

Dementia and assistance in dying: A catch-22

Persons suffering from dementia are not eligible for medical assistance in dying, and this is inhumane.

George Szasz, CM, MD

In February 2023, the Parliament of Canada's Special Joint Committee on Medical Assistance in Dying released its second report, recommending, among other things, "that a person of full age and capacity be permitted to make an advance request for medical aid in dying following a diagnosis of a serious and incurable illness leading to incapacity."¹ Persons suffering solely from a mental illness who meet all other eligibility criteria will become eligible for medical assistance in dying (MAID) in

Canada as of 17 March 2024.² Regrettably, neither of these options will be available to those suffering the symptoms and signs of dementia, which presents a catch-22 situation when it comes to eligibility for MAID. A patient must possess the capacity to provide informed consent for MAID immediately prior to the procedure, but because patients who are suffering from dementia lack the capacity to give informed consent, they are ineligible for MAID.

Currently, persons must meet all the following criteria to be eligible for MAID:

- Be 18 years of age or older and have decision-making capacity.
- Be eligible for publicly funded health care services.
- Make a voluntary request that is not the result of external pressure.
- Give informed consent to receive MAID, meaning that the person has consented to receiving MAID after they have received all information needed to make this decision.
- Have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2024).
- Be in an advanced state of irreversible decline in capability.
- Have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.²

My wife's case history might help explain the problems related to these eligibility requirements.

Sixty years into our marriage, the four horsemen of dementia—amnesia, aphasia,

apraxia, and agnosia—grabbed hold of my vital, healthy partner. Over a 9-year period, she was devastated and destroyed mentally and physically. Her earliest signs of dementia included forgetfulness, anxiety when left alone or when in a large group, being disorganized when packing for a trip, and losing her way in previously familiar territory. She lost her driver's licence after failing the Montreal Cognitive Assessment test for dementia. She became furious with her medical advisor, and with me, accusing us of colluding. She had no insight into her unfolding dementia. I could no longer leave her at home alone. I took her shopping with me, watching that she did not take inappropriate items off the shelves or grab other shoppers' carts. While in the company of others, she could not follow the conversation and often broke in with inappropriate comments. I had to excuse us from invitations. Gradually, I needed help to help her with bathing, dressing, and going to the bathroom.

Over the next 5 years, we had a rotation of 56 dedicated shift-working caregivers assisting us around the clock. During those years she gradually lost her speech and comprehension abilities and no longer recognized who was who. When touched, she would reflexively hit back; she screamed when being washed or bathed; she became incontinent; and she often needed manual help to empty her bowel. At night she became panicky; she yelled out, punched the air, and often hit herself. Our medical advisors thought she was most likely suffering

Dr Szasz is a member of the Order of Canada and professor emeritus in the Department of Psychiatry in the UBC Faculty of Medicine. For the first 10 years of his career, he was a family physician on the North Shore. In the following 6 years, he was a faculty fellow of the Milbank Foundation, assisting medical dean Jack McCreary's development of the "health team" concept through experiments in interprofessional education programs. In 1970 he cofounded the Faculty of Medicine's Sexual Medicine Clinical, Teaching, and Research Unit. His clinical focus for the next 25 years was on the sexual and reproductive rehabilitation of persons with physical disability. After retiring from UBC, he was a member and chair of the Medical Advisory Committee of the Library of the College of Physicians and Surgeons of BC. Now in his 95th year, he continues rowing at the Vancouver Rowing Club and writing for the BCMJ.

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from a frontotemporal disorder or perhaps a vascular problem. She did not have any insight into her worsening condition. She lived in a different world.

At about the 5-year mark she fell and fractured her hip. When she came back from the hospital 3 days after surgery, we had a hospital bed installed with an overhead sling lift to get her into and out of bed. Physiotherapy was ineffective; she had no ability to comprehend rehabilitation. She was essentially helpless, as she could not move around in bed and could not feed herself. With the need for more intensive care, we then had live-in caregivers looking after her for almost 2 years. Her physical and mental deterioration was rapid. To avoid COVID-19 infection, she was transferred to a long-term care facility. I visited her daily, and from time to time I helped feed her. She opened her mouth as the spoon came near, then chewed and chewed the small bit of food while seemingly sightlessly

looking up at the ceiling. She had no recognition that I was there. On her last day she had a small bit of food at dinner time, then put her head on the pillow, and like the elegant person she used to be, she closed her eyes, went to sleep, and never woke up.

As this sad case history illustrates, a diagnosis of dementia is not an exact science. Medical opinions may vary, or time may be required to observe the unfolding symptoms and signs of the condition. An informed request for assistance in dying and consent that is given far in advance of any signs or symptoms of dementia would not be accepted because of the complications arising out of who would activate the request and at what stage of the disorder, while consent for assisted dying would not be considered “informed” if given once the patient was at the earliest stages of dementia because of their memory and comprehension deficits at that point.

We must find a way to provide persons suffering from dementia the option

to escape this inhumane and intractable condition with medical assistance. Having biometric measurements that indicate when the brain’s functioning has been reduced to a vegetative state would be of great value. That indicator, along with a legally documented prior request for a medically assisted end to life, might provide the signal for a humanitarian exit.

A year and a half after her unassisted death, the memories of her suffering still haunt me. Her experiences were inhumane. ■

References

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