

Brief for the House of Commons' Standing Committee on
Justice and Human Rights regarding Bill C7
An Act to amend the Criminal Code - Medical Assistance in Dying

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It is an honour to present to the Committee as an expert in the field of Medical Assistance in Dying (MAID).

Background

I became involved in MAID in February 2016 in anticipation of the legal availability of this treatment option when a young patient with a brain tumor asked, "So, you will help me?". As their family physician there was nowhere to refer this patient to at the time. It was the start of an uncharted professional and personal path - challenging, sacred and filled with breathtaking responsibility.

Over the past 4 ½ years it has continued to be the most challenging, yet rewarding work of my 20 year long career. I practice in rural BC, serving a small city, several towns, hamlets and remote islands. Being one of the first MAID providers in the province has led to many unexpected discoveries: Talking about MAID includes a thorough review of and if needed, improvement of palliative care, other treatments and enhanced supports. It not only addresses elephants in the room such as vulnerability, disability, mental health, fears and hopes, but also reveals the true nature of suffering, most often not physical, but loss of autonomy, quality of life, existential anxiety and more. It has been published that MAID assessments have therapeutic benefit in reducing anxiety – and this patients tell me is liberating, allowing them to live more freely to the end, whether they eventually die naturally or have MAID. The vast majority of our patients have strong survival instincts and most do not want to die – they just have very little control over nature's path. MAID has thrown us many curved balls and stretched our understanding of life and dying. It has tested our moral fiber, seeing intense suffering, with a primary obligation to fulfill the law, even if it that means saying no. It is medicine in a much more intimate and person centered form that I have otherwise ever experienced. I never anticipated hearing "Thank you for saving my life", moments before an assisted death. The patient who had advanced cancer explained that it allowed them to die being who they are and not who or what they did not want to become.

I hope to give the Committee a glimpse of the human and humane side of MAID. The law, as necessary safeguard to us all, can seem theoretically distant and cold. It likely never seems safe enough for those who harbor fears of slippery slopes or potential abuse of the vulnerable or disabled. And probably does not go far enough for those who have witnessed the ravages of dementia, stroke and other conditions that could be ameliorated by advance consent for MAID. And mental health does not yet feature as sole request, no matter how real and debilitating it is compared to physical illness.

To address some of the common fears briefly: Every basket has a rotten apple. We have not had a rotten apple in all the years MAID has been diligently en meticulously

practiced in Canada. It speaks to the moral fiber of physicians and nurse practitioners, our high standards, guidance of organizations such as CAMAP (Canadian Association of MAID Assessors and Providers) and abiding spirit and commitment to the law, written to balance the rights of all individuals involved fairly. To complement that many MAID providers are palliative care specialists – and we support excellent palliative care for all patients and believe MAID is one of the treatments in the spectrum of palliative care options. The majority of MAID providers are family physicians who form the backbone of the medical system and palliative care in Canada – many of us have stepped up our game and obtained further training in palliative care to ensure that we can offer patients the best care possible. We work as a team with the primary care physician or nurse practitioner, specialists and family.

As for vulnerability and disability: Our conversations and assessments are detailed, nuanced, patient centered and unhurried compared to modern day medicine. We may spend weeks if needed on very complex cases to decide on eligibility. It may include consultation with medical specialists, allied health professionals, family and if need be even seek legal counsel. It always respects and honours the patient. We are well aware of system inefficiencies and how they may affect patients. MAID is never the answer for those gaps. We hold government responsible for ongoing efforts to ensure good care of those who are disabled, negatively affected by social determinants of health or who are vulnerable.

Bill C7

I would like to take the opportunity to thank parliament for the proposed amendments as stated in Bill C7. Following some of the debates of the House of Commons it was heartening to see that it was a difficult decision for many to come too and sometimes very personal on both sides of the vote. The Carter decision and Bill C14 spared many Canadians indescribable suffering, but also inadvertently caused some. The witnessed formal request form requiring witnesses is a safeguard to ensure the patient makes a voluntary request, but it also became a barrier to access for some, a breach of privacy or source of anxiety. It can very difficult to orchestrate 2 witnesses at the same time, especially in remote locations or where there is no extended family or friends. It can also constitute a breach of privacy for some patients who do not want to let their family of friends know yet. There were significant limitations in care homes where nearly all staff were involved with the patient's care. Conscientious objecting facilities made it impossible at times to complete a formal request and created anxiety for patients and providers. I greatly appreciate that the safeguard can be equally well upheld with one witness instead of two, but allow for greater practicality and privacy.

More so even, removing the 10-day period of reflection shows hearing the voice of the patient. Most patients contemplate MAID long before they seek consultation. Research shows that patients with Huntington's chorea for instance often contemplate it for years, even already at the time of diagnosis. While there are patients who may only learn of MAID late down the road, coming to a decision of this magnitude is never hasty. For many the 10-day wait period will come and go

and they may only have MAID weeks or even months later. There have been cases where patients asked for MAID, especially in the context of conscientious objection, who after a prolonged wait for MAID consultation had to endure the additional 10 days of reflection that was extremely painful to bear. For many, waiting 10 days whilst already suffering intolerably is simply inhumane. Thirty percent of patients require MAID to be expedited due to imminent death or high risk of loss of capacity. It creates significant stress and pressure on patients, families and providers. More so even, patients fear loss of capacity and therefore forfeiting access to MAID. This is present during the waiting period, but also persists thereafter. The 10-day wait period and requirement for consent at the time of MAID share the same anxiety and distress. Both meant as safeguards, both with unintended consequences. It reduces the solace they otherwise receive from having eligibility for MAID. The case of Audrey Parker eloquently illustrated the impact of having to choose between an earlier death and fear of loss of capacity. As a MAID provider I can emphatically state that seeing a patient suffer, in all the ways they had hoped not to suffer due to loss of MAID as an option after loss of capacity, is the hardest element to bear in the entire MAID process.

Focus of the brief

The focus of the brief is on two specific items:

1) Clarification of expertise

Firstly, assessment for patients without reasonable foreseeable death (non-RFND) MAID providers anticipate that the removal of reasonably foreseeable natural death will make assessments more complicated and delicate. We anticipate an increase in request volume, but not as much as likely feared by the public, based on statistics from the Netherlands and Belgium, which have correlated well with the Canadian experience to date. We do anticipate having to do even more complex and nuanced assessments and appreciate the longer wait period to create space for this to happen.

We appreciate that access to MAID has to remain equitable and that Bill C7 does not intend to disadvantage patients in rural locations. As a rural MAID assessor and provider, I travel to remote locations as needed and do telehealth consultations for many more. As a family physician I treat all conditions within the vast scope of medicine. Wait times for specialist consultation is unacceptably long in nearly all areas of medicine and countrywide. By design of the Canadian health care system, family physicians and nurse practitioners are the backbone of the health care system. I understand that for non-RFND cases at least one of the assessors has to be an “expert” in the condition, but not necessarily a specialist. If specialist assessment was required, MAID would be near impossible as wait times for several specialties such as neurology and psychiatry are 12-18 months in many parts of the country, even in major centers. Whilst I am comfortable being a family physician “expert” in most illnesses that I can imagine patients would want MAID for, how is expertise defined? Or measured? If found lacking expertise on review of a case, we may face imprisonment. Does expertise means comfortable with operational knowledge,

prior management of the illness or any other measures? And how is that documented to a legal standard, or monitored?

As solution I would propose agreement that family physicians (FP) and nurse practitioners (NP) ought to have the necessary knowledge and experience to treat and therefore assess most medical conditions. Even in illnesses such as rheumatoid arthritis and inflammatory bowel disease where patients often require specialist care and specialist medications, the primary care providers co-treat and manage with the specialists. It argues for sufficient knowledge to manage the illness and patient. If the FP/NP feel that they are not competent to do so compared to the average physician/NP (legal standard), that they may refer to another assessor or if needed, another expert or specialist. Some fields such as chronic pain and addiction are sub-specialties in family medicine, but not seen formal specialists. It is worth noting that if a specialist opinion is sought, that such a specialist may have no MAID knowledge and may not wish to be a MAID assessor. It may not be possible to find for instance a neurologist MAID assessor in a city, never mind a rural setting. In such a case I would suggest, similarly to the current track followed for capacity assessment, that the 2 MAID assessors be FP/NP/other specialty MAID assessors and to use the “expert” or “specialist” as a third assessing professional, if needed only, perhaps completing a form similar to the current capacity assessment form – attesting to criteria such as grievous and irremediable, severity of illness, potential treatments available, without having to do a full MAID assessment. This would also be a solution for the body of MAID providers who are specialists such as anesthesiologists. They may have knowledge or skill pertaining to certain illnesses, but not all, due to their scope of work, but may involve a second assessor who does or if not possible the third “expert” or “specialist” option. Excluding the ‘other specialty’ MAID assessors may compromise access to MAID in several communities.

2) Final consent waiver

As an advocate for current and future patients and voice of patients past, I am grateful to see the proposed amendment include a waiver of final consent. Thank you for the section on greater clarity (3.3). As the overwhelming majority of MAID procedures are by intravenous administration, this section was critical for practical purposes.

Part A

I am concerned with the practical application of the law as set out in the bill:

(3.2)(a)(ii) states they entered into an arrangement in writing ... would administer a substance to cause their death on a *specified day*.

And (iii) they were informedof the risk of losing the capacity to consent...prior to the *day specified* in the arrangement

And (iv) consented to administrationon or before the *day specified*...

The process is clear, but the practical implication of choosing a specific date is filled with landmines. It is medically very hard to know and predict prognosis. Predicting loss of capacity, which is often unexpected, may be even harder. Patients may be hesitant to choose a specific date as many hope to still live as long as possible. It may

provoke anxiety and become another unintended harm. Some patients will exceed our expectations of survival. In such a case do we tear up the prior legal binding form and sign a new one, or simply re-date and resign the original, or submit both new and old forms for review after completion of a procedure or natural death? As solution I propose not using a specific date in the future, but rather a time frame going forward from the time of signature, which would allow for revisiting when the end of time period draws near. It is subtly different than writing down a specific date to die and may cause less anxiety.

Part B

MAID providers may not be available when a patient request MAID due to vacation, attending a conference, illness and potentially COVID quarantine. If the other assessor involved in the case is also a MAID provider, they can step into the provider role and perform the procedure. If the second assessor is not a qualified provider, a new provider has to be found. They have to assess the patient before providing MAID. With a written waiver on final consent, the waiver should be transferable to the other possible providers in the event that the primary provider is not available.

Part C

Following the recent court case in Nova Scotia of Mr. Jack Sorenson who's wife prevented him from accessing MAID while still competent until settled in court, it behooves government to consider that this may also occur after a patient has lost capacity. Families may simply not report loss of capacity until after natural death, which MAID providers may not be aware of and is likely not remediable.

In the event of a written agreement in place, providers will need guidance as to how to proceed if families explicitly prevent MAID from occurring against clear instructions from a patient to proceed.

Most patients will die within a few days after loss of capacity and may not be perceived to be suffering by the family and MAID provider. In such a case, can by mutual agreement, both the family and MAID provider choose not to provide the patient with MAID? This will likely require some form of documentation from the provider without burdening a grieving family.

In all practical likeliness MAID would only be provided for a patient who has lost capacity if the provider is informed of the loss of capacity, family is supportive to go ahead and there is time to plan and perform the procedure before natural death takes place.

Thank you for consideration of these recommendations.

Respectfully
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