

DATE: 2 November 2018

TO: THE HONOURABLE GINETTE PETITPAS TAYLOR
MINISTER OF HEALTH
FEDERAL GOVERNMENT OF CANADA

cc: The Honourable Jody Wilson-Raybould
Minister of Justice and Attorney General
Federal Government of Canada

The Honourable Filomena Tassi
Minster of Seniors
Federal Government of Canada

RE: MAID(MEDICAL ASSISTANCE IN DYING)

The passage of legislation(C-14) respecting *Medical Assistance In Dying(MAID)* in June, 2016 was likely the most compelling health legislation since the creation of *the Canada Health Act* in 1967. Unfortunately, two years later, we recognize that MAID is a failure by design. Not a complete failure – many terribly ill and dying have successfully accessed MAID, but many more – with equally grievous and irremediable conditions -- are being denied access to MAID. The legislative framers – acting on the basis of fears expressed by some medical fraternities and the conscientious objections of a few religious organizations – created limitations to the expressed, unanimous intent of the Supreme Court of Canada(“*Carter vs Canada*”, February 6, 2015) to provide “**choice in dying as a right for all Canadians.**”

Many barriers remain for some of Canada’s most critically ill individuals. MAID, as it’s written and interpreted, threatens to rob thousands of desperately ill patients of their rightful choice to assistance in dying. Bill C-14 is much more restrictive than the Carter decision. *The Carter decision made assisted dying available to any consenting, competent adult suffering intolerably from a grievous and irremediable medical condition.* However, the new law includes two provisions that are much narrower in scope. To qualify for assisted dying under Bill C-14, an individual must be in an advanced state of irreversible decline and their natural death must be “reasonably foreseeable.” The vague language of the eligibility criteria — specifically this “reasonably foreseeable” clause — makes the

new law ambiguous at its best and unconstitutional at its worst.

Despite assurances from the federal government that individuals do not have to be terminal in order to qualify, too many medical practitioners interpret the eligibility criteria for themselves. Some providers interpret the “reasonably foreseeable” clause to mean that only those individuals whose deaths are imminent will qualify for MAID. In fact, some Canadian doctors have already been advised by lawyers to err on the side of caution and to only provide MAID to those who are terminally ill.

This means that individuals who were granted the right to a peaceful death by the Supreme Court may now find themselves barred from access. For example, patients with excruciating conditions like ALS, Multiple Sclerosis, and Parkinson’s disease are at risk of being denied a dignified death because their deaths may not be imminent. Other individuals, like those who have endured a serious stroke or a series of strokes, may also be trapped in intolerable suffering with no natural end in sight. For many of these individuals, this intolerable suffering can persist for years, and to force them to continue languishing in agony is exactly the kind of fate the Supreme Court ruled against.

Under the new law, ***advance requests for dying are not permitted***. This means Canadians with dementia -- with competence-eroding conditions like Alzheimer’s and Huntington’s disease, will not be granted the right to request an assisted death. According to MAID, they cannot request assistance until death is “*reasonably foreseeable*.” At which time, these individuals will most certainly be found ineligible for MAID because they will likely lose competence before they reach the required “advanced state of irreversible decline” outlined in the eligibility criteria. And, in an additional effort to further ‘protect’ the patient, MAID requires the two attending medical practitioners to ascertain – just before administering the lethal potion – that the patient understands the right to refuse and wishes to continue with the procedure. This second ‘surety’ may seem reasonable for patients with sound minds, ***but those afflicted with dementia will not be of sound mind by the time they require MAID***.

This denial of the right to choose death can be changed by accepting an “***Advance Request for Dying***.” Such request can be prepared, signed and witnessed in advance, while the patient is still competent. The request should state in clear, uncertain terms the conditions requiring MAID and the name of a “Substitute Decision Maker” who will present the request at the appropriate time to a medical practitioner – previously selected and named by the patient in the “*Advance Request*.”*

* *Note: Even before MAID was created, an Ipsos Reid poll in February, 2015 found that 85% of respondents support the Supreme Court’s decision. Of those, 90% support allowing patients with a diagnosis of a grievous and irremediable medical condition to provide advance consent for physician-assisted dying. 76% of health care professionals are in favour of advanced consent in dying.*

This is only an example of how MAID could be improved to ensure it meets the mandate of the Supreme Court of Canada .. to provide “***choice in dying as a right for all***”

Canadians.”

There are other Canadians who are being denied their rights, ie: minors under the age of eighteen years and those experiencing psychological difficulties. Clearly, the original framers of MAID – fearing inappropriate usage and other uncertainties associated with assisted dying – chose an easier path. However, that was June, 2016. Much has happened since then.

Right after the implementation of MAID, Health Canada mandated the collection of data respecting its use* with a report due before the end of 2018.

** Note: On August 9, 2018, Health Canada revealed its final regulations for a national system for monitoring medical assistance in dying (MAID). The regulations, which will come into force on November 1, outline what information needs to be reported to the federal government after a clinician receives a request for medical assistance in dying. The regulations also require Health Canada to release at least once a year a public report based on the data that is collected.*

Since the legalization of assisted dying in June 2016, methods for collecting information about MAID have differed from one province or territory to the next. The implementation of this national monitoring system is intended to “provide Canadians with a clear picture of how the legislation is working across the country, and create consistent data sets among jurisdictions and regions,” Health Canada said in a statement explaining the regulations.

This data collection is good, but serves little purpose if it is not analysed, evaluated and used as a means to improve MAID and its use across Canada. At the present time there are no plans to use such information -- just to collect it.

On the other hand, from May 7 to July 13, 2018 Health Canada conducted a national survey on the provision of palliative care. Although the survey did not directly ask for information related to the impact of MAID, it did ask for information on “*Advance Care Planning*” and “*Challenges Facing People With Life Threatening Illnesses.*” A preliminary report is due in September, 2018. Undoubtedly, MAID will have an impact on palliative care, and presumably, some of that may be reflected in the report – which may include some recommendations.

A large number of Canadians are affected by the failures of MAID -- dementia alone accounts for more than those experiencing prostate and breast cancer combined. Something can be done by a government, sure of its facts, to lead by providing legislative changes for MAID, before a time consuming and expensive chase through the Provincial and Federal Courts of Law – as was done to create MAID in the first instance.

With reports and facts available this Fall, the Government should call a review panel to review this new information with an aim to present recommendations for consideration by the Ministers of Health and Justice early in 2019. This new panel does not need to start from scratch. The Federal Government convened a Provincial/Territorial Expert Advisory Group(EAG) which presented its excellent report in December 2015. It was

immediately followed by a Special Joint Parliamentary Committee which submitted its report to the House of Commons (and the Senate) prior to the discussion and passage of MAID legislation in June, 2016. The Minister could convene a new panel with representation from the previous panels and others recognized for their experience and knowledge of issues related to use of MAID.

Now is the best time for proactive leadership. Now is the best time to ensure that every Canadian, suffering intolerably from a grievous and irremediable medical condition, may request assistance in dying. Now is the best time to ensure the rights of all Canadians to a "Choice in Dying."

May I help?

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References:

1. Sandra Martin's article, *Canada's Physician-Assisted Dying Debate Has Only Just Begun*, is a primary reference. See ..

<http://globe2go.newspaperdirect.com/epaper/viewer.aspx?noredirect=true>

This article was first published in the *Globe & Mail* - January 27, 2018 . Sandra Martin has researched and written extensively on this subject for more than twenty years and is author of the best seller - *A Good Death* - first published in 2016.

2. Dying With Dignity Canada is a national organization, based in Toronto, which supports physician assisted dying throughout Canada. Its website - www.dyingwithdignity.ca - is a major source of real stories and real people choosing to effect a better means of dying.