



Canadian Association of MAiD  
Assessors and Providers



Association Canadienne des Évaluateurs  
Et Prestataires de l'AMM

Written Brief to the  
The House of Commons' Standing Committee on Science and  
Research in view of the  
Statutory Review of the Provisions of the Criminal Code Relating  
to Medical Assistance in Dying and their Application

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Thank you to the committee for the opportunity to provide some information during this important review process. I present myself as the President of the Canadian Association of MAiD Assessors and Providers (CAMAP)- the clinical subject-matter experts on MAiD in CANADA- and as an experienced practitioner. As my remarks to the committee will necessarily be time-limited, I have prepared this brief to more fully explore some of my points.

## **1. A positive start**

Canada should be satisfied with the way it has implemented MAiD. Several elements of our model have proven important from a clinical point of view and essential to providing high quality care for Canadians.

### Clinician-administered MAiD is permitted

The fact that Canada allows *both* self-administered MAiD and clinician-administered MAiD- the option chosen by over 99% of all people who have proceeded with an assisted death in Canada- has reduced discrimination against the physically disabled and increased access to care to some of the most seriously ill patients we have assessed. Notably, by example, clinician-administered MAiD allows access to care for those with amyotrophic lateral sclerosis (ALS), or other similarly degenerative neurological conditions, who would otherwise be unable to self-administer medications once meeting the eligibility criteria of being in an advanced state of decline in capability. The finding that the vast majority of people accessing MAiD in Canada have chosen clinician-administered care is in-line with the experience of other jurisdictions that allow clinician-administered MAiD where very similar, large majorities of those who have received an assisted death have chosen clinician-administered care (in Belgium over 99% in 2021; in the Netherlands 97% in 2021; and Luxembourg over 99% of all cases ever reported) (1,2,3) In fact, where not yet allowed, in the state of California as an example, court challenges have recently arisen to allow for this important option (4).

### MAiD is not restricted to terminal illness or imminent death

This important element places the patient appropriately at the centre of their own care, allowing them to decide when, during the course of their decline, they deem their suffering to be sufficiently intolerable and their decision to end their life an overwhelming necessity. It also recognizes that health care practitioners are not particularly good at prognosticating (5) and therefore removes an arbitrary and subjective barrier from care. This appropriately prioritizes suffering as the central element required for eligibility.

### Access to palliative care

While it is true that not all Canadians have equal access to quality palliative care and more needs to be done to improve this, national data (6) suggests that 83% of all those

who received MAiD in Canada in 2020 were receiving palliative care, and of those who were not, 88% had access to palliative care if they had wished it. This strongly suggests that it is not for lack of access to palliative care that people choose an assisted death.

### Bill C7

I note that Bill C7 fixed the unconstitutionality of the requirement of a reasonably foreseeable natural death, removed the problem-causing, false safeguard of a 10 day waiting period, and added the essential waiver of final consent option for a very specific population of patients.

Data to date suggests an expected number of Canadians are accessing and receiving MAiD (6 and 7), and that the people who proceed with MAiD are at least anecdotally disproportionately advantaged versus socioeconomically vulnerable (more formal data to come). Well done.

## **2. Assisted dying is distinct from suicide**

Through our work we have seen evidence of the distinction between what others might hope to conflate- MAiD and suicide. Suicide is almost always a traumatic event, often violent, frequently impulsive, usually carried out alone or in secrecy, and it leaves devastation in its wake- for families, for first responders, often entire communities. By contrast, medical assistance in dying involves a legal framework, a rigorous process, the involvement of multiple health care practitioners and the option to involve many loved ones. We have witnessed the therapeutic effects of telling someone they are eligible for an assisted death, and have seen people live longer than they thought they would be able to simply because they knew they had this option available. As the American palliative care physician Tim Quill so eloquently once stated- "suicide implies some form of self destruction, assisted dying involves a form of self-preservation". They are simply not the same.

A recent study (8) by the Office for National Statistics (ONS ) in England studied suicide rates among those with cancer with a low survival rate, those with chronic obstructive pulmonary disease (COPD), and those with chronic ischemic heart conditions diagnosed in England between 2017 and 2020. Results showed that suicide rates among people with cancers with low survival rates and chronic obstructive pulmonary disease (COPD) were 2.4 times higher than average. Those with chronic ischaemic heart conditions, involving narrowed arteries, were at almost a two times higher risk. Dignity in Dying UK, an advocacy group, believes that up to 650 terminally ill people commit suicide every year in the UK, and the results of this study have renewed calls for a change in their law regarding the prohibition of assisted dying (9). It seems they too, from a very practical lens, recognize the important distinction between suicide and assisted dying.

### **3. There are far too few clinicians involved in this work to sustain its practice**

The clinical work of assisted dying was especially challenging in the beginning- no training, no guidance documents or medical standards were available. A lack of clarity around how to determine if the law had been met, the possibility of criminal liability, and a general fear of 'getting it wrong' meant few clinicians initially stepped forward to provide this care. The establishment of CAMAP by early practitioners helped fill that significant void, and while tremendously proud of all we have accomplished and continue to do, government must recognize that there continues to be insufficient numbers of clinicians available to do this work.

Data from the most recent Health Canada annual report (6) states that 1345 unique practitioners report having provided MAiD in 2020, an increase of 17.7% from the prior year. But 40% of these practitioners completed only 1 MAiD procedure, 45% completed 2-9 MAiD procedures, and only 15% completed 10 or more procedures. Despite the overall increase in the number of unique practitioners providing MAiD, the percentage increase in overall cases of MAiD (34.2% higher in 2020 than in 2019), means that the few practitioners involved in multiple MAiD procedures have had to increase their work significantly. This leaves the entire program vulnerable to a very few; to illness, personal scheduling limitations, and impending retirements.

One obvious step that can help is in facilitating the use of nurse practitioners who stand willing and able to do this work and are permitted to do so under federal legislation. Prohibitive provincial barriers have meant despite being within scope of practice, many nurse practitioners are informed by employees they are not allowed to do this work. Some of those who are permitted must do so entirely within their limited hours of employment, and for those who choose to do the work independently and outside the hours or scope of their salaried employment- strictly on weekends or evenings- they have no source of compensation for the hundreds of hours of work they have done and continue to do. This is a tremendous source of lost potential and an egregious taking-advantage of a predominantly female, skilled health care force; skilled and willing workers in this country who are slowly, and understandably, walking away from this unsustainable (non) model of providing care; a frankly offensive situation. Please, do better.

Covid has of course had a significant effect on the workforce- health care workers are tired or finally burned out.

Please recognize that the vast majority of those who do this work do so outside of or on top of full, other clinical practices. This means weekend and evening work; not particularly conducive to the extra time required for many of these suffering patients. This means many some clinicians volunteered for years before being granted distinct billing numbers outside of their routine clinical work to be able to claim any sort of remuneration.

A significant number of those who do this work are nearing retirement. Also note: administrative burden, the difficult gathering and coordination of health records from multiple non-communicating sources, the general education on process and resources required for families, the creation of follow-up bereavement programs, research...all are needed to provide this care to the highest of standards. You simply cannot expect individual clinicians to carry the enormity of this work without proper support. Resourced care-coordination is more consistently required.

Barriers abound. The only solution to *not* creating a 'specialty' of MAiD providers- and we do *not* recommend development of such a specialty- is to facilitate the larger clinical workforce (family physicians, oncologists, neurologists, palliative care clinicians...) to include this type of care within their current practice. In order to tackle this problem, governments federally and provincially must work with regulating bodies and educational institutions to facilitate the inclusion of training at undergraduate and graduate levels of medical and nursing education..

Essential resources required to deliver MAiD to the highest level of standards remain limited. Recent amendments to the law (Bill C7) mean new patient populations- those whose death is not reasonably foreseeable- now have potential access to MAiD. Some very complex situations are now coming to light. Society has not adequately resourced the required supports for many that we are now assessing. Moral distress is beginning to appear in clinicians in addition to the significant administrative burden already present. Patients, and clinicians assessing them, need access to expertise (there are so few experts for so many in need) and more substantial community resources. We suggest considering creative ways to set up provincial referral bases of experts willing to be consulted. We do not suggest MAiD applicants jump any waiting times, but any help ensuring access to expertise would be enormously helpful. There are multiple regions of this country where whole medical departments have or are considering opting out of providing expert consultative services to our patient population. This is expected to worsen with the anticipated addition of mental health patients to the program in 2023. We are not in any way suggesting MAiD be curtailed due to the failings of our society to provide the minimum resources required for mental health, palliative care or disability supports. But rather strenuously suggest that MAiD and community resources be developed and supported in parallel.

Projects like the Canadian MAiD Curriculum Project are essential, and we are grateful for Health Canada's ongoing financial support. This project will create a high quality, standardizing training curriculum for both new clinicians interested in learning how to assess and provide MAiD, and for existing assessors and providers looking to update their skills. In addition to the training modules themselves, the project has a fully developed research component, which will allow the team to evaluate how the training is developed and implemented across the country. Final product will be an accessible, bilingual, mixture of asynchronous online and expert-facilitated in-person modules that are accredited by national nursing, family practice, and specialist medical associations.

#### **4. Mature Minors** (more of an individual contribution than on behalf of CAMAP)

Coming from a background in family medicine, I have seen the torment of families who are faced with the truly unbearable - the birth of a non-viable child or one with terminal illness, and I have had the experience of journeying with them. Mature minors in Canada already make their own health care decisions- in the denial or acceptance blood products or with regard to reproductive health care choices as examples. We already have experience in assessing their capacity to make independent decisions; this is not new territory. In the catastrophic circumstance of a mature minor with an illness that is causing unbearable suffering who in very rare cases might ask for access to MAiD, to discriminate solely on the arbitrary basis of age seems indefensible and in fact, blatantly cruel.

I have referenced the Council of Canadian Academies (CCA) report of 2018 - The State of Knowledge on Medical Assistance in Dying for Mature Minors (10) and there is more information about successful models of care for mature minors in Appendix A.

Despite an initial discomfort, you might find the safeguarded allowance of MAiD for mature minors the most clear-cut of all the issues that you are considering.

#### **5 Advanced requests**

CAMAP urges this committee to undertake a comprehensive review of past reports (11,12,13), past recommendations, seek input from front-line clinicians and any currently available data, and make a decision about this matter that the majority of Canadians wish to see resolved.

## Final thoughts

Canada has taken a significant step forward with the carefully regulated introduction of medical assistance in dying for people who are suffering unbearably despite all efforts. There are a number of successful elements that have been implemented. It remains unclear, however, who or what is responsible for the ongoing access issues faced by many of our patients. It would help to clarify who will take responsibility for addressing these challenges- the federal government, or the provinces/territories. There continue to be tax-payer funded facilities which raise impenetrable barriers to this care for patients who are in need and through no particular choice of their own, find themselves located within an 'objecting' care facility. As clinicians charged with doing this work, we are still far too few. Help train us, compensate us, and adequately resource our communities, or we will be unable to help Canadians in the way you have trusted us to do.

## SUMMARY OF POINTS:

1. Overall, Canada should be satisfied with the way it has implemented MAiD
2. Assisted dying is distinct from suicide
3. There are too few clinicians involved in this work to sustain its practice
  - Suggest facilitating more fulsome recruitment of nurse practitioners
  - Suggest facilitating MAiD education at undergraduate and graduate medical and nursing institutions
  - Suggest removing any remaining barriers to remuneration for this work
  - Suggest fulsome administrative support and care-coordination in all jurisdictions
  - Suggest creation of provincial/territorial expert consultant referral bases
  - Suggest community mental health, palliative care, and disability resources be developed and supported in parallel with MAiD services.
4. Clarification of responsibility for access issues at publicly-funded objecting facilities is requested (federal or provincial?)
5. Access to advanced requests for MAiD is favoured by the majority of the public
6. Access to MAiD for mature minors should be considered

## Appendix A

### BASIC DATA

	Total Reported MAiD 2021	# cases involving a minor	#cases involving a minor EVER reported
Netherlands	7666	1	13 (since 2002)
Belgium	2699	0	3 (since 2014)

### RELEVANT MODELS

#### **BELGIUM- Mature Minors**

In 2014, Belgium became the first country to allow for voluntary child euthanasia if they are terminally ill and in great pain and if they have parental consent (prior to this, Belgium's Law on Euthanasia also extended to adolescents over the age of 15 who had been 'legally emancipated' by judicial decree).

The law (Euthanasia Act 2002, section 3§1) now permits children of any age to request euthanasia provided that:

- they understand the consequences of their decision as verified and certified by a child psychiatrist or psychologist.
- the child must be in a 'medically futile condition that will result in death in the short term
- the child is in constant and unbearable physical suffering that cannot be alleviated
- the child must display the 'capacity of discernment'
- the child must be conscious at the moment of making the request

#### **THE NETHERLANDS- Mature minors**

The Netherlands introduced a similar rule for children over the age of 12 years in 2018.



The Act applies to assisted dying for individuals aged 12 and over, and imposes a number of additional requirements with regard to assisted dying requests from minors:

- if the patient is a minor between the ages of 12 and 16, termination of life at the patient's request may only be carried out with the consent of the parent(s) or guardian (section 2 (4) of the Act);
- if the patient is a minor aged 16 or 17, the parent(s) or guardian must be consulted in the decision-making process, but their consent is not required (section 2 (3) of the Act).

## INFANTS

The Groningen Protocol is established in 2004 in the Netherlands

The protocol was created by a committee at the University Medical Center Groningen after extensive consultation with physicians, lawyers, and parents, and in consultation with the Groningen district attorney. It was ratified by the Dutch National Association of Pediatricians in 2005.

According to its authors, the Groningen Protocol was developed in order to assist with the decision-making process and to help achieve the best outcome when considering actively ending the life of a newborn. This is achieved by providing the information required to assess the situation within a legal and medical framework.

The final decision about "active ending of life on infants" is **not** in the hands of the physicians but with the parents, with physicians and social workers agreeing to it. Criteria are, amongst others, "unbearable suffering" and "expected quality of life". Only the parents may initiate the procedure.

For the Dutch public prosecutor, the termination of a child's life (under age 1) is acceptable if four requirements are properly fulfilled:

1. The presence of hopeless and unbearable suffering.
2. The consent of the parents to termination of life.
3. Medical consultation having taken place.
4. Careful performance of the termination.

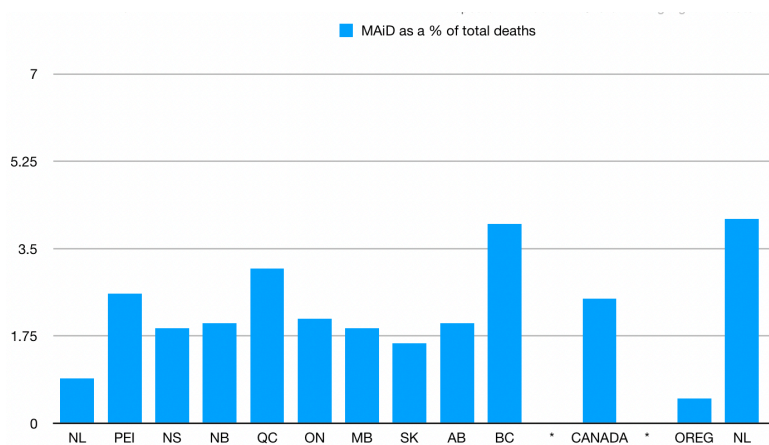
Doctors who end the life of a baby must report the death to the local medical examiner, who in turn reports it to both the district attorney and to a review committee.

In 2005 a review study was undertaken. The summary suggested that life-ending measures can be acceptable in these cases under very strict conditions: the parents must agree fully, on the basis of a thorough explanation of the condition and prognosis; a team of physicians, including at least one who is not directly involved in the care of the patient, must agree; and the condition and prognosis must be very well defined. After the decision has been made and the child has died, an outside legal body should determine whether the decision was justified and all necessary procedures have been followed.

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