Brief – Advance consent for medical assistance in dying – Catherine Leclerc

I am writing because I have a personal stake in the development of medical assistance in dying legislation. I would like to offer some thoughts on the advance consent for medical assistance in dying (MAID) for people with cognitive neurodegenerative diseases (CNDs).

There are several cases of Alzheimer's disease (AD) in my family. My mother, Yvette, has been ravaged by dementia for 16 years now. We have had to accept that the memories that connect our lives have fallen into oblivion, and we have watched helplessly as the very essence of her humanity disappears.

Elegant and proud, she perfectly juggled maintaining a career, running a business and raising her children. Today, she wanders the corridors of a long-term care home. She no longer recognizes us nor communicates in words or gestures. She is dependent on staff for her essential needs. She would not survive without her caregivers.

Although she is cared for, receives palliative care and is surrounded by her loved ones, I have a deep conviction that if she were lucid for just a few hours, she would hug us then take her own life. I love her, I miss her, but MAID would certainly be the most compassionate gesture we could offer her. We had many discussions about MAID while she still had her mental faculties. Her opinion was clear and unambiguous. She would rather die than live in this state of dependence.

The illness has not made her aggressive; she has remained gentle, she smiles, and sometimes she laughs. It is easy for a health care professional who assesses her once a year to perceive that she is comfortable with the disease. Yvette has what some call "happy dementia." Happy dementia is a trap. Yvette smiles, not because she is not in pain, but simply because the disease has not yet taken away her ability to do so.

Being predisposed to AD, I started thinking about my end of life at a very young age, should I be diagnosed. Since AD patients are helpless and at the mercy of their symptoms, I quickly saw that this would not be a dignified end to life.

I have been closely following the development of the federal and provincial legislation and reports, along with court decisions, including Quebec's Act Respecting End-of-Life

Care,[1] the Carter decision,[2] the first Report of the Special Joint Committee on MAID[3] and the Truchon-Gladu decision.[4]

I also submitted a brief[5] and appeared before the Select Committee on the Evolution of the Act respecting end-of-life care.

My decision doesn't stem from a lack of palliative care or medical resources. I welcome palliative care insofar as it relieves physical pain to a point that I consider tolerable and acceptable. In fact, the 2020 Second Annual Report on MAID in Canada[6] states that 83% of Canadians who sought MAID first received palliative care.

It's not the stigma of dementia that scares me. It's just that I refuse to live through years of suffering and dependence in a meaningless existence, deprived of my abilities, stripped of consciousness, identity, self-determination and memories. This constitutes for me the definition of existential suffering beyond human tolerance.

In the event of an AD diagnosis and without the option of advance consent for MAID once I have met certain clinical and functional criteria, the only choices left are:

- To sacrifice precious years with my loved ones by applying for MAID while I am still able to consent.
- To commit suicide at the desired moment at the risk of not being able to end my life when the time comes.

I rely on the principle of self-determination: the choice to live or die is individual and personal. That way, with complete freedom of conscience, people diagnosed with CNDs can give their end-of-life directives while they are still able to choose and consent to care in a free and informed manner.

The role of the state is to legislate this right, and the role of the medical profession is to respect the treatment plans of individuals. These choices belong to each person according to their values, convictions and beliefs. In order to protect the most vulnerable in our society, the request could only be made by and for oneself.

MAID legislation has a high degree of social acceptability. The report[7] from the government's 2020 public consultation, to which over 300,000 Canadians responded,

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[1] An Act Respecting End-of-Life Care
[2] *Carter v Canada*
[3] Government of Canada - Report of the Special Joint Committee on Medical Assistance in Dying
[4] Decision - *Truchon v Attorney General of Canada* - 2019 QCCS 3792 (soquij.qc.ca)
[5] Brief by Catherine Leclerc - Select Committee on the Evolution Respecting End-of-Life Care
[6] Second Annual Report on Medical Assistance in Dying in Canada 2020
[7] What we heard report: A public consultation on medical assistance in dying

shows that 78% of Canadians support advance consent. Following the report[8] of the Select Committee on the Evolution Respecting End-of-Life Care in Quebec, the Quebec government moved forward with advance consent and introduced Bill 38 [9] on May 25, 2022.

Dementia onset occurs in 7 stages[10][11] and differs from person to person. The unique nature of each individual must be considered. Following diagnosis, each person can think about what they want according to their situation: to let the disease carry out its natural course or to ask that they be freed from their suffering at a specific moment that they themselves will have determined. If this is the case, they would be able to make an early request for MAID when a combination of criteria that they consider intolerable are present. The request could be recorded on the advance medical directives form.[12]

Examples of indicators and criteria

Indicators	Criteria
Clinical progression	Stage of the disease[13] Biomarkers MRI, FDG-PET
Cognitive functions	Results of ?/30 on the MMSE[14] Neuropsychometric tests Talking, recognizing their loved ones, doing basic math
Autonomy	Eating, dressing, walking, bathing, incontinence, etc.

The possibility of giving an advance consent directive to receive **MAID** for **CNDs** is to allow an individual to retain free will over their life, care and death, in accordance with their own convictions, until the very end. It is a way to respect the decision they made before AD takes away this mental faculty. To live with dignity is also to die with dignity—our dignity. For my mother, it is already too late, but for us, there is still time.

[8] Gouvernement du Québec - Rapport de la Commission spéciale sur l'évolution des soins de fin de vie - December 8, 2021
[9] Bill 38, An Act to amend the Act Respecting End-of-Life Care and other legislative provisions
[10] Fédération Québécoise Société Alzheimer - The stages of Alzheimer's disease
[11] Fédération Québécoise Société Alzheimer - Diagnosis and screening
[12] Government of Québec - Advance Medical Directives
[13] Fédération Québécoise Société Alzheimer - The stages of Alzheimer's disease
[14] INESSS - Interpretation Sheet MMSE Scale