

Brief – Author Jaclyn Chabot

Loi concernant les soins de fin de vie

Re. Bill 11 – An Act to amend the Act respecting end-of-life care and other legislative provisions–

### Identification of the Author

I work in healthcare in clinical research, have a background as a scientist, and a Masters in Bioethics from McGill University. During my Masters in Bioethics at McGill University, my focus was on the lack of voice given to people in middle stage dementia, particularly in research surrounding their communications. The voices of older persons with dementia are vastly drowned out by the many who do not have any cognitive impairment, and who perhaps believe they understand better than those with lived experience.

I not only speak from experience gained during my Masters. My father has Alzheimers, recently diagnosed and either in or beginning middle stage. I am sharing his journey day to day. I myself have dealt with illness and know from lived experience how important it is to receive caring support. Giving voice and autonomy means listening to people about what they are living with RIGHT NOW. I encourage all interested to educate yourselves further on the importance of autonomy and giving voice to older adults with dementia: my thesis link - <https://escholarship.mcgill.ca/concern/theses/1j92gd30z> .

I am against Bill 11 wherein it allows an advance request for medical aid in dying so that a person can receive such aid once they have become incapable. Most specifically, I find many sections lack clarity or seem problematic with respect to how they may be applied to persons with progressing cognitive impairment such as dementia. The bill would allow persons suffering from a serious and incurable illness leading to incapacity to give consent to care to make an advance request for medical aid in dying so that they can receive such aid once they have become incapable. While the bill attempts to prescribe applicable rules, several criteria are problematic due to objective requirements which may be impacted by unrecognized social stigmas. Furthermore, this is a population that is historically excluded from having their subjective voices heard. Finally, fear may be driving this desire to run away from life via advanced MAID – we’ve heard terms like having it as an ‘escape hatch’ in the media.

### SECTION 1 – Problematic objective requirements

There are several problematic sections in this bill due to objective requirements which could be impacted by unrecognized social stigmas. In order for medical aid in dying to be administered to a person who has become incapable of giving consent to care, one criterion requires the **observation** of the suffering the person is experiencing. It is crucially important to recognize before adopting this bill that there exists a significant risk of paternalism when any surrogate for someone deemed to have less competence believes they have better insight than the person themselves (Sherwin & Winsby, 2010).

I find a dilemma with section 18 (p. 8) wherein it is stated:

“1.—Criteria for obtaining medical aid in dying “29.1.

**In order to obtain medical aid in dying following an advance request, a patient must, (2) at the time medical aid in dying is to be administered:** (a) be incapable of giving consent to care due to their illness; (b) still meet the criteria set out in subparagraphs b and c of subparagraph 1; (c) be in an advanced state of irreversible decline in capability; and (d) **objectively appear to be experiencing** i. due to their illness, **the suffering they described in the request,** and ii. **enduring and unbearable physical or psychological suffering** that cannot be relieved under conditions considered tolerable.”

And in Section 18 (pg 14)

“29.14. If every trusted third person designated in an advance request is prevented from acting or refuses or neglects to do so, the patient having made the request must undergo the examination prescribed in the third paragraph of section 29.13 in relation to the suffering the patient appears to be experiencing where a competent professional, as applicable, (1) **finds, at first glance, that the patient objectively appears to be experiencing** (a) the suffering described in the request; or (b) enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable; or (2) is notified by a person that they believe the patient is experiencing such suffering. A competent professional must, before carrying out the examination, take reasonable measures to notify every trusted third person designated in the request of the situation.”

There seems to be undue pressure placed upon the “competent professional providing assistance” to precisely understand exactly how the intended recipient of MAID is experiencing suffering or pain – and in some cases, to make this impression “at first glance”. Firstly, an experience of pain and suffering is **subjective**. From my own personal experiences of living with chronic pain, while health professionals can be empathetic, they never fully comprehend my experience unless they too have lived experience of it. Secondly, if the goal is to assess loss of dignity as the undue suffering, time must be taken to carefully reach such a conclusion. Finally, there remains a significant risk of the professional bringing in their own bias (which could be unrealized due to existing endemic stigma). Understanding of suffering is subjective and it cannot necessarily be easily assessed in a passing moment for the context in which this bill is meant to be applied. For example, in research with this population, it is understood that temperament must be assessed daily, that there must be an ability to recognize changing mood or tiredness, and an understanding that sometimes a visit should be deferred, for example when a person seems less lucid (Cooney *et al.*, 2013; Murphy *et al.*, 2015). Furthermore, it is known that people with dementia change their minds (McKillop & Wilkinson, 2004). With such day-to-day variability, first glances and single objective impressions of suffering experienced could be mistaken.

A second problematic section only loosely describes the possibility of withdrawal.

“29.5. **The competent professional providing assistance to the patient must notify them that the advance request, made in compliance with this Act, will not automatically lead to the administration of medical aid in dying. For that purpose, the competent professional must, in particular, inform the patient of the following:** (1) an eventual finding that they objectively appear to be experiencing the suffering described in the request will not by itself suffice to allow medical aid in dying to be administered; (2) the aid may be administered to them only if two competent professionals are of the opinion that both of the following criteria have been met: (a) the patient objectively appears to be experiencing enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable; and (b) the patient meets all the other criteria set out in subparagraph 2 of the first paragraph of section 29.1; and **(3) the possibility of withdrawing or modifying the advance request and the applicable terms and conditions for the withdrawal or modification.**”

The way in which this possibility is presented matters a good deal. From personal experiences with my own father, persons with cognitive impairment are easily confused when presented with choices or decisions they need to make. This becomes particularly difficult and sometimes distressing when it

comes to important medical decisions. As afore mentioned, lucidity and feelings may change from day to day. Would the possibility of withdrawing be presented on a single day? Would it be presented over a series of days? Would there be a careful assessment for lucidity each time? These are questions requiring measured and thoughtful attention.

Although there appears to be a free right to refuse MAID before it is administered due to advance request (section 18, p. 14):

**“29.19. Before administering medical aid in dying following an advance request, the competent professional must (1) be of the opinion that the patient meets all the criteria set out in subparagraph 2 of the first paragraph of section 29.1 and the first paragraph of section 29.2; and (2) obtain the opinion of a second competent professional confirming that the criteria that must be the subject of an opinion under subparagraph 1 have been met. The second paragraph of section 29 applies to the professional consulted. Any refusal to receive medical aid in dying expressed by the patient must be respected and it is prohibited to disregard it in any manner.**

this statement is immediately followed by:

**“For the purposes of the third paragraph, a clinical manifestation resulting from the patient’s medical state does not constitute a refusal to receive medical aid in dying.”**

How the above applies to a person with cognitive impairment who has lost capacity must be carefully and clearly described.

We should be extremely careful to ensure the decision to receive MAID, at this point, is “INFORMED AND VOLUNTARY”: Do they understand? If they have lost capacity, and are told as much by a professional in paternalistic position who insists they previously requested this, are they free from coercion or undue influence? Persons living with cognitive impairment must have things clearly explained to them. Are there going to be protections in place to ensure that older adults are not confused about what MAID is and what the advance directive means? It is conceivable that a person could believe they are being asked whether they *feel like dying sometimes*, versus being asked to *acknowledge receiving a lethal injection*. “Would you like to die?” is a very different question from “would you like a doctor to give you an injection of something that will make you die?”. There must be protections in place before such an expansion to ensure no older adult misunderstands.

While the request for advanced MAID can be rescinded in the presence of two witnesses or via a notary (“29.11. **A patient who is capable of giving consent to care may, at any time, withdraw their advance request by means of the form prescribed by the Minister**”; Section 18, pg 12), there seems to be no requirement to regularly remind the person of their request to assess for their continued consent (as is done for example with consent in research procedures) of their advanced MAID request. For a person with memory problems, without regular check ins, it understandable their request will be forgotten. This presents another complexity – whether carers could be held liable for ‘withholding’ the opportunity for rescinding before loss of capacity if they do not regularly check this consent.

For at least half a century, Western culture has highly valued reason, cognition, and financial productivity and has frequently associated old age with powerlessness, the result of disease, disability, or uselessness – thereby placing a particular lens on aging in our society (Harrigan, 2010). The assumption that whether someone can live a good life (or not) is directly tied to their ability both to

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understand good versus bad and to critically reflect on life choices takes a dangerous route by classifying people with cognitive impairments as incapable of having a good life (Burchardt, 2004). We must recognize that older adults are often victims of ageism, a particular form of oppression (Sherwin & Winsby, 2010, p. 186) which is the discrimination and stereotyping of people - whether consciously or unconsciously - solely on the grounds of age, resulting in assumptions that the older adults are weak, frail, and incapable (CMPA, 2016; Harrigan, 2010). It has been noted that the worst effect of brain disease is not the functional impairments it causes, but rather, the threat it poses to self and personhood – which itself is dependent on other people (Fazio *et al.*, 2018).

## SECTION 2 – Problematic exclusion of subjective voices

Older adults with dementia have been historically excluded from having their subjective voices heard, whereas much is heard from the perspectives of caregivers ((e.g., Orange *et al.*, 1994; Vittoria, 1998; van den Hooff & Goossensen, 2015; Entwistle *et al.*, 2010; Wullink *et al.*, 2009; Cooney *et al.*, 2013; Savundranayagam *et al.*, 2016). This population themselves should be broadly consulted before the institution of this bill. Persons without dementia but working with them or for them should not be given a louder voice; this acts to exacerbate stigma and assumptions regarding that population's ability to communicate. This stigma towards their communications can be linked to active infringing on their right to have a voice – which they must have in such a serious decision as end of life. Margaret Oldfield, a social scientist and disability scholar, similarly pointed to the discrimination of viewing dementia as only a medical diagnosis, which leaves people devalued, infantilized, and ultimately left out of decisions concerning their own livelihood (Oldfield, 2021). It has been found that older patients with dementia feel unheard by their care takers and are often not permitted to even express their views or are dismissed as digressing or rambling (Orange *et al.*, 1994; Tyrrell *et al.*, 2006).

While it may be understandably difficult to properly understand communications of this population, it is not impossible. Doing so should involve time, special skills, and expertise, such as employing speech language therapists having expertise in working with communicatively impaired older adults (Olthof-Nefkens *et al.*, 2021). Researchers exploring patterns of communication in residential dementia care (Ward *et al.*, 2008), have found that not only are people with dementia capable of communicating, but they also put a lot of effort into trying to engage with those around them. Factual numbers from the population that would be affected by this advance directive would better inform decision makers.

There must also be balance in this discussion. People should not be presented only with disturbing images of what dementia may look like which incite fear. All the MAID discussions or presentations I have ever been partied to are missing balance. While we hear a personal and very tragic story from a person or about their parent who is suffering in horrific ways to justify wanting advance directives, there lacks a story from a person or about their parent suffering with the same “illness” who sees value in their life and disagrees with allowing advance directives. Before expanding MAID, we should know what proportion of people with middle stage / late stage / end stage dementia would immediately accept a lethal injection, and this must be clearly distinct from a person saying they are ready to die. Being ready for death and wishing for a lethal injection to end one's life are vastly different. My father has indicated he is ready to accept death when it comes, but he would never want or accept a lethal injection. Though he may at times dislike it, he is **not afraid** of where his dementia is leading – I believe this is where the difference lies. He knows there is still value in his life, even though there are days where he struggles to hold on to that belief more than others. For example, his joy in being alive was clearly communicated to me, my sisters, my maternal grandmother (102 years!), and his 6 grandchildren at his 86<sup>th</sup> birthday celebration this past March 19<sup>th</sup>, 2023.

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Jim Mann<sup>1</sup> can provide a balanced perspective of living with dementia. Mann has been a leading voice in Canada for rights of persons with dementia, refuting negative assumptions made about living with dementia. He not only lost his mother to Alzheimer's but he also currently lives with Alzheimer's dementia (diagnosed in 2007). He is a Researcher, Author, Volunteer, and describes himself as Living Well with Dementia. He was awarded an honorary Doctor of Laws degree from UBC in 2020, acknowledged as the single-most influential person in Canada for countering negative stereotypes and promoting an inclusive society in which persons with dementia can make an active and meaningful contribution. His has broad involvement in participatory research and in giving voice to and destroying stigma for persons with dementia (see [www.flippingstigma.com](http://www.flippingstigma.com)). According to the Alzheimer Society of Canada's charter of rights for people with dementia (Mann, 2020), people with dementia have the right to be involved in decisions affecting them. Upon reading this very brief, Mann had a few comments to add which I share here:

- Regarding apparent suffering: "The measurement for some is forgetting names - it's as basic as that. [However] Many would suggest that forgetting the names of your children and close relatives is not suffering."
- Mann communicated to me that he feels that "Stigma is the basis for this [expansion of MAID] I believe, as well as the continued depiction of a person living with dementia who is frail, elderly, unable to communicate, and unaware of everything and everyone around them. They don't want any part of that end-stage. They also don't want that burden of care placed on their spouse or their children. What's the point, they say."

### SECTION 3 – Main driver for advanced directives

Life and death decisions should never be made merely based on fear or assumptions. This proposed expansion seems to be largely facilitating assumption-making by people who are fearful for their future selves. They are fearful that in the future, people will not treat them with dignity; they are fearful that they will suffer. We should carefully consider:

- What about those who end up with "happy dementia"?
- What if it is solely the objective opinion of a healthcare professional that, for example, not recognizing family or going to the bathroom on one's own is unbearable? Is it only the 'worried-well' who are the ones who don't want to be like this?
- Are you really suffering with advanced dementia?
- Are we excluding important voices from this debate? If yes, should such a discussion continue *without* involving these people in the conversation?
- How much stigma is driving this?

When I was 20 years old, and a good friend once told me that they never wanted to live a day past forty, that they would rather be shot than get old. That same person today not only does not recall saying this, but they also love their life and have no interest in having it end any time soon. Our decisions change because we change as we age, and we learn that reality is not always as bad as it seemed. Similarly, I could be fearful based on the amount of travel I do that I will die in a horrific car accident - but having autonomy and being given a voice does not mean that I should act rashly based on those fears of my future. Yes, the percent chance could be significant, that alone does not mean I should be granted access to making a life and death decision based on a hypothetical future.

<sup>1</sup> Contacted for permission to name and reference: "Thanks for forwarding your submission and, yes, the mention of me is fine. Thank you for checking."

Instead of fueling and promoting fear, the government should be seriously looking at the drivers of this fear, which in my opinion is the state of health care in Canada and Quebec which in turn drives stigma and fear. Indeed, it has already been observed that the government has allowed such deterioration of the public health system that human rights are being violated (Sibbald & Stanbrook, 2016). There is a serious lack of funding resulting in poor care, which may be the real reason people are fearful and assuming the worse. Decision makers in Canada should take a step back and acknowledge the stigma our society lives with, and the fears that come with it. There is a real social fear here at play – people with dementia do not want to be housed in what is available today.

It is stigmatizing to say that people suffer from Alzheimers. People LIVE with Alzheimers. Our society loves to label anything with suffering as something that is broken, and which needs to be either fixed or discarded. We should really be focused on walking the journey with people living with *anything* difficult (everyone has difficulties) and help each other through life.

## CONCLUSION

In conclusion, we must hear more from the people who are currently living in the health state that would be affected by this expansion of MAID. We should take care to value the voices who are loud and who are quiet alike. We should carefully re-evaluate the role stigma is playing in these decisions, and the role current poor care is playing. It would behoove us to establish how persons with dementia who have lost their decision-making capacity would feel right now if they were told that their younger self had given permission, in fact, a directive, that they should die by medical assistance.

What will they say about this generation hundreds of years from now – a generation that instead of correcting and improving their care of older persons, chose to ignore their voices, and to decide that **their lives were not valuable enough to invest in**? This is the fundamental root of this issue.

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