

Thoughts on medical assistance in dying by advance request

Brief submitted to the Standing Senate Committee on Legal and Constitutional Affairs

Catherine Ferrier MD

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I am a physician with over 30 years' experience diagnosing, treating, and caring for frail older people, often suffering from Alzheimer's disease and other dementias. In addition to seeing patients in the clinic, I often visit their homes as the geriatric consultant to a home care service. My professional "niche" includes capacity assessment, as well as assessment and intervention for patients and families in crisis because of cognitive, psychiatric, and social problems. I regularly see abused and neglected elderly patients. I often testify in court for abused patients or for those whose families are squabbling over powers of attorney and inheritance issues.

I see no protection for patients such as mine in the present law or in Bill C-7. The voluntariness of a request for death from someone in their position is non-verifiable, certainly for the average doctor and even for those with experience such as mine, unless an extensive assessment of their family and social supports and circumstances is done, which the Bill does not require.

Lacking space to address all my concerns related to Bill C-7, I will focus on the question of MAiD by advance request, both as proposed in the Bill (for patients already approved for MAiD who may lose decision-making capacity) and as promoted enthusiastically by some Senators and witnesses to the Committee (for patients with dementia). Areas of concern include *marginalization*, *consent*, and *applicability*.

There is evidence that many people having requested MAiD, who retain decision-making capacity, change their minds: 42% in one Quebec study¹ and 23% in the 2019 report of Quebec's *Commission sur les soins de fin de vie*. The provision in the Bill to allow for advance consent in this situation would thus put people at risk of dying prematurely by MAiD, contrary to their wishes. Advocacy for this provision is based on the unproven assumption that death by lethal injection is preferable to natural death with good palliative care. There is no data that compares the two with regard to suffering or any other parameter. Neither patient autonomy nor beneficence would be advanced, and both could be harmed, by such a change in the law.

Listening to those who advocate for MAiD by advance request for patients with dementia, my patients, my first reaction is horror at the demeaning and discriminatory terms in which they are depicted. To state that people who no longer recognize family members, are bedridden or are dependent for hygiene or feeding have lost their dignity is a marginalizing and ableist depiction from the perspective of the worried well who are afraid of their own future fragility. All human

beings have dignity and deserve humanitarian care, especially those who are fragile and vulnerable. Among the many lessons of the COVID-19 pandemic is the amount of death and suffering that resulted from the relatively recent tendency to house frail seniors together in nursing homes, rather than supporting the efforts of their families to keep them at home, where they have a shared history and natural bonds with those who care for them.

Unlike the people with physical disabilities who have spoken so eloquently at the committee hearings, this population can in no way represent themselves in the public square. They need others to speak on their behalf and to protect them from ideological trends.

It will be countered that no one will be euthanized under such a provision who has not freely consented to it. But the notion of consent by advance directive is not as straightforward as it might appear to those unfamiliar with the complex situations of clinical medicine.

It is universally accepted in Western society that consent for medical treatment must be *free* and *informed*. Whether either of those conditions is met when a person consents in advance to an unknown, hypothetical future situation is controversial. For this reason, the Council of Canadian Academies Expert Panel Working Group on Advance Requests for MAID, after examining all the provincial laws on advance directives, observes that:

... their application [of instructional directives] depends on how relevant the written instructions are to the specific medical situation. In British Columbia, for example, an advance directive does not apply if a healthcare practitioner reasonably believes that the instructions do not pertain to the decision at hand; the instructions are unclear; the directive does not reflect significant changes that have occurred in the maker's wishes, values, or beliefs; or, since the directive was written, there have been significant medical advances that might benefit the maker. Furthermore, in emergencies, healthcare practitioners are not required to locate and consult advance directives before providing life-saving treatments....ⁱⁱ

Many experts in advance care planning now favour, instead of a directive giving specific instructions, a process of reflection on broad health care goals, conversations with loved ones and the designation of a proxy decision-maker.ⁱⁱⁱ

Looking specifically at the question of advance requests for MAiD by people in the early stages of dementia, I would like to say first that in 36 years of caring daily for such patients, I have never been asked to facilitate death. Concerns lie elsewhere: medical treatment, which is limited, and obtaining good family and community support for the present and for the future.

There is no doubt that receiving such a diagnosis is a major life crisis. Those of us who have been through even lesser crises know that our judgment is not at its best when flooded with emotions,

fears, and questions. Most would be sensible enough to defer life-changing decisions until we are calm enough to think clearly. But for the person diagnosed with dementia the clock is ticking and the advance directive must be signed before decision-making capacity is lost.

For my patients, the existence of an option to choose death in this situation would not lead to peace, but rather to anxiety, conflict, and, in some cases, elder abuse.

A few years ago, there was a story in the Montreal Gazette^{iv} about a patient of mine who lost her freedom and life's savings after a protection mandate, later found to be forged, stripped away her rights without anyone speaking to her or questioning the validity of the mandate. To advocate, as some have done^v, for *legally binding* advance requests for MAiD for patients with dementia, betrays a naïve and shocking ignorance of the many subtle ways in which fragile seniors can be manipulated and abused.

Regarding the practical implementation of such a provision, the Council of Canadian Academies Expert Panel Working Group on Advance Requests for MAiD found that in the Netherlands, the only country permitting such an act that has adequate data for study, it is rarely carried out.

“... both physicians and relatives of people with dementia “... are more positive about respecting AEDs [advance euthanasia directives] in principle than in practice. Relatives of patients with dementia generally support euthanasia if an AED exists... but when they are faced with the decision to follow an AED, most decide against it.”

“A 2007 to 2008 survey of 434 Dutch elderly care physicians revealed that, while 110 indicated that they had treated a patient with dementia who had an AED, only 3 physicians had actually performed euthanasia in such a case... The top reason given for lack of compliance with an AED was that in the physician's opinion the patient experienced “no unbearable suffering” or “no hopeless suffering” ... More than half... believed that it was “impossible to determine whether an incompetent person experiences his/her ‘dementia’ as unbearable and hopeless suffering” ... Most... felt that it was “impossible to determine at what moment an advance directive for euthanasia of a person with dementia is to be carried out” ... All patients with dementia who received euthanasia... were “deemed competent and able to communicate their wishes” ... Indeed, ... annual reports from 2002 to 2017 indicate *that all or most of the patients who received euthanasia due to suffering caused by dementia were in the initial stages of the disorder and still had decisional capacity.*”^{vi} (italics mine)

Dutch academic Boris Brummans wrote in his 2007 article *Death by Document*^{vii} of his father's euthanasia death through an advance directive. He had cancer, not dementia, but the issues are the same.

I used to be in favor of euthanasia... As so often, actual experience altered my point of view in such a way that I now no longer know where I'm standing. Although the euthanasia was meant to liberate my dad from the conventional constraints of suicide, its textual, declarative form turned him into a prisoner of himself (and us into his cellmates). By signing the euthanasia declaration... my father created a persona of, and *for*, himself that transcended space and time, based on the person he *thought* he would be. On what were these thoughts based? Hollow images of a self not yet lived; meager ideas about a life not yet fleshed out. Similarly, we signed the declaration... ready to act on his behalf... In retrospect, it seems that our writing projected our past selves into the future in ways that deprived us, especially my dad, from the very liberty we thought to have signed for.

Imagine that the person has reached the stage at which the advance directive authorizes death. Imagine that he is unaware of his cognitive deficits and is living happily with his family or in a residential setting. Imagine that he has a loving family; he enjoys the time together as do they. Who will give the euthanasia order? How will they explain it to their father? He doesn't want to die. Will that directive take precedence over his current wishes and those of everyone around him? Perhaps he wrote it in order to relieve them of the burden of caring for him; instead, they will carry the burden of guilt for the rest of their days if they follow it. If the situation is less happy, and behaviour problems, incontinence or wandering make care burdensome, imagine the guilt at having ordered that euthanasia. Capital punishment for wetting the bed.

Imagine, now, a family that is less loving, one that is fighting over the inheritance while mother is still alive: over how much of it is spent paying for nursing care. This is a common scenario in my practice. Now who will give the euthanasia order? And in whose interest?

Imagine that there is no family, and the administration of the nursing home is under orders from the Ministry to find beds for patients to be transferred from the hospital...

In summary, from my perspective after decades spent caring for the frailest of our frail elders, those who built our society and merit our care, I urge you to reject the temptation of allowing MAiD to be authorized by a written document for a person unable to consent. To do so can only further marginalize this group of Canadians and expose them to abuse and harm.

Catherine Ferrier MD, CCFP (COE), FCFP

Division of Geriatric Medicine, McGill University Health Centre
1650 Cedar Avenue, room D17-113, Montreal QC H3G 1A4

Tel. work [514-934-8015](tel:514-934-8015); cell [514-623-5737](tel:514-623-5737)

ⁱ Seller L et al, *Situating requests for medical aid in dying within the broader context of end-of-life care: ethical considerations*. Journal of Medical Ethics Feb 2019, 45 (2) 106-111; DOI: 10.1136/medethics-2018-104982

ⁱⁱ Council of Canadian Academies, 2018. The State of Knowledge on Advance Requests for Medical Assistance in Dying. Ottawa (ON): The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies, page 92. <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>

ⁱⁱⁱ <https://www.advancecareplanning.ca/>

^{iv} <http://montrealgazette.com/news/veronika-piela>

^v The Standing Senate Committee on Legal and Constitutional Affairs, meeting, November 24, 2020 to examine the subject matter of Bill C-7, An Act to amend the Criminal Code (medical assistance in dying), quote from Dr. Alain Naud: “*Une fois le diagnostic posé, après un certain temps, après avoir bien étudié la question, un individu pourrait faire une demande en signant un formulaire devant témoin. On pourrait répéter la demande après trois ou six mois en sachant que le malade est toujours apte à donner son consentement. Cette demande aurait une valeur contraignante...*”

^{vi} Council of Canadian Academies, 2018. The State of Knowledge on Advance Requests for Medical Assistance in Dying. Ottawa (ON): The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies, section 5.5 (page 120). <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>

^{vii} Brummans, Boris H. J. M. Death by Document: Tracing the Agency of a Text. *Qualitative Inquiry* 2007 13: 711 (<http://qix.sagepub.com/content/13/5/711>)