

## Brief for the Commons

I'm Professor of Medicine and Adjunct Professor of Law at the University of Toronto. As an oncologist, I've been centrally involved in the development of palliative care in Canada and internationally. My work created and helped to establish the field of quality of life research in cancer, leading to the establishment of the WHO Collaborating Centre for Quality of Life in Cancer in Winnipeg. More recently I served on the Council of Canadian Academies Expert Panel on MAiD.

My submission to the Committee is based on three premises, leading to two specific recommendations.

### Premises

1. In bringing forward Bill C-14, in response to *Carter* the Government of Canada created a unique exception to the criminal code. Its concern for the significance of that exception is reflected, in part, in two specific mandates:
  - a. that an expert panel be struck to collect the evidence regarding three areas *excluded* from the exception, namely mature minors, mental health as a sole criterion, and the permissibility of advance directives.
  - b. The experience be reviewed after five (5) years
2. In creating the exception to the criminal code, a federal jurisdiction, the Government of Canada retains an obligation of oversight as to whether the conduct and application of the legislation meets with its intent.
3. The frame of reasoning used to develop both C-14 and C-7, here under consideration, is legal. It is a reasoning and evidence structure inappropriate to what is a medical treatment. We base our decision on whether a new cardiac surgical procedure, or cancer treatment is to be used based on the scientific evidence which underlies its potential, *and* a careful evaluation of the evidence of its use.

Since the *Carter* Supreme Court decision making medical euthanasia possible in Canada, more than 13,000 Canadians have availed themselves. We don't know how many others have considered it, or who have been denied. I have long argued for rich, detailed examination of each case so that we can learn by real experience rather than legal and philosophical circumlocution. We are not doing that, and it is plausible, even likely, that as a consequence we are ending people's lives based on a presumption of diagnosis, or conversely denying access, absent the salient facts. That is a concern when we acknowledge that those who assess and provide MAiD are by and large advocates, without externally validated training and assessment standards, and sparse independent overview.

Moreover, I believe that in our attempts to relieve suffering by ending life we may have created a new disease, called MAiDism.<sup>1</sup> This is a phenomenon often seen in medicine, where the introduction of a new disease concept or treatment leads an increase in suffering *because* of concern about it. Put simply, MAiDism is a disease where the prospect of arranging one's suicide leads to an increase in suffering for both the patient and those surrounding. My clinical experience leading to this concern is outlined in Appendix 1.

### Recommendations

That the Government include in C-7 an obligation that:

1. *before* any change is implemented a careful review of all cases involving MAiD (approximately 13,000 as of February 2020) be completed and made public.
2. that specific *clinical* criteria for the evaluation and documentation of each case be established. They are as follows:

From the patient's perspective:

1. Who are you? Tell me about your life and how you have come to consider actively ending your life.
2. Let me understand in depth the nature of your suffering. What is its cause: physical, psychological, social, existential or spiritual? Perhaps there is more than one cause, but for each one, let me understand its pattern, what makes it worse or better. For each one, let me understand its history. For each one, help me to understand, from your perspective, the possible things that could have been done, or tried which did not help enough. Were options not available? Were you unwilling or unable to try other options?
3. Suffering is a perception. Different people respond differently to circumstances which can cause suffering. That is not a value judgment, simply a statement of fact, scientific fact. Help me to understand why you perceive your suffering is intolerable to the point of wanting to end your life.
4. How do you live, and to whom are you connected? Do you have relationships in which you can share your feelings, fears, concerns and desires – including the wish to have your life ended? If you have such relationships, what have been their responses? If not, why not, and are you open to forming such bonds?
5. How much of your desire to end your life draws from concerns about your dignity, autonomy, and ability to control your life?
6. Where, if at all, does faith, formal or otherwise, fit in your life?

From the physician's perspective:

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<sup>1</sup> The author is aware that *maidism* is an archaic term for pellagra, a disease resulting from Vitamin B3 (niacin) deficiency. The repurposing of the term seems poetically appropriate to the matter at hand.

1. Have we ascertained that the patient has the capacity to make such a decision, and by what means?
2. Has the assessment included input from health professionals who know the patient's history in detail?
3. What is the patient's life trajectory?
4. Has the assessment included input from those in the patient's intimate circle; family, close friends and colleagues? If the patient does not wish such input, do we know why?
5. How did the patient meet the criteria?
6. Given the concerns raised about patients' underlying vulnerabilities, such as dependence on expensive technologies, or need for specialized longer-term care, have those concerns been directly addressed?
7. Have you ascertained that there are no inappropriate external coercive forces at play?
8. Was this a difficult or straightforward decision to make, and why so? Be specific.

I recently published a detailed analysis of the complex issues surrounding the evolution of medically assisted dying in Canada. It can be found by following this link:

<https://www.macdonaldlaurier.ca/moving-fast-little-evidence-medical-assistance-dying-mli-commentary-harvey-schipper/>

## Appendix 1: Have we created a new disease

Since the *Carter* Supreme Court decision making medical euthanasia possible in Canada, more than 13,000 Canadians have availed themselves. We don't know how many others have considered it, or who have been denied. I have long argued for rich, detailed examination of each case so that we can learn by real experience rather than legal and philosophical circumlocution. We are not doing that, and it is plausible, even likely, that as a consequence we are ending people's lives based on a presumption of diagnosis, or conversely denying access, absent the salient facts. That is a concern when we acknowledge that those who assess and provide MAiD are by and large advocates, without externally validated training and assessment standards, and sparse independent overview.

We have many experiences in medicine where seemingly obvious, intuitive concepts are widely adopted only to be found, later, to have caused irreparable harm. In attempting to relieve one form of suffering, we have on occasion created another. Blood letting, ever-more extensive surgery for breast cancer, lobotomy for mental disorders and the unfettered use of oxycontin are examples to our present day. The legal conceptualization of MAiD as outlined in *Carter* and subsequently encoded in Bill C 14, reflected narrowly constrained cases of irremediable decline, accompanied by unrelieved suffering as experienced by the sufferer, in the context of serious disease. Moreover, its moral fundamental was strict individual autonomy. Individual autonomy is a uniquely Western, perhaps libertarian, view which explicitly sets aside the concerns of those other than the individual in question. This singular view runs counter to a current and growing concern about respecting the diversity of life views in Canadian society.

I believe that in our attempts to relieve suffering by ending life we may have created a new disease, called MAiDism.<sup>2</sup> Put simply, MAiDism is a disease where the prospect of arranging one's suicide leads to an increase in suffering for both the patient and those surrounding. Allow me to cite three cases, all of which came to my attention within one week. I am neither a MAiD assessor, nor a provider. However, by virtue of long experience as an oncologist and in the foundations of palliative care, I am often consulted about end of life issues, including MAiD.

The first case concerns a man in his late 80's with a strong family history of Alzheimer's Dementia, and a wife so afflicted. He has now learned he too has early dementia. Without a psychogeriatric assessment he is told MAiD is no longer a possibility. The fact is, that's not necessarily so. The unattended-to issue is whether this gentleman has the cognitive capacity to make such a decision. Moreover, there is almost no scientific experience in assessing cognitive capacity in the face of existential suffering. The law is being applied helter-skelter, absent the professional education otherwise required of any medical intervention.

The second case is that of an elderly woman who is living alone, trapped by COVID, and afraid that she might fall and end up in hospital, where she most of all does not want to be. She was approved for MAiD. A friend then took the time to understand her concerns, which led to her

accepting supportive care in her home, which was both available and which she could afford. The MAiD providers, it turned out, simply considered her age and co-morbidities, felt she qualified and never raised to possibility that there might be solutions short of ending life. As one eminent psychiatrist has opined, MAiD has become a service rather than, as intended, a last resort relief of unendurable suffering. This woman is now tormented by a persistent question, “When do I ask to receive MAiD?” The question tortures her, which leads to the third case.

A woman in her 90’s has had a long history of episodic anxiety and moderate depression. She has a number of co-morbidities including mild heart failure, but is otherwise quite healthy. Ever since the *Carter* decision she has obsessed with the possibility of ending her life. The isolation of COVID exacerbated this obsession, and despite the active discouragement of her family, she sought and received approval for MAiD. One of the assessors, citing COVID, made her judgement solely on telephone conversations. The patient has now made and cancelled appointments for euthanasia four times. In addition to the torment the patient reports, the family has been exposed to a continuing roller-coaster of emotional angst. I suspect, based on this and similar experience, that in addition to easing suffering for some, we have created a new, serious, difficult to treat, and occasionally fatal disease – MAiDism, for others.

MAiDism may be an emerging mental disorder, accompanied by reinterpretation of somatic symptoms leading to a progressive, obsessive-compulsive desire to explore and perhaps seek MAiD. Obsessive loops, as is well known to clinicians, can be self-perpetuating, leading to severe depression and even suicidal behavior. Part of the clinical picture may also be the threat of application and finally undertaking the procedure to manipulate family behavior. How does this play out? When caught in the obsessive loop, pain that may be intermittent and perhaps manageable with relatively simple medication becomes a central focus, and, in its perception, becomes worse. Those close to the sufferer are drawn into the loop of despair, only to experience their own pain. Some of that surely comes from the sense of impending loss of a loved one. However, the cognitive dissonance between their observation of the daily realities and what is projected by the patient can be anguishing. The more caring you are, the more you are drawn into trying to relieve the suffering, but all manner of attempts; professional help, distraction, medication, appeals to reason and appeals to emotion fail to address the fixation.

You seek help from the experts. That’s what you would do if the problem were cardiac, for example. You consult with the cardiologist. The cardiologist looks at a range of possibilities before advocating a heart transplant. But there’s a difference here. In contrast to other medical experts, the MAiD experts are in fact advocates of a singular approach to the problem. That is their formal mandate. Does the patient fit the criteria? To someone with an obsessive-compulsive fixation that is precisely the wrong treatment. It is as likely to exacerbate the disease as relieve it.

Who might be most susceptible to MAiDism? Perhaps those with histories of depression or anxiety, particularly with an obsessive component. Perhaps those of advancing age, where in the normal course of decline, the ability to appreciate nuance is diminished. Perhaps those

who have recently received very disturbing news about loss or vulnerability they have not had time to internalize and reflect on. Perhaps it is a reaction to a transient threat to autonomy or identity which is not recognized as such. It may also affect those whose emotional regulation is somewhat disinhibited by age, or medication. We don't know how common this is, but anecdotes point to circumstances to explore. We also need to better understand the circumstances which might drive people who otherwise wouldn't consider MAiD to contemplate their medically assisted suicide.