

The informed consent paradox

The complexities presented when an essential feature of ethical medical practice is confronted by those with cognitive decline.

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Obtaining informed consent from patients undergoing various medical procedures is an essential feature of ethical medical practice. In the context of requesting medical assistance in dying (MAID), a primary requirement is that the applicant fully understands what is going to happen.

I was mulling over this requirement when I celebrated my 66th wedding anniversary on my own. My lifelong partner was biologically alive, bedridden in the full grip of amnesia, agnosia, aphasia, and apraxia at the time, until she recently passed away. It was about 8 years ago when she began her slide into one of the dementias—it's still not clear which one. She slept, or as we interpreted it, she was “totally out of it,” much of the day. We didn't know if she could see, and if so, what she saw. She may or may not have heard, but she did not respond. She could not turn or adjust her position in bed. She was incontinent of bladder and bowel. Her skin was fragile and broke down easily. She had

skin problems in her sacral area, which were difficult to manage. She sometimes screamed or yelled in a defensive manner even when she was just being gently attended by her kind caregivers. During the night, even with some sedatives, she tended to scratch her eyes or face vehemently while emitting to us meaningless sounds. She chewed and chewed her pureed, pasty food, offered to her by the half teaspoon. Eventually, she would swallow.

We cared for my very much loved wife at home until recently, when she was moved to a long-term care facility, essentially in a vegetative state. Knowing her, I believed that, if she could consider it, she would have preferred to be on a rocket to another planet. But because she existed only on a basic biological level, it was impossible for her to ask for or give consent to a medically assisted exit from Earth. And therein lies the paradox of the informed consent requirement when applied to those with cognitive decline.

On one hand, the present rules are that neither representation agreements nor power of attorney arrangements could speak on her behalf in her situation. On the other hand, her care, or more precisely, the care of her body, had been taken over by caregivers and medical specialists without her consent. In her predementia life, she was a very private person and would never give consent to some of the well-meaning but intimate, invasive care. Ironically, that humanitarian, loving care likely prolonged her vegetative state and even robbed her of a chance for an earlier, natural death.

Oddly enough there *is* a widely accepted provision in certain medical situations that potentially provides exit from life without

informed consent. For the last number of years, ambulance crews entering a house first look for a document that is supposed to be displayed on household refrigerators. If signed, the document certifies that the person named declines to give permission for resuscitation procedures, even if they might prolong life. The signature implies that, if it comes to it, death would be accepted as preferable to a postresuscitation-related chronic physical or cognitive decline. This scenario resembles the concerns of many well persons anxious about their future in case of the onset of a cognitive decline.

Following the principle of the no-resuscitation instruction on a piece of signed paper attached to the refrigerator, it would be logical to accept the formal, registered, bona fide request of a still well-functioning person in the presence of a physician: “I wish to receive medical assistance in dying if or when I reach a such and such stage of dementia.” The statement should be formally supported by significant family members. This pre-stated request could then be called upon by the family at the agreed-upon exit point, and when the time came, it could be accepted as informed consent and honored with understanding and love.

As things are today, Canada's MAID law is under revision to include people with mental illness in the future. That will be an important step forward, but dementia is a brain disorder with devastating physical consequences, and persons with severely declining cognitive function need to be given special consideration. ■

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