

MAID VOLUNTEER ADVOCACY COUNCIL:
MAID IN CASES WHERE A **M**ENTAL **D**IAGNOSIS IS THE **S**OLE **U**NDERLYING **M**EDICAL **C**ONDITION (“MAID MD-SUMC”)

Introduction

The federal government announced that the legislative review of the three exclusions from the 2016 MAID legislation: advance requests, mental illness as the sole underlying medical condition, and mature minors, would begin in 2020. We believe that all individuals seeking MAID MD-SUMC should be assessed similarly, if not identically, to those who are suffering from a grievous physical condition. The entire membership of the MVAC, which wrote this report, has two key qualities:

- a) Its members have been diagnosed with some form of mental illness in their lifetimes.
- b) Its members reached a consensus on the views in this report. While the [CCA report](#) is highly informative, its members were unable to reach agreement in many areas.

This report’s contributors list can be found on the final page.

Proposed Recommendations

The MVAC recommends that:

1. Individuals suffering solely from mental illness ought to have equal access¹ to MAID as those who suffer from physical illnesses², with the same eligibility criteria and safeguards. This includes adjusting and clarifying the definition of ‘irremediable’³ and removing from consideration the term ‘incurable’, as the SCC ruled in *Carter* (and as the QCCS further re-asserted in *Truchon* [[par. 497](#)]) that the former term is the correct term to use.
2. The 90 day waiting period requirement in Bill C-7 for individuals whose death is not reasonably foreseeable ought to be removed. This removal should apply equally to those with physical and mental illness.
3. The Government must drastically improve the health care system with regard to mental illness, particularly on including affordable access in a timely manner.
4. If Bill C-7 is passed as is, with mental illness explicitly excluded from eligibility for MAID, then the Bill must be referred to the Supreme Court, and further Parliamentary review must occur within two years.

¹ As a midpoint vis-a-vis Bill C-7 sec. 3.1(e), we believe the only unique safeguard needed for MAID MD-SUMC is as follows: “If an assessor has difficulty determining any eligibility criteria, they may consult confidentially and/or involve outside medical or legal expertise in the assessment. Upon them requesting this assistance, the assessor’s assessment cannot finish until the requested expert provides their opinion.” To minimize this as an access barrier, a national list should be published of all qualifying professions.

² CCA Report ([p 195](#)): “Most people with mental disorders have the capacity to make highly consequential decisions about medical treatment.” Moreover: the double standard of those with mental illness & an eligible physical illness, who have been presumed as having capacity for MAID **since 2016**. (See also [Starson v. Swayze](#)).

³ To replace Bill C-14 sec. 241.2 (2), with this definition: “The patient has been made aware of all currently accessible and available treatments that the medical community considers to have a notable chance of improving their illness or state of health. Upon completing this process, the patient has self-determined that they have not received sufficient relief or improvement, and they continue to wish to receive MAID.” (See Dr. Gaind’s quote [55] in [PDAM Report](#)).

Context

Legal Considerations

Current MAID legislation does not explicitly exclude those with mental illness as a sole underlying condition from accessing MAID. However, individuals with MD-SUMC are not eligible for MAID due to the reasonably foreseeable death requirement. This is because the nature of mental illness itself is not seen to cause an individual's death in the same way a physical illness, such as cancer, causes death. Bill C-7, as it is currently drafted, goes further than Bill C-14 to explicitly exclude mental illness from the definition of illness, disease, or disability, and thereby prevents individuals with MD-SUMC from accessing MAID. Yet, evidence accepted and favoured by the SCC and the QCCS in *Carter* and *Truchon*, respectively, demonstrates that there is no evidence establishing that it is impossible to reliably assess the mental capacity of an individual with a psychiatric condition⁴, nor that this should exclude or restrict those with mental illness from accessing MAID⁵. In fact, in *Canada v EF*, the individual in question applied for MAID based on suffering solely caused by a conversion disorder (a psychiatric illness categorized in the DSM-V as a "somatic symptom and related disorder"), yet it was determined that she had full capacity to make informed decisions, including consent to terminate her life through MAID. In addition, the [CCA report](#) that was commissioned by our own federal government, concludes that: "Most people with mental disorders have the capacity to make highly consequential decisions about medical treatment," (p 195).

This exclusion of mental illness under the definition of disease, illness, or disability raises constitutional issues, particularly under section 15⁶. Arbitrarily excluding individuals solely because they have a mental illness rather than a physical illness is contrary to the entrenched right of those with physical or mental disabilities to have equal protection and rights under the law. This is consistent with the UN Convention on the Rights of Persons with Disabilities, which was ratified by Canada in 2010⁷. Individuals do not get to choose their illness; it is an immutable characteristic. As such, if an illness creates unbearable suffering for that individual, it is not justifiable to exclude an individual's access to MAID because of arbitrary exclusion criteria that singles out certain disorders.

The Benelux countries, Switzerland and Germany allow individuals to access euthanasia (Benelux) or assisted suicide (Switzerland and Germany) based solely on mental or physical suffering, with no requirement for a "terminal illness" or "reasonably foreseeable death". However, in Belgium there are two additional safeguards that apply when an individual is not terminally ill, including a one month waiting period and the requirement that the consultant must be an expert in the condition causing the

⁴ *Truchon v Canada* (AG) 2019 QCCS 3792, para 420 and *Carter v Canada* (AG) 2015 SCC, paras 104-6.

⁵ *Truchon v Canada* (AG) 2019 QCCS 3792, para 421.

⁶ Canadian Charter of Rights and Freedoms, s 15, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11.

⁷ UN Convention on the Rights of Person with Disabilities, Articles 12, 17, and 25.

individual's suffering⁸. This is very similar to the proposed Bill C-7. The countries with the largest number of cases and which, therefore, provide the most robust evidence surrounding MAID MD-SUMC are the Netherlands and Belgium⁹. The government must consider the clear evidence of strong safeguards from these jurisdictions¹⁰ when considering the issue of MAID MD-SUMC in Canada, while considering Canada's unique cultural and geographical context.

Ethical and Psychosocial Considerations

Capacity, Autonomy, and Informed Consent

It is crucial that individuals have the capacity to make decisions in order to provide informed consent to accepting or declining a specific treatment. This capacity means that individuals have the ability to "understand and appreciate the nature and consequences of their decisions"¹¹. As highlighted above, mental illness does not automatically render individuals incapable of making free and informed decisions about their care. Many psychologists agree that this group of patients can possess the required competency to make healthcare decisions¹². Research also shows that they are capable of discussing end-of-life decision-making with emotional and cognitive stability¹³. Just like an individual with physical illness, if there is a question about the capacity of the individual with a mental illness to make a decision, then their capacity can be assessed and determination made. The team completely agrees that individuals must have capacity at the time of requesting access to MAID. However, the assumption that mental illness automatically precludes individuals from having capacity to make health care decisions is false. Clare Mudge, a New Brunswick councilmember with PTSD, described the conflicting legal standards that currently can apply to the same person:

*"If I acted out in my illness (ex: had a fit of rage or dissociated) and committed a crime, I would **not** be considered "non compos mentis". The government would consider me mentally fit to stand trial and take responsibility for my actions - even if they weren't choices made by my rational mind. However, when it comes to choosing my own end, they would say that I am **not** of sound mind to make that decision. Therefore, the government would expect me to properly understand the impact my actions had on other people (within this hypothetical trial), but conversely, I would remain legally unable to understand actions that affect just myself. I know the difference between right and wrong, and changing someone's status when it suits your needs but disregards theirs, is wrong."*

--(Read Clare's full story below on p. 5).

Additionally, it is false to presume that patients with mental disorders would have a disproportional tendency and desire to seek MAID. Some studies have found that patients with severe and persistent mental disorders were less likely to consider MAID than patients with chronic physical disorders when

⁸ Canadian Council of Academies, "The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition" (Dec 2018), p. 117 [CCA Report].

⁹ Ibid, p. 112.

¹⁰ BMC Psychiatry, "[Euthanasia..in patients suffering from psychiatric disorders...](#)" (2019).

¹¹ Ibid, p. 31.

¹² Canadian Psychological Association, "[Medical Assistance in Dying and End-of-Life Care](#)" (May 2018), p. 6.

¹³ CCA Report at p. 104.

presented with hypothetical scenarios of intractable pain or suffering¹⁴. Though it is true that suicidal ideation accompanies mental disorders more frequently than other diseases, ideation is often found to poorly correlate with attempted or completed suicide¹⁵. Actually making a suicide attempt is most attributable to impulsive action and is not usually premeditated. Taken together, there is little reason to believe that patients with mental disorders will have a greater propensity towards choosing MAID.

Clinical Considerations

Clinicians – What differences could there be on the impact on clinicians who provide MAID for cases of mental illness as opposed to physical illness?

The focus on the patient is of primary concern; however, there also needs to be consideration given to healthcare professionals who treat patients with mental illness and are requested to provide MAID. An extended essay in the Journal of Medical Studies describes the dilemma clinicians at the Hospital for Sick Children (Sick Kids) in Toronto must address as they develop a policy to regulate MAID provision in a paediatric setting¹⁶. The article describes the contradictory and confusing environment in which they would be operating. For example, some confusion stems from the fact that MAID clinical guidelines are at odds with the Carter decision.

The authors ponder whether MAID is practically and ethically distinct from other medical procedures that result in the end of life, or whether it is equivalent to other medical procedures that result in the end of life. If it is the latter, then contrary to what is considered to be best practice in the literature on the subject, the obligation is on the physician to put MAID forward as a treatment option, as they would any other applicable option. They are, after all, the experts. Ultimately, the authors propose a policy for Sick Kids that perceives MAID as “practically and ethically equivalent to other medical interventions that result in the end of life”¹⁷.

An additional consideration is shown by this [survey](#) that was sent to all medical students in 15 of 17 Canadian medical schools¹⁸. It signals changing attitudes towards MAID: 71 per cent of respondents reported being willing to provide MAID under a legal framework that permits it. The students were not asked specifically about MAID in cases of MD-SUMC; however these results show that the next generation of doctors will enter the field with more willingness to see MAID as an option for end-of-life treatment.

¹⁴ Ibid, p. 105.

¹⁵ Lukasczek K, Engelhardt H, Baumert J, Ladwig KH, (Sep 2015). *No correlation between rates of suicidal ideation and completed suicides in Europe: Analysis of 49,008 participants (55+ years) based on the Survey of Health, Ageing and Retirement in Europe (SHARE)*. <https://pubmed.ncbi.nlm.nih.gov/26443056/>; and Rogers ML, Ringer FB, Joiner TE, (Sep 2018). *The association between suicidal ideation and lifetime suicide attempts is strongest at low levels of depression*. <http://www.ncbi.nlm.nih.gov/pubmed/30292084>

¹⁶ DeMichelis C, Zlotnik Shaul R, Rapoport A. “Medical Assistance in Dying at a Paediatric Hospital”. J Med Ethics Epub. doi:10.1136/medethics-2018-104896

¹⁷ Ibid, p. 2.

¹⁸ Falconer, J., Couture, F., Demir, K. K., Lang, M., Shefman, Z., & Woo, M. (2019). Perceptions and intentions toward medical assistance in dying among Canadian medical students. BMC medical ethics, 20(1), 22. <https://doi.org/10.1186/s12910-019-0356-z>

Anecdotal Stories

A Nova Scotian retired paramedic offered her story for this report, and it highlights these concerns:

"Hello, my name is Lisa Marr. I am 51 years of age, and I live with ADHD, bipolar type 2 major depressive disorder, and GAD. I also live with PTSD from a 20-year career as a paramedic. My first depressive episode was at 8 years of age. That was the beginning of a lifetime of duress. I have not been able to wake up a single day since I was 8, not wishing I was dead. There are cases where major depression is hopeless, and we must realize that mental pain is not less than physical pain. It is overwhelming and over-compassing, involving my every thought, every day. Now adding PTSD to it, I am forced to take many medications that rarely help, as I am treatment-resistant. People with mental illness as a primary diagnosis should qualify for MAID, based on a history of treatment resistance.

We as a nation, with public healthcare and equal opportunities, must loosen the restrictions for MAID so that all citizens who need it, can access it. Under the Charter, everyone is equal under the law and the right to equal benefits and freedoms, without discrimination based on mental or physical disabilities. The Charter has recognized and enforced the rights of minority and disadvantaged groups. Currently, our access to MAID does not comply with this.

Adding MAID as a Charter right for those with mental illness as a sole diagnosis would give Canadians a more equal chance to control their suffering, and that is our goal."

Clare Mudge has severe PTSD from multiple traumas, as well as severe Generalized Anxiety Disorder (GAD). She describes the battles she has had to live through:

"I have been a relative shut-in since I was sexually assaulted in 2014, which I didn't report. That decision was made following being kidnapped and having an attempt made on my life by a taxi driver in 2008. The perpetrator got a plea bargain for just a forcible confinement charge. A month later, my car and my right ear were damaged by a corporate helicopter. The company was found guilty and fined \$50,000 by Transport Canada. These are only 3 of my traumas, I have many others. I feel that justice wasn't delivered: as those who injured me continue to live free and prosperous lives, I have become a prisoner in my own home - terrified of the actions of others. I was denied funding for appropriate therapy by my province 3 different times. I was denied disability benefits.

*Once a working single-mother and university student, I have now slipped into poverty. I have been placed in low-income housing in a crime-ridden neighbourhood. I try to survive on \$400 per month. My physical and mental health deteriorate as life drags on. I spend the long hours of every day wishing for an end. So as the Governments of New Brunswick and Canada denied me the right to **live** with dignity and compassion - so too am I denied the right to **die** with dignity and compassion.*

It's emotional for me to share so much of my story, but I am walking proof that the changes outlined on page one of our report need to be considered. I don't feel it is ethical for the government to deny someone autonomy over their own life if they aren't a criminal: I didn't choose to commit any crime. I don't deny myself access to recovery. I was even politically involved as a responsible citizen prior to my traumas. I have never done anything to deserve such unjust treatment or have my Constitutional Rights ignored by my country or my province. Thank you for giving me an opportunity to have a voice - even if I am still denied a choice."

Another personal submission is from John Scully, a longtime- journalist and war correspondent at the CBC, who has become a MAID advocate during his battles with mental illness:

"I bitterly resent the thought of having my life decided by those who've never suffered mental illness. I know the pain. I know the reality. I know what it means to decide whether to live or die. They [the CCA experts who do not have first-hand experience with mental illness] do not.

To say that loss of hope is merely temporary and can be restored overtime defies reality. Loss of hope is a terminal knell. That's why people kill themselves. There's no way back. That's what depression does. I've known at least five souls who lost hope. And with hope so went their dignity and reason to live. [My friend] Daryl couldn't get a job. The rejection gutted him. He was bipolar and very sick. No-one, no treatment, could give him any hope. Daryl jumped. So loss of hope is an easily treated condition? My other buddies, mentally ill too, also lost hope. I spoke to one of them before he killed himself. I tried to convince him that hope was still possible. But I was lying, desperately. His funeral was four days later.

Loss of hope, dignity, self-esteem are not clinical aberrations. They must not be cavalierly dismissed as "easily treated conditions." They're brutal realities of the viciousness of depression. And they defy the pious assertions of academics and panels and medical journals. It's not for their amusement that psychiatrists spell out "refractory depression" as treatment-resistant depression. No. They do it because it signals the end of the road for their pills, potions, chatter, and zapping. There's nothing left. No hope. Nothing. Of course, many refuse to admit this unpalatable and potentially deadly fact, because it exposes their helplessness.

Would I kill myself using MAID? It's still just a hypothetical question. But my answer remains the same. Yes. Instead of trying suicide for the third time, I would avail myself and my family of the calm planning, the dignity, the moral comfort and the certainty offered by MAID.

I'll give the final word to Toni, my very astute, perceptive and realistic wife for 54 years: 'If you're in such pain that you want to die, need to die, my answer is 'of course.'"

Challenges

1. Access to Mental Health Care Services

One major challenge identified by the team is the current shortfalls of the healthcare system regarding timely access to mental health services and lack of Medicare funding for potential treatments, including medications. It has been well-documented that the current mental health care funding is not meeting the needs of Canadians¹⁹. In 2015, Canada spent 7.2 percent of health expenditure on mental health services, which is significantly lower than expenditures in other countries for similar services, including England, where spending on mental health services was 13 percent in 2014²⁰. As of January 2020, wait times for many mental health resources in Ontario exceed one year²¹. The current long wait times for

¹⁹ Mental Health Commission of Canada, "Strengthening the Case for Investing in Canada's Mental Health System: Economic Considerations", (Mar 2017). Retrieved from:

https://www.mentalhealthcommission.ca/sites/default/files/2017-03/case_for_investment_eng.pdf

²⁰ Ibid, p. 7.

²¹ CBC News, "Wait times for some mental health services up to 1 year long in Waterloo-Wellington

accessing mental health services, such as counselling or cognitive behavioural therapy, prolong individual suffering and create a system where individuals who can pay out of pocket for such services privately have greater access.

The team recognizes the concern that individuals who cannot access the therapies or treatments within their assessed path toward “irremediability” in a timely manner, or at all, may opt for MAID instead. However, enabling Canadians to have timely and adequate access to mental health services eliminates the concern that lack of treatment may cause an individual to opt for MAID. Therefore, this team urges the government to increase funding to mental health services to adequately meet the needs of Canadians (see recommendation 3).

However, the above concern *should not* be addressed by forcing individuals to wait until the day an adequate mental health care system is in place before their MAID request will be listened to. Why should they be relegated to a life of torment due to society’s failure to provide an appropriate support system?

2. Knowledge Gaps

The team recognizes that there is a need for further research and better evidence regarding the complex relationship between mental illness and its impact on individual capacity, autonomy, and desire to die. This includes research both in Canada and in jurisdictions where MAID MD-SUMC is legal. These gaps were clearly outlined in the CCA report²².

The team argues that there should be research done that collects information surrounding MD-SUMC requests. The number of individuals requesting MAID, the reasons for requesting MAID, and their treatment and diagnosis ought to be collected through research to gain further insight into such requests. It is essential that any research conducted about MD-SUMC involves those impacted by mental illness through the entire research process, including research design, conduction, and implementation. On this topic, the team agrees with the Canadian Bar Association’s view that “reporting requirements should only be triggered by formal requests for MAID, not by preliminary discussions on eligibility.”²³ Those impacted by mental illness must be at the table, to avoid the risk of new findings being unrepresentative of their everyday experience.

3. Artificial Distinction between Mental and Physical Illness

Social Sharing” (Jan 29 2020). Retrieved from:

<https://www.cbc.ca/news/canada/kitchener-waterloo/wait-times-for-some-mental-health-services-up-to-a-year-long-in-waterloo-wellington-1.5441205>

²² CCA Report, p. 107.

²³ Canadian Lawyer. “CBA working group comments on proposed changes to...” (May 12 2020) <https://www.canadianlawyermag.com/practice-areas/criminal/cba-working-group-comments-on-proposed-changes-to-medical-assistance-in-dying-legislation/329562>

Creating an artificial distinction between mental and physical illness is problematic and poses many challenges when creating legislation, having healthcare practitioners provide services, and for those living with mental illness. The proposed Bill C-7 notes that “For the purposes of paragraph (2)(a), a mental illness is not considered to be an illness, disease or disability”²⁴. The artificial distinction between physical and mental illness is blurred and there has been little attention paid to the repercussions of this distinction. For example, dementia is a prevalent mental disorder affecting older adults²⁵. Yet, CIHI excludes dementia cases when reporting statistics on mental disorders²⁶. This distinction is also blurred for conditions such as post-concussive syndrome. If the government makes such a distinction between mental and physical illness, there will be a lack of clarity regarding which conditions are in fact eligible under Canada’s MAID laws. The team argues that the government should remove the distinction between physical and mental illness to provide clarity in the legislation and respect the constitutional right of those with mental disability to have equal rights and protection under the law.

The exclusion of mental illness under Bill C-7 is problematic because it sends a message to Canadians that mental illness is considered lesser than physical illness and does not result in intolerable suffering. This message perpetuates stigma against those with mental illness by phrasing it as something that is not an illness, suggesting it is within one’s control and there is something inherently wrong with those with mental illness. This message internalizes the mental illness rather than externalizes it. Though the intent of the government in excluding mental illness is to do more research before legalization, the *effect* of excluding mental illness from the very definition of illness, disease, or disability is harmful to those living with mental illness and Canadian society broadly.

Contrary to the federal government’s phrasing, this team argues that mental illness most certainly is an illness, disease, and disability.

²⁴ Bill C-7, An Act to amend the Criminal Code (medical assistance in dying). 1st Reading, 1st Session, 42nd Parliament.

²⁵ CCA Report, p. 37.

²⁶ Canadian Institute for Health Information, “Health System Resources for Mental Health and Addictions Care in Canada” (Jul 2019). Retrieved from:
<https://www.cihi.ca/sites/default/files/document/mental-health-chartbook-report-2019-en-web.pdf>

The MAID Volunteer Advocacy Council consists of Canadians who came together in the past year from British Columbia to Newfoundland and Labrador, in order to gather first-hand experiences from those most impacted by the current flaws in Canada's MAID regime.

This report would not have been made possible without the help of each of these members and other contributors: Jack Hopkins, Julia Borges, Nicole Curtis, Erin Britton, Lise Brown, Lisa Marr, Dr. Pierre Milot, Clare Mudge, Harmeet Nanner, Cindy Player, Dr. Ron Posno, Rita Scagnetti, John Scully, and Renate Tilson.

Our proposed recommendations:

1. Individuals suffering solely from mental illness ought to have equal access²⁷ to MAID as those who suffer from physical illnesses²⁸, with the same eligibility criteria and safeguards. This includes adjusting and clarifying the definition of 'irremediable'²⁹ and removing from consideration the term 'incurable', as the SCC ruled in *Carter* (and as the QCCS further re-asserted in *Truchon* [par. 497]) that the former term is the correct term to use.
2. The 90 day waiting period requirement in Bill C-7 for individuals whose death is not reasonably foreseeable ought to be removed. This removal should apply equally to those with physical and mental illness.
3. The Government must drastically improve the health care system with regard to mental illness, particularly on including affordable access in a timely manner.
4. If Bill C-7 is passed as is, with mental illness explicitly excluded from eligibility for MAID, then the Bill must be referred to the Supreme Court, and further Parliamentary review must occur within two years.

²⁷ As a midpoint vis-a-vis Bill C-7 sec. 3.1(e), we believe the only unique safeguard needed for MAID MD-SUMC is as follows: "If an assessor has difficulty determining any eligibility criteria, they may consult confidentially and/or involve outside medical or legal expertise in the assessment. Upon them requesting this assistance, the assessor's assessment cannot finish until the requested expert provides their opinion." To minimize this as an access barrier, a national list should be published of all qualifying professions.

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²⁹ To replace Bill C-14 sec. 241.2 (2), with this definition: "The patient has been made aware of all currently accessible and available treatments that the medical community considers to have a notable chance of improving their illness or state of health. Upon completing this process, the patient has self-determined that they have not received sufficient relief or improvement, and they continue to wish to receive MAID." (See Dr. Gaind's quote [55] in [PDAM Report](#)).