

Brief submitted to the Standing Committee on Justice and Human Rights
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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 fighting over powers of attorney and inheritance issues.

Lacking space to address all my concerns related to Bill C-14, I will focus on those most pertinent to the people I care for.

I see little or no protection for patients such as mine in Bill C-14. Virtually all of them have a *grievous and irremediable medical condition* (241.2(1)(c)). Given their age, natural death is *reasonably foreseeable* (241.2 (2) (d)). 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.

Elder abuse is rampant and is exceedingly difficult to identify and control. In this context the loose criteria in the Bill and the exemption from criminal liability for people, including non-health professionals, who claim to have mistakenly believed that the person met the criteria set out in the law (art. 227(3)), is very dangerous.

My other major concern is related to the notion of advance requests for euthanasia or assisted suicide. They are not permitted according to the text of the law, but the preamble refers to exploring "*other situations... in which a person may seek access to medical assistance in dying, namely situations giving rise to... advance requests...*" That this would even be considered is alarming, in ways that are not apparent to the healthy people, afraid of future dementia, who lobby for it.

Dutch academic Boris Brummans wrote in his 2007 article *Death by Document*¹ 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.

The mantra is "choice": I choose to die rather than live with the "indignity" of dementia, of dependence, of becoming a burden. Brummans questions whether one can truly choose for one's future self. As I also question, having seen my patients through the many stages of their disease.

A diagnosis of dementia – or of cancer, other neurologic diseases or sudden disability due to an accident – 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 overwhelming 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.

Troubling? I think so.

Imagine that the person has reached the stage at which the advance directive authorizes death. Imagine that he is no longer aware 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. Troubling indeed. 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.

¹ 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>)

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. Now who will give the euthanasia order? And in whose interest? Ever more troubling.

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

Only a few weeks ago there was a story in the Montreal Gazette² 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. Elder abuse is rampant. The system is overburdened. If we allow death to be authorized by a written document we're giving abusers another, more definitive, tool. A dead person cannot tell tales.

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 recommend, for their safety:

1. Restrict access to euthanasia or assisted suicide to people for whom death is imminent;
2. Require prior authorization by a Court for each request for euthanasia or assisted suicide, after a complete assessment has been made of the person's circumstances and any factors leading to a desire for death and that can be addressed in other ways;
3. Remove from the preamble the reference to euthanasia by advanced directive. Do not go this way.

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² <http://montrealgazette.com/news/veronika-piela>