Most Canadians want the right to plan ahead for an assisted death if they get dementia. So why is it so complicated?

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Sandra Demontigny, who was diagnosed with Alzheimers at 39, at her house in Levis, Que. on Feb. 7. Since her diagnosis, Ms. Demontigny, now 43, has become a vocal advocate for expanding the country's assisted dying legislation

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Linda Brose has never forgotten the last sentence she heard her mother say. Thelma Revesz was, by then, living in a nursing home in Melfort, Sask. She had already lost her laugh to dementia, and now the last bright parts of her were fading fast.

That day, she whispered: “What will become of me?”

Ms. Brose wrapped her arms around her mom while they wept together. They both knew the answer. Ms. Brose’s grandmother had also had dementia; toward the end, she became paranoid, convinced her family caregivers were stealing from her. She carried a doll around as if it was her baby.

“Lord save me from that,” Ms. Revesz had written in her journal. And then she worked hard, Ms. Brose said, to stay fit and active. But as she approached her 80s, she began to forget. Her crossword puzzles were left blank. She grew fearful living alone. In a terrible echo from the past, she became convinced she had a baby and that someone was trying to steal it.

Couldn’t you just overdose me with insulin, she begged Ms. Brose, who is a nurse. She asked another daughter to suffocate her with a pillow. “I would do it for you,” she’d say. Eventually, the words drifted away. For years, until her mother died in 2002, Ms. Brose would visit and find her slumped in her wheelchair, crying. “We were helpless, and she was helpless. There were so many tears.”

Ms. Brose, now 74, is determined not to suffer the same fate. If diagnosed with dementia, she will ask for an assisted death while she still has the mental capacity to consent, even if that means going early. But what she really wants is a choice that Canadian law doesn’t currently allow: the power to dictate in advance the terms of a euthanasia request that would take effect much later, when she has lost the ability to live independently.

That’s an option most other Canadians want as well – and with some urgency. Over the next 25 years, cases of Alzheimer’s disease and other forms of dementia will triple to 1.7 million, with 685 patients diagnosed each day, according to the Alzheimer Society of Canada.

In a late January survey, conducted for The Globe and Mail by Nanos Research, 80 per cent of respondents agreed, or somewhat agreed, that Canadians should be able to make advance requests outlining their conditions for assisted death, for when they can no longer legally give consent.

Canada’s current legislation requires people to clearly consent to medical assistance in dying, known as MAID, on the day it is provided – with a limited exception. A patient whose natural death is deemed to be “reasonably foreseeable,” and who is suffering intolerably and has been approved for MAID, may waive final consent if they are at risk of losing capacity before their scheduled date. That could be up to six months away, in certain cases, if the MAID provider agrees.

The exception was meant for patients nearing end of life, whose conditions may rapidly deteriorate. But a healthy person with Alzheimer’s might live for years, losing their mental capacity long before their physical health declines. As the law stands, they cannot write an advance request for MAID today, in anticipation of intolerable suffering in the future.

This week, a parliamentary committee reviewing the MAID law released a report recommending that the federal government allow advance requests for adults facing a future loss of capacity because of an incurable illness. (The committee was not unanimous, however: a group of Conservative members opposed expanding the law.) A bill to make this change, introduced by one of the Senators on the committee, has reached second reading in the Senate.

The Quebec government has already announced plans to move forward with advance requests, following public consultations and a legislative committee report that supported the change. The province’s Minister of Health and Seniors, Sonia Bélanger, has promised to introduce the legislation this year.

Should Ottawa follow suit, Canada will be one of only three countries, along with the Netherlands and Colombia, to allow advance requests for illnesses such as dementia. (Belgium and Luxembourg also have advance euthanasia directives, but only for cases when people are deemed irreversibly unconscious.)

In public submissions to the parliamentary committee, Canadians made deeply personal pleas for advance requests. A woman from Vancouver Island explained how her husband with Alzheimer’s was trying to live as long as possible without losing the right to die – by renewing his MAID request every six months.

A 77-year-old in B.C. vowed that, if she is diagnosed with dementia and the law still hasn’t changed, she will request MAID immediately, foregoing whatever happy times she might have left. Sons and daughters, including Ms. Brose, described parents who spent their last years trapped in misery or agitation, unable to communicate or care for themselves.

For many Canadians, this is the very objective of MAID – to allow a person control over their fate, and relieve unbearable suffering. In practice, however, delivering MAID to a patient who can't confirm they want to die complicates the "assisted" part of an assisted death.

Canada's MAID laws give priority to the patient's voice. Patients say when their suffering has grown intolerable, and when their treatment is at an end. But at the later stage of dementia, a patient's voice is silent. If advance requests are allowed, a doctor or nurse practitioner, ideally working with a trusted caregiver, would have to assess suffering and decide death's timing by interpreting instructions from the past.

As Dutch research has shown, making that final call for someone who can't confirm their desire to have an assisted death is emotionally challenging for family members, and ethically daunting for health care professionals. In surveys, doctors have been significantly less supportive than the general public of assisted dying for advanced dementia. In a brief to the parliamentary committee, the Canadian Association of Palliative Care Physicians opposed advance requests, in part because of the undue burden they would place on clinicians.

"As an ethics professor, I think this is one of the hardest problems you can ever have," said Theo Boer, a Dutch researcher who studies assisted dying in the Netherlands. He served for nine years on a regional committee charged with reviewing euthanasia cases.

Based partly on that experience, Dr. Boer said he believes euthanasia laws are expanding too far, and that the definition of suffering is becoming too broad. But when it comes to illnesses such as Alzheimer's, he acknowledged that "it's really a devil's choice." People don't want death while they still enjoy living. Doctors are reluctant to kill someone who doesn't understand what is happening. And then there's the long-standing ethical debate: Can a person in the present truly know the mind of their future self?

In the Netherlands, assisted dying for advanced dementia remains controversial, 20 years after euthanasia was legalized in the country. A case involving a patient with Alzheimer’s is the only one in which a Dutch doctor administering an assisted death has been charged with murder.

The “coffee case,” as it’s known, became a test for the county’s assisted dying laws. One of the issues was that the patient, in her 70s, had written an advance directive years earlier that was difficult to interpret. In the document, she said she wanted “to be given voluntary euthanasia, when I think the time is right.” And she did not want to be placed in a nursing home.

But when her dementia advanced and she required more care than her family could provide, she did not definitively agree to an assisted death. At a nursing home, a geriatrician proposed a wait period. The patient had happy mornings and terrible afternoons, when she would become aggressive with caregivers and wander the halls looking for her husband. Sometimes, she would say that she didn’t want to keep living; other times, she answered, “not just now.”

Guided by her directive, the doctor, with her family’s support, finally declared the patient’s suffering intolerable, a requirement in Dutch law, and scheduled an assisted death. Presuming she might resist when the needle was administered, the physician slipped a sedative into the patient’s coffee, to prevent a struggle. As the needle was inserted, she woke up and had to be held down by family members during the procedure.

In April, 2020, the Dutch Supreme Court cleared the doctor, ruling that the patient’s advance directive was properly followed. But the case had a sobering effect on many physicians, Dr. Boer said, particularly when it came to surreptitiously using a sedative to calm a patient before administering an assisted death.

In 2021, 210 Dutch patients with dementia diagnoses received euthanasia, he said, but only a handful of cases involved patients who had lost all capacity. Families find it much easier, his research has shown, to withdraw or never start treatment than to actively end a loved one’s life.

The Dutch experience highlights the difficulty of following advance directives that are vaguely worded, or may not fully reflect the future their authors imagined. And it also makes clear the importance of informed third parties who can advocate for patients. A person might say they want euthanasia when they can no longer recognize their family. But which family members, and what level of recognition? (What if, for instance, they are still delighted to see the friendly strangers who keep visiting?)

Or maybe a patient has an advance request for when they can't eat or use the bathroom on their own. But what if they appear happy, despite this limitation? What if, like the patient in the coffee case, they express a desire to live in morning, but want to die in the evening?

Aside from the inherent difficulty of administering advance requests, doctors and experts have raised concerns about a lack of resources, which might lead patients to think assisted death is their best option. Long-term care homes are expensive. Community-based supports for dementia and palliative care are underfunded. The health care system, in general, is overwhelmed and backlogged. Many aging Canadians will have to rely on family caregivers. An increasing number of seniors will have no family nearby to help.

Melissa Andrew, an associate professor of geriatric medicine at Dalhousie, said she worries that economic considerations might factor in to people's MAID decisions. At the same time, she said, "I don't think we should take away the choice for the next 10 years while we try to fix the system."

Experts who are more critical of expanding MAID argue that people aren't only their diagnoses; they make choices based on the context and values of the world around them. How society moves forward on advance requests will have wider, long-term consequences, Dr. Boer suggested. Western society already fears decline and judges weakness, he said. As euthanasia becomes more widely accepted, what will happen to our willingness to care for seniors and invest in inclusive communities for disabled people?

"If the former mobile, independent, healthy me has power over the vulnerable, fragile me, I get goosebumps," he said. "What kind of human dignity do we then ascribe to people with limited capabilities?"

Advance requests speak for the competent self, not the sick person we may become. The "disability paradox," well founded in research, suggests that life is often better than we think it will be. Aging itself is a journey of shifting priorities; we find meaning in unexpected places.

For Sandra Demontigny, a single mother from Levis, Que., who was diagnosed with early-onset Alzheimer's at age 39, that argument denies the reality of a dementia diagnosis. Her father died of the same illness at age 53. In the later stage, he wandered relentlessly until he crawled in exhaustion, becoming aggressive with the people he loved most. “I cannot see the meaning in that life,” Ms. Demontigny said.

Why shouldn’t the values of a person’s capable self trump the version that can’t communicate or care for themselves? Ms. Demontigny said she suffers now, not knowing how long her healthy body might last while her mind crumbles and what that will mean for her children.

An advance directive, she said, would allow her to live today, free from worry about what happens at the end. If that is not allowed, she will have to ask for MAID before she is truly ready, just to guarantee her wishes are respected. “I will lose time,” she said, “but I don’t want to take the risk.”

Since her diagnosis, Ms. Demontigny, now 43, has become a vocal advocate for expanding the country’s assisted dying legislation. In a few months, she will travel to a beach in Gaspé, Que., with her best friend and make a video to accompany her written advance request, hoping the law will change in time for her to use it. She wants to die long before her brain forgets how to swallow, before she cannot look after herself, and before she no longer knows her children. “Even if I seem happy,” she has told them, “know that is not me.”

The video is meant to reinforce the written document, to reassure her children and doctors that they are making the right decision, and to remind herself, when the day comes, to trust her best friend’s guidance.

“Everybody has their own limits,” she said. “There should not be only one way to leave this world.”

https://www.theglobeandmail.com/canada/article-dementia-maid-assisted-death-canada/

We have this incredible, insufferable capacity (especially in public moral arenas) to find ways to make “everything” about “us.” TJB