousie University, and Dr. Derryck Smith, Clinical Professor Emeritus, Department of Psychiatry, University of British Columbia, empirical research from several jurisdictions fails to demonstrate that MAID presents a risk to vulnerable populations, including persons with disabilities. These witnesses suggested that, if anything, vulnerable populations face barriers to accessing MAID.

Parliament of Canada, Special Joint Committee on Medical Assistance in Dying, <u>Medical Assistance in Dying and Mental Disorder as the Sole Underlying Condition: An Interim Report</u>, 1st Session, 44th Parliament, June 2022.

⁹ Minister of Health, <u>Government Response to the First Report of the Special Joint Committee on Medical</u>
Assistance in Dying, 20 October 2022.

Statement by Ministers Lametti, Duclos and Bennett on medical assistance in dying in Canada, 15 December 2022.

<u>Dr. Harvey Max Chochinov</u>, Distinguished Professor of Psychiatry, University of Manitoba, however, suggested that data in Canada relating to who is accessing MAID is limited at this point since it relates primarily to those whose natural death is reasonably foreseeable.

Nurse practitioner <u>Diane Reva Gwartz</u> pointed to some of the barriers to accessing MAID:

Unfortunately, in many communities [,] institutional policies prevent the provision of MAID to those requesting it. For example, in my community, due to hospital policies and resources, it is difficult to receive MAID in the hospital system. The rehabilitation centre and hospice both have policies that specifically prohibit the provision of MAID in their centres. It is inequitable and unjust that individual institutions are able to establish policies that deprive those who require their services the opportunity to access an assisted death.

She also told the committee that geography can impede access to MAID, and that there is limited awareness of MAID among patients and families. The small numbers of MAID assessors and providers can also limit access; ¹¹ this challenge is likely to be exacerbated as more individuals become eligible to apply for MAID. ¹² The committee heard that addressing the lack of remuneration for nurse practitioners involved in MAID assessments and provisions might improve access. ¹³

Access to Healthcare

Access to healthcare is one of many social determinants of health. A number of witnesses commented on how challenges accessing both primary and specialized healthcare affect individuals in the context of MAID. For example, in response to a question about whether he had observed situations in which a patient was informed that there were no doctors available to provide treatment appropriate to their condition and were then offered MAID, Dr. Félix Pageau, Physician, Geriatrician and Ethicist, Université Laval, told the committee that "a contentious case came up in the research I conducted for my master's degree." When asked whether there were any statistics

Parliament of Canada, Special Joint Committee on Medical Assistance in Dying (AMAD); *Evidence*, 25 April 2022 (Diane Reva Gwartz; Dr. Stefanie Green); *Evidence*, 7 October 2022 (Mike Kekewich).

¹² Evidence, 25 April 2022 (Gwartz).

^{13 &}lt;u>Evidence</u>, 25 April 2022 (Gwartz); <u>Evidence</u>, 21 October 2022 (Julie Campbell).

The list of "social determinants of health" can vary by organization. See for example, <u>Social Determinants of Health</u>, World Health Organization, and Government of Canada, <u>Social determinants of health and health inequalities</u>.



available to show the frequency of this happening, Dr. Pageau replied that "[a]ccording to Quebec data, one of the primary reasons why people request medical assistance in dying is that they feel they aren't getting appropriate services or treatment." The committee notes that this reference to Quebec data conflicts with the 2021–2022 Annual Report of Quebec's Commission on end-of-life care, which explains that 66% of individuals who received MAID had a cancer diagnosis. In addition, 65% of individuals who received MAID had a survival prognosis of three months or less and 84% of individuals who received MAID had a survival prognosis of one year or less. In addition, 65% of individuals who received MAID had a survival prognosis of one year or less.

As part of consultations with members, <u>Tim Guest</u>, Chief Executive Officer of the Canadian Nurses Association, told the committee that "we heard that limited access to primary care in rural and remote settings has led to patients directly reaching out to urban centres for MAID services." He also stated that individuals may access MAID sooner than they would have if they had better access to health and social services. Nurse practitioner <u>Julie Campbell</u> told the committee that "[a]s we increase the complexity of patients who may be eligible [for MAID], we need to access expertise in a variety of conditions, including services with significant waiting lists, like specialty pain and psychiatric supports."

With respect to the social determinants of health, <u>Dr. James Downar</u> told the committee:

I think it's very important to say that we really do need to address social determinants of health, including housing, food security, pharmacare and dental care, because these are important to the health of all Canadians. I think it's important to recognize that these measures are really not about medical assistance in dying at all, because structurally vulnerable individuals are already far less likely to use medical assistance in dying than anybody else. We should do these things simply because they're a good idea and the right thing to do.

<u>Dr. Stefanie Green</u>, President of the Canadian Association of MAID Assessors and Providers (CAMAP), MAID Practitioner, and Advisor to the BC Ministry of Health, explained the challenges inherent to the MAID evaluation process when access to healthcare or other supports is lacking:

what do we do in a situation when someone truly meets the criteria of eligibility for MAID but the clinician believes that maybe something more could be offered that's not actually reasonably available to that patient? That's causing distress in some of my colleagues, and we are not moving those cases forward, but we do ask that the

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Commission sur les soins de fin de vie, <u>Rapport annuel d'activités</u>, December 2022, p. 16 [AVAILABLE IN FRENCH ONLY].

¹⁶ Ibid.

government, federally and provincially, help to fix that situation and help make more robust the resources that can be made available.

According to <u>Dr. Stefanie Green</u>, "MAID and community resources for mental health, palliative care, and disability supports [should] be developed and supported in parallel."

Psychiatrist <u>Dr. Cornelia Wieman</u>, stressed the importance of understanding "access" broadly:

[It's] not just having a health care professional team or services available to provide care in a reasonable amount of time. Medical care and attention can be impeded by people choosing not to access services because of, in this instance, anti-[I]ndigenous racism and discriminatory treatment. Indigenous people choose not to access health services out of a fear of how they will be treated.

Jurisdictional Issues and Harmonization

While there is no specific reference to "health" under sections 91 and 92 of the <u>Constitution Act, 1867</u>, section 92(7) gives provinces jurisdiction over most hospitals. Many other health-related matters, such as the delivery of healthcare services, the practice of medicine, and the regulation of health professionals, are also within provincial jurisdiction based on sections 92(13) and 92(16).

At the same time, Parliament can and has exercised its jurisdiction over health matters under its criminal law power (section 91(27)), the federal spending power (section 91(1A)), and its general taxing power (section 91(3)). Through its spending power, the federal government may establish conditions for federal healthcare grants to the provinces and territories, including conditions that are within provincial jurisdiction and therefore cannot be directly legislated by Parliament.¹⁷

Several witnesses stressed the need to ensure that MAID-related laws, policies and practices are consistent across the country. Professor <u>Jennifer Chandler</u> spoke to the challenges of harmonization in a federal state. While detailed regulation at the federal level could be viewed as encroaching on provincial healthcare jurisdiction, provinces and territories may develop inconsistent approaches if given too much leeway. <u>Jennifer Chandler</u> saw professional associations such as CAMAP as a promising source for developing a consistent approach to MAID across Canada.

For additional details, please see Martha Butler and Marlisa Tiedemann, <u>The Federal Role in Health and Health Care</u>, Publication no. 2011-91-E, Library of Parliament, 20 September 2013.



According to <u>Dr. Donna Stewart</u>, Professor, University of Toronto, Senior Scientist, Toronto General Hospital Research Institute, Centre for Mental Health, "[i]t's essential that federal, provincial and territorial governments work to facilitate collaboration between physician and nurse regulatory bodies in the development of standards of practice for MAID." She suggested that this could avoid cumbersome legislation.

<u>Bryan Salte</u> was similarly in favour of relying on the judgment of medical professionals, under the guidance of regulatory bodies:

I am a regulator. I've worked with professional regulation for a long time. One role of professional regulation is to ensure that professional standards are upheld. One concern I would have, if this was incorporated in some form of regulation or statute, is that it is then difficult to change and it really may be quite rigid in terms of how it is addressed. I would support the minimum level of safeguards incorporated into the legislation [....]

In terms of any additional requirements, I think you can rely upon the regulators across Canada to provide guidance, which I think we have done. When we provide that guidance to our members, we say what we expect of them if they are to be involved in medical assistance in dying.

The committee heard that discrepancies in wording between the Code and Quebec's <u>Act respecting end-of-life care</u> are causing confusion among healthcare providers and patients. ¹⁸ In particular, <u>Dr. Louis Roy</u>, Physician, Collège des médecins du Québec, and <u>Dr. Mauril Gaudreault</u>, President, Collège des médecins du Québec, noted that the Code eligibility criteria refer to "illness," "disease," and "disability," whereas Quebec's legislation only refers to "illness." According to <u>Dr. Mauril Gaudreault</u>, this has resulted in more restricted access to MAID in Quebec. The issue of disability as it relates to MAID is discussed in more detail under "Protections for Canadians with Disabilities."

<u>Catherine Claveau</u>, President of the Barreau du Québec, noted that the Barreau du Québec and other professional associations have asked repeatedly for the Quebec and federal laws to be harmonized. At the same time, she affirmed that provincial and federal jurisdiction over MAID can be exercised concurrently, and urged support for provincial efforts to broaden MAID, such as those underway in Quebec with respect to advance requests.

Monitoring Safeguards and Data Collection

Throughout its meetings, the committee heard how improved data collection could help to evaluate the effectiveness of MAID safeguards. In particular, witnesses recommended improving data collection on access to and quality of palliative care in the context of

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Evidence, 7 October 2022 (Dr. Louis Roy); Evidence, 18 November 2022 (Catherine Claveau).

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MAID and in other situations, and access to disability support services. The committee notes that the recent enactment of the <u>Regulations Amending the Regulations for the Monitoring of Medical Assistance in Dying</u> on 1 January 2023 addresses some, but not all, of the concerns raised relating to improved data collection.

It should be noted that in December 2022, Quebec's Commission sur les soins de fin de vie tabled its annual report which includes data on where palliative care was received. 19

Practitioners: Supports, Training, Education and Standards

The committee heard that supports and training for all healthcare professionals are key to the effective, equitable and safe delivery of MAID in Canada.

<u>Tim Guest</u> told the committee that a Canadian Nurses Association study found that some nurses limited their involvement with MAID due to a lack of supports.

<u>Diane Reva Gwartz</u> mentioned the importance of administrative supports and community liaison activities. Support also includes appropriate remuneration.²⁰

In a background document, Dr. Gordon Gubitz, Professor, Division of Neurology, Department of Medicine, Faculty of Graduate Studies at Dalhousie University, explains the development of CAMAP's Canadian MAID Curriculum Project. ²¹ This training for assessors and providers considers the needs of Indigenous, racialized, disabled, and marginalized Canadians, and will lead to the development of a "standardized approach to MAiD assessments and provisions across Canada."

Dr. Mona Gupta, Associate Clinical Professor and Chair of the Expert Panel on MAID and Mental Illness (Expert Panel), indicated the importance of training in the context of MAID MD-SUMC, which the committee also flagged in its interim report on mental disorder. In the government response to the interim report, the federal Minister of Health, the Honourable Jean-Yves Duclos explained that, in addition to funding CAMAP's curriculum development, the federal government "is actively engaging [provinces and territories] and the Federation of Medical Regulatory Authorities of Canada on the development of consistent practice standards." ²² In its brief, the <u>Canadian Medical</u>

¹⁹ Commission sur les soins de fin de vie, <u>Rapport annuel d'activités</u>, December 2022 [AVAILABLE IN FRENCH ONLY].

²⁰ Evidence, 25 April 2022 (Gwartz; Green).

The Canadian Medical Assistance in Dying (MAID) Curriculum Development Project: Overview, Background document, November 2021.

²² Minister of Health, Government Response to the First Report of the Special Joint Committee on Medical Assistance in Dying, 20 October 2022.



<u>Association</u> states that its consultations have indicated strong support for the increased clarity and consistent application that clinical guidance would provide.

The committee agrees that the federal government can play a leadership role in the development of practice standards and training. For that reason, the committee recommends

Recommendation 1

That the Government of Canada, in partnership with provinces and territories, continue to facilitate the collaboration of regulatory authorities, medical practitioners and nurse practitioners to establish standards for medical practitioners and nurse practitioners for the purpose of assessing MAID requests, with a view to harmonizing access to MAID across Canada.

Recommendation 2

That the Government of Canada, through relevant federal departments and in collaboration with relevant regulatory authorities, medical practitioners, and nurse practitioners, continue to address the quality and standardization of MAID assessment and delivery.

Engagement with Indigenous Peoples

Some witnesses highlighted the importance of engaging Indigenous Peoples on the topic of MAID. The committee referenced this issue in its interim report in the context of MAID MD-SUMC:

While the Committee notes that consulting with Indigenous communities on the issue of MAID MD-SUMC was not part of the Expert Panel's mandate, the Expert Panel stated that "Indigenous peoples in Canada have unique perspectives on death which need to be considered in the context of the emergence of MAID including MAID MD-SUMC. However, engagement with Indigenous peoples in Canada concerning MAID has yet to occur." ²³

Parliament of Canada, Special Joint Committee on Medical Assistance in Dying, <u>Medical Assistance in Dying</u> and <u>Mental Disorder as the Sole Underlying Condition: An Interim Report</u>, 1st Session, 44th Parliament, June 2022.

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<u>Dr. Cornelia Wieman</u> agreed that meaningful consultation with Indigenous peoples has not occurred. She emphasized that hearing from Indigenous witnesses during the committee study "cannot be considered to be a fulsome consultation with [F]irst [N]ations, Métis or Inuit."

Further, <u>Dr. Cornelia Wieman</u> noted that there are diverse opinions among Indigenous Peoples with respect to MAID:

Perspectives on MAID are on a spectrum. I have heard of medically assisted deaths occurring in [F]irst [N]ations communities that are grounded in ceremony, where the whole community is aware of what is happening and the dying person is drummed into the next world. On the other end of the spectrum are those who are still acutely distressed by their individual experiences of historical, intergenerational and contemporary traumas. Their view of MAID is that it essentially amounts to genocide.

This becomes even more complicated when we consider MAID in the MD-SUMC category. There is the potential for the spread of misinformation, as we have seen during the COVID pandemic, to the extent that some people believe [I]ndigenous youth who are suicidal will be able to access MAID. We all know that would not be allowed to happen, but these are reasons why broader engagement is necessary.

Last, I will note the fatigue of [F]irst [N]ations communities associated with engagement and consultation, speaking from my experience in British Columbia. There has been so much going on over the past several years that communities have had to contend with that asking for further consultation at this time on a highly charged topic such as MAID in general, and MAID MD-SUMC specifically, is daunting. First [N]ations communities are more likely to want to discuss the youth suicide crisis than MAID MD-SUMC, and yet they must be consulted.

The government response to the committee's interim report noted the following with respect to engagement of Indigenous Peoples and MAID:

Health Canada recognizes the importance of meaningful engagement and ongoing dialogue with Indigenous peoples to support culturally safe implementation of MAID. We are committed to working with Indigenous partners to identify and support distinctions-based priorities with respect to an engagement process at the federal level. To date, Health Canada has reached out to National Indigenous Organizations to discuss their preferred role in a national engagement with First Nations, Inuit and Metis on the topic of MAID.

The department will complement any engagement on MAID with existing feedback received from Indigenous organizations from: the process of revising the MAID monitoring regulations (currently underway); previous



research into distinctions-based views on end-of-life care; testimony at Parliamentary Committees in relation to MAID; as well as Indigenous Services Canada's engagement processes on the holistic continuum of care and Indigenous Health Legislation. Further, consultation and engagement with Indigenous partners will be informed by any applicable obligations under the *United Nations Declaration on the Rights of Indigenous Peoples Act*.²⁴

The committee acknowledges the Government of Canada's commitment to work with Indigenous partners "to identify and support distinctions-based priorities with respect to an engagement process at the federal level," and wishes to emphasize the importance of periodic reporting on this engagement process. Since this committee is a special joint committee and will cease to exist after 17 February 2023, other parliamentary standing committees should be seized of this issue.

The committee recommends therefore

Recommendation 3

That, every six months, Health Canada provide updates to the House of Commons Standing Committee on Indigenous and Northern Affairs and the Standing Senate Committee on Indigenous Peoples on its engagement with First Nations, Inuit and Métis on the subject of MAID.

Noting that organizations like CAMAP play a key role in the delivery of MAID in Canada, as do provincial and territorial regulatory authorities and provincial and territorial health professional associations, the committee also recommends

Recommendation 4

That the Government of Canada work with First Nations, Inuit and Métis partners, relevant organizations, such as the Canadian Association of MAID Assessors and Providers, regulatory authorities, and health professional associations to increase awareness of the importance of engaging with First Nations, Inuit and Métis on the subject of MAID.

24 Minister of Health, <u>Government Response to the First Report of the Special Joint Committee on Medical Assistance in Dying</u>, 20 October 2022.

MAID and Prisons

Under the <u>Constitution Act, 1867</u>, the federal government has legislative authority over federal penitentiaries (section 91(28)). The committee heard that, according to the internationally recognized principle of equivalence of care, incarcerated persons should have the same access to healthcare, including MAID, as those living in the community. However, systemic deficiencies in prisoner healthcare, including palliative care, are well documented. Law Professor <u>Adelina Iftene</u> noted that dementia and other cognitive impairments are often misdiagnosed in prison due to first responders' lack of expertise.

Emphasis was placed on the importance of parole by exception (i.e. compassionate release) when considering MAID for prisoners. Under section 121 of the <u>Corrections and Conditional Release Act</u>, parole by exception may be granted in exceptional cases. It may be available to a prisoner who is terminally ill as well as to those not serving life sentences whose health is likely to suffer "serious damage" or for whom continued confinement would constitute "excessive hardship" should they remain in prison.

Associate Professor <u>Jessica Shaw</u> and <u>Adelina Iftene</u> explained that, despite the low risk posed by most prisoners with terminal illness or intolerable suffering, parole by exception is rarely granted in practice. According to <u>Jessica Shaw</u>, two of the three prisoners documented as having received MAID applied for parole beforehand, but were denied. She and <u>Adelina Iftene</u> agreed that parole by exception should be more readily accessible to those seeking end-of-life care, including, but not limited to, MAID.

The committee also heard about the challenges of ensuring that consent to MAID is voluntary in the prison context. <u>Adelina Iftene</u> explained:

I think the conversation is more complicated when it comes to people in custody, simply because there are concerns regarding their ability to provide consent on a free basis. I think that as long as we do not have compassionate mechanisms working for individuals who are experiencing limiting life circumstances or intolerable suffering...to be transferred to the community to make end-of-life decisions there, this conversation is going to be very complicated.

<u>Jessica Shaw</u> noted that the legalization of MAID MD-SUMC presents particular difficulties for prisoners, who may be driven to seek death due to the psychological suffering associated with imprisonment. She stressed the need to distinguish between remediable suffering and incurable mental disorder in this context.

^{25 &}lt;u>Evidence</u>, 25 October 2022 (Adelina Iftene); <u>Evidence</u>, 22 November 2022 (Jessica Shaw).

^{26 &}lt;u>Evidence</u>, 25 April 2022 (Dr. Leonie Herx); <u>Evidence</u>, 25 October 2022 (Iftene).



Witnesses also had concerns about the governing policy and process for MAID in prisons. Adelina Iftene worried about a lack of oversight, given that Correctional Service Canada is exempt, in cases of MAID, from its usual obligation to review all deaths in prisons. Jessica Shaw was appreciative of Correctional Service Canada's development of MAID guidelines but cautioned that they do not align with federal policy in some instances. In a paper prepared for Public Safety Canada, she notes, for example, that the guidelines require a prisoner seeking MAID to meet with the Chief of Health Services prior to being assessed for eligibility, which may amount to a third assessment or at least cause bureaucratic delay. The guidelines also prevent a prisoner from seeking a further opinion if either of the two assessors finds them ineligible for MAID. This is not the case for Canadians outside the prison system, who have the option to seek another assessment if they are deemed ineligible.

The committee agrees that incarcerated individuals should be allowed to receive MAID and related end-of-life care in the community in certain circumstances, with due attention to potential security concerns. For that reason, the committee recommends.

Recommendation 5

That the Government of Canada, through Correctional Service Canada, support approved track one MAID recipients being able to die outside a prison setting only for the event itself and any immediate preparatory palliative care that is required.

PALLIATIVE CARE IN CANADA

FUNDING

While the provinces have primary responsibility for the delivery of healthcare services, including palliative care, as mentioned above, the federal government plays a role in the financing of such services through health transfers.

The federal government announced in Budget 2017 that it would provide \$6 billion over 10 years, beginning in 2017–2018, to the provinces and territories for home care initiatives, which are to include palliative care elements.²⁷

This funding is provided through a separate federal Home Care and Mental Health Transfer to the provinces and territories.²⁸ All provinces and territories have entered into bilateral agreements with the federal government on how these funds will be spent based on an August 2017 Common Statement of Principles on Shared Health Priorities.²⁹

In December 2018, the Minister of Health tabled the report <u>Framework on Palliative Care in Canada</u> (the Framework), as required by <u>Bill C-277</u>, <u>An Act providing for the development of a framework on palliative care in Canada</u>. In August 2019, Health Canada published the <u>Action Plan on Palliative Care—Building on the Framework on Palliative Care in Canada</u> (action plan). The latter document describes the department's five-year plan, which includes five goals with various areas for action. Health Canada states that progress will be measured in each area of action by a set of indicators that is to be developed. ³⁰ The five goals of the action plan are:

²⁷ Department of Finance Canada, <u>Building a Strong Middle Class</u>, Budget 2017, p. 156.

Note that the <u>Common Statement of Principles on Shared Health Priorities</u> explains that Quebec has an asymmetrical agreement:

Recognizing the Government of Québec's desire to exercise its own responsibilities within the health field and to fully assume the planning, organizing and managing of health services, including mental health and addiction services and home and community care, the Government of Canada and the Government of Québec agreed on March 10, 2017 to an asymmetrical arrangement distinct from this Statement of Principles and based on the asymmetrical agreement of September 2004. The Government of Québec will continue to report to Quebecers on the use of all health funding and will continue to collaborate with other FPT governments by sharing information and best practices.

²⁹ Government of Canada, <u>Shared Health Priorities and Safe Long-term Care Fund</u>. Those agreements expired in 2022 but have been extended for 2022–2023.

³⁰ Health Canada, <u>Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada</u>, August 2019.



- raise awareness of how palliative care can improve quality of life;
- improve palliative care skills and supports;
- improve data collection and research;
- improve access to palliative care for underserved populations; and
- improve access to culturally sensitive palliative care for Indigenous communities.

A number of witnesses noted the importance of the federal role in establishing national standards for palliative care³¹ and expressed the need to provide appropriate funding for the Action Plan.³²

<u>Abby Hoffman</u>, Senior Executive Advisor to the Deputy Minister, Department of Health, explained that while there has been increased federal funding for home and community care (which includes palliative care), provinces determine what resources to allocate to palliative care.

<u>Dr. Leonie Herx</u>, Chair and Associate Professor, Palliative Medicine, Queen's University and Chair, Royal College Specialty Committee in Palliative Medicine, <u>Dr. Ebru Kaya</u>, President, Canadian Society of Palliative Care Physicians and Associate Professor of Medicine, University of Toronto, and <u>Dr. José Pereira</u>, Professor and Director, Division of Palliative Care, Department of Family Medicine, McMaster University opined that the provision of MAID has negatively affected resources for palliative care. <u>Abby Hoffman</u> did not think that "money is being diverted from palliative care to the promotion of MAID," and <u>Dr. Alain Naud</u>, Family and Palliative Care Physician, had not seen evidence that MAID led to reduced funding for palliative care. In response to a question on MAID negatively affecting palliative care funding, <u>Dr. James Downar</u> explained that "the money comes to the provinces and the provinces decide how it's spent, but there's never a sort of 'earmarked' anything in the physicians' services budgets anywhere that 'this goes to palliative care and MAID' and you have to fight over it."³³

³¹ See Evidence, 9 May 2022 (Dr. Romayne Gallagher); Evidence, 21 October 2022 (Derek Ross).

³² See for example <u>Evidence</u>, 25 April 2022 (Herx); <u>Evidence</u>, 7 October 2022 (Dr. José Pereira); <u>Evidence</u>, 18 October 2022 (Daniel Nowoselski); <u>Evidence</u>, 21 October 2022 (Ross; Dr. Sandy Buchman).

³³ See also *Evidence*, 5 May 2022 (Dr. Georges L'Espérance); *Evidence*, 23 September 2022 (Dr. Natalie Le Sage).

The committee agrees that implementation of the Action Plan on Palliative Care must be adequately funded in order to improve access to palliative care across Canada. For that reason, the committee recommends

Recommendation 6

That the Government of Canada, through relevant federal departments and respecting the jurisdiction of provinces and territories, consider increasing funding for the implementation of the Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada, and make targeted and sustained investments in innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with life-limiting illness and their caregivers.³⁴

ACCESS

While Abby Hoffman indicated that MAID and palliative care "are not completely separate and distinct," other witnesses emphasized the importance of recognizing the distinction between the two. 35 For example, Dr. Leonie Herx told the committee that "[p]alliative care does not hasten death and is internationally recognized as a practice that is distinct from MAID philosophically, clinically and legally." Similarly, Dr. José Pereira stated that "[i]t's not only professional societies or associations of palliative care [that make the distinction between palliative care and MAID]; it's also the World Health Organization that doesn't see MAID as part of [palliative care]." Psychiatrist and Associate Professor Dr. Madeline Li told the committee that while "[c]onceptually, MAID and palliative care are arguably distinct...clinically speaking there needs to be better integration to ensure high-quality end-of-life care, with attention to vulnerability." ³⁶ Dipti Purbhoo, Executive Director of The Dorothy Ley Hospice, explained that a recent review

The Government of Canada and the Government of Quebec agreed to an asymmetrical arrangement distinct from the Statement of Principles and based on the asymmetrical agreement of September 2004.

See, for example, AMAD, <u>Evidence</u>, 25 April 2022 (Herx); <u>Evidence</u>, 28 April 2022 (Dr. James Downar and Dr. Ebru Kaya); <u>Evidence</u>, 7 October 2022 (Dr. Geneviève Dechêne; Pereira); <u>Evidence</u>, 21 October 2022 (Ross).

³⁶ According to the *Final Report of the Expert Panel on MAID and Mental Illness*,

[&]quot;Structural vulnerability refers to the impacts of the interaction of demographic attributes (sex, gender, socioeconomic status, race/ethnicity, sexuality, institutional location), with assumed or attributed statuses related to one's position in social, cultural, and political hierarchies (including normality, credibility, and whether one deserves to receive care). In the healthcare context, structural vulnerability requires reflection on these forces that "constrain decision-making, frame choices, and limit life options" and the manner that these in turn impact health outcomes."



of their staff showed that 70% of physicians had changed their perspective on providing MAID:

[t]hey've seen that MAID can be one of the options in their tool kit as it relates to palliative care... I think they have changed and evolved to consider MAID as one option in the tool box [sic] of options that exist for palliative care versus seeing MAID as something separate and distinct from palliative care.

As part of the eligibility requirements, the Code requires that an individual "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." Where a person's natural death is not reasonably foreseeable, the Code also requires that the medical practitioner or nurse practitioner "ensure that the person has been informed of the means available to relieve their suffering, including, where appropriate...palliative care and has been offered consultations with relevant professionals who provide those services or that care." Derek Ross, Executive Director of Christian Legal Fellowship, recommended that individuals should not just be informed of options but also offered consultations with the relevant providers.

Abby Hoffman stated that more than 80% of people who chose MAID had palliative care, and that of those who didn't have palliative care, the "overwhelming majority" had access to it. She noted that there are gaps in providing palliative care services in people's homes and that Indigenous communities are significantly underserved.

Speaking to access to palliative care in Canada more generally, <u>Dr. Leonie Herx</u> stated that those who are "poor, [I]ndigenous, homeless, incarcerated or living in a rural area" are less likely to receive palliative care, and that palliative care is only available to 30% to 50% of Canadians. <u>Dr. José Pereira</u> also indicated that only about 15% to 25% of patients have access to specialist palliative care teams. <u>Dr. David Henderson</u>, Senior Medical Director, Integrated Palliative Care Nova Scotia Health, explained that the lack of access to primary care for some patients means that the only way to access palliative care is through emergency departments.

<u>Cheryl Romaire</u>, who was advised that that she was not eligible for palliative care because she did not have a terminal diagnosis, told the committee that regardless of a diagnosis, every patient who is approved for MAID should have access to palliative care. Witnesses also mentioned the lack of paediatric palliative care and palliative care for

38 Section 241.2(3.1)(g).

³⁷ Section 241.2(1)(e).

individuals with dementia.³⁹ Paediatric palliative care is discussed further in "Mature Minors" under "Access to Supports and Services".

<u>Dr. Romayne Gallagher</u>, Clinical Professor, Palliative Medicine, University of British Columbia, indicated that improving access to high-speed Internet would allow for telehealth and improve access to palliative care. Access could also be improved if individuals were better informed about the role of palliative care. ⁴⁰ To that end, physician <u>Dr. Marjorie Tremblay</u> proposed a national palliative care awareness campaign.

The committee agrees with witnesses who spoke about the importance of palliative care. 41 Concerned that Canadians do not have sufficient, equitable access to quality palliative care, the committee recommends

Recommendation 7

That, with the understanding that palliative care is not a prerequisite to access or receive MAID, the Government of Canada work in partnership with the provinces and territories on the following action items:

- a) Continue the National Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada and look into innovative approaches and early-stage research aimed at improving health system performance and quality of care for people living with lifelimiting illness and their caregivers.
- b) Support the efforts of provinces and territories to develop initiatives aiming to improve home-based palliative care and culturally appropriate palliative care for underserved populations as well as access to this care.
- c) Identify ways to improve access to high-quality, culturally appropriate, palliative and end-of-life care, in a timely manner by:
 - Supporting palliative home care;

^{39 &}lt;u>Evidence</u>, 6 June 2022 (Maria Alisha Montes); <u>Evidence</u>, 5 May 2022 (Raphael Cohen-Almagor); <u>Evidence</u>, 21 October 2022 (Campbell).

⁴⁰ See, for example, <u>Evidence</u>, 28 April 2022 (Kaya; Buchman); <u>Evidence</u>, 18 October 2022 (Dr. David Henderson; Kelly Masotti); <u>Evidence</u>, 21 October 2022 (Ross).

^{41 &}lt;u>Evidence</u>, 7 October 2022 (Dechêne, Downar); <u>Evidence</u>, 18 October 2022 (Dipti Purbhoo); <u>Evidence</u>, 21 October 2022 (Buchman; Dr. Nathalie Zan).



- Supporting specialized paediatric palliative care; and
- Supporting access to advance care planning.

DATA AND RESEARCH

As mentioned above, one of the goals of Canada's Action Plan on Palliative Care is to "[s]upport health system quality improvement through enhanced data collection and research."

<u>Abby Hoffman</u> noted the limitations on information that is currently collected as part of the practitioner reporting requirements when MAID is provided:

We have information about whether the individual has had palliative care, but the extent of that care is not well documented. It is the case in many parts of the country—in most parts of the country, in fact—that there are time limits on palliative care in terms of the amount of care one can get and the proximity to death one anticipates, and so on.

<u>Mike Kekewich</u>, Director, Champlain Regional MAID Network, Champlain Centre for Health Care Ethics, The Ottawa Hospital, told the committee that Health Canada would be collecting additional palliative care data in the future.⁴²

Many witnesses agreed that improving palliative care in Canada involves establishing standards and measuring both access to and the quality of palliative care. ⁴³

Dr. Leonie Herx proposed "a national system that's linked to Accreditation Canada's standards and that's administered so that provinces collect data on outcomes for patients that is patient-reported." In addition to measuring the quality of and access to palliative care, Dr. Ebru Kaya indicated the importance of knowing who is providing palliative care to MAID patients. Nurse practitioner Julie Campbell explained that collecting palliative care data outside of the MAID context is also important. In its brief, the Canadian Cancer Society recommended "improv[ing] palliative care research and systematic, standardized data collection by developing data systems to measure access

Most of the <u>Regulations Amending the Regulations for the Monitoring of Medical Assistance in Dying</u> came into force on 1 January 2023. The previous version of Schedule 3 requires that as part of the required reporting information, a practitioner indicate whether a patient <u>received</u> palliative care, and if so, the length of time a patient received palliative care (if known). The revised regulations require a practitioner to indicate instead whether the patient <u>required</u> palliative care, and if they received it, "the type of palliative care they received, how long they received it and the place where it was received, if known."

43 <u>Evidence</u>, 25 April 2022 (Herx); <u>Evidence</u>, 28 April 2022 (Dr. Marjorie Tremblay); <u>Evidence</u>, 9 May 2022 (Gallagher); <u>Evidence</u>, 18 October 2022 (Nowoselski); <u>Evidence</u>, 7 October 2022 (Dechêne; Kekewich); <u>Evidence</u>, 21 October 2022 (Campbell).

to palliative care, both at home and in community settings such as long-term care facilities and residential hospices."

Family physician <u>Dr. Pierre Viens</u> noted the importance of a more precise definition of palliative care, particularly for reporting purposes under the <u>Regulations for the</u> <u>Monitoring of Medical Assistance in Dying</u>.

The committee agrees that improving data about access to palliative care and establishing standards by which the quality of palliative care is measured is an important step in improving palliative care. The committee therefore recommends

Recommendation 8

That the Government of Canada, in collaboration with the provinces and territories, work to develop data systems to collect disaggregated data for Black, Indigenous, racialized, disabled, and 2SLGBTQ+ communities beyond the regulations that went into force January 1, 2023.

TRAINING/ACCREDITATION

Witnesses recommended more funding for palliative care training programs, including for specialists, ⁴⁴ and that training should include "integrat[ing] a palliative approach to care in all care settings." ⁴⁵

In its <u>brief</u>, the Canadian Cancer Society recommends that the federal government "[p]rovide all healthcare providers, including allied providers, with appropriate education and training on the basic principles and practices of palliative care to ensure people with cancer receive the highest quality of care." It also recommends that the federal government "[e]nsure an appropriate level of education and training for healthcare providers and students regarding all facets of end-of-life care, including their obligations and responsibilities relative to MAID."

The committee agrees that supporting training and education opportunities for palliative care specialists as well as for all healthcare providers is essential to delivering high-quality palliative care.

^{44 &}lt;u>Evidence</u>, 28 April 2022 (Kaya); <u>Evidence</u>, 7 October 2022 (Pereira).

^{45 &}lt;u>Evidence</u>, 21 October 2022 (Campbell).



EXISTENTIAL SUFFERING

<u>Dr. Nathalie Zan</u> explained that even with optimal palliative care, existential suffering is difficult to relieve. According to <u>Dr. Madeline Li</u>, focusing on psychosocial care within palliative care, such as CALM therapy (Managing Cancer and Living Meaningfully therapy), dignity therapy or meaning-centred psychotherapy helps to address existential suffering. <u>Dr. Harvey Chochinov</u> explained that affirming personhood at end-of-life is important. He also supported dignity therapy and CALM therapy.

The committee heard that psychedelics, psilocybin in particular, could potentially support individuals dealing with existential distress, but barriers prevent patient access. Currently, psilocybin is only available through Health Canada's <u>Special Access Program</u>. A number of witnesses supported funding for research on psychedelics. 46 <u>Spencer Hawkswell</u>, President and Chief Executive Officer of TheraPsil and Dr. James Downar both recommended that regulations relating to accessing psilocybin be reviewed. 47 <u>Dr. Valorie Masuda</u> shared her experience treating patients with psilocybin:

Over the past three years I have legally and successfully treated 20 patients suffering from irremediable demoralization, fear and depression under a section 56 exemption or the special access program. I treat these patients with psilocybin, which is a psychedelic medicine that is highly efficacious and safe. With one treatment I have witnessed a total alleviation of demoralization and fear. It is a treatment that I now offer to patients I see suffering from this kind of distress who may have otherwise accessed MAID.

<u>Dr. Madeline Li</u>, who has applied for Canadian Institutes of Health Research funding to study psilocybin in cancer and palliative care, told the committee that psychedelics are "not going to be the panacea or antidote to MAID in any way," and that psychedelics would not "necessarily change a patient's mind."

The committee agrees that the regulatory process relating to promising therapies, such as psilocybin, should be reviewed to identify possible barriers or inefficiencies. The committee therefore recommends

Recommendation 9

That Health Canada review the Special Access Program, other programs and policies, and relevant laws and regulations to determine whether there are ways to improve access to

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⁴⁶ Evidence, 7 October 2022 (Pereira); Evidence, 18 October 2022 (Gallagher; Dr. Madeline Li; Nowoselski).

⁴⁷ Correspondence to the committee.

promising therapies, such as psilocybin, for both research purposes and for individual use as part of palliative care supports.



PROTECTIONS FOR CANADIANS WITH DISABILITIES

BACKGROUND

To be eligible for MAID under the Code, a person must have a "grievous and irremediable medical condition," which is defined as "a serious and incurable illness, disease or disability" that has led to an "advanced state of irreversible decline" and intolerable suffering. These provisions follow the ruling in the <u>Carter</u> decision, which held that prohibiting a competent adult from accessing MAID is unconstitutional where, among other things,

the person 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. [para 4]

As noted in "Jurisdictional Issues and Harmonization," under Quebec's <u>Act respecting</u> <u>end-of-life care</u>, eligibility is limited to those with a "serious and incurable illness";⁵⁰ no reference is made to "disability."

As discussed in "Parliamentary and Legislative Background," MAID was initially only available to those whose natural death was reasonably foreseeable or, in Quebec, to those at the end-of-life. In the <u>Truchon</u> decision, however, the Quebec Superior Court found these criteria to be unconstitutional, resulting in the expansion of MAID via Bill C-7. Consequently, MAID is now available to Canadians with disabilities whose natural death is not reasonably foreseeable, at least outside of Quebec, provided they meet all other eligibility criteria.

The committee heard extensive testimony on the socio-economic challenges, and widespread ableism, faced by persons with disabilities. Current efforts to address this at the federal level include <u>Bill C-22</u>, <u>An Act to reduce poverty and to support the financial security of persons with disabilities by establishing the Canada disability benefit and making a consequential amendment to the Income Tax Act, introduced on 2 June 2022</u>

⁴⁸ s. 241.2(1)(c).

⁴⁹ s. 241.2(a).

^{50 &}lt;u>Act respecting end-of-life care</u>, s. 26; <u>Evidence</u>, 18 November 2022 (Dr. Mauril Gaudreault).

to establish a Canada disability benefit. Eligibility criteria and the amount of the benefit are to be established by regulations (clauses 4, 5 and 11(1)(c)). On 7 October 2022, the federal government also released <u>Canada's Disability Inclusion Action Plan</u>, 2022. The Plan builds on <u>consultations</u> held from June to September 2021.

The <u>Regulations on the Monitoring of Medical Assistance in Dying</u> require the collection of information about disability support services received or accessible to those who request MAID. On 1 January 2023, these regulations were amended to require additional information, including whether the person requesting MAID has a disability or disabilities, if they consent to provide that information, and about the type of disability support services received.

BALANCING INDIVIDUAL AUTONOMY AND THE PROTECTION OF THE VULNERABLE

Witnesses held strongly opposing views on how to balance persons with disabilities' individual autonomy and structural vulnerability. Many felt that persons with disabilities should be treated as individuals, with vulnerability assessed on a case-by-case basis. ⁵¹

Dr. Alain Naud referred to the following conclusion from the *Truchon* decision:

The vulnerability of a person requesting medical assistance in dying must be assessed exclusively on a case-by-case basis, according to the characteristics of the person and not based on a reference group of so-called "vulnerable persons". Beyond the various factors of vulnerability that physicians are able to objectify or identify, the patient's ability to understand and to consent is ultimately the decisive factor, in addition to the other legal criteria. [para 466]

Some witnesses, including some individuals with disabilities, spoke against medical paternalism, underscoring the rights of persons with disabilities to make their own healthcare decisions, 52 which, according to Colleen Sheppard and Derek Jones, 53 is consistent with the Charter and the UN Convention on the Rights of Persons with Disabilities. "You have to be able to fully assume your autonomy, during life and at the time of death; there is no greater demonstration of what it means to be human," stated Ghislain Leblond, Former Deputy Minister. Amélie Duranleau, Executive Director, Quebec

^{51 &}lt;u>Evidence</u>, 13 April 2022 (Abby Hoffman); <u>Evidence</u>, 25 April 2022 (Dr. Alain Naud); <u>Evidence</u>, 16 May 2022 (Andrew Adams); <u>Evidence</u>, 18 November 2022 (Gaudreault).

^{52 &}lt;u>Evidence</u>, 16 May 2022 (Ghislain Leblond); <u>Evidence</u>, 22 November 2022 (Shaw); <u>Evidence</u>, 22 November 2022 (Liana Brittain).

Reference document provided to the committee.



Intellectual Disability Society, added that many persons with intellectual disabilities are also capable of making important life decisions, including about MAID.

In contrast, others emphasized the risks of broader impacts of MAID policy on persons with disabilities,⁵⁴ and the duty to protect those who may be vulnerable. <u>Tim Stainton</u>, Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia, felt this duty has been overshadowed by an increasingly individualistic conception of autonomy. According to <u>Sarah Jama</u>, Executive Director, Disability Justice Network of Ontario, persons with disabilities face "systemic coercion" due to the expansion of MAID, and individual rights "should not supersede the harms faced by others." "What you are doing is going to powerfully affect whether people with disabilities in this country see ourselves as welcomed and valued citizens," explained <u>Catherine Frazee</u>, Professor Emerita, School of Disability Studies, Toronto Metropolitan University.

Many witnesses—including those supportive of individual choice—questioned whether persons with disabilities, when burdened with socio-economic disadvantages and lacking access to essential supports and services, had meaningful choices regarding MAID. Ahona Mehdi, Member and Just Recovery Research Lead, Disability Justice Network of Ontario, emphasized the "collective responsibility" to address social circumstances that contribute to suffering. Locelyn Downie supported the need for better access to supports and services, but advised: "Don't constrain access to MAID, because you should never make individuals hostage to fixing systemic problems." Lessica Shaw stated: "[I]f we don't live in a country where people are supported...it still comes down to who decides how long and how much suffering is enough. And I think that rests with the person."

The committee recognizes that a delicate balance must be struck between promoting individual autonomy and protecting against socio-economic vulnerabilities.

DISCRIMINATION AND STIGMA

The different views on how to balance individual choice and protection from harm were often tied to differing interpretations of discrimination. Many witnesses underscored the pervasive ableism faced by persons with disabilities—compounded by ageism and

See for example: <u>Evidence</u>, 18 November 2022 (Gabrielle Peters); <u>Evidence</u>, 25 November 2022 (Megan Linton; Catherine Frazee; Isabel Grant).

Evidence, 16 May 2022 (Sarah Jama); Evidence, 30 May 2022 (Bill Adair); Evidence, 6 June 2022 (Ahona Mehdi); Evidence, 18 November 2022 (Krista Carr; Kerri Joffe; Peters); Evidence, 22 November 2022 (Heidi Janz).

racism⁵⁶—in the healthcare system and more generally.⁵⁷ The committee heard about historical and ongoing institutionalization and maltreatment of persons with disabilities,⁵⁸ the lack of infrastructure permitting their equal participation in society,⁵⁹ and the tendency of care providers to underestimate their potential or actual quality of life.⁶⁰

Some witnesses worried that pre-existing ableism, and other intersecting forms of discrimination, may result in MAID being offered coercively or prematurely to persons with disabilities. ⁶¹ Kerri Joffe, Staff Lawyer, ARCH Disability Law Centre, and Gabrielle Peters, Co-Founder, Disability Filibuster, noted how this could negatively affect the relationship between patients with disabilities and their doctors. On the other hand, Jessica Shaw believed, based on her research, that medical ableism discourages persons with disabilities from accessing healthcare information and services, including MAID.

The availability of MAID for persons with disabilities was also described as stigmatizing, entrenching the notion that disabled lives have less value.⁶² According to many witnesses, the removal of the reasonably foreseeable death criterion under Bill C-7 has effectively singled out persons with disabilities in a discriminatory manner, making them the only vulnerable group with a "special pathway to MAID"⁶³ if they are suffering intolerably.⁶⁴ Krista Carr, Executive Vice-President, Inclusion Canada, explained:

What we're talking about here is that we have two tracks. We have a track for people at end of life who are suffering intolerably and whose lives are going to be finished soon, and they get to choose the timing, etc., but we have this other track that has pigeonholed one particular group of people. Anybody else in the country, by virtue of being any other marginalized population—[I]ndigenous, racialized or whatever—who

^{56 &}lt;u>Evidence</u>, 25 April 2022 (Pageau); <u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Conrad Saulis).

^{57 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Dr. Ramona Coelho); <u>Evidence</u>, 6 June 2022 (Mehdi); <u>Evidence</u>, 18 November 2022 (Carr; Peters); <u>Evidence</u>, 22 November 2022 (Dr. Karen Ethans; Janz; David Shannon; Shaw); <u>Evidence</u>, 25 November 2022 (Grant).

⁵⁸ Evidence, 18 November 2022 (Carr; Peters); Evidence, 25 November 2022 (Grant; Linton).

⁵⁹ Evidence, 18 November 2022 (Peters).

^{60 &}lt;u>Evidence</u>, 18 November 2022 (Peters); <u>Evidence</u>, 22 November 2022 (Ethans).

^{61 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Coelho; Saulis and Samuel Ragot); <u>Evidence</u>, 6 June 2022 (Mehdi).

^{62 &}lt;u>Evidence</u>, 9 May 2022 (Trudo Lemmens); <u>Evidence</u>, 30 May 2022 (Ragot); <u>Evidence</u>, 6 June 2022 (Mehdi).

^{63 &}lt;u>Evidence</u>, 25 November 2022 (Frazee).

^{64 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 18 November 2022 (Carr; Peters); <u>Evidence</u>, 22 November 2022 (Shannon; Tim Stainton); <u>Evidence</u>, 25 November 2022 (Frazee; Grant; Linton).



says they are suffering intolerably from factors that are external to their personal characteristics isn't getting offered death. We're giving them support to live good lives.

Others contended that denying persons with disabilities access to MAID would itself be stigmatizing and discriminatory, because it would imply that they are less capable of making their own decisions about MAID.⁶⁵ As noted by <u>Catherine Claveau</u>, this view aligns with the holding in the <u>Truchon</u> decision.

ACCESS TO SUPPORTS AND SERVICES

A resounding theme throughout the committee's hearings was the level of socio-economic disadvantage faced by persons with disabilities—a phenomenon linked to discrimination and stigma, as <u>Gabrielle Peters</u> noted. Witnesses underscored the connection between disability and poverty, ⁶⁶ and the need for better social supports such as income assistance and accessible and affordable housing. ⁶⁷ <u>Krista Carr</u> stated that 73% of Canadians with disabilities living outside the family home lived in poverty. While legislation to enact a Canada disability benefit is currently before the House of Commons, <u>Tim Stainton</u> opined that it has been slow to move forward.

Witnesses also noted that persons with disabilities face long wait times and high costs for specialized healthcare, and called for better access to services such as pain management, assistive devices, psychiatric and psychological services, counselling, home care, and palliative care.⁶⁸

The committee heard that persons with disabilities, including young adults, have been forced into institutions due to inadequate home care funding.⁶⁹ While noting the lack of data on institutionalized persons with disabilities, <u>Megan Linton</u>, PhD Candidate, opined

^{65 &}lt;u>Evidence</u>, 9 May 2022 (Jocelyn Downie) (referring to people with dementia); <u>Evidence</u>, 16 May 2022 (Leblond); <u>Evidence</u>, 27 September 2022 (Jennifer Chandler); <u>Evidence</u>, 18 November 2022 (Claveau).

^{66 &}lt;u>Evidence</u>, 13 April 2022 (Mausumi Banerjee); <u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Adair, Coelho and Michelle Hewitt); <u>Evidence</u>, 6 June 2022 (Mehdi); <u>Evidence</u>, 22 November 2022 (Shannon).

^{67 &}lt;u>Evidence</u>, 30 May 2022 (Adair; Coelho; Hewitt; Ragot); <u>Evidence</u>, 6 June 2022 (Mehdi); <u>Evidence</u>, 22 November 2022 (Ethans; Janz; Shaw).

See for example: <u>Evidence</u>, 5 May 2022 (Helen Long); <u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Adair; Ragot); <u>Evidence</u>, 6 June 2022 (Mehdi); <u>Evidence</u>, 16 June 2022 (Cheryl Romaire); <u>Evidence</u>, 22 November 2022 (Ethans); <u>Evidence</u>, 25 November 2022 (Grant).

^{69 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Hewitt); <u>Evidence</u>, 18 November 2022 (Carr; Joffe); <u>Evidence</u>, 22 November 2022 (Ethans; Stainton); <u>Evidence</u>, 25 November 2022 (Grant).

that they receive lower income supports than non-institutionalized persons with disabilities, and often live in poorly maintained facilities.

Some witnesses feared that persons with disabilities could be offered MAID in place of supportive, palliative or other care, 70 and Krista Carr said she had heard accounts of this happening. Witnesses expressed concerns that poor conditions in long-term care settings are driving persons with disabilities to seek MAID instead. Kerri Joffe relayed having clients who have sought, and in some cases received, MAID due to unmet disability-related needs. Reports of such cases were also referenced by others. Hink we have created a system where death is easier for people with disabilities ... than living with dignity, stated Associate Adjunct Professor Heidi Janz. On the other hand, Dr. Chantal Perrot made the following comments in a brief submitted to the committee:

I will comment on a patient whose life and death received considerable media attention following her MAiD death. She asked me to advocate for others in her situation. She gave permission to share information about her publicly. This thoughtful, mature, intelligent woman has been mischaracterized as choosing MAiD simply because of lack of housing. Hers was a much more complex and considered decision than media reports suggest. ... She wrote a note I received after her death: "...THANK YOU for helping me to end my suffering... for believing that MCS is real, that my suffering is REAL... for continuing to be in my corner, and believe I deserved to have MAiD, rather than trying to persuade me to stay alive... Even if I were to find a medically-safe, affordable home, I would still be isolated from the rest of the community, unable to go into public buildings OR visit friends/family [due to the risk of exposure to triggers]... With my health deteriorating... I made the only decision that I felt was available: I chose MAiD now...".

She has also been mischaracterized as living in poverty. She would be appalled. Yes, she received social assistance, but, apart from not being able to build that safe bubble, she was clear that she had: adequate resources to live; no debt; savings; and financial concerns were not contributing to her choice to have MAiD. Unfortunately, those opposed to

⁷⁰ See for example: <u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Coelho); <u>Evidence</u>, 6 June 2022 (Mehdi).

^{71 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Coelho; Hewitt); <u>Evidence</u>, 18 November 2022 (Carr); <u>Evidence</u>, 22 November 2022 (Janz); <u>Evidence</u>, 25 November 2022 (Linton).

^{72 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Hewitt); <u>Evidence</u>, 18 November 2022 (Peters); <u>Evidence</u>, 22 November 2022 (Janz; Stainton); <u>Evidence</u>, 25 November 2022 (Grant; Linton).



MAiD and special interest groups wanting to misuse her life and history have created a false impression of who she was and how she chose to live and die.

According to <u>Dr. James Downar</u>, there is evidence that only a small percentage of people who have received MAID had trouble accessing disability services and palliative care. He stated: "there is absolutely no data suggesting that the practice of MAID at this point is driven to any degree by poor access to palliative care, socio-economic deprivation or any isolation."

A number of witnesses advocated for MAID to be developed "in parallel" with resources such as mental healthcare, palliative care, and disability supports. ⁷³ <u>Jocelyn Downie</u> suggested that the current conversation about MAID presents an opportunity to discuss supports for persons with disabilities and mental illnesses in Canada.

The committee is deeply concerned about persons with disabilities' lack of access to adequate care and support. This issue must be tackled in parallel with improving access to MAID. A person should not be approved for MAID due to socio-economic suffering. For these reasons, the committee recommends

Recommendation 10

That the Government of Canada continue to support persons with disabilities by implementing measures to reduce poverty and ensure economic security.

ELIGIBILITY CRITERIA AND SAFEGUARDS

While some witnesses viewed the existing eligibility criteria and safeguards as adequate to protect persons with disabilities, ⁷⁴ others disagreed.

Many disability rights advocates felt strongly that the reasonably foreseeable death criterion—which they referred to as "the great equalizer" —must be reinstated to avoid discriminating against persons with disabilities. ⁷⁶ "Everyone dies, and this is the only safeguard that removes making value judgments about the worth of disabled lives from

^{73 &}lt;u>Evidence</u>, 25 April 2022 (Green); <u>Evidence</u>, 5 May 2022 (Long); <u>Evidence</u>, 9 May 2022 (Downie).

^{74 &}lt;u>Evidence</u>, 18 November 2022 (Sylvie Champagne); <u>Evidence</u>, 22 November 2022 (Shaw).

^{75 &}lt;u>Evidence</u>, 18 November 2022 (Carr); <u>Evidence</u>, 25 November 2022 (Grant).

See for example: <u>Evidence</u>, 18 November 2022 (Carr); <u>Evidence</u>, 22 November 2022 (Janz; Stainton); <u>Evidence</u>, 25 November 2022 (Frazee; Grant; Linton).

the equation," explained <u>Isabel Grant</u>, Professor, Allard School of Law, University of British Columbia. As acknowledged by <u>Catherine Frazee</u>, however, reinstating this criterion would run contrary to the ruling in the <u>Truchon</u> decision.

Amélie Duranleau emphasized that disability "should never be a criterion for access to MAID." <u>David Shannon</u>, Barrister and Solicitor, pointed out that a disability cannot be deemed "grievous and irremediable" if disability is understood as rooted in remediable social barriers. Dr. <u>Mauril Gaudreault</u>, on the other hand, supported harmonizing the Quebec and federal statutes so that Quebec residents with disabilities have the same access to MAID as other Canadians living with a disability.

<u>Catherine Frazee</u> recommended clarifying that socio-economic circumstances cannot form the basis of a request for MAID, since intolerable suffering must be caused by a medical condition under the Code.

As already mentioned in "Palliative Care in Canada," when natural death is not reasonably foreseeable, the Code requires a person to be "informed of the means available to relieve their suffering" and to be offered relevant consultations for services. In several witnesses' experience, however, the problem is not a lack of information but rather a lack of access to services.⁷⁷ As explained by Kerri Joffe,

the concern of the clients I've worked with is not so much that they're not being informed of what's available, but it's that they have, for years or months or really extended periods of time, tried to avail themselves of the services that are in fact available to them, and either they have encountered extensive barriers in not being able to access those services or the supports they needed were simply not available.

Bill Adair, Executive Director, Spinal Cord Injury Canada, and Dr. Karen Ethans, Associate Professor suggested that the waiting period for MAID where natural death is not reasonably foreseeable should be longer than 90 days. They explained that patients often struggle with suicidality following a severe injury, and can take years to adapt to their disability, at which point they often report a high quality of life. David Shannon's lived experience bore this out. Alicia and Christie Duncan similarly recommended a mandatory waiting period for patients with mental disorders or non-terminal disabilities, with no exemptions, based on their family's experience with MAID.

⁷⁷ Evidence, 18 November 2022 (Carr; Joffe; Alicia and Christie Duncan).

^{78 &}lt;u>Evidence</u>, 30 May 2022 (Adair; Coelho); <u>Evidence</u>, 22 November 2022 (Ethans; Shannon).



Some witnesses supported the establishment of an independent body to review MAID assessments prospectively,⁷⁹ or to provide retrospective oversight of MAID cases.⁸⁰ Others emphasized the importance of improved data collection and monitoring,⁸¹ including with respect to institutionalized persons with disabilities.⁸² Physician Dr. Ramona Coelho believed that cases of non-compliance with safeguards are not being accurately captured by Health Canada's monitoring regime, raising concerns about inadequate data collection. Others also raised concerns about non-compliance with existing safeguards.⁸³

Given the concerns expressed by disability rights advocates, the committee feels it is important to clarify that, although persons with disabilities may be eligible for MAID, disability alone is not sufficient to determine eligibility. For this reason, the committee recommends

Recommendation 11

That the Government of Canada, through the Department of Justice, and in consultation with organizations representing persons with disabilities, explore potential amendments to the *Criminal Code* that would avoid stigmatizing persons with disabilities without restricting their access to MAID. Options considered should include replacing references to "disability" in section 241.2(2) of the *Criminal Code*, with attention to the potential legal ramifications of such an amendment across Canada.

NEED FOR CONSULTATION

According to <u>Mausumi Banerjee</u>, Director, Office for Disability Issues, Department of Employment and Social Development Canada, the Office for Disability Issues ensures that organizations representing persons with disabilities are engaged in the

⁷⁹ Evidence, 18 November 2022 (Duncan); Evidence, 22 November 2022 (Stainton).

^{80 &}lt;u>Evidence</u>, 22 November 2022 (Shannon). Trish Nichols also recommended an "independent review board" without specifying whether this should be prospective or retrospective.

^{81 &}lt;u>Evidence</u>, 22 November 2022 (Stainton).

⁸² Evidence, 25 November 2022 (Linton).

^{83 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 16 June 2022 (Trish and Gary Nichols).

development of MAID policy.⁸⁴ However, a number of witnesses testified that persons with disabilities have not been adequately consulted on MAID.⁸⁵

Gabrielle Peters, Krista Carr and Tim Stainton felt that persons with disabilities were not heard in the policy discourse surrounding Bill C-7. Others expressed concerns regarding the role and treatment of persons with disabilities in the current committee's hearings. According to Isabel Grant, "ableism, sadly, has also permeated these hearings."

Sarah Jama felt that the committee's brief submission process was not inclusive of persons with disabilities who may be unable to make written submissions online.

Witnesses also stressed the need to hear from Black, racialized, and Indigenous People, as well as youth with disabilities, on the topic of MAID. 87

In its response to the committee's interim report, the government described the following project funded by Budget 2021:

Another project planned in the short term...would focus on the views and experiences of persons living with disabilities that will inform and complement the information collected through the federal MAID monitoring system. This research is expected to generate evidence that responds to the concerns of organizations representing persons with disabilities and inform future policy development.

The committee wishes to acknowledge the importance of ongoing, in-depth consultations with individuals and organizations representing persons with disabilities, including Black, racialized, Indigenous and young persons with disabilities, as MAID laws and policies continue to evolve. For this reason, the committee recommends

Recommendation 12

That the Government of Canada convene an expert panel to study and report on the needs of persons with disabilities as they relate to MAID, similar to the Expert Panel on MAID and Mental Illness.

⁸⁴ Evidence, 13 April 2022 (Banerjee).

^{85 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 6 June 2022 (Mehdi); <u>Evidence</u>, 18 November 2022 (Carr; Peters).

^{86 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Coelho); <u>Evidence</u>, 25 November 2022 (Grant).

^{87 &}lt;u>Evidence</u>, 16 May 2022 (Adams; Jama); <u>Evidence</u>, 30 May 2022 (Saulis); <u>Evidence</u>, 6 June 2022 (Mehdi, Franco Carnevale; Montes).



MEDICAL ASSISTANCE IN DYING WHERE MENTAL DISORDER IS THE SOLE UNDERLYING MEDICAL CONDITION

BACKGROUND

When the Code provisions relating to MAID were amended by Bill C-7 to include individuals whose deaths are not reasonably foreseeable, eligibility for MAID MD-SUMC was explicitly excluded until 17 March 2023. The amendments included a requirement that experts carry out an independent review "respecting recommended protocols, guidance and safeguards to apply to requests made for medical assistance in dying by persons who have a mental illness." That review was carried out by the Expert Panel on MAID and Mental Illness; the Expert Panel's final report was released in May 2022.

Knowing that witnesses had concerns about whether protocols, guidance and safeguards at the provincial/territorial level would be in place by March 2023, the committee released an interim report exclusively on MAID MD-SUMC in June 2022. That interim report summarized what the committee heard about MAID MD-SUMC in the spring of 2022, including the testimony of Dr. Mona Gupta, Chair of the Expert Panel. The interim report concluded:

[I]f the Expert Panel's recommendations are to be implemented, the work must proceed quickly as March 2023 is fast approaching. We must have standards of practice, clear guidelines, adequate training for practitioners, comprehensive patient assessments and meaningful oversight in place for the case of MAID MD-SUMC. This task will require the efforts and collaboration of regulators, professional associations, institutional committees and all levels of government and these actors need to be engaged and supported in this important work.

Although some work is already underway to implement the recommendations of the Expert panel, there is concern that more remains to be done to ensure that all necessary steps have been taken to be ready by the March 2023 deadline when MAID provisions can be considered in the case of people suffering from a mental disorder as the

88 Bill C-7, An Act to amend the Criminal Code (medical assistance in dying), clause 3.1.

sole underlying cause. We urge the federal government to work with the Provinces and Territories and others to ensure that the recommendations of the Expert Panel are implemented in a timely manner.⁸⁹

The Government of Canada responded to the interim report in October 2022. Federal Health Minister the Honourable Jean-Yves Duclos indicated that government efforts to implement the Expert Panel's recommendations have "focused on health system preparedness to address complex MAID cases, including but not limited to those involving a mental disorder diagnosis." The response explains that "[w]hile the development of practice standards falls outside of direct federal responsibility, we are leading work with key partners to complete this work in advance of March 2023."

As mentioned above, on 15 December 2022, Minister Lametti, Minister Duclos, and Minister Bennett announced that they will be seeking to extend the date for eligibility for MAID MD-SUMC. This addresses the committee's key concern that more time is needed for standards to be developed and training to be undertaken before the law permits MAID MD-SUMC. Bill C-39, An Act to amend An Act to amend the Criminal Code (medical assistance in dying) was introduced in the House of Commons on 2 February 2023 and proposes a one-year delay to the date for eligibility for MAID MD-SUMC.

As the themes raised in the fall meetings on mental disorder reflect those heard in the spring and were considered in detail in the interim report, the final report provides a more high-level synopsis of testimony.

POTENTIAL DISCRIMINATION

A number of witnesses suggested that not allowing MAID MD-SUMC could be discriminatory⁹¹ and that a distinction in the law between mental and physical disorders "is unlikely to stand up to court review."⁹² Referring to the 2020 Supreme Court of

Parliament of Canada, Special Joint Committee on Medical Assistance in Dying, <u>Medical Assistance in Dying</u> and <u>Mental Disorder as the Sole Underlying Condition: An Interim Report</u>, 1st Session, 44th Parliament, June 2022.

⁹⁰ Minister of Health, <u>Government Response to the First Report of the Special Joint Committee on Medical</u>
Assistance in Dying, 20 October 2022.

^{91 &}lt;u>Evidence</u>, 25 April 2022 (Green); <u>Evidence</u>, 27 September 2022 (Chandler); <u>Evidence</u>, 4 October 2022 (Shakir Rahim); Dr. Chantal Perrot, <u>Submission to the Special Joint Committee on Medical Assistance in Dying regarding Statutory Review: Medical Assistance in Dying.</u>

^{92 &}lt;u>Evidence</u>, 4 October 2022 (Dr. Michael Trew). See also <u>Evidence</u>, 5 May 2022 (L'Espérance).



Canada decision in *Ontario (Attorney General) v. G.*, ⁹³ Shakir Rahim, Lawyer, Kastner Lam LLP, told the committee that "the recommendation of the expert panel on MAID MD-SUMC conforms to the spirit and letter of the section 15 (equality) jurisprudence."

CAPACITY

Having the capacity to make healthcare decisions is a key eligibility criterion for MAID, and an essential component of informed consent in the medical context more generally. As explained by <u>Dr. Gail Beck</u>, Interim Psychiatrist-in-Chief and Chief of Staff, Clinical Director, Youth Psychiatry Program, Royal Ottawa Health Care Group, capacity requires understanding one's condition and treatment options, appreciating the implications of the decision, and being able to communicate the decision. ⁹⁴ The committee heard that assessing capacity in the context of a mental disorder is routine, ⁹⁵ including identifying whether someone is in crisis.

The Expert Panel considered capacity in the context of MAID MD-SUMC, explaining that:

In other areas of practice, difficulties in assessing capacity are not resolved by refusing to permit access to the intervention to all persons or a subgroup of persons. When the assessment is so difficult or uncertain that the clinicians involved cannot establish that a person is capable of giving informed consent, the intervention is not provided. Similarly, the assessors must be of the opinion the person is capable of making decisions about MAID and if the assessors cannot form this opinion, then MAID cannot [...]be provided.⁹⁶

<u>Dr. Georges L'Espérance</u>, President and Neurosurgeon, Quebec Association for the Right to Die with Dignity, put forward the position that "persons with significant cognitive impairment be completely and permanently disqualified from receiving medical assistance in dying, except where there is absolute certainty that the person's decision-making ability is intact." ⁹⁷

93 <u>Ontario (Attorney General) v. G</u>, 2020 SCC 38.

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^{94 &}lt;u>Evidence</u>, 6 June 2022 (Bryan Salte); <u>Evidence</u>, 4 November 2022 (Dr. Gail Beck; Dr. Arundhati Dhara); <u>Evidence</u>, 1 November 2022 (Dr. Gordon Gubitz).

⁹⁵ Evidence, 25 May 2022 (Dr. Derryck Smith).

⁹⁶ Government of Canada, *Final Report of the Expert Panel on MAID and Mental Illness*, May 2022, p. 42.

^{97 &}lt;u>Evidence</u>, 5 May 2022 (L'Espérance).

IRREMEDIABILITY

To be eligible for MAID, a person must have a "grievous and irremediable medical condition." As <u>Jennifer Chandler</u> explained, "irremediable" is not a medical or scientific term. Rather, as noted above, "grievous and irremediable" is defined in the law as incurability, being in an advanced state of irreversible decline, and "enduring physical or psychological suffering that is intolerable to [the person] and that cannot be relieved under conditions that [the person] consider[s] acceptable." ⁹⁸

Many witnesses discussed challenges relating to assessing irremediability in the context of MAID MD-SUMC. Some witnesses expressed the opinion that MAID MD-SUMC should not be permitted because there cannot be certainty with respect to the incurability of a mental disorder. ⁹⁹ Other witnesses told the committee that certainty is not required ¹⁰⁰ and that there are ways to consider irremediability (years of treatment with negligible response, for example). ¹⁰¹

With respect to the Expert Panel's discussion on irremediability, psychiatrist and MAID assessor Dr. Justine Dembo told the committee:

The panel report states that MAID assessors should establish incurability and irreversibility with reference to treatment attempts made, the impacts of those treatments and the severity of the illness, disease or disability. The panel also states that, as with many chronic conditions, the incurability of a mental disorder cannot be established in the absence of extensive attempts at interventions with therapeutic aims. This means that someone who has not had access to adequate care would not be eligible for MAID. Therefore, MAID could never be used as a substitute for good psychiatric care.

The Final Report of the Expert Panel also emphasized the need for considering eligibility on a case-by-case basis, and that it is not possible to establish rules about the number of types of treatments and interventions, or the number of times each must be attempted over what period of time. ¹⁰² The Expert Panel also explained that determining incurability and irreversibility involves the individual requesting MAID and the assessor coming to a shared understanding. As Dr. Alison Freeland, Chair of the Board of

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    Criminal Code, s. 241.2(2).
    Evidence, 25 May 2022 (Sean Krausert; Brian Mishara); Evidence, 26 May 2022 (Maher; Synyor); Evidence, 4 October 2022 (Dr. Marie Nicolini; Mark Henick)
    See for example Evidence, 26 May 2022 (Gupta; Dr. Tyler Black).
    Evidence, 25 May 2022 (Smith); Evidence, 4 October 2022 (Trew); Evidence, 7 October 2022 (Roy).
    Government of Canada, Final Report of the Expert Panel on MAID and Mental Illness, May 2022,
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Recommendations 2 and 3.



Directors, Co-Chair of MAiD Working Group, Canadian Psychiatric Association told the committee,

ideally, these are shared decisions because the patient is listening to the psychiatrist's perspective and input, and we are there to think about hope and recovery. At the same time, we have to listen to a competent patient's perspective and what they want to come up with a decision that forges a path forward for the patient that they find appropriate for them... ideally these are transparent, informed conversations between two people who care about somebody's outcome, treatment and care.

Some psychiatrists told the committee that they have encountered very few individuals who would meet the criteria for MAID MD-SUMC.¹⁰³ <u>Dr. Donna Stewart</u> noted that in the Netherlands, 95% of MAID requests based on mental disorder were rejected in 2020.

While the Expert Panel and some witnesses addressed how irremediability could be considered in the absence of certainty, Nancy Guillemette, Member for Roberval, Government of Quebec, Chair of Quebec's Select Committee on the Evolution of the Act respecting end-of-life care, explained that Quebec decided that MAID MD-SUMC should not be permitted at this time because of the challenges of determining irremediability as well as the lack of social consensus.

MAID AND SUICIDE

Witnesses disagreed about whether a request for MAID MD-SUMC can be distinguished from suicidality. For example, <u>Dr. Donna Stewart</u> explained that "to sort out suicidality from a well-considered request for MAID after somebody has suffered for many years, tried many treatments, has carefully thought this out and feels that this is best for them" is part of a psychiatrist's role. The Expert Panel stated that "[i]ndividualized suicide assessments ... are already part of current MAID assessment practices as are suicide prevention efforts when these are warranted." ¹⁰⁴ In addition, the Expert Panel explained that:

[i]n these high-stakes clinical situations the clinician must undertake three actions simultaneously: 1. consider a person's capacity to give informed consent to make such decisions; 2. consider whether or not suicide prevention interventions should be activated, including against the will of the person if necessary; and, 3. consider what other types of

^{103 &}lt;u>Evidence</u>, 23 September 2022 (Dr. Guillaume Barbès-Morin; Dr. Justine Dembo; Dr. Cornelia Wieman); <u>Evidence</u>, 4 October 2022 (Christine Grou).

¹⁰⁴ Government of Canada, Final Report of the Expert Panel on MAID and Mental Illness, May 2022, p. 45.

interventions could be helpful to the person including nonintervention. ¹⁰⁵

Professor <u>Brian Mishara</u>, Director, Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices (CRISE), Université du Québec à Montréal did not believe it was possible to distinguish a request for MAID from suicidality. ¹⁰⁶

<u>Brian Mishara</u> also expressed the opinion that this issue was not addressed by the Expert Panel: "If you look at the expert panel report carefully and you try to find some indication of how you differentiate between someone who is suicidal and someone who is requesting MAID, all they say repeatedly is that it is not possible to provide fixed rules." However, <u>Dr. Tyler Black</u>, ¹⁰⁷ Clinical Assistant Professor at the University of British Columbia, explained to the committee,

motivations in MAID and suicide are rarely the same. In suicide, it's very rare to have a combination of fatalistic motivation, which is a controlled response to a perceived stress, an agreed-upon lack of remedy and a rational calculation of the likelihood of change, whereas in MAID this is almost always the case. In the literature, psychiatrists generally agree with the patient's unbearable suffering and futility of treatment in psychiatric MAID cases in the countries where this has been studied.

...the wish to die is not indicative of a mental illness. While depression does include suicidality as one of its nine criteria, the presence of a serious mental health diagnosis is absent in 40% to 50% of all who die by suicide. Many who experience suicidal thinking do not have a diagnosable mental illness, and the vast majority do not die by suicide.

<u>Dr. Black</u> continued:

[T]here are decades of experience of MAID in some countries and some with psychiatric MAID, and it suggests that it's well practised, well accepted and represents only a small fraction of all MAID deaths, 1% to 2%. Given the number of people with suicidal thinking, there is simply no credible foundation for the fear that allowing MAID for psychiatric conditions would create a flood of deaths in Canada.

One study estimated suicidal thinking as an 8% lifetime risk for adults in the Netherlands, yet 65 or 0.0004% of adults in the Netherlands have died of MAID in any given year due to psychiatric reasons.

<u>Dr. Natalie Le Sage</u>, Physician, Clinical Researcher and MAID Provider and <u>Christine Grou</u>, President and Psychologist, Ordre des psychologues du Québec, indicated that an

¹⁰⁵ Ibid., p. 44.

See also the Centre for Addiction and Mental Health's brief.

¹⁰⁷ Dr. Black also submitted the following brief to the committee: Evidence regarding MAID and Suicide.



individual in crisis or dealing with an untreated or undertreated mental disorder would not be eligible for MAID MD-SUMC.

Regardless of opinions on whether a request for MAID MD-SUMC can be distinguished from suicidality, witnesses generally agreed on the need for improved suicide prevention. 108

STRUCTURAL VULNERABILITY AND ACCESS TO HEALTHCARE

The committee heard from witnesses about structural vulnerability and its possible implications for MAID MD-SUMC. As the Expert Panel summarizes,

While structural vulnerability may contribute to a person's experience of a chronic medical condition, the Panel does not believe persons in situations of structural vulnerability should be excluded systematically from access to MAID. Rather, local MAID coordinating services should ensure assessors are equipped to present requesters with a complete picture of any additional means available to relieve suffering and should make all reasonable efforts to ensure requesters have access to these means. 109

<u>Dr. Guillaume Barbès-Morin</u>, Psychiatrist, Association des médecins psychiatres du Québec, explained "[t]he vulnerability of people with mental health problems is not something new. Mechanisms already exist to take this into consideration, and clinicians already surround themselves with multidisciplinary teams to try and best assess all of the relevant factors."

While the Expert Panel and witnesses agreed that better social supports and improved access to care are needed, most witnesses did not believe that MAID MD-SUMC should be prohibited due to a lack of social supports. Diane Reva Gwartz emphasized that additional resources for MAID practitioners are needed, particularly for MAID MD-SUMC given the complexity of those assessments.

108 <u>Evidence</u>, 4 October 2022 (Nicolini; Trew; Grou).

109 Government of Canada, Final Report of the Expert Panel on MAID and Mental Illness, May 2022, p. 62

See for example, <u>Evidence</u>, 25 April 2022 (Green); <u>Evidence</u>, 9 May 2022 (Downie); Government of Canada, <u>Final Report of the Expert Panel on MAID and Mental Illness</u>, May 2022, p. 62.

SAFEGUARDS, STANDARDS AND PRACTICAL CONSIDERATIONS

Many witnesses who supported MAID MD-SUMC referred to the safeguards included in the Expert Panel's report, some of which are discussed above in the sections "Irremediability" and "MAID and Suicide." While the Expert Panel concluded that no additional safeguards specific to MAID MD-SUMC need to be added to the Code, Dr. Marie Nicolini, Senior Researcher, KU Leuven University and Georgetown University, disagreed, and also expressed the opinion that safeguards cannot be discussed until the standards for MAID MD-SUMC are determined. Psychologist and Professor Georgia Vrakas told the committee that, in her opinion, there were no safeguards that could be implemented to make MAID MD-SUMC safe.

The Expert Panel's conclusion that the existing Code safeguards are sufficient for MAID MD-SUMC does not mean that additional safeguards are not required at the clinical level. As <u>Dr. Donna Stewart</u> told the committee, "[t]he main concern is the uncertainty that currently exists about what the standards are going to be. The sooner this can be firmed up, the more reassured the practitioners will be." <u>Dr. Justine Dembo</u> indicated, however, that there is already experience with other track two assessments, and that "the issues that come up in track two and mental illness are very similar...assessors and providers are getting practice and are prepared to be able to implement the recommendations by March 2023." Similarly, <u>Jennifer Chandler</u> explained that assessors are already assessing capacity for individuals with a mental disorder where there is a comorbidity for which they are eligible for MAID for both track one and track two, and <u>Dr. Mona Gupta</u> did not consider that there was a significant training gap that needed to be addressed for those already involved in assessments.

While the delivery of healthcare falls to the provinces and territories, the committee heard that standards of practice, process and safeguards should be harmonized across Canada. ¹¹¹ This was Recommendation 1 of the Expert Panel's Final Report:

The federal, provincial and territorial governments should facilitate the collaboration of physician and nurse regulatory bodies in the development of Standards of Practice for physicians and nurse practitioners for the assessment of MAID requests in situations that raise questions about incurability, irreversibility, capacity, suicidality, and the impact of structural vulnerabilities. 112

^{111 &}lt;u>Evidence</u>, 27 September 2022 (Chandler; Dr. Donna Stewart).

Government of Canada, Final Report of the Expert Panel on MAID and Mental Illness, May 2022, p. 52.



While the Expert Panel did not recommend that two psychiatrists be involved in each MAID MD-SUMC application, this was the recommendation from <u>Dr. Guillaume Barbès-Morin</u>. <u>Dr. Justine Dembo</u> indicated that two psychiatric assessments might sometimes be required, and the Council of Canadian Academies report on MAID MD-SUMC discussed the potential role of two psychiatrists as recommended by the Flemish Psychiatric Association:

[T]he recent advisory document from the VVP [Flemish Psychiatric Association] recommends that during the process of evaluating eligibility for psychiatric EAS [euthanasia and assisted suicide], physicians should maintain a "two track" process involving two different psychiatrists: one conducts a thorough and extended evaluation for MAID eligibility, while the other explores treatment options with the person requesting MAID from a recovery-oriented perspective. 113

<u>Dr. Natalie Le Sage</u> pointed out, however, that requiring two psychiatric assessments could be a barrier to accessing MAID. <u>Christine Grou</u> recommended including the expertise of psychologists and neuropsychologists, potentially as independent assessors.

Psychiatrist <u>Dr. Michael Trew</u>, Clinical Associate Professor, University of Calgary, proposed that if an individual has been found ineligible for MAID MD-SUMC, there should be a waiting period before the individual can consult another healthcare provider to avoid "doctor shopping."

In Recommendation 16 of its report, the Expert Panel proposes that "the federal government should play an active role in supporting the development of a model of prospective oversight for all or some track two cases that could be adapted by provinces and territories." While prospective oversight "for many track two cases" was supported by Dr. Donna Stewart and the Canadian Psychiatric Association, which indicated that oversight could start at the federal level and then shift to retrospective oversight by provinces and territories after a period of time, Dr. Louis Roy from the Collège des médecins du Québec observed that it should be reserved for more "contentious" cases. The importance of monitoring and collecting information was emphasized by Ellen Cohen, National Coordinator Advocate, National Mental Health Inclusion Network and Jennifer Chandler.

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Council of Canadian Academies, Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition, <u>The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition</u>, 2018, p. 183.

Government of Canada, Final Report of the Expert Panel on MAID and Mental Illness, May 2022, p. 75.

MAID MD-SUMC ELIGIBILITY IN MARCH 2023

While the committee respects that some witnesses do not think that individuals whose sole underlying medical condition is a mental disorder should be eligible for MAID, the committee believes that such individuals should have access to MAID, provided that they meet the eligibility requirements. The committee is also aware of the need to ensure that individuals who are vulnerable do not seek MAID as an alternative to inadequate social and healthcare supports. While the committee supports MAID MD-SUMC, it is concerned that there has not been sufficient time to develop the standards of practice referred to by the Expert Panel. Witnesses were clear that these standards are key to ensuring a thoughtful, consistent approach to MAID MD-SUMC. The committee notes the ministers' announcement that eligibility for MAID MD-SUMC will be delayed. As mentioned above, Bill C-39 proposes a one-year extension to March 2024. The committee recognizes that this delay in eligibility for MAID MD-SUMC may prolong the suffering of some individuals.

The committee remains seized of this issue and wants to ensure that standards are in place before eligibility for MAID MD-SUMC is permitted. For that reason, the committee recommends

Recommendation 13

That, five months prior to the coming into force of eligibility for MAID where a mental disorder is the sole underlying medical condition, a Special Joint Committee on Medical Assistance in Dying be re-established by the House of Commons and the Senate in order to verify the degree of preparedness attained for a safe and adequate application of MAID (in MD-SUMC situations). Following this assessment, the Special Joint Committee will make its final recommendation to the House of Commons and the Senate.



MATURE MINORS

BACKGROUND

MAID for Minors in Canada and Internationally

In Canada, a person must be at least 18 years old to access MAID. However, minors with the requisite capacity are generally entitled to make their own healthcare decisions. The exact parameters of minor consent to healthcare vary by province. A <u>Canadian</u> <u>Paediatric Society</u> study cited by several witnesses shows that pediatricians have been fielding questions about MAID for minors. 116

Minors can legally access MAID in only a few jurisdictions worldwide. In the Netherlands, MAID is allowed for minors aged 12 and over, and may soon be expanded to include younger children. ¹¹⁷ In Belgium, there is no minimum age, so long as the minor has the requisite capacity. ¹¹⁸ As noted by several witnesses, the number of minors accessing MAID where it is legal is very low. ¹¹⁹

What is a "Mature Minor"?

The term "mature minor" refers to a common law doctrine according to which "an adolescent's treatment wishes should be granted a degree of deference that is reflective of his or her evolving maturity." This doctrine was endorsed by the Supreme Court of Canada in <u>A.C. v. Manitoba (Director of Child and Family Services)</u>. According to <u>Bryan Salte</u>,

the discussion around the Council of Canadian Academies table was that "decisional capacity" is a much better term than "mature minors" because "mature minors", as a

See for example: <u>Evidence</u>, 25 April 2022 (Green); <u>Evidence</u>, 6 June 2022 (Salte; Carnevale); <u>Evidence</u>, 15 November 2022 (Cheryl Milne).

See for example: *Evidence*, 6 June 2022 (Constance MacIntosh; Mehdi).

¹¹⁷ Evidence, 4 November 2022 (Dr. Eduard Verhagen); CCA Report, p. 138.

¹¹⁸ CCA Report, p. 138.

^{119 &}lt;u>Evidence</u>, 6 June 2022 (MacIntosh); <u>Evidence</u>, 1 November 2022 (Kimberley Widger); <u>Evidence</u>, 4 November 2022 (Verhagen); <u>Evidence</u>, 15 November 2022 (Dr. Dawn Davies).

¹²⁰ A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30, para 23.

legal term, is understood by lawyers and judges, but is not so clearly understood by members of the public.

<u>Jay Potter</u>, Acting Senior Counsel, Department of Justice, suggested that Parliament may need to define "mature minor" if MAID is expanded to this group.

NEED FOR FURTHER CONSULTATION AND RESEARCH

One of the most resounding messages from witnesses was the need for greater engagement with directly affected youth and their families on the topic of MAID for mature minors, including youth with terminal illnesses, youth with disabilities, youth in the child welfare system and Indigenous youth. 121 "[R]especting our responsibilities to young people would include studying their perspectives and bringing their voices into deliberations about expanded access," stated Dr. Randi Zlotnik Shaul, Director, Department of Bioethics, Hospital for Sick Children. The committee was concerned to hear that youth have been largely excluded from such discussions in both clinical care and policy-making contexts, 122 and that there is little national or international data capturing their views and experiences regarding end-of-life issues. 123

The committee heard that this knowledge gap was a major source of concern for the Council of Canadian Academies Expert Panel Working Group on MAID for Mature Minors (CCA Mature Minors Working Group). Mary Ellen MacDonald, Endowed Chair in Palliative Care at McGill University described

an experience of frustration that we were trying to advance policy and practice ideas without having ample evidence from youth themselves on the topic at hand. We continually circled back to the lack of research we could draw upon to help think forward about what MAID for mature minors could and should look like.

This experience led her and her colleagues to submit a proposal to Health Canada for a three-year study examining the views of youth and their caregivers on MAID and other end-of-life issues, which could provide an evidence base for recommendations. ¹²⁵

Evidence, 6 June 2022 (Mehdi; Montes; Carnevale); Evidence, 1 November 2022 (Widger); Evidence, 4 November 2022 (Neil Belanger and Mary Ellen Macdonald); Evidence, 15 November 2022 (Davies; Milne; Dr. Randi Zlotnik Shaul).
 Evidence, 6 June 2022 (Montes; Carnevale).

^{123 &}lt;u>Evidence</u>, 4 November 2022 (Macdonald); <u>Evidence</u>, 21 October 2022 (Ross).

^{124 &}lt;u>Evidence</u>, 4 November 2022 (Macdonald); <u>Evidence</u>, 15 November 2022 (Shaul).

^{125 &}lt;u>Evidence</u>, 4 November 2022 (Macdonald).



Witnesses described other preliminary efforts to better understand youth perspectives on this topic. Franco Carnevale, Professor and Clinical Ethicist, and founder of the VOICE childhood research program at McGill University, conducted interviews with youth leaders with disabilities at Holland Bloorview Kids Rehabilitation Hospital. Kevin Liu, a member of the VOICE Youth Advisory Council, conducted a study examining the views of youth aged 16–24 years (not including youth with terminal illnesses) on MAID, the results of which are currently under review for publication. The participants' perspectives varied, but many recognized the benefits of MAID and that youth could make MAID-related decisions. Moving forward, Kevin Liu said it was important to seek input from vulnerable groups, including Indigenous youth and youth with terminal illnesses. Youth councils and children's hospitals were recommended as good places to start. 126

The committee heard compelling testimony about the lived experience of two families, both of whom lost teenaged sons to bone cancer. <u>Caroline Marcoux</u> described her son Charles' desire to access MAID to relieve his anxiety and pain, and to gain control over his death:

I know that the decision to expand access to medical assistance in dying to mature minors is not to be taken lightly, nor did Charles, from the height of his 17 years, at the end of his life, take it lightly. It might not have hastened his death by much, since he was already at the end of life. ... But he was ready and he deserved that choice. It would have been his decision, in the end. It would have been he who chose the time to leave and the people who would be with him.

<u>Mike Schouten</u>, on the other hand, relayed how excellent palliative care enabled his family "to spend every living moment we had yet with [our son] Markus living well," without ending Markus' life prematurely. 127

While <u>Cheryl Milne</u>, Executive Director, David Asper Centre for Constitutional Rights, and <u>Dr. Randi Zlotnik Shaul</u> affirmed the importance of hearing from youth, they cautioned that the time-sensitive needs of minors seeking MAID must also be considered. "A delay is not a neutral position," observed <u>Dr. Randi Zlotnik Shaul</u>. 128

The committee agrees that a balance must be struck between addressing the urgent needs of currently suffering minors and soliciting more information from youth to

^{126 &}lt;u>Evidence</u>, 25 November 2022 (Kevin Liu); <u>Evidence</u>, 15 November 2022 (Davies).

¹²⁷ It should be noted that Markus had reached the age of majority before his death, and would thus have been able to request MAID as an adult had he wished to do so.

¹²⁸ Evidence, 15 November 2022 (Shaul).

ensure that MAID policy decisions are properly evidence-based. For that reason, the committee recommends

Recommendation 14

That the Government of Canada undertake consultations with minors on the topic of MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, within five years of the tabling of this report.

Recommendation 15

That the Government of Canada provide funding through Health Canada and other relevant departments for research into the views and experiences of minors with respect to MAID, including minors with terminal illnesses, minors with disabilities, minors in the child welfare system and Indigenous minors, to be completed within five years of the tabling of this report.

ACCESS TO SUPPORTS AND SERVICES

As in the case of adults, some witnesses raised concerns about providing MAID to minors who may not have adequate access to care, supports and services. ¹²⁹ While some saw this as a reason to halt the expansion of MAID, ¹³⁰ others viewed it as a distinct issue that ought to be addressed in parallel with the provision of MAID. ¹³¹

Myeengun Henry, Indigenous Knowledge Keeper, University of Waterloo, and Conrad Saulis, Executive Director, Wabanaki Council on Disability, highlighted the importance of Indigenous healing practices to support Indigenous youth who are suffering. Mr. Saulis referred to "a vacuum of youth programming and support for [I]ndigenous youth." Professor Roderick McCormick worried that many Indigenous and other youth are not aware of, or do not accurately understand, their treatment options. He also emphasized the need for improved mental health services for Indigenous and other youth.

^{129 &}lt;u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 30 May 2022 (Saulis); <u>Evidence</u>, 6 June 2022 (Mehdi; Montes); <u>Evidence</u>, 4 November 2022 (Belanger and Elizabeth Sheehy).

E.g. <u>Evidence</u>, 16 May 2022 (Jama); <u>Evidence</u>, 6 June 2022 (Mehdi; Montes); <u>Evidence</u>, 4 November 2022 (Belanger; Sheehy).

¹³¹ E.g. Evidence, 4 November 2022 (Dhara); Evidence, 15 November 2022 (Davies; Shaul).



<u>Kimberley Widger</u>, Associate Professor, spoke about the value of specialized pediatric palliative care teams, a point <u>Mike Schouten</u> affirmed based on his family's experience:

[I]t was incredibly comforting to know that they were always one step ahead of us...every day when they would come to our house, the Canuck Place hospice nurses would assess Markus and say, "I think we need this type of medication" or "We need an extra dose of this type of medication to treat this" or "Let's bring in some more bedding", or pillows or oxygen. Whatever it had to be, they were always ahead of us.

<u>Professor Widger</u>'s research found that many minors do not have access to this kind of care, and that there are "concerning inequities" regarding who has access. Others raised similar concerns regarding palliative care for minors generally. Roderick McCormick, referred to a "near total absence of palliative care services" for Indigenous youth.

According to the testimony of several medical professionals, however, even excellent palliative care may not always be sufficient to alleviate a minor's suffering. This was the lived experience of Caroline Marcoux's son Charles: "The [palliative care] team did its best, within the limits of the options available to it, but was never able to completely relieve the pain," she explained.

The committee wishes to underscore the importance of ensuring that all minors have access to the care, supports and services they need, including specialized paediatric palliative care delivered in a culturally appropriate manner (see recommendations under "Palliative Care").

CAPACITY AND AGE

The applicable standard for capacity to make healthcare decisions, and the clinical capacity assessment process, are similar regardless of age.¹³⁴

Witnesses described various contextual factors that may affect a minor's decisional capacity, including their level of development, ¹³⁵ experiences with illness, ¹³⁶ cultural and

132 <u>Evidence</u>, 6 June 2022 (Montes); <u>Evidence</u>, 21 October 2022 (Ross); <u>Evidence</u>, 4 November 2022 (Belanger; Dhara; Sheehy); <u>Evidence</u>, 15 November 2022 (Shaul).

^{133 &}lt;u>Evidence</u>, 4 November 2022 (Dhara); <u>Evidence</u>, 15 November 2022 (Davies; Shaul).

^{134 &}lt;u>Evidence</u>, 1 November 2022 (Gubitz); <u>Evidence</u>, 4 November 2022 (Dhara); <u>Evidence</u>, 15 November 2022 (Milne).

^{135 &}lt;u>Evidence</u>, 1 November 2022 (Gubitz; Kathryn Morrison).

^{136 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 6 June 2022 (Salte); <u>Evidence</u>, 1 November 2022 (Morrison); <u>Evidence</u>, 4 November 2022 (Beck); <u>Evidence</u>, 15 November 2022 (Davies; Shaul).

familial influences,¹³⁷ and the way they are engaged in the decision-making process itself.¹³⁸ It was widely acknowledged that the frontal lobe of the brain, which plays a key role in risk assessment and decision-making, is not fully developed until well into adulthood.¹³⁹ On the other hand, <u>Bryan Salte</u> pointed to evidence showing that individuals with terminal illnesses are "very informed about their condition and very thoughtful about the decisions they make." Several other witnesses affirmed, based on both professional and personal experience, that adolescents suffering from serious illnesses tend to possess an uncommon level of maturity.¹⁴⁰

<u>Dr. Timothy Ehmann</u>, Child and Adolescent Psychiatrist, and <u>Mike Schouten</u> worried that there are many systemic influences on a minor's decision-making, including the government's MAID policy itself. According to <u>Cheryl Milne</u>, while minors often make decisions with their families, this does not mean that their consent is not voluntary.

Several witnesses underscored that decisional capacity is time and treatment-specific, and that the threshold for capacity depends on the gravity of the decision. ¹⁴¹ Some felt that the decision to seek MAID is simply too weighty for a minor to make. ¹⁴² Several others pointed out that Canadian minors are already allowed to make decisions about withholding or ceasing treatment, even when such decisions may hasten death. ¹⁴³ While Elizabeth Sheehy, Professor Emerita of Law, University of Ottawa, and Dr. Timothy Ehmann viewed such decisions as substantially different from the decision to seek MAID, Dr. Dawn Davies, Pediatrician, Palliative Care Physician, viewed them as comparable. Kathryn Morrison, Clinical and Organizational Ethicist, suggested that a decision that leads to death when a long future is possible may actually be weightier than a decision to seek MAID when one is already at the end-of-life.

^{137 &}lt;u>Evidence</u>, 1 November 2022 (Morrison); <u>Evidence</u>, 4 November 2022 (Beck); <u>Evidence</u>, 15 November 2022 (Dr. Timothy Ehmann; Milne).

¹³⁸ *Evidence*, 6 June 2022 (Carnevale).

^{139 &}lt;u>Evidence</u>, 6 June 2022 (Mehdi; Montes; Salte); <u>Evidence</u>, 4 November 2022 (Beck; Sheehy); <u>Evidence</u>, 15 November 2022 (Roderick McCormick).

^{140 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 4 November 2022 (Beck); <u>Evidence</u>, 15 November 2022 (Davies) (speaking from professional experience) and Caroline Marcoux (speaking from her personal experience as mother of a teenager deceased from cancer).

 <u>Evidence</u>, 6 June 2022 (MacIntosh; Salte); <u>Evidence</u>, 1 November 2022 (Gubitz; Morrison); <u>Evidence</u>,
 4 November 2022 (Dhara; Sheehy); <u>Evidence</u>, 15 November 2022 (Milne; Shaul).

^{142 &}lt;u>Evidence</u>, 6 June 2022 (Montes); <u>Evidence</u>, 4 November 2022 (Sheehy).

See for example: <u>Evidence</u>, 6 June 2022 (Salte; Carnevale); <u>Evidence</u>, 25 April 2022 (Green); <u>Evidence</u>, 15 November 2022 (Milne).



Many witnesses held firm convictions that neither suffering¹⁴⁴ nor capacity¹⁴⁵ is a function of age. This was often supported by clinical observations.¹⁴⁶ Others questioned the constitutionality, or at least the justifiability, of denying access to MAID based on age.¹⁴⁷ Dr. Randi Zlotnik Shaul explained:

I think having the capacity piece not tied exclusively to an age is giving recognition to fact that the lived experience of an individual informs their ability to understand and appreciate the question before them. In terms of social context and in terms of experience in living with an illness, all these pieces will inform and add to the maturity they may have ...

Most clinicians were confident that healthcare professionals could appropriately assess capacity on a case-by-case basis. ¹⁴⁸ <u>Dr. Arundhati Dhara</u>, Family Physician, stated:

We need to approach MAID for mature minors the same way we do for every patient: Each is unique and must be treated with careful consideration of their personal circumstances in the context of their life.

She noted that MAID providers operate within a "community of practice" which enables them to seek further opinions when faced with complex cases. <u>Dr. Timothy Ehmann</u>, on the other hand, expressed the view that according to his understanding of the research literature, capacity assessments of minors are unreliable.

While clinicians generally supported a capacity-based approach, <u>Elizabeth Sheehy</u> felt that a clear minimum age was important to avoid recourse to the courts. Should a minimum age be adopted, <u>Constance MacIntosh</u> recommended setting it at 12 years old, based on psychological evidence that a child younger than 12 is very unlikely to have the necessary decisional capacity for MAID.

144 <u>Evidence</u>, 1 November 2022 (Morrison); <u>Evidence</u>, 4 November 2022 (Dhara); <u>Evidence</u>, 18 November 2022 (Gaudreault).

145 <u>Evidence</u>, 6 June 2022 (MacIntosh; Salte); <u>Evidence</u>, 4 November 2022 (Beck); <u>Evidence</u>, 15 November 2022 (Shaul).

146 <u>Evidence</u>, 1 November 2022 (Gubitz; Widger [regarding two minors of the same age with very different capacities]); <u>Evidence</u>, 4 November 2022 (Dhara).

147 <u>Evidence</u>, 6 June 2022 (MacIntosh; Salte); <u>Evidence</u>, 1 November 2022 (Dr. Kathryn Morrison); <u>Evidence</u>, 15 November 2022 (Milne).

148 <u>Evidence</u>, 25 April 2022 (Green; Naud); <u>Evidence</u>, 6 June 2022 (MacIntosh; Salte); <u>Evidence</u>, 4 November 2022 (Beck; Dhara); <u>Evidence</u>, 15 November 2022 (Davies).

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A December 2021 report published by the Collège des médecins du Québec concludes that minors aged 14 and older should have access to MAID with parental consent, ¹⁴⁹ which accords with Quebec's existing healthcare consent law. ¹⁵⁰ Several representatives of the Collège reiterated this position in their testimony, ¹⁵¹ including Collège president Dr. Mauril Gaudreault, who explained:

for mature minors aged 14 to 18 years, our thinking was based on the following considerations. First of all, suffering does not pay any attention to age. Suffering has no age. Then, the act already acknowledges that minors, aged 14 and over, have the right to consent on their own to certain types of care, such as abortion. The consent of parents or the guardian is compulsory, of course, when care represents a serious risk to a minor's health.

In its brief submitted to the Committee, the Collège similarly states:

The Collège believes that MAID can be requested by minors aged 14 to 17, if jointly requested by the person with parental authority or guardian. The Collège bases its position on the fact that suffering is independent of age and that suffering experienced by minors can be as intolerable as it is for adults.

Even though she supported a capacity-based approach, <u>Dr. Randi Zlotnik Shaul</u> proposed the option of a staged expansion of access, beginning with 16 or 17 year-olds, in order to provide an opportunity for further youth engagement on the topic.

Given the many factors that influence a minor's decision-making capacity, the committee believes that eligibility for MAID should not be denied on the basis of age alone. For that reason, the committee recommends

Recommendation 16

That the Government of Canada amend the eligibility criteria for MAID set out in the *Criminal Code* to include minors deemed to have the requisite decision-making capacity upon assessment.

¹⁴⁹ Collège des médecins du Québec, <u>Recommandation de positionnement du groupe de réflexion sur l'aide</u> <u>médicale à mourir et les soins de fin de vie</u>, 10 December 2021 [AVAILABLE IN FRENCH ONLY].

^{150 &}lt;u>Civil Code of Québec</u>, ss. 14 and 17; <u>Evidence</u>, 18 November 2022 (Gaudreault).

^{151 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 7 October 2022 (Roy); <u>Evidence</u>, 18 November 2022 (Gaudreault).



OTHER ELIGIBILITY CRITERIA AND SAFEGUARDS

Mature minors make up a potentially vulnerable group calling for heightened societal protection. ¹⁵² While acknowledging that MAID for mature minors should therefore involve special safeguards, a number of witnesses emphasized that these should not create onerous barriers to access. ¹⁵³

Reasonably Foreseeable Death and Mental Disorder

Most witnesses agreed that MAID should only be expanded to include mature minors whose natural death is reasonably foreseeable, at least initially. ¹⁵⁴ As explained by Kathryn Morrison and Cheryl Milne, there is greater uncertainty regarding the vulnerabilities at play in cases where natural death is not reasonably foreseeable, necessitating further study. Dr. Gordon Gubitz noted that the Canadian public may not be ready for track two MAID for minors, and recommended, along with others, a cautious, stepped approach. ¹⁵⁵ Bryan Salte, however, questioned the constitutionality of limiting MAID for mature minors to track one.

Others held firm convictions that track two MAID and MAID MD-SUMC are unacceptable for minors, and feared these would inevitably follow any expansion to track one. ¹⁵⁶ Elizabeth Sheehy was particularly concerned about the discriminatory impacts of allowing MAID for minors with disabilities, who often face mental health challenges and may struggle to imagine a positive future for themselves. Ahona Mehdi worried that minors with disabilities may feel like a burden due to the costs associated with their care, including parental time off work. Conrad Saulis relayed the fears of Indigenous youth regarding MAID, given the mental health and youth suicide challenges in their communities. Kathryn Morrison, however, opined that the uncertainties raised by track two MAID and MAID MD-SUMC "should not undermine the case for a mature minor to access MAID under track one."

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^{152 &}lt;u>Evidence</u>, 6 June 2022 (Carnevale); <u>Evidence</u>, 1 November 2022 (Morrison); <u>Evidence</u>, 4 November 2022 (Sheehy); <u>Evidence</u>, 15 November 2022 (Ehmann).

^{153 &}lt;u>Evidence</u>, 6 June 2022 (Carnevale); <u>Evidence</u>, 15 November 2022 (Davies; Milne).

 ^{154 &}lt;u>Evidence</u>, 1 November 2022 (Morrison); <u>Evidence</u>, 4 November 2022 (Verhagen); <u>Evidence</u>,
 15 November 2022 (Davies; Milne).

¹⁵⁵ E.g. Evidence, 1 November 2022 (Widger); Evidence, 15 November 2022 (Shaul).

Evidence, 4 November 2022 (Belanger; Sheehy); Evidence, 15 November 2022 (Ehmann); Evidence,22 November 2022 (Stainton).

While some witnesses remained open to the possibility of track two MAID for mature minors in future, there was a general consensus that MAID is not appropriate for mature minors suffering solely from a mental disorder. Dr. Randi Zlotnik Shaul and Dr. Dawn Davies concurred with the CCA Mature Minors Working Group finding that a mental disorder is unlikely to be deemed irremediable prior to the age of majority. Youth psychiatrist Dr. Gail Beck explained that a person could not exhaust all treatments for a mental disorder by the age of majority.

The committee agrees with the many witnesses who opined that MAID for mature minors should be limited to track one at this stage, especially given the lack of youth perspectives on the topic. For that reason, the committee recommends

Recommendation 17

That the Government of Canada restrict MAID for mature minors to those whose natural death is reasonably foreseeable.

Other Safeguards

Some witnesses stressed that there are already robust safeguards built into the clinical approach to capacity assessment for minors making healthcare decisions. ¹⁵⁹ To build on this, <u>Constance MacIntosh</u> recommended codifying—via the Code or regulations—and potentially enhancing, the process for assessing the capacity of minors seeking MAID. She also recommended more detailed, publicly available guidelines from healthcare associations on assisting youth with decision-making, and more consistency in how such decisions are approached across the provinces. <u>Kathryn Morrison</u> directed the committee to the safeguards outlined in the report of the CCA Mature Minors Working Group, which include the creation of standards of practice for assessing the capacity of minors seeking MAID, and the development of safeguards such as professional competency requirements at the provincial level.

¹⁵⁷ See for example: <u>Evidence</u>, 5 May 2022 (L'Espérance); <u>Evidence</u>, 6 June 2022 (Carnevale); <u>Evidence</u>, 4 November 2022 (Beck; Belanger); <u>Evidence</u>, 15 November 2022 (Davies).

¹⁵⁸ CCA Report at p. 124

^{159 &}lt;u>Evidence</u>, 6 June 2022 (MacIntosh); <u>Evidence</u>, 15 November 2022 (Milne; Shaul).



<u>Kimberley Widger</u> thought that specialized pediatric palliative care teams should be involved in assessing minors seeking MAID to ensure that all care options have been fully explored—a suggestion that others agreed with.¹⁶⁰

The committee agrees that standards of practice for capacity assessment should be established in the context of MAID for mature minors. For this reason, the committee recommends

Recommendation 18

That the Government of Canada work with provinces, territories and First Nations, Inuit and Métis communities and organizations to establish standards for assessing the capacity of mature minors seeking MAID.

The committee also heard evidence about the importance of parental involvement in the decision-making process, which ultimately affects the whole family. ¹⁶¹ As already noted, the Collège des médecins du Québec has taken the position that parental consent should be required for minors to access MAID. Parental consent is also a requirement in Belgium and the Netherlands for certain age groups. ¹⁶² Other witnesses supported a requirement for parental consultation, but not consent. ¹⁶³ Kathryn Morrison observed that, as with adults, family members can be "autonomy supporting but also autonomy limiting." She cautioned that a parental consent requirement would be incompatible with the current framework for consent to treatment. Bryan Salte added that parents may be reluctant to consent to the death of their child. Despite these concerns, there was testimony that in most cases, youth and caregivers agree on end-of-life decisions. ¹⁶⁴

Other safeguards that were discussed included requiring the opinion of a psychiatrist on the minor's maturity, as in Belgium, ¹⁶⁵ requiring a "cooling off" period between the initial MAID request and the administration of MAID, ¹⁶⁶ and having an Indigenous healer or practitioner on hand to support the decision-making process for Indigenous youth. ¹⁶⁷

160 Evidence, 1 November 2022 (Gubitz; Morrison). Evidence, 1 November 2022 (Gubitz); Evidence, 4 November 2022 (Beck). 161 Evidence, 1 November 2022 (Morrison); CCA report. 162 163 Evidence, 6 June 2022 (MacIntosh; Salte). 164 Evidence, 6 June 2022 (Salte; Carnevale); Evidence, 4 November 2022 (Verhagen); Evidence, 15 November 2022 (Davies). Evidence, 25 April 2022 (Naud). See CCA Report at p. 140. 165 Evidence, 6 June 2022 (Salte). 166 167 Evidence, 6 June 2022 (Myeengun Henry).

<u>Dr. Dawn Davies</u> felt that any "extra level of sober second thought" should occur within the context of the minor's healthcare team, rather than via an external review panel, to avoid placing an additional burden on the minor. <u>Constance MacIntosh</u> recommended the implementation of post-facto review boards.

The committee agrees with those witnesses who supported a requirement for parental consultation, but not consent, in the context of MAID for mature minors. For that reason, the committee recommends

Recommendation 19

That the Government of Canada establish a requirement that, where appropriate, the parents or guardians of a mature minor be consulted in the course of the assessment process for MAID, but that the will of a minor who is found to have the requisite decision-making capacity ultimately take priority.

The committee also agrees with those witnesses who suggested that it is important to proceed cautiously in allowing MAID for mature minors. For this reason, the committee recommends

Recommendation 20

That the Government of Canada appoint an independent expert panel to evaluate the *Criminal Code* provisions relating to MAID for mature minors within five years of the day on which those provisions receive Royal Assent, and that the panel report their findings to Parliament.



ADVANCE REQUESTS

BACKGROUND

At this point in time, the Code provisions allow the final consent that is required immediately before MAID is provided to be waived in certain circumstances. A person whose natural death is reasonably foreseeable, who has been approved for MAID and who has arranged for MAID to be provided on a certain day can enter into a written agreement consenting to the administration of MAID if they lose capacity to consent. In the case of a loss of capacity to consent, MAID can be administered unless the person demonstrates "refusal to have the substance administered or resistance to its administration." In the case of a loss of capacity to consent, MAID can be administered unless the person demonstrates "refusal to have the substance administered or resistance to its administration."

An advance request for MAID would allow a person who is at risk of losing capacity to consent to MAID to set out the conditions under which they would want MAID to be provided, should such a loss of capacity occur. An advance request for MAID should not be confused with an advance medical or healthcare directive, in which an individual gives permission for another person to make healthcare decisions on their behalf if the individual becomes incapable of doing so. An advance medical or healthcare directive can also include an individual's treatment preferences as guidance for a designated substitute decision-maker.¹⁷⁰

A number of polls indicate that Canadians support being able to make an advance request for MAID,¹⁷¹ and many witnesses echoed that there is public support.¹⁷² Helen Long, Chief Executive Officer, Dying with Dignity Canada told the committee that "[b]y far, the most frequently asked questions we receive are those related to advance requests for MAID." Geriatric physician <u>Dr. David Lussier</u> noted that there is broad acceptance of advance requests in Quebec, including among those "with major neurocognitive disorders and their loved ones," as well as among health professionals. PDAM and the <u>Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying</u>

Section 241.2(3.2) of the *Criminal Code*.

¹⁶⁹ Section 241.2 (3.2)(c).

For an explanation of healthcare directives, see Canadian Medical Protective Association, <u>Healthcare</u> directives: What you really need to know.

¹⁷¹ *Evidence*, 5 May 2022 (Long).

Evidence, 9 May 2022 (Louise Bernier); Evidence, 21 October 2022 (Dr. Serge Gauthier); Evidence,
 25 October 2022 (Dr. Blair Bigham); Evidence,
 1 November 2022 (Perrot).

both recommended that advance requests be permitted, as did Quebec's Select Committee on the Evolution of the Act respecting end-of-life care. ¹⁷³ In the spring of 2022, Quebec introduced Bill 38 which would have permitted advance requests for MAID in some circumstances, ¹⁷⁴ but that bill was put on hold and did not proceed prior to the provincial election.

In poignant testimony, <u>Sandra Demontigny</u>, who is 43 years old and has early onset Alzheimer's, shared what an advance request would mean for her:

... I don't want to experience the final phase of the disease, completely dependent and unable to express myself very much, if at all. I've seen it and I don't want to live through it. That's what I would specify in an advance request. It would definitely give me more time.

Without wishing to put pressure on you, if advance requests were not approved by Parliament, then unfortunately, I would have to decide to leave before entering that phase, in order to avoid becoming trapped.

<u>Dr. Serge Gauthier</u>, Emeritus Professor and neurologist, emphasized that many of his patients desire advance requests, with some having even signed documents indicating their request. Some of his patients advised that they would contemplate suicide without having advance requests as an option.

<u>Dr. Ellen Wiebe</u> noted that while her research confirmed that public support for advance requests is overwhelming, there is hesitation among MAID providers to act on one should they be permitted by law.

While some witnesses expressed the opinion that moving forward with advance requests for MAID is problematic, the majority of witnesses were supportive of permitting this option. Witnesses shared ways in which individuals who make the request, their families, and their healthcare team can be confident that they are proceeding with MAID at the appropriate time. Dr. David Lussier explained that there have already been cases in which individuals with dementia who still have capacity to consent have accessed MAID, as "there is a moment when the decline is advanced and the disease is serious enough to be considered incurable."

Assemblée Nationale du Québec, <u>Report of the Select Committee on the Evolution of the Act respecting endof-life care</u>, December 2021.

¹⁷⁴ Bill 38, An Act to amend the Act respecting end-of-life care and other legislative provisions.



The potential risks relating to advance requests, the experiences of other jurisdictions that permit advance requests for MAID, and the process and safeguards suggested by witnesses are summarized below.

POTENTIAL RISKS OF PERMITTING ADVANCE REQUESTS FOR MAID

Some witnesses expressed the opinion that the difficulty in predicting the rate of decline of an individual with a neurodegenerative condition, and the complexity involved in anticipating what an individual might find intolerable in the future make advance requests problematic. 175

Witnesses concerned about allowing advance requests suggested that such requests stem from ableism, ageism, and stigma. The committee heard that some individuals might make an advance request out of fear of being a burden on caregivers.

In the opinion of <u>Trudo Lemmens</u>, Professor, Scholl Chair, Health Law and Policy, Faculty of Law, University of Toronto, an advance request for MAID "expresses in law also the view that life with cognitive disability involves loss of dignity." At the same time, <u>Jocelyn Downie</u> suggested that by not letting someone make an advance request, "you're in a sense saying that people with dementia can't be trusted to make decisions for themselves in the future because they're too vulnerable to these external pressures and so on... that itself is stigmatizing of persons with dementia."

Some witnesses emphasized the need for better support for people with dementia, including access to geriatricians (of which there is a shortage),¹⁷⁷ palliative care and hospice care.¹⁷⁸ <u>Dr. Melissa Andrew</u>, Professor of Medicine in Geriatrics, Dalhousie University, noted the need for action on the <u>National Dementia Strategy</u>.

<u>Dr. Félix Pageau</u> emphasized that research "could establish reliable scales for assessing physical, psychological and existential suffering for patients with advanced dementia." According to <u>Dr. Ross Upshur</u>, Professor, Dalla Lana School of Public Health and Department of Family and Community Medicine, University of Toronto, addressing the

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^{175 &}lt;u>Evidence</u>, 25 April 2022 (Pageau); <u>Evidence</u>, 5 May 2022 (Michael Bach); <u>Evidence</u>, 9 May 2022 (Gallagher); <u>Evidence</u>, 28 October 2022 (Chung; Dr. Marcia Sokolowski); <u>Brief from the Christian Medical and Dental</u> <u>Association of Canada</u>.

^{176 &}lt;u>Evidence</u>, 5 May 2022 (Bach); <u>Evidence</u>, 28 October 2022 (Beaudry; Chung).

¹⁷⁷ *Evidence*, 25 April 2022 (Pageau).

^{178 &}lt;u>Evidence</u>, 5 May 2022 (Cohen-Almagor); <u>Evidence</u>, 9 May 2022 (Gallagher).

knowledge gaps that were identified by the Council of Canadian Academies¹⁷⁹ is essential "in order for there to be evidence-informed supports for substitute decision-makers, clinicians and others, because the circle of individuals around MAID is quite extensive."

Some witnesses were of the opinion that providing advance consent is not true consent, ¹⁸⁰ suggesting that it cannot be fully informed ¹⁸¹ and it cannot be withdrawn. ¹⁸² Trudo Lemmens opined that the Council of Canadian Academies report on advance request "shows that there is no evidence that procedural solutions can easily address the legal and ethical concerns." Finally, Michael Bach, Managing Director, Institute for Research and Development on Inclusion and Society, suggested that permitting advance requests is a slippery slope: "[a]uthorize advance requests and the hinges start to come off the door."

Some witnesses were concerned that a substitute decision-maker would be deciding when the advance request should be acted upon. ¹⁸³ Jocelyn Downie disagreed:

There is no room for substitute decision-making in this context. It is the individual who was saying what is to be done to them at a point at which they have lost decision-making capacity, and the clinician assesses the objectively assessable conditions because you've sorted that out by writing down your written request. You figured out what will work. It is something that clinicians can assess, and they determine whether those conditions have been met or not.

With respect to disease progression, many witnesses talked about "happy dementia," and Dr. David Lussier explained how this relates to suffering and advance requests:

In some cases, there is undeniable objectifiable suffering, accompanied by non-verbal signs of pain and psychological and behavioural symptoms associated with dementia, such as aggressiveness. In other cases, which are, rightly or wrongly, called pleasant dementia cases, patients are happy in their day-to-day lives despite their cognitive disorders and loss of autonomy. However, if they had seen themselves in that state,

¹⁷⁹ Council of Canadian Academies, <u>The State of Knowledge on Advance Requests for Medical Assistance in Dying</u>, 2018.

¹⁸⁰ *Evidence*, 25 April 2022 (Pageau); *Evidence*, 5 May 2022 (Bach).

^{181 &}lt;u>Evidence</u>, 5 May 2022 (Cohen-Almagor); <u>Evidence</u>, 9 May 2022 (Dr. Catherine Ferrier).

¹⁸² Evidence, 28 October 2022 (Dr. Alice Maria Chung).

^{183 &}lt;u>Evidence</u>, 25 April 2022 (Pageau); <u>Evidence</u>, 5 May 2022 (Bach); <u>Evidence</u>, 28 October 2022 (Dr. Ross Upshur).



they might not have wanted to live. Should the eligibility criterion be contemporaneous suffering or anticipated suffering? That's an important and complex question. ¹⁸⁴

Personal accounts of loved ones with dementia challenged the concept of "happy dementia." Sandra Demontigny, who also supported her father through dementia, told the committee

[t]o be quite honest, I don't believe in [happy dementia]. Contented dementia amounts to symptoms of a disease being expressed. It's not that the person is content, but rather that brain plaques have disrupted their neurotransmitters, causing what appears to be expressions of joy.

In her brief, <u>Catherine Leclerc</u> shares the experience of her mother, who has lived with dementia for 16 years:

The illness has not made her aggressive; she has remained gentle, she smiles, and sometimes she laughs. It is easy for a health care professional who assesses her once a year to perceive that she is comfortable with the disease. Yvette has what some call "happy dementia." Happy dementia is a trap. Yvette smiles, not because she is not in pain, but simply because the disease has not yet taken away her ability to do so.

<u>Judes Poirier</u>, Full professor of Medicine and Psychiatry, McGill University, Centre for Studies in the Prevention of Alzheimer's Disease, shared his opinion of "happy dementia":

Are these people happy? No. My mom would not have repeatedly asked me to die. There are biological changes over which we have no control, as I explained earlier. Underestimating psychological pain is often the problem in our fine health care system. We look for physical problems and tend to see psychological problems less. I think that is where the problem lies. In research, we have tools to document it.

I'm sorry, but in my opinion, happy dementia is a strange myth.

The committee heard that permitting advance requests could lead to coercion and abuse, ¹⁸⁶ and that there might be problems interpreting the written documents that establish the advance request. ¹⁸⁷ How to address situations in which a person with an

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¹⁸⁴ *Evidence*, 25 October 2022 (Dr. David Lussier).

See <u>Evidence</u>, 25 October 2022 (Sandra Demontigny); <u>Brief—Advance consent for medical assistance in dying—Catherine Leclerc</u>.

^{186 &}lt;u>Evidence</u>, 25 October 2022 (Pageau); <u>Evidence</u>, 9 May 2022 (Ferrier); <u>Evidence</u>, 28 October 2022 (Chung).

^{187 &}lt;u>Evidence</u>, 25 October 2022 (Pageau); <u>Evidence</u>, 28 October 2022 (Sokolowski).

advance request appears to be resisting at the time MAID is to be administered was mentioned by a number of witnesses. ¹⁸⁸ <u>Dr. David Lussier</u> told the committee that "[a]t an advanced stage, many individuals resist all contact and treatment and become aggressive when touched. As a result, they reject attempts to insert any intravenous device without previously being sedated or restrained." While any conscious refusal or resistance should be respected, ¹⁸⁹ unconscious resistance could be addressed by including in an advance request direction about what action a clinician is to take, or not take, if there are signs of resistance. ^{190,191}

SAFEGUARDS AND SCOPE OF THE REQUEST

Most witnesses who supported advance requests indicated that they should only be available once a person has received a diagnosis. Danielle Chalifoux, Lawyer and Chair, Institut de planification des soins du Québec, suggested however that restricting advance requests to people with a diagnosis would be contrary to the Charter, and Dr. Chantal Perrot indicated that it should be available to more people than those with neurocognitive conditions.

Many witnesses spoke about the importance of very clear, observable criteria that a person would need to set out in an advance request for MAID, such as not being able to recognize one's family members, being bedridden, or not being able to eat, that would constitute their intolerable suffering. ¹⁹³ As <u>Peter Reiner</u>, Professor of Neuroethics, Department of Psychiatry, University of British Columbia explained, clear criteria, including an explanation of why a specific situation would be considered to be intolerable suffering, would support clinicians, reinforcing "the idea that they were doing the right thing at the right time."

^{188 &}lt;u>Evidence</u>, 5 May 2022 (Hon. James S. Cowan); <u>Evidence</u>, 9 May 2022 (Dr. Lilian Thorpe); <u>Evidence</u>, 1 November 2022 (Peter Reiner).

^{189 &}lt;u>Evidence</u>, 5 May 2022 (Cowan); <u>Evidence</u>, 9 May 2022 (Downie).

^{190 &}lt;u>Evidence</u>, 1 November 2022 (Reiner); <u>Evidence</u>, 25 October 2022 (Lussier).

As mentioned above, the *Criminal Code* addresses the situation of a person who has waived final consent but appears to be refusing the administration of MAID in section 241.2(3.2).

See for example, <u>Evidence</u>, 5 May 2022 (L'Espérance); <u>Evidence</u>, 21 October 2022 (Gauthier); <u>Evidence</u>, 25 October 2022 (Lussier).

^{193 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 9 May 2022 (Dr. Laurent Boisvert; Danielle Chalifoux; Downie); <u>Evidence</u>, 21 October 2022 (Nancy Guillemette); <u>Evidence</u>, 1 November 2022 (Reiner).



In addition to having a written document setting out the advance request, witnesses emphasized the importance of making sure that one's wishes are known to family and healthcare providers.¹⁹⁴

Proponents of advance requests emphasized the importance of periodically reaffirming a request, ¹⁹⁵ although there was no agreement on how frequently the reaffirmation should take place. As <u>Dr. Chantal Perrot</u> told the committee, "I don't think a clinician could reasonably be expected to act on an advance request that was written 25 years ago and was never revisited or reaffirmed." Finally, some witnesses suggested there should be a national database of advance requests to ensure continuity of the request if a person moved from one province or territory to another. ¹⁹⁶

To make a well-informed decision relating to an advance request, <u>Sandra Demontigny</u> emphasized the importance of healthcare supports:

I have access to a psychologist and a social worker. I speak freely with them about my experience with Alzheimer's and the process I'm going through. It does me a lot of good. If they can't answer my questions, they will, when required, go and obtain information for me and tell me about what they found. It's important for people to have access to these services, which are difficult to obtain in the health system. However, to make a well-informed decision after having examined the entire range of possibilities, what's required, in my opinion, is access to qualified professional.

<u>Nancy Guillemette</u> told the committee: "I am convinced that we can create a process that will respect people's values and their right to self-determination, while protecting vulnerable individuals. It is very important not to lose sight of that aspect." The committee agrees. As <u>Liana Brittain</u> told the committee,

I believe it is our responsibility as a society to educate everyone, in particular those with physical disabilities like me about what options are available to them in collaboration with the medical community as they make the final leg of their end of life journey. This is true people-patient centred care, care where the individual is in charge of taking responsibility and actively participating in their own plan. I may be physically disabled but I want to know what are my choices. I want to weigh those options and make an informed decision about what I can choose to do next in consultation with the experts. I don't want to feel vulnerable.

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¹⁹⁴ See for example *Evidence*, 1 November 2022 (Reiner).

^{195 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 5 May 2022 (L'Espérance); <u>Evidence</u>, 25 October 2022 (Lussier); <u>Evidence</u>, 1 November 2022 (Reiner); <u>Evidence</u>, 1 November 2022 (Dr. Jennifer Gibson).

^{196 &}lt;u>Evidence</u>, 25 April 2022 (Naud); <u>Evidence</u>, 1 November 2022 (Perrot).

In keeping with the eligibility criteria and safeguards set out in the existing Code provisions relating to MAID, the committee emphasizes that an advance request must be voluntary, non-coercive, well-considered and made by a person with the requisite capacity.

The committee recognizes that while permitting advance requests for MAID would require an amendment to the Code, provinces and territories will be the ones developing standards and safeguards. As <u>Pierre Deschamps</u>, Lawyer and Ethicist, explained to the committee,

there can be no doubt that provincial statutes, as in Quebec's case, will be required to determine the circumstances in which an advance request for medical assistance in dying may be activated when a person is considered incapable of giving consent yet is still conscious, even if minimally so.

As mentioned above, Quebec's Select Committee on the Evolution of The Act Respecting End-Of-Life Care recommended that advance requests be permitted. The committee agrees that the Quebec committee's recommendations provide guidance for other legislators who may contemplate permitting advance requests and has thus attached the Select Committee's recommendations and observations as an Appendix to this report.

Finally, <u>Sandra Demontigny</u> eloquently and movingly shared with the committee the sense of peace that advance requests might provide in situations like hers:

I am working to calm my vanishing brain and my troubled heart. I feel a need to be reassured about my future so that I can do a better job of living out my remaining days and coping with the more frequent trials I will be experiencing.

My plan is to make the most of my final years while life is still good, with a free mind and without fear.

For these reasons, the committee recommends

Recommendation 21

That the Government of Canada amend the *Criminal Code* to allow for advance requests following a diagnosis of a serious and incurable medical condition disease, or disorder leading to incapacity.



Recommendation 22

That the Government of Canada work with provinces and territories, regulatory authorities, provincial and territorial law societies and stakeholders to adopt the necessary safeguards for advance requests.

Recommendation 23

That the Government of Canada work with the provinces and territories and regulatory authorities to develop a framework for interprovincial recognition of advance requests.

APPENDIX A: NATIONAL ASSEMBLY OF QUÉBEC REPORT OF THE SELECT COMMITTEE ON THE EVOLUTION OF THE ACT RESPECTING END-OF-LIFE CARE

National Assembly of Québec Report of the Select Committee on the Evolution of the Act respecting end-of-life care

LIST OF RECOMMENDATIONS AND OBSERVATIONS

Recommendations

Recommendation 1

The Committee recommends that a person of full age and capacity be permitted to make an advance request for medical aid in dying following a diagnosis of a serious and incurable illness leading to incapacity.

Recommendation 2

The Committee recommends that when a person makes an advance request for medical aid in dying, the physician ensure:

- a) The free nature of the request by verifying, among other things, that it is not the result of external pressure;
- b) The informed nature of the request, in particular by ensuring that the person has fully understood the nature of his or her diagnosis, by informing the person of the foreseeable course and prognosis of the disease, and of the possible therapeutic options and their consequences.

Recommendation 3

The Committee recommends that the advance request for medical aid in dying be entered on a form intended solely for that purpose; that it be completed and signed before a physician; that it be countersigned by two witnesses or made in notarial form.

Recommendation 4

The Committee recommends that the person clearly identify the manifestations of his or her health condition that should give rise to the advance request.

Recommendation 5

The Committee recommends that the advance request remain valid unless the person indicates otherwise; that it may be amended as long as the person is capable of doing so.

Recommendation 6

The Committee recommends that advance requests for medical aid in dying be recorded in the Advance Medical Directives Register.

Recommendation 7

The Committee recommends that a reference to an advance request for medical aid in dying be indicated on the back of the health insurance card.

Recommendation 8

- a) The Committee recommends that the person designate on the form a trusted third party responsible for making known his or her advance request for medical aid in dying and for advocating on his or her behalf for the processing of the request at the appropriate moment; that the trusted third party consent in writing to the role assigned to him or her;
- b) The Committee recommends that, in the absence of or inability to act of a designated trusted third party, the responsibility to protect the patient's wishes and to act be assumed by a member of the health care team.

Recommendation 9

The Committee recommends that when the trusted third party files the application on the advance request, the physician review both the application and the advance request, take them into consideration, and act on them without delay.

Recommendation 10

The Committee recommends that before administering medical aid in dying, the physician must

- 1. Be of the opinion that the person meets all of the following criteria:
 - a) the person is an insured person within the meaning of the Health Insurance Act (chapter A-29);
 - b) the person suffers from a serious and incurable illness;
 - c) the person is in an advanced state of irreversible decline in capability;
 - d) the person experiences constant and unbearable physical or psychological suffering, including existential suffering, which cannot be relieved in a manner deemed tolerable. This suffering is observed and validated by the physician.
- 2. Confer with members of the care team who are in regular contact with the person making the request, if applicable;
- 3. Obtain the opinion of a second physician confirming compliance with the criteria. The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second medical opinion. The physician consulted must consult the patient's record, examine the patient and provide the opinion in writing.

Recommendation 11

The Committee recommends that access to medical aid in dying not be extended to persons whose only medical condition is a mental disorder; that, to this end, section 26 of the Act respecting end-of-life care be amended.

Observations

The Committee suggests:

 That the existence of advance medical directives be indicated on the back of the health insurance card.

- That the application to initiate the processing of the advance request be made in writing.
- That it be possible to attach a complementary video to the application, but that the written request take precedence.
- That the physician discuss with the patient the medical advances related to his or her illness.
- That specialized nurse practitioners be allowed to administer medical aid in dying.
- That the government conduct an awareness campaign on the possible use of advance medical directives.
- That a reminder be given of the importance of systematically consulting the Advance Medical Directives Register.

APPENDIX B LIST OF WITNESSES

The following table lists the witnesses who appeared before the committee at its meetings related to this report. Transcripts of all public meetings related to this report are available on the committee's <u>webpage for this study</u>.

Organizations and Individuals	Date	Meeting
Department of Health	2022/04/13	2
Abby Hoffman, Senior Executive Advisor to the Deputy Minister		
Venetia Lawless, Manager, End of Life Care Unit, Strategic Policy Branch		
Jacquie Lemaire, Senior Policy Advisor, End of Life Care Unit, Strategic Policy Branch		
Department of Justice	2022/04/13	2
Joanne Klineberg, Acting General Counsel		
Jay Potter, Acting Senior Counsel		
As an individual	2022/04/25	3
Audrey Baylis, Retired Registered Nurse		
Dr. K. Sonu Gaind, Professor		
Dr. Leonie Herx, Chair and Associate Professor, Palliative Medicine, Queen's University and Chair, Royal College Specialty Committee in Palliative Medicine		
Dr. Alain Naud, Family and Palliative Care Physician		
Dr. Félix Pageau, Physician, Geriatrician and Ethicist, Université Laval		
Diane Reva Gwartz, Nurse Practitioner, Primary Health Care		
Canadian Association of MAiD Assessors and Providers	2022/04/25	3
Dr. Stefanie Green, President, MAID Practitioner, Advisor to BC Ministry of Health		

Organizations and Individuals	Date	Meeting
Canadian Nurses Association	2022/04/25	3
Tim Guest, Chief Executive Officer		
Barbara Pesut, Principal Research Chair Palliative and End of Life Care, University of British Columbia, Okanagan		
As an individual	2022/04/28	4
Dr. Sandy Buchman, Chair and Medical Director, Freeman Centre for the Advancement of Palliative Care, North York General Hospital and Past President, Canadian Medical Association		
Dr. Harvey Max Chochinov, Distinguished Professor of Psychiatry, University of Manitoba		
Dr. James Downar, Critical Care and Palliative Care Physician		
Dr. Marjorie Tremblay, Physician		
Dr. Pierre Viens, Family Physician		
Canadian Society of Palliative Care Physicians	2022/04/28	4
Dr. Ebru Kaya, Presiden, Canadian Society of Palliative Care Physicians and Associate Professor of Medicine, University of Toronto		
As an individual	2022/05/05	5
Dr. Melissa Andrew, Professor of Medicine in Geriatrics, Dalhousie University, Nova Scotia Health Authority		
Dr. Michael Bach, Managing Director, Institute for Research and Development on Inclusion and Society		
Dr. Raphael Cohen-Almagor, Professor of Politics, University of Hull		
Pierre Deschamps, Lawyer and Ethicist		
Association québécoise pour le droit de mourir dans la dignité	2022/05/05	5
Dr. Georges L'Espérance, President and Neurosurgeon		

Organizations and Individuals	Date	Meeting
Dying with Dignity Canada	2022/05/05	5
Hon. James S. Cowan, Member of the Board of Directors and Former Senator		
Helen Long, Chief Executive Officer		
As an individual	2022/05/09	6
Louise Bernier, Professor, Faculty of Law, Université de Sherbrooke		
Dr. Laurent Boisvert, Physician		
Dr. Jocelyn Downie, University Research Professor, Faculties of Law and Medicine, Dalhousie University		
Dr. Catherine Ferrier, Physician, Division of Geriatric Medicine, McGill University Health Centre		
Romayne Gallagher, Clinical Professor, Palliative Medicine, University of British Columbia		
Dr. Trudo Lemmens, Professor, Scholl Chair, Health Law and Policy, Faculty of Law, University of Toronto		
Dr. Susan MacDonald, Associate Professor of Medicine and Family Medicine, Memorial University		
Dr. Lilian Thorpe, Professor, University of Saskatchewan		
Institut de planification des soins du Québec	2022/05/09	6
Danielle Chalifoux, Lawyer and Chair		
As an individual	2022/05/16	7
Andrew Adams		
Ghislain Leblond, Former Deputy Minister		
Derryck Smith, Clinical Professor Emeritus, Department of Psychiatry, University of British Columbia		
Disability Justice Network of Ontario	2022/05/16	7
Sarah Jama, Executive Director		
The Canadian Bar Association	2022/05/16	7
David E. Roberge, Member, End of Life Working Group		

Organizations and Individuals	Date	Meeting
As an individual	2022/05/25	8
Dr. Valorie Masuda, Doctor		
Kwame McKenzie, Professor of Psychiatry		
Brian Mishara, Professor and Director, Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Pratices (CRISE), Université du Québec à Montréal		
Derryck Smith, Clinical Professor Emeritus, Department of Psychiatry, University of British Columbia		
Canadian Association for Suicide Prevention	2022/05/25	8
Sean Krausert, Executive Director		
The Canadian Bar Association	2022/05/25	8
David E. Roberge, Member, End of Life Working Group		
As an individual	2022/05/26	9
Tyler R. Black, Clinical Assistant Professor, University of British Columbia		
Mark Sinyor, Professor		
Georgia Vrakas, Psychologist and Professor		
Dr. Ellen Wiebe, Medical Doctor		
Canadian Psychiatric Association	2022/05/26	9
Alison Freeland, Chair of the Board of Directors, Co-Chair of MAiD Working Group		
Expert Panel on MAID and Mental Illness	2022/05/26	9
Mona Gupta, Associate Clinical Professor		
Ontario Association for ACT & FACT	2022/05/26	9
John Maher, President		
As an individual	2022/05/30	10
Ramona Coelho, Physician		
Jocelyne Landry		
Disability Without Poverty	2022/05/30	10
Michelle Hewitt, Co-Chair, Board of Directors		

Organizations and Individuals	Date	Meeting
Quebec Intellectual Disability Society	2022/05/30	10
Amélie Duranleau, Executive Director		
Samuel Ragot, Senior Policy Analyst and Advocacy Advisor		
Spinal Cord Injury Canada	2022/05/30	10
Bill Adair, Executive Director		
Wabanaki Council on Disability	2022/05/30	10
Conrad Saulis, Executive Director		
As an individual	2022/06/06	11
Franco Carnevale, Professor and Clinical Ethicist		
Myeengun Henry, Indigenous Knowledge Keeper, University of Waterloo		
Constance Macintosh, Professor		
Maria Alisha Montes		
College of Physicians and Surgeons of Saskatchewan	2022/06/06	11
Bryan Salte, Lawyer		
Disability Justice Network of Ontario	2022/06/06	11
Ahona Mehdi, Member and Just Recovery Research Lead		
As an individual	2022/06/16	13
Gary Nichols		
Trish Nichols		
Cheryl Romaire		
As an individual	2022/09/23	16
Ellen Cohen, National Coordinator Advocate, National Mental Health Inclusion Network		
Dr. Justine Dembo, Psychiatrist, Medical Assistance in Dying assesor		
Dr. Natalie Le Sage, Physician, Clinical Researcher and Medical Assistance in Dying Provider		
Dr. Cornelia Wieman, Psychiatrist		
Association des médecins psychiatres du Québec	2022/09/23	16
Dr. Guillaume Barbès-Morin, Psychiatrist		

Organizations and Individuals	Date	Meeting
As an individual	2022/09/27	17
Jennifer Chandler, Professor		
Dr. Donna Stewart, Professor, University of Toronto, Senior Scientist, Toronto General Research Institute, Centre for Mental Health		
Association des groupes d'intervention en défense de droits en santé mentale du Québec	2022/09/27	17
Doris Provencher, General Director		
As an individual	2022/10/04	18
Mark Henick, Mental Health Advocate		
Dr. Eric Kelleher, Consultant Liaison Psychiatrist, Cork University Hospital		
Dr. Marie Nicolini, Senior Researcher, KU Leuven University and Georgetown University		
Shakir Rahim, Lawyer, Kastner Lam LLP		
Dr. Michael Trew, Clinical Associate Professor, University of Calgary		
Ordre des psychologues du Québec	2022/10/04	18
Dr. Christine Grou, President and Psychologist		
Dr. Isabelle Marleau, Psychologist and Director, Quality and development of the practice		
As an individual	2022/10/07	19
Dr. Geneviève Dechêne, Family Doctor		
Dr. James Downar, Professor and Head, Division of Palliative Care, University of Ottawa		
Dr. José Pereira, Professor and Director, Division of Palliative Care, Department of Family Medicine, McMaster University		
Collège des médecins du Québec	2022/10/07	19
Dr. Louis Roy, Physician		

Organizations and Individuals	Date	Meeting
The Ottawa Hospital	2022/10/07	19
Mike Kekewich, Director, Champlain Regional MAID Network, Champlain Centre for Health Care Ethics		
TheraPsil	2022/10/07	19
Spencer Hawkswell, President and Chief Executive Officer		
As an individual	2022/10/18	20
Ilora Finlay, Baroness Finlay of Llandaff, Professor of Palliative Medicine		
Dr. David Henderson, Senior Medical Director, Integrated Palliative Care Nova Scotia Health		
Dr. Madeline Li, Psychiatrist and Associate Professor		
Canadian Cancer Society	2022/10/18	20
Kelly Masotti, Vice-President Advocacy		
Daniel Nowoselski, Advocacy Manager, Hospice Palliative Care		
Canadian Society of Palliative Care Physicians	2022/10/18	20
Dr. Romayne Gallagher, Clinical Professor, Palliative Medicine, University of British Columbia		
The Dorothy Ley Hospice	2022/10/18	20
Donna Cansfield, Chair of the Board of Directors		
Dipti Purbhoo, Executive Director		
As an individual	2022/10/21	21
Dr. Sandy Buchman, Chair and Medical Director, Freeman Centre for the Advancement of Palliative Care, North York General Hospital and Past President, Canadian Medical Association		
Julie Campbell, Nurse Practitioner		
Serge Gauthier, Emeritus Professor		
Dr. Nathalie Zan, Doctor		
Christian Legal Fellowship	2022/10/21	21
Derek Ross, Executive Director		
Government of Quebec	2022/10/21	21
Nancy Guillemette, Member for Roberval		

Organizations and Individuals	Date	Meeting
As an individual	2022/10/25	22
Dr. Blair Bigham, Doctor, Emergency and Critical Care Medicine, McMaster University		
Sandra Demontigny		
Adelina Iftene, Law Professeur		
Dr. David Lussier, Geriatric Physician		
Dr. Félix Pageau, Geriatrician and Researcher		
Dr. Dorothy Pringle, Professor Emeritus, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto		
As an individual	2022/10/28	23
Dr. Jonas-Sébastien Beaudry, Associate Professor, McGill University		
Dr. Alice Maria Chung, Clinical Associate Professor		
Dr. Jude Poirier, Full professor of Medicine and Psychiatry, McGill University, Centre for Studies in the Prevention of Alzheimer's Disease		
Dr. Marcia Sokolowski, Psychologist and Philosopher		
Dr. Ross Upshur, Professor, Dalla Lana School of Public Health and Department of Family and Community Medicine, University of Toronto		
Dr. Ellen Wiebe, Medical Doctor		
As an individual	2022/11/01	24
Dr. Jennifer Gibson, Associate Professor, Director of Joint Centre for Bioethics, University of Toronto		
Dr. Gordon Gubitz, Professor, Division of Neurology, Department of Medicine, Faculty of Graduate Studies at Dalhousie University		
Dr. Kathryn Morrison, Clinical and Organizational Ethicist		
Dr. Chantal Perrot, Doctor		
Peter Reiner, Professor of Neuroethics, Department of Psychiatry, University of British Columbia		
Kimberley Widger, Associate Professor		

Organizations and Individuals	Date	Meeting
As an individual	2022/11/04	25
Dr. Gail Beck, Interim Psychiatrist-in-Chief and Chief of Staff, Clinical Director, Youth Psychiatry Program, Royal Ottawa Health Care Group		
Dr. Arundhati Dhara, Family Physician		
Mary Ellen Macdonald, Endowed Chair in Palliative Care		
Elizabeth Sheehy, Professor Emerita of Law, University of Ottawa		
Dr. Eduard Verhagen, Pediatrician and Head of the Beatrix Children's Hospital		
Indigenous Disability Canada	2022/11/04	25
Neil Belanger, Chief Executive Officer		
As an individual	2022/11/15	26
Dr. Dawn Davies, Pediatrician, Palliative Care Physician		
Dr. Timothy Ehmann, Medical Doctor, Child and Adolescent Psychiatrist		
Caroline Marcoux		
Roderick McCormick, Professor		
Cheryl Milne, Executive Director, David Asper Centre for Constitutional Rights		
Hospital for Sick Children	2022/11/15	26
Randi Zlotnik Shaul, Director, Department of Bioethics		
As an individual	2022/11/18	27
Alicia Duncan		
Christie Duncan		
ARCH Disability Law Centre	2022/11/18	27
Kerri Joffe, Staff Lawyer		
Barreau du Québec	2022/11/18	27
Sylvie Champagne, Secretary of the Order and Director of the Legal Department		
Catherine Claveau, President of the Quebec bar		

Organizations and Individuals	Date	Meeting
Collège des médecins du Québec	2022/11/18	27
Dr. Mauril Gaudreault, President		
Dr. André Luyet, Executive Director		
Disability Filibuster	2022/11/18	27
Gabrielle Peters, Co-Founder		
Inclusion Canada	2022/11/18	27
Krista Carr, Executive Vice-President		
As an individual	2022/11/22	28
Liana Brittain		
Dr. Karen Ethans, Associate Professor		
Dr. Heidi Janz, Associate Adjunct Professor		
David Shannon, Barrister and Solicitor		
Dr. Jessica Shaw, Associate Professor		
Dr. Tim Stainton, Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia		
As an individual	2022/11/25	29
Dr. Catherine Frazee, Professor Emerita, School of Disability Studies, Toronto Metropolitan University		
Isabel Grant, Professor, Allard School of Law, University of British Columbia		
Megan Linton, PhD Candidate		
Kevin Liu		
Jennifer Schouten		

Mike Schouten

APPENDIX C LIST OF BRIEFS

The following is an alphabetical list of organizations and individuals who submitted briefs to the committee related to this report. For more information, please consult the committee's webpage for this study.

Anonymous Author

Action Life Ottawa

Acton, Gillian

Adams, Andrew

Alloway, Ruth

Alzheimer Society of Canada

Anderson, Kathi

Anderson, Lyle

Anderson, Paul

Appel, John H.

ARCH Disability Law Centre

Aroosi, Eva

Association for Reformed Political Action Canada

Association québécoise pour le droit de mourir dans la dignité

Atkinson-Ghulati, Madeleine

Baker, Nancy

Banting, Tammy

Barr, Susan

Bartolacci, Rachel

Bates, Nina

Bauchet, Max

Beach, Nancy

Bedard, Therese

Bélisle, Paul C.

Beverly, Mary Jordan

Biscardi, Mario

Bjarnason, Sigrid

Blaauw, Rhoda

Black, Tyler R.

Blood, Guy

Bolzon, Julia

Bonnell, Clare

Boschung, Karol

Bousquet, Maryel

Bray, Christine

Brisson, Daniel

British Columbia Humanist Association

Bronsard, Daniel

Brose, Linda

Brown, Thomas

Bruton, Albert

Burrell, Althea

Buscemi, Georges

Bystrzycki, Les

Cale, Grace

Campaign Life Coalition

Canadian Academy of Child and Adolescent Psychiatry

Canadian Association for Suicide Prevention

Canadian Association of MAiD Assessors and Providers

Canadian Association of the Deaf

Canadian Cancer Society

Canadian Conference of Catholic Bishops

Canadian Federation of Catholic Physicians and Societies

Canadian Hospice Palliative Care Association

Canadian Medical Association

Canadian Nurses Association

Canadian Nurses Protective Society

Canadian Paediatric Society

Canadian Physicians for Life

Canadian Psychiatric Association

Canadian Society of Palliative Care Physicians

Cardin, Benoit

Care Not Kill

Carignan, Madeleine

Case, Shelley

Catholic Health Alliance of Canada

Cavanagh, Thomas

Centre for Addiction and Mental Health

Charbin, Jacques

Christian Legal Fellowship

Christian Medical and Dental Association of Canada

Clifford, John

Coates, Elisa

Coelho, Ramona

Collège des médecins du Québec

Collins, Derek

Community Living Ontario

Cook, Cherith

Cooke, David

Council of Canadians with Disabilities

Cox, Ann

Crassweller, Lynn Darlene

Cross, Pamela

Czerny, Robert

Daigle, Michael

Damer, Eric

Darroch, Lauren

Davison, Allan

Dawn Canada

Day, Daniel

De Voy, April

Dean, Michael

DeKoninck, Thomas

Dembo, Justine

Demontigny, Sandra

Desbrisay, Judith

Desjardins, Cheryl

Dickinson, Marylou

Dignity Denied

Dion, Daniel

Douglas, Carol

Downie, Jocelyn

Drake, Ryan

Drijber, Philip

Dube, Sally

Dunderdale, Joann

Dunn, Gail

Dunnet, Ed

Dying with Dignity Canada

Easton, Alexander

Eaton, Evelyn

Ehmann, Timothy

Environmental Health Association of Québec

European Institute of Bioethics

Eusanio, Laura

Euthanasia Prevention Coalition

Evangelical Fellowship of Canada

Expert Advisory Group

Faber, Gloria

Fernandes, Nisha

Ferrier, Catherine

Fournier, Micheline

Friesen, Gordon

Fundytus, Linda

Fung, Edward

Gaind, K. Sonu

Gallagher, Romayne

Garnet, Bobbie

Gibson, Margaret

Gilbert, Daphne

Girard, Damien

Giroux, Nicole

Glave, James

Good, Bonnie

Hale, Kerrie

Hamilton, Eaton

Hammond, Katherine

Harding, Sheila

Harnum, Victoria

Hatcher, Simon

Hauptman, Robert

Heintzman, John

Heintzman, Mary Jane

Heller, Deborah

Hendricks, Amy

Henry, Mj

Herring, Mary

Hertgers, Gary

Herx, Leonie

Hickli, Hope

Hiemstra, Yvonne

Hitchcok, Sue

Hodgson, Charles

Holmes, Angela

Hospice Care Ottawa

Hubick, Kalie

Hunter, Jane

Iacobelli, Celeste

Inch, Carolyn

Inclusion Alberta

Inclusion BC

Inclusion Canada

Johnston, Barbara

Jonassen, Paul

Kafie, Stephanie

Kingma, Fenny

Kingma, Lloyd

Klan, Linda

Klassen, Karen

Klinke, Barbara

Klinke, Jennifer

Klyn, Alice

Knapp, Brenda

Koester, Karen

Kohler, John

Kossy, Maxine

Kozack, Faye

Krebes, David

Krenz, Janet

Kristof, Lorand

Lakovic, Natalie

Lamoureux, Juliette

Lang, Scott

Langdale, Wendy

Langdon, Colette M.

Laplante, Larry

Latham, Linda

Latourelle, Nicole

Le Sage, Natalie

Leclerc, Catherine

Lemmens, Trudo

Lewis, Elaine

Living With Dignity

Loewen, Helen

Lomond, Pam

Louise Lucy, Sheils

Lyon, Christopher

Macapagal, Athena

Maccabee, Louise

MacDonald, Alexander

Macdonald, Geraldine Jody

MacDonald, Susan

MacEachern, John Wayne

Macintosh, Constance

Mackay, Amy

MacLean, Roz

Macphail, Gisela

Maher, John

Mansell, Graham

Mark, Devon Joy

Marsolais, Gilles

Matuszewska, Monika

McArthur, Judith

McConnan, Jody

Mccormac, Susan

McCormick, Roderick

McCullough, Greg

McGovern, Bernard

McGraw, Debra

Mcguire, Peter

McTrowe, Mary-Anne

Millaire, Karine

Milne, Carolyn

Mitchener, Sharon

Mogk, John

Moore, Brigitte

Moran, Sherry

Morck, Paul

Moreau, Nancy

Morin, Lorraine

Morissette, Louis

Morphet, Mignon

Morton, Julie

Mueller-Wilm, Carol

Muir Meredith, Thomas

Muir, Alex

Munro, Debbie

Naiman, Joanne

National Association of Catholic Nurses - Canada

Naud, Alain

Navratil, Donna

Nelder, Mary

New Brunswick Association for Community Living

Newman, Nicholas

Ng, Deanna

Nicholas, Graydon

Nichols, Gary

Nicolini, Marie

Nordeman, Michelle

Not Dead Yet

Novosedlik, Natalia

Obreiter, Maureen

O'Brien, Gwynneth

Ogle, Linda

Olson, Karen

Ontario District Branch of the American Psychiatric Association

Opas, Karen

Oram, Martha

Ortega, Maranda

Osmond, Helen

Pageau, Félix

Paille, Louise

Pain BC

Paquin, Louiselle Pasta, Victor Patenaude, Lucie Paul, Joanne Paul, Robert Paulley, Lynda Payette, Lorraine Penninga, Jeremy Perrot, Chantal Peters, Claudia Petkau, Susannah Pilon, Liette Pipes, Lori Pollock, Christie Posno, Ron Pugh, Wendy **Quality End-of-life Care Coalition of Canada** Quick, Ernest J. Rafuse, Luke Ramsawakh, Dev Ramsell, David Reed, Chin Jong Reid, Judy Reiner, Peter

Rhodes, Adrian Richard, Jo-An

Reznor, Betsey

Roberts, Patricia

Robinson, Christine

Réseau Compassion Network

Robinson, Lacey

Robinson, Stewart K.

Romaire, Cheryl

Rose, Anne

Rose, Mary

Ross, Susan

Ross, Virginia

Ruth, Nancy

Rutledge, Rosaleen

Salomons, Liz

Schouten, Mike

Schutten, André

Schutten, James

Secord, Tanya

Semeniuk, Jana

Shaw, Marnie

Sheeter, Ingrid

Shulman, Richard

Sims, Juanita

Slingerland, Eric

Sperdakos, Sophia

Stanley, Gillian

Steele, Lynne

Steele, Robert

Steinberg, Craig

Stephens, Dorothy

Swartz, Cynthia

Tait, Shannon

Tang, Sephora

Telfer, Sandra

The Canadian Bar Association

Thomas, Aislinn

Thompson, Gail

Thorpe, Lilian

Torrie, Marlyen

Tost, Kathy

Toteda, Luisa

Toujours Vivant-Not Dead Yet

Triggs, Bruce

Trouton, Konia

Trudgeon, Helen

Turnbull, Marne

Unger, Nathan

van Kampen, Catherine

van Roijen, Bart

Vandelden, Lynn

Varkay, Madeleine

Vernon, Deb

Viens, Pierre

Vivas, Lucas

Vrakas, Georgia

Vroom, Elyse

Walker, Harvey

Walker, Jean

Watson, Frank

Watts, Susan

Webster, Barbara

Wellner, Debra

Whitney, Derek

Wicks, Trevor

Wiens, Dennis

Wolfs, Maria

Woodruff, Jay

Wright, Harry

Wuthrich, Sarah

Yang, Jerome

Yong, Paul

Zimmerman, Darlene

REQUEST FOR GOVERNMENT RESPONSE

Pursuant to Standing Order 109, the committee requests that the government table a comprehensive response to this Report.

A copy of the relevant Minutes of Proceedings (Meetings Nos. 2 to 36) is tabled.

Respectfully submitted,

Hon. Marc Garneau and Hon. Yonah Martin Joint Chairs

The Liberal Government's Failures Respecting Medical Assistance in Dying: A Call for Caution Against Repeating Past Mistakes

Special Joint Committee on Medical Assistance in Dying: Dissenting Report

This Dissenting Report reflects the views of the Conservative Senator and Members of Parliament who serve on the Special Joint Committee on Medical Assistance in Dying (the "Committee"): Senator the Honourable Yonah Martin (Senator, British Columbia), M.P. Michael Cooper (Co-Vice Chair of the Committee, St. Albert – Edmonton), M.P. Dominique Vien (Bellechasse – Les Etchemins – Lévis), and M.P. Dr. Stephen Ellis (Cumberland – Colchester).

<u>Introduction</u>

We wish to acknowledge that Medical Assistance in Dying ("MAID") is a complex and deeply personal issue about which reasonable and well-intentioned people can disagree.

However, there are serious issues with Canada's MAID regime and vulnerable persons are being put at risk because of the Liberal government's failures. Regardless of one's perspective on MAID in principle, these issues cannot be ignored.

After eight years of growing poverty and desperation under Justin Trudeau, Canadians are turning to MAID because they can't afford to live a dignified life. There are several reported cases of potential abuse, non-compliance with MAID safeguards, and instances of Canadians seeking MAID for reasons such as poverty and a lack of access to adequate housing. There have been at least six reported instances of Veterans improperly being offered MAID by Veterans Affairs Canada employees.

Reports of abuse and non-compliance have garnered alarm across Canada and internationally, including from the UN Special Rapporteur on the rights of persons with disabilities.⁵ After eight years of failure, the Liberals cannot be trusted to stand up for the most vulnerable and their loved ones.

We are offering this Dissenting Report because we cannot endorse every recommendation that the Committee put forward in the Report. We outline our objections and additional

¹ Leffler, Brennan and Dimain, Marianne. "How poverty, not pain, is driving Canadians with disabilities to consider medically-assisted death" *Global News*, October 8, 2022.

² "Remembering Lives Lived," Living With Dignity – Investing in Life for PWD's, Living With Dignity Canada, https://living-with-dignity.ca/remembering-lives-lived/?fbclid=lwAR1NeUwRXK5OgXlcyGhwdr5NJ30SFj0xwe9PLGIDslosZOC7AqU8YKirk7g; Commission sur les soins de fin de vie. Rapport Annuel d'Activites; 2019.; Office of the Chief Coroner. Memorandum: Medical Assistance in Dying Update. October 9, 2018; Kotalik, Jaro. "Medical Assistance in Dying: Challenges of Monitoring the Canadian Program." *Canadian Journal of Bioethics* Volume 3, No. 3, 2022: p.205.

³ Favro, Avis. "Woman with chemical sensitivities chose medically-assisted death after failed bid to get better housing" *CTV News* April 13, 2022.

⁴ Higgins, Michael. "Our veterans ask for help. They're offered assisted death" National Post, December 2, 2022

⁵ Zhu, Yuan Yi. "Why is Canada Euthanizing the Poor?" *The Spectator*, April 30, 2022; Quinn, Gerard, Mahler, Claudia, De Schutter, Olivier, 3 February 2021, Mandates of the Special Rapporteur on the rights of person with disabilities; the Independent Expert on the enjoyment of all human rights by older persons; and the Special Rapporteur on extreme poverty and human rights, OL CAN (2.2021) (ohchr.org)

considerations in the following sections, broken down by each topic that the Committee studied.

MAID Where a Mental Disorder is the Sole Underlying Medical Condition

Conservatives raised significant concerns with the Liberal government's plan to expand MAID to cases where a mental disorder is the sole underlying medical condition ("MAID MD-SUMC") in our Dissenting Interim Report, *The Legal and Clinical Problems Respecting Medical Assistance in Dying in Cases Where a Mental Disorder Is the Sole Underlying Medical Condition* (the "Dissenting Interim Report"). These include but are not limited to the following:

- 1. The lack of meaningful study and consultation regarding the expansion of MAID to include MAID MD-SUMC;
- 2. The difficulty in predicting irremediability in cases where a mental disorder is the sole underlying medical condition;
- 3. Clinical concerns and inherent risks of MAID MD-SUMC to vulnerable persons; and
- 4. General concerns with the Expert Panel and Expert Panel Report.

Since these concerns have been explained in detail in the Dissenting Interim Report, we will not elaborate on them in this Dissenting Report. We note, however, that our concerns have not been allayed by the remaining testimony that the Committee heard.

We further note that since our Dissenting Interim Report was tabled, the Association of Chairs of Psychiatry in Canada, which includes the heads of psychiatry departments at all 17 medical schools issued a statement raising some of the same concerns in our report and called on the Liberals to extend the sunset clause for MAID MD-SUMC.⁶

In an admission of failure, the Liberals introduced 11th hour legislation, Bill C-39, to extend the sunset clause by one year until March 17, 2024.

Back in June 2022, when our Dissenting Interim Report was tabled, we called on the Liberals to put a halt on this expansion. This was based on a large body of evidence at the Committee from experts, including leading psychiatrists, who said MAID MD-SUMC cannot be implemented safely. The Liberals ignored our call and refused to acknowledge the evidence of experts. Then, only on February 2, 2023, with 17 sitting days to shepherd legislation through both the House of Commons and the Senate before the expiration of the sunset clause, did the Liberals finally introduce Bill C-39. This last-minute legislation illustrates the Liberals shambolic approach to MAID MD-SUMC.

All of this could have been avoided had the Liberals put evidence ahead of ideology, before initiating this radical expansion of MAID. Instead, the Liberals accepted a Senate amendment to Bill C-7, setting in motion the implementation of MAID MD-SUMC with an arbitrary deadline of March 17, 2023. This decision was made before any meaningful study and consultation took

⁶ Baines, Camille. "Canada should delay MAID for people with mental disorders: psychiatrists" CTV News, December 1, 2022

place. In short, the Liberals embarked on this expansion without first determining whether it could be implemented safely.

With Bill C-39, the Liberals are setting a new arbitrary deadline of March 17, 2024. Given the incompetent and reckless record of the Liberals on this issue, we have no confidence in them to get it right. Offering MAID to those who are suffering from mental illness is likely to be problematic a year from now. There is no evidence to indicate that the difficulties around predicting irremediability, the other clinical concerns, and the inherent risks to vulnerable persons will be resolved by then. A future arbitrary deadline is not an acceptable solution to the problem the Liberal government has created.

We also note that the Liberals have failed to deliver on their 2021 election platform commitment to dedicate \$4.5 Billion to the Canada Mental Health Transfer. No allocation of funds was dedicated in either Budget 2022 or the 2022 Fall Economic Statement. This inaction could not come at a worse time, with nearly a quarter of Canadian adults reporting that they have unmet mental health needs. During the 2021 election campaign, Justin Trudeau stated that mental health is a "priority" of his government. Like much of what Justin Trudeau says, these were empty words. 9

Mature Minors

Conservatives do not support MAID for mature minors at this time.

To begin with, there are "significant knowledge gaps" respecting mature minors and MAID.¹⁰ This was the conclusion of the 2018 Council of Canadian Academies Report: *The State of Knowledge of Medical Assistance in Dying for Mature Minors* (the "CCA Report on Mature Minors").

Knowledge gaps identified include: (1) "a paucity of evidence" capturing the voices of youth and families that would be most affected by MAID for mature minors; (2) little available evidence on the views of mature minors perceived as particularly vulnerable, including those with disabilities, Indigenous youth, and those in the child welfare system; (3) limited clinical studies focused on health issues, including in respect of end-of-life care affecting youth, and even fewer of youth within the age range of what is likely a mature minor; and (4) data gaps across Canada for MAID, including data on the youngest patients who have requested MAID.¹¹

It is not evident that these and other knowledge gaps have been closed. Some of these knowledge gaps were specifically identified by witnesses who appeared before the Committee, including the lack of consultation with youth.¹²

⁷ Wright, Teresa. "Federal Liberals face criticism about \$875M in missing mental health spending" Global News, June 21, 2022

⁸ Health Canada: GC InfoBase - Infographic for Health Canada

⁹ Wright, Teresa. "Federal Liberals face criticism about \$875M in missing mental health spending" Global News, June 21, 2022

¹⁰ Council of Canadian Academies, The State of Knowledge on Medical Assistance in Dying for Mature Minors, p.154

¹¹ <u>Ibid.</u>, pp.153-154

¹² Evidence, 4 November 2022 (Mary Ellen MacDonald); Evidence, 15 November 2022 (Randi Zlotnik Shaul).

These knowledge gaps are compounded by the fact that mature minors may access MAID in only three jurisdictions in the world, namely: Colombia, Belgium, and the Netherlands, each with few cases of mature minors receiving MAID. The limited experience with MAID for mature minors in other jurisdictions, and the dearth of international data applicable in the Canadian context underscores that significant work remains to close these knowledge gaps.¹³

Also of significance, issues around the decision-making capacity of mature minors remain unresolved. The CCA Report on Mature Minors notes that decisions with increased risk or complexity incite greater concern over the ability of minors to appreciate the consequences of their choice and make it voluntarily. Arguably, there is not a weightier health decision than MAID, given the irreversibility of the procedure.

Moreover, several witnesses noted that the frontal lobe of the brain, which plays a critical role in balancing risks and rewards and decision-making, is not fully developed until well into adulthood. This raises questions about the appropriateness of MAID for mature minors. ¹⁵ As Dr. Maria Alisha Montes, a clinical associate professor of pediatrics, said:

"I would argue that MAID for mature minors carries the highest amount of risk, as the consequence is death. It's irreversible. We need to ask ourselves if we should be legalizing this for mature minors when biology shows us that the ability to balance risks and rewards is one of the last areas of the brain to mature."

There are also practical challenges with assessing the capacity of mature minors. Dr. Timothy Ehmann, a child and adolescent psychiatrist, testified that a standardized, reliable assessment for the capacity and competence of minors does not exist, and that unaided competence judgments, even from "seasoned and otherwise skilled physicians" are unreliable. Dr. Ehmann's testimony is supported by the CCA Report on Mature Minors, which observed that "no standardized approaches are available to assess minors' capacity or psychological maturity" and indicated: "the mere fact that somebody does something frequently, does not necessarily mean that they do it well." Difficulties around accurately assessing the capacity of a minor, and the consequent risk of erroneous capacity findings, is particularly concerning in the context of MAID, which results in the termination of life.

So long as these issues remain unresolved, it would be irresponsible for the Liberal government to move ahead with any expansion of MAID for mature minors. Minors are a uniquely vulnerable group, having regard for their level of cognitive development. It must be emphasized that accessing MAID is arguably the highest stakes medical decision an individual can make. The

¹³ Evidence, 4 November 2022 (Mary Ellen MacDonald); Council of Canadian Academies, The State of Knowledge on Medical Assistance in Dying for Mature Minors, p.116

¹⁴ Council of Canadian Academies, The State of Knowledge on Medical Assistance in Dying for Mature Minors, p.68

¹⁵ Evidence, 6 June 2022 (Maria Alisha Montes); Evidence, 6 June 2022 (Ahona Mehdi); Evidence: 6 June 2022, (Bryan Salte); Evidence, 4 November 2022 (Dr. Gail Beck); Evidence, 4 November 2022 (Elizabeth Sheehy); Evidence, 15 November 2022 (Dr. Dawn Davies); Evidence, 15 November 2022 (Randi Zlotnik Shaul).

 $^{^{\}rm 16}$ Evidence, 15 November 2022 (Timothy Ehmann).

¹⁷ Council of Canadian Academies, <u>The State of Knowledge on Medical Assistance in Dying for Mature Minors</u>, p.81

government needs to further study the issue and consult directly with minors. There must also be clear evidence and a general professional consensus that it can be implemented safely. Based upon the evidence before the Committee, and the CCA Report on Mature Minors, such evidence and consensus are lacking.

Advance Requests

Unlike the Liberals, Conservatives welcome varying views on matters of conscience. Advance requests for MAID ("ARs") are a complex and deeply personal issue. There is a diversity of opinion from members of the Conservative caucus on ARs, including from Conservative members of the Committee. We wish to share our varying observations and conclusions in this section.

Observations of Senator the Honourable Yonah Martin, M.P. Michael Cooper, and M.P. Dr. Stephen Ellis

The above-noted members of the Committee do not support ARs. Based on the evidence at the Committee, we believe that there are significant legal, ethical, and practical challenges with ARs.

The Supreme Court of Canada in the *Carter* decision emphasized multiple times that a person requesting MAID must clearly consent. 18 This necessarily implies contemporaneous consent. Accordingly, ARs appear to fall outside of the parameters set by the Supreme Court.¹⁹

As acknowledged by the Council of Canadian Academies report titled The State of Knowledge on Advance Requests for Medical Assistance in Dying (the "CCA Report on ARs"): "[t]he primary risk involved in ARs for MAID is the risk that a person will receive an assisted death against their wishes." 20 This risk is supported by Health Canada data. Health Canada's First, Second, and Third Annual Reports on Medical Assistance in Dying in Canada reveal that on average, approximately 20% of patients who withdrew their request for MAID did so immediately before the provision of MAID (20.2% in 2019, 22% in 2020, 12.1% in 2021).²¹

¹⁸ Carter v. Canada, 2015 SCC, paras. 4, 127, 147

¹⁹ Evidence: Brief, Dr. Trudo Lemmens, "Why Advance Requests for MAID Raise Fundamental Ethical and Human Rights Concerns", pp.1-2

²⁰ Council of Canadian Academies, The State of Knowledge on Advance Requests for Medical Assistance in Dying, p.173

²¹ Health Canada, First Annual Report on Medical Assistance in Dying in Canada 2019, p.39; Health Canada, Second Annual Report on Medical Assistance in Dying in Canada 2020, p.33; Health Canada, Third Annual Report on Medical Assistance in Dying in Canada 2021, p.43

Moreover, ARs cannot deliver the fully informed consent of the patient, because of the difficulty of predicting future preferences, capacities, and circumstances.²² As Dr. Romayne Gallagher, a clinical professor in palliative medicine, indicated:

"...medical and social science literature reminds us that people are poor at anticipating what life would be like with a life-changing illness or disability. People adapt to illness and disability and adjust their needs for a decent quality of life. Many medical conditions have long and unpredictable courses." 23

Dr. Gallagher further stated that decades of research into effective forecasting reveals that people tend to think that the future will always be worse than it turns out to be.²⁴

Dr. Alice Maria Chung, a geriatrician, indicated that ARs are ethically problematic in that patients, who for example are living with end-stage dementia, would be unable to withdraw their consent. Dr. Chung noted that a patient's ability to withdraw their consent is essential to informed consent.²⁵

In addition to the practical difficulties of a patient predicting the future, there are also difficulties in accurately interpreting ARs. As the CCA Report on ARs states: "the main issue with ARs for MAID is the uncertainty faced by those responsible for following the request when it comes to gauging when or whether the patient desires an assisted death." ²⁶

Physicians are unable to reaffirm consent.²⁷ There is subjectivity and inconsistency in how ARs are interpreted and how they are applied.²⁸ These difficulties are compounded by the fact assessing someone's suffering is highly subjective, and there is extensive clinical uncertainty about how this can be done.²⁹ Moreover, it is unclear how physicians and MAID assessors can determine that a person is suffering intolerably if they are unable to communicate their level of suffering. It is equally unclear how it is possible to resolve this question.

There are also legitimate concerns that ARs will lead to abuse, discriminate against persons with cognitive impairment, and are inconsistent with the International Convention on the

Evidence, 5 May 2022 (Michael Bach); Evidence, 5 May 2022 (Dr. Raphael Cohen-Almagor); Evidence, 25 April 2022 (Félix Pageau); Evidence, 9 May 2022 (Dr. Trudo Lemmens); Evidence, 9 May 2022 (Dr. Lillian Thorpe); Evidence, 28 October 2022 (Dr. Alice Maria Chung); Evidence, 28 October 2022 (Dr. Marcia Sokolowski); Evidence: Brief, Dr. Lillian Thorpe, "Presentation requested related to advanced requests for medical assistance in dying", p.1 ²³Evidence, 9 May 2022, (Romayne Gallagher).

²⁴ Ibid.

²⁵ Evidence, 28 October 2022 (Dr. Alice Maria Chung).

²⁶ Council of Canadian Academies, <u>The State of Knowledge on Advance Requests for Medical Assistance in Dying</u>, p.176

²⁷ Evidence, 9 May 2022, (Romayne Gallagher).

²⁸Evidence, 28 October 2022 (Dr. Marcia Sokolowski); Evidence, 28 October 2022 (Dr. Ross Upshur); Evidence, 28 October 2022 (Dr. Alice Maria Chung).

²⁹ Evidence, 28 October 2022 (Dr. Jonas-Sébastien Beaudry).

Rights of Persons with Disabilities, which recognizes the inherent legal capacity of persons with cognitive disabilities, and implies a duty to enable expressions of current interest. 30

As the CCA Report on ARs concludes:

"The practical application of [ARs], the details of professional judgments in these cases, the societal impacts of allowing [ARs], and the applicability of this evidence to the Canadian context <u>remain significant knowledge gaps</u>." [emphasis added]

Based on the evidence at the Committee, and having regard for the foregoing, it is evident that much work is left to do before consideration can appropriately be given to expanding MAID to include ARs.

Observations of M.P. Dominique Vien

Ms. Dominique Vien supports recommendations on advance requests. For Ms. Vien, it seems clear that a large majority of the population supports advance requests for medical assistance in dying in specific cases of diagnosis of degenerative diseases, for example.

In Quebec, the Special Commission on the evolution of the law concerning end-of-life care, in its report adopted unanimously and tabled in the National Assembly in December 2021, made the following recommendation:

"The Commission recommends that a person of full age and capacity be permitted to make an advance request for medical assistance in dying following a diagnosis of a serious and incurable illness leading to incapacity."31

This recommendation was included in Bill 38 which could not be passed due to the 2022 provincial election.

The implementation of advance requests to receive medical assistance in dying should be framed and supported by safeguards and very specific criteria on which applicants and providers could base themselves.

The State of Palliative Care in Canada

We are generally satisfied with the way the evidence respecting palliative care in Canada is captured in the Final Report. We support each recommendation respecting palliative care.

However, we wish to underscore the failure of the Liberal government to deliver upon commitments to improve access to quality palliative care across Canada since MAID became

³⁰Evidence, 5 May 2022 (Dr. Raphael Cohen-Almagor); Evidence, 28 October 2022 (Dr. Alice Maria Chung); Evidence, 9 May 2022 (Dr. Catherine Ferrier); Evidence, 9 May 2022 (Dr. Trudo Lemmens); Evidence: Brief, Dr. Trudo Lemmens, "Why Advance Requests for MAID Raise Fundamental Ethical and Human Rights Concerns", p.2 ³¹National Assembly of Quebec, Select Committee on the Evolution of the Act respecting end-of-life care, Report of the Select Committee on the Evolution of the Act respecting end-of-life care, Recommendation 1 (December 2021)

legal. Although the Liberal government committed \$6 billion to palliative care in Budget 2018, only a small percentage of that funding has gone out the door.

Regardless of funding, seven years after MAID became legal in Canada, under the Liberals, there has been no meaningful improvement in the state of palliative care. Only 30% to 50% of Canadians have access to palliative care of an unknown quality, and only approximately 15% to 25% of Canadians have access to specialist palliative care to address complex issues.³²

Although the latest Health Canada data indicates that 80.7% of MAID recipients received palliative care, nearly one in five MAID recipients did not.³³ A closer look at the data reveals that at least 40% of those who received MAID had little or no palliative care, with 21% receiving it in the last two weeks and 18% who received it less than four weeks prior to MAID.³⁴ This is concerning given that early palliative care can alleviate suffering before it comes irremediable.35

Limited or poor palliative care may be a factor in driving Canadians to opt for MAID.³⁶ However, there is limited data available regarding the duration and quality of palliative care received by persons who access MAID.³⁷ We therefore recommend that data collection respecting MAID and palliative care be expanded in scope and include the quality and duration of palliative care for those who access MAID.

Having access to quality palliative care is especially critical now that MAID is legal. Early on, following the Carter decision, the importance of palliative care in the context of MAID was recognized in the Final Report of the External Panel on Options for a Legislative Response to Carter v. Canada, which observed that: "a request for physician-assisted death cannot be truly voluntary if the option of proper palliative care is not available alleviate a person's suffering."38 As Dr. David Henderson, Senior Medical Director, Integrated Palliative Care, Nova Scotia Health, observed:

"If the majority of society feels...that every person can end their life at their choosing, then so be it. However, we are still responsible for protecting the vulnerable and ensuring that people have a choice that includes access to palliative care...and a health care system that allows for dignity for all, not just those who want to end their life."

Since the passage of Bill C-14, the original MAID legislation, the Liberals have prioritized the rapid expansion of MAID, while neglecting palliative care. Consequently, they are denying many Canadians who are suffering from meaningful and truly autonomous end-of-life options.

³⁸ Dr. Harvey Max Chochinov, Professor Catherine Frazee, Professor Benoit Pelletier, "Final Report on Options for a Legislative Response to Carter v. Canada" (December 15, 2015), page vii.

³² Evidence, 25 April 2022 (Dr. Leonie Herx) (April 25, 2022); Evidence, 7 October 2022 (Dr. José Pereira).

³³ Health Canada, Third Annual Report on Medical Assistance in Dying in Canada 2021, p.27

³⁴ Ibid., p.27; Evidence, 25 April 2022 (Dr. Leonie Herx); Evidence, 18 October 2022 (Romayne Gallagher).

³⁵ Evidence, 25 April 2022 (Dr. Leonie Herx); Evidence, 18 October 2022 (Romayne Gallagher).

³⁶ Evidence, 25 April 2022 (Dr. Leonie Herx); Evidence, 18 October 2022 (Dipti Purbhoo).

³⁷ Evidence: Ebru Kaya (April 28, 2022); Romayne Gallagher (October 18, 2022)

Pediatric Palliative Care

Access to pediatric palliative care is sorely lacking in Canada³⁹. As noted in the CCA Report on Mature Minors, increasing the availability of pediatric palliative care is a safeguard against minors choosing MAID because of a lack of end-of-life care options⁴⁰. We therefore call on the Liberal government to prioritize improving access to pediatric palliative care.

Protections for Persons with Disabilities

There is a disturbing trend of reports of persons applying for MAID who are motivated by socio-economic suffering. ⁴¹ That is why we support the Committee's recommendations calling on the Liberal government to provide more support and better access to care to Canadians who live with disabilities. No Canadian should feel that MAID is their only option because they are unable to receive the care and support that they need and deserve.

Having said that, we are disappointed that the Committee, in its study, did not undertake a comprehensive retrospective review of the provisions of the *Criminal Code* relating to MAID, including the adequacy of existing safeguards. We submit that this was part of the Committee's mandate pursuant to clause 5(1) of Bill C-7. Instead, the Committee generally focused on the prospective expansion of the MAID regime. This was a missed opportunity, especially at a time when there is growing concern about the effectiveness and enforcement of existing safeguards.

Nonetheless, a consistent theme among members of the disability rights community and their advocates who appeared before the Committee is the need to strengthen safeguards, particularly in Track Two cases. ⁴² Several witnesses expressed the view that the only safeguard that can protect persons with disabilities from wrongful death is to restore the "reasonably foreseeable natural death" eligibility criteria. ⁴³ We therefore recommend that the Government of Canada strike an expert panel to review the adequacy of existing safeguards. The panel should include impacted groups and their advocates and be tasked with determining if additional safeguards are necessary and report its findings to the relevant Ministers. The report should be used to inform future MAID legislation.

³⁹ Evidence, 1 November 2022 (Kimberly Widger).

⁴⁰ Council of Canadian Academies, The State of Knowledge on Medical Assistance in Dying for Mature Minors, p.153

⁴¹ Evidence, 22 November 2022 (Dr. Heidi Janz); Evidence, 18 November 2022 (Kerri Joffe).

⁴² Evidence, 30 May 2022 (Michelle Hewitt); Evidence, 25 November 2022 (Dr. Catherine Frazee); Evidence, 22 November 2022 (David Shannon); Evidence, 18 November 2022 (Alicia Duncan); Evidence, 18 November 2022 (Kerri Joffe); Evidence, 16 June 2022 (Trish and Gary Nichols).

⁴³ Evidence, 18 November 2022 (Krista Carr); Evidence, 22 November 2022 (Dr. Tim Stainton; Evidence, 22 November 2022 (Dr. Heidi Janz); Evidence, 25 November 2022 (Dr. Catherine Frazee) (November 25, 2022); Evidence, 25 November 2022 (Isabel Grant).

It is important to note that the overwhelming majority of disability rights organizations in Canada, since the initial debates on Bill C-7, strongly oppose Track Two MAID.⁴⁴ It is disturbing that the Liberal government has ignored these voices and failed to address their concerns.

Conclusion

The Liberals' rushed and reckless approach to Canada's MAID regime has put the lives of vulnerable Canadians at risk. We caution the Liberal government against repeating the mistakes they made concerning MAID MD-SUMC. MAID policy must be grounded in evidence, consultation with impacted groups, and with serious consideration given to protecting the vulnerable.

Respectfully submitted,

The Honourable Yonah Martin, Senator British Columbia

Michael Cooper, M.P. St. Albert – Edmonton

Dr. Stephen Ellis, M.P. Cumberland – Colchester

Dominique Vien, M.P. Bellechasse – Les Etchemins – Lévis

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⁴⁴ Evidence, 18 November 2022 (Krista Carr).

Special Joint Committee on Medical Assistance in Dying: Supplementary Opinion

This Supplementary Opinion was prepared by four independent senators who serve on the Special Joint Committee on Medical Assistance in Dying (the "Committee"): the Honourable Pierre J. Dalphond (Quebec – De Lorimier) (PSG), the Honourable Marie-Françoise Mégie (Quebec – Rougemont) (ISG), the Honourable Stanley Kutcher (Nova Scotia) (ISG) and the Honourable Pamela Wallin (Saskatchewan) (CSG).

The Committee's report summarizes views, concerns and opinions expressed by individuals and groups who contributed to its work. We are grateful to them. The report also contains 23 recommendations reflecting considerable consensus amongst the members of the Committee, and we urge the Government of Canada to act upon them.

The following supplementary information is meant to help readers identify some publicly available information related to issues addressed during the Committee's study.

I. <u>HEALTH CANADA THIRD ANNUAL REPORT ON MEDICAL ASSISTANCE IN DYING IN CANADA 2021</u>

Excerpts from Third Annual Report on Medical Assistance in Dying 2021

Highlights

The Third Federal Annual Report on Medical Assistance in Dying presents data for the 2021 calendar year, using data collected under the <u>Regulations for the Monitoring of Medical</u>
<u>Assistance in Dying</u>. It builds upon the <u>First</u> and <u>Second Annual Reports on Medical Assistance in Dying</u>. With three full years of data collection now complete, three-year trends provide even greater insight into the picture of medical assistance in dying (MAID) in Canada.

The data is based on reports from medical and nurse practitioners and pharmacists on written requests for MAID and MAID provisions across Canada for the 2021 calendar year. [...]

Growth in the number of medically assisted deaths in Canada continues in 2021

• In 2021, there were 10,064 MAID provisions reported in Canada, accounting for 3.3% of all deaths in Canada.

[...]

Profile of MAID recipients

- In 2021, across Canada, a slightly larger proportion of men (52.3%) than women (47.7%) received MAID. This result is consistent with 2020 (51.9% men vs 48.1% of women) and 2019 (50.9% men vs 49.1% women).
- The average age at the time MAID was provided in 2021 was 76.3 years, slightly higher than the averages in 2019 and 2020 (75.2 and 75.3 respectively). The average age of women during 2021 was 77.0, compared to men at 75.6.
- Cancer (65.6%) is the most commonly cited underlying medical condition in the majority of MAID provisions, during 2021, slightly down from 69.1% in 2020. This is followed by cardiovascular conditions (18.7%), chronic respiratory conditions (12.4%), and neurological conditions (12.4%). Three-quarters of MAID recipients had one main condition, while onequarter had two or more main underlying medical conditions.
- In 2021, 2.2% of the total number of MAID provisions (219 individuals), were individuals whose natural deaths were not reasonably foreseeable (non-RFND) (in Quebec since 2019 and the rest of Canada after the passage of the new legislation on March 17, 2021). The most commonly cited underlying medical condition for this population was neurological (45.7%), followed by other condition (37.9%), and multiple comorbidities (21.0%). The average age of individuals receiving MAID who were non-RFND was 70.1.

The majority of MAID recipients received palliative care and disability support services

- During 2021, the majority of MAID recipients (80.7%) received palliative care. This compares similarly to 2019 and 2020 (82.1% and 82.8% respectively). Of the MAID recipients who did not receive palliative care, 88.0% had access to these services if they required them.
- In 2021, 43.0% of individuals who received MAID required disability support services. Of these, the majority, 87.4%, received disability support services. These results are similar to 2019 and 2020 findings.
- The use of palliative care and disability support services is similar amongst all main conditions except for neurological conditions where the use of palliative care is lower (56.0%) and the requirement for disability support services is higher (66.8%)

Nature of suffering among MAID recipients

 The most commonly cited intolerable physical or psychological suffering reported by individuals receiving MAID in 2021 was the loss of ability to engage in meaningful activities (86.3%), followed closely by the loss of ability to perform activities of daily living (83.4%).
 [...]

The total number of practitioners providing MAID continues to grow, and primary care physicians remain as the principal MAID providers

- The total number of unique practitioners providing MAID increased to 1,577 in 2021, up 17.2% from 1,345 in 2020. Similar to 2020, 94.4% of all practitioners administering MAID were physicians, while 5.6% were nurse practitioners. Physicians provided 91.6% of MAID procedures during 2021, while nurse practitioners took on an increasing share, performing 8.4% of MAID provisions.
- Family physicians continue to provide the majority of MAID provisions (68.2%), consistent with 2019 and 2020 results.

Private residences continue to be the primary setting for the administration of MAID in Canada

- In 2021, 44.2% of MAID provisions took place in private residences, continuing to be the primary setting for the administration of MAID in Canada. [...] The remainder of 2021 MAID provisions took place in hospitals (28.6%), palliative care facilities (19.6%), residential care facilities (6.1%), and other settings (1.5%). These levels are similar with 2020 results.
- The Atlantic provinces had a higher proportion than other jurisdictions of MAID provisions for individuals living in rural areas, ranging from 42.1% in Nova Scotia to 46.2% in Prince Edward Island. By contrast, Alberta (84.1%), British Columbia (83.6%), Ontario (81.6%), Manitoba (80.7%), and Québec (79.1%) had the highest proportion of MAID recipients living in urban areas. This is consistent with 2020 and roughly representative of each jurisdiction's general pattern of population distribution.

Requests not resulting in a medically assisted death

- There were 12,286 written requests for MAID in 2021. This represents an increase of 27.7% over the number of written requests in 2020. The majority of written requests (9,950 or 81.0%) resulted in the administration of MAID.
- The remaining 2,336 requests (19.0%) resulted in an outcome other than MAID: 231 individuals withdrew their request (1.9% of written requests); 487 individuals were deemed ineligible (4.0% of written requests); and 1,618 individuals died prior to receiving MAID (13.2% of written requests).
- The main reasons for the withdrawal of a MAID request was the individual changed their mind (62.3%) or that palliative care was sufficient (38.5%). For 12.1% of withdrawals (28 individuals), withdrawal occurred just prior to the MAID procedure when asked to provide their final consent.

In 2021, 487 individuals were deemed ineligible for MAID, representing 4.0% of all written requests. [...] The most common reason for a determination of ineligibility was due to the individual not being capable of making decisions with respect to their health (33.1%)., consistent with 2020 results.
 [...]

II. 2021-2022 ANNUAL REPORT OF THE COMMISSION SUR LES SOINS DE FIN DE VIE

Excerpts from the <u>Annual Report on Activities prepared by the Commission sur les soins de fin</u> <u>de vie</u> tabled in the National Assembly of Quebec on December 9, 2022.

SUMMARY

The mandate of the Commission sur les soins de fin de vie (hereinafter referred to as the "Commission") is to examine all matters relating to end-of-life care and to oversee the application of specific requirements relating to medical aid in dying. This annual report highlights the Commission's activities and achievements and presents data on palliative and end-of-life care made available to the Commission for the period from April 1, 2021 to March 31, 2022.

Medical Aid in Dying (MAID)

- The number of medically assisted deaths and the percentage of deaths involving MAID have been rising since the Act respecting end-of-life care (ARELC) went into effect.
- 3,663 individuals received MAID between April 1, 2021 and March 31, 2022 (5.1% of deaths). This amounts to a year-over-year increase of 51%, or 1,236 more medically assisted deaths.
 - Most individuals were 60 years of age or older (93%), suffering from cancer (66%), given a survival prognosis of 1 year or less (84%) and enduring irremediable physical and psychological suffering (95%).
 - They received MAID in a hospital centre (54%), at home (33%), in a residential and long-term care centre/CHSLD (8%) and in a palliative care hospice (5%).
 - o On average, MAID is administered 26 days after the request is signed.
- Almost all cases of medically assisted deaths (over 99%) were administered in compliance with the requirements of the Act respecting end-of-life care.
- Almost two-thirds of formal requests for MAID were administered (68%).
- The main reasons given to explain why MAID was not administered following a formal request were the following: death occurred before completion of the assessment process or before administration of MAID (34%); individuals did not meet or no longer met the criteria for eligibility prescribed in the Act respecting end-of-life-care (22%) or the request was withdrawn (18%).

• 1,418 physicians participated in medically assisted deaths; this represents an increase of 26% versus 2020-2021 (85% were general practitioners and 15% were physician specialists).

Palliative/end-of-life care and continuous palliative sedation

- 58,846 individuals were receiving palliative/end-of-life care between April 1, 2021 and March 31, 2022. They benefitted from palliative/end-of-life care at home (44%), in a hospital centre (35%), in a residential or long-term care facility/CHSLD (13%) and in a palliative care hospice (8%).
- 1,838 individuals received continuous palliative sedation during the current period (2.6% of deaths).

Conclusion

The Commission notes that requests for MAID are increasing and that MAID has become an important subject of public debate in Quebec. Why does Quebec have more medically assisted deaths per million people when compared with Ontario, Canada and Belgium? The Commission would like to see this social debate continue and, when parliamentary business resumes in fall 2022, it would also welcome the tabling of a bill to ensure that an advance request for MAID can be completed by anyone who has been diagnosed with a serious and incurable neurocognitive disorder, in anticipation of incapacity to provide consent.

III. PUBLIC OPINION POLLS: SUPPORT FOR MEDICALLY-ASSISTED DYING IN CANADA

Excerpts from the <u>2023 Ipsos poll: Support for medically-assisted dying in Canada (MAID for mental disorders)</u>

A strong majority (82%) of Canadians agree that with the appropriate safeguards in place, an adult with the capacity to provide informed consent should be able to seek an assessment for medical assistance in dying for a severe, treatment-resistant mental disorder for which they experience intolerable suffering. Support is comprised of 34% who strongly support and 48% who somewhat.

Younger Canadians tend to be more supportive of this policy: those between the ages of 18-34 (87%) exhibit stronger levels of agreement than those aged 35-54 (77%). Interestingly, those over the age of 55 (41%) are more likely to strongly agree than those between the ages of 18-34 (29%) and 35-54 (32%).

Moreover, Quebec residents (91%) are more like [sic] to agree that those suffering from solely a severe mental disorder can access the MAID assessment compared to residents in Alberta (76%), Ontario (78%) and Atlantic Canada (79%).

Excerpts from the 2022 Ipsos poll: Support for medically-assisted dying in Canada

Support for MAID and advance requests remain firm among Canadians, and the proportion of Canadians who support removing the "Reasonably Foreseeable" requirement from federal assisted-dying law has risen by 13-points over last year. Canadians are thus becoming more adamant about ensuring that patients have the right to choose end-of-life choices they desire. More specifically:

[...]

• 85% support advance requests for those with a grievous and irremediable condition. [...]

IV.FINAL REPORT OF THE EXPERT PANEL ON MAID AND MENTAL ILLNESS

Final Report of the Expert Panel on MAiD and Mental Illness

Excerpts from the Government of Canada Website on the Expert Panel on MAiD and Mental Illness

Canada's new medical assistance in dying (MAID) law came into force on March 17, 2021. The new law expanded eligibility to MAID to include individuals whose death is not reasonably foreseeable, while also amending other aspects of the law.

The new MAID legislation temporarily excludes, until March 17, 2023, eligibility for MAID for individuals with a mental illness as their sole underlying medical condition. The legislation includes an obligation for the Minister of Health and the Minister of Justice to initiate an independent expert review "respecting recommended protocols, guidance and safeguards to apply to requests for medical assistance in dying by persons who have a mental illness."

The Expert Panel on MAID and Mental Illness was launched to undertake this review. A report containing the Panel's conclusions and recommendations was tabled in Parliament on May 13, 2022. The findings will assist the Government in developing its approach for safely providing access to MAID for persons with a mental illness. This work will also help ensure that practitioners are equipped to assess these requests in a safe and compassionate way based on rigorous clinical standards and safeguards that are applied consistently across the country.

V. <u>2019 SUPERIOR COURT OF QUEBEC DECISION IN TRUCHON C. PROCUREUR GÉNÉRAL DU</u> CANADA

Excerpts from Truchon c. Procureur général du Canada, 2019 QCCS 3792 (CanLII)

4. Conclusions on the Evidence

[466] From the evidence as a whole, the Court concludes as follows:

- 1. Medical assistance in dying as practised in Canada is a strict and rigorous process that, in itself, displays no obvious weakness;
- 2. The physicians involved are able to assess the patients' capacity to consent and identify signs of ambivalence, mental disorders affecting or likely to affect the decision-making process, or cases of coercion or abuse;
- 3. The vulnerability of a person requesting medical assistance in dying must be assessed exclusively on a case-by-case basis, according to the characteristics of the person and not based on a reference group of so-called "vulnerable persons". Beyond the various factors of vulnerability that physicians are able to objectify or identify, the patient's ability to understand and to consent is ultimately the decisive factor, in addition to the other legal criteria;
- 4. The physicians involved are able to distinguish a suicidal patient from a patient seeking medical assistance in dying. Moreover, there are important distinctions between suicide and medical assistance in dying with respect to both the characteristics of the people involved and the reasons that motivate them;
- 5. Neither the national data in Canada or Quebec nor the foreign data indicate any abuse, slippery slope, or even heightened risks for vulnerable people when imminent end of life is not an eligibility criterion for medical assistance in dying.

VI. 2020 SUPREME COURT OF CANADA DECISION IN ONTARIO (ATTORNEY GENERAL) V. G

Excerpts from Ontario (Attorney General) v. G 2020 SCC 38

[74] [...] The inclusion of *any* method of exempting and removing those found NCRMD [not criminally responsible on account of mental disorder] from the registry based on individualized assessment would be less impairing of their <u>s. 15(1)</u> rights and could actually increase the

registry's effectiveness by narrowing its application to individuals who pose a greater risk to the community.

- [75] [...] Individual assessment does not need to perfectly predict risk certainty cannot be the standard [...]
- [76] I accordingly conclude that the Attorney General has not met his burden under $\underline{s. 1}$ to demonstrate that the infringing measure is not minimally impairing of the right and therefore has not justified the $\underline{s. 15(1)}$ infringement.