

MY BEACON OF HOPE

I am very pleased the Federal Government is reviewing C-14(MAID) with respect to the Quebec Supreme Court Decision (*Gladu and Truchon*, Sept. 2019). I understand too, that the Government is opening a planned further review of the legislation in June. My opinions below respect the Quebec Court's direction. I'll save additional comment for the June review.

I am a person with dementia having been assessed in August, 2016. My comments reflect direct, personal experience as well as the views of more than thirty-five hundred other Canadians across this entire country. They reached out to me following a CBC Radio One Broadcast (Sept. 2018) featuring an interview with Michael Enright and myself discussing my wish for an assisted death. With so many wanting to discuss their common concerns, I created a website (referenced below) to share information and opinion. So, I am not alone. Many Canadians – even those without dementia or facing a grievous death - are very concerned about the limitations of MAID.

Currently, Canada has more than 500,000 citizens with diagnosed dementia (that's more than cases of breast cancer and prostate cancer combined). There are at least half that number who have not yet been assessed - nor will they be. They refuse to seek an assessment because they fear dementia .. and while those fears may be based upon ignorance, those fears are real and based upon the same fears as the legislators who created C-14.

They fear the so-called last stage of dementia or end-of-life(EOL). That may be real, but they don't realize there is life after diagnosis - almost ten to fifteen years. Of that time, five to ten years may be active and fulfilling. They can make reasoned judgments about their life-style .. and particularly, their health and safety. People with dementia are the same after diagnosis as they were before diagnosis. Certainly, the neurodegenerative decline is present, but the last stage(EOL) is years away - maybe ten years.

This means the revised MAID need not .. “protect the vulnerable.”

It's true, people with dementia may become vulnerable during those last few years deemed as end-of-life. But, ironically, failure to access MAID may increase vulnerability sooner and during the five to ten year period following diagnosis. The fears associated with end-of-life can be diminished - or even set aside - if the person with dementia can be assured of MAID .. at the appropriate time. For many people, like me, access to MAID offers a real “beacon of hope.” With MAID, I can focus upon full exercise of my capabilities for as long as possible .. knowing that my end-of-life fears can be resolved with a dignified and peaceful death of my choice. I am not vulnerable knowing MAID is my future .. when I'm ready to choose. It is my “beacon” and my rock.

This means the legislators must remove (like the Quebec Court) the “death in the foreseeable future” clause. They must also remove “last or late stage protection.” That's the requirement for the attending physician to obtain reaffirmation of the wish to die with assistance .. at the moment of administration. Obviously this requirement alone disallows anyone with dementia in the end-of-life stage any consideration of MAID .. unless they “go” earlier than end-of-life while they can be still considered as rational and cogent.

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This “last or late stage protection” impacts more than those with dementia. Many people - like Audrey Parker with a grievous and irremediable prediction of death - choose to die months earlier than preferred because they fear a future inability to provide such verbal reaffirmation. Some, facing the same fearful dilemma, choose to forgo pain relieving medications/treatments so they can answer such affirmation questions surely and cogently.

How does this really protect the vulnerable - the real life patient who's going to die .. or does it protect the physician .. or the legislator? Can the patient change her/his mind? Absolutely, anyone may change her/his mind. But if the request for MAiD is presented and accepted well in advance of the anticipated death, then the patient, whether they have dementia, cancer or some other life-ending disease, has sufficient time prior to death to reconsider and decline any such assistance. Such last minute changes are typically expected by any health professional.

Dementia people in their end-of-life condition cannot cogently decide anything. Therefore, in the five to ten years - prior to the end-of-life stage - people with dementia must have the right to file an “Advance Request” for MAiD -- while they are still cogently able. In that request, they must authorize someone with their Power of Attorney for Health or Substitute Decision Maker to fulfill their wishes. Such designation of authoritative trusteeship applies to all other aspects of health care like a “Do Not Resuscitate(DNR) Order.

To ensure MAiD fulfilment, and to assist their Attorney and physician, the patient should include some description or delineation of EOL concerns which they don't wish to experience and would prefer assisted death. (See attachment - My Eight Conditions) With such delineation, the designated Attorney and physician can confidently proceed with the requested choice of MAiD.

Other issues related to the Quebec Decision, are primarily bureaucratic in nature and practice and add nothing to health care. For example:

1. Why is MAiD not considered as a medical treatment and separate from the normal provision of public health care? Does planning death make it different? Death is a major consideration in the provision of medical treatments for cancer, liver/ kidney diseases and many other similar, fearful elements of living. It cannot be pulled out of the life cycle of living from birth to dying. Death is a reality of life -- albeit the end. MAiD has to be a medical treatment.
2. Why do we need two medical practitioners to determine diagnosis and the patient's cognitive ability to make a medical decision? Decisions about medical treatment are made all the time - between physician and patient. If any doubt or concern exists then either the physician or patient can request consultation from another practitioner. MAiD decisions can be private, confidential and just between patient and physician - just like any other medical decision and plan.
3. Why do we need two independent witnesses? Can they really protect the patient? Do we need such protection for other medical decisions like a DNR or intubation or physical restraints or any other intrusive and feared treatment? Can silenced witnesses really substitute for misinformed, misguided and manipulative family members? After serving as an independent witness for more than sixty signings, I can say with some authority, that patients desirous of MAiD have persevered through concerns about loss of privacy and personal dignity and resent being required to use independent witnesses. Also, in too many instances, I've learned of patients foregoing MAiD because they “have to” to find and use independent witnesses.

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For years in Canada, we have practised medicine with 'care' as the primary operative. We treasure and protect, both patient and medical practitioners, with confidence and the right to privacy. This caring relationship is paramount to our practice. Why do we require the medical practice of MAiD to confuse and disregard this preeminent principle?

The Alzheimer's Society of Canada has an excellent Charter of Rights for People with Dementia. Essentially, it states that people with dementia must have all the rights and freedoms as other Canadians - as denoted in the the Canadian Act of Rights and Freedoms. Yet, MAiD sets all that aside. People with dementia are being denied their rights *vis a vis* their right to request an assisted death. The corrected legislation can change all that. Please ..

- remove the "foreseeable future" clause;
- remove "late or last stage protection";
- provide the opportunity for an "Advance Request"; and
- reestablish the opportunity for a caring and private relationship between patient and medical practitioner.

Until this legislation can be so changed, people with dementia (and a whole host of others) will be denied their rights. In effect, C-14 is contradictory to the dictates of the Supreme Court of Canada. We should not have to go to court to correct 'bad' law. Legislators can correct the missteps of the current law.

Submitted by ..

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ATTACHMENT: MY EIGHT CONDITIONS

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Note: These 'Eight Conditions' were created as part of my Power of Attorney for Personal Care(Health) to assist my attorney and physician in completing my request of medical assistance in dying.

When I am unable to recognize and/or cognitively and adequately respond — with appropriate emotion and thought — to family members, care providers or friends; or

When I become persistently abusive — either verbally and/or physically; or

When I become frequently lost or wander without awareness or knowledge of my whereabouts; or

When I require physical restraints and/or a locked door facility; or

When I present the symptoms of acute depression or paranoia or melancholia or elective muteness; or

When I frequently experience visual, auditory, olfactory or tactile hallucinations; or

When I require assisted personal care because I am frequently incontinent; and/or

When I am unable to eat, clean or dress myself without assistance.

These are clear and definitive. When any one or more of these conditions is prevalent, then I want to die a medically-assisted death. At that point, I won't be able to competently communicate anything, since my brain will have lost most of its functioning. But my POA agent will be able to present my "condition" to my physician at the appropriate time as the reason to enact assisted dying as specified in my previously filed official request.