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HEALTH

Complexities of Choosing an End Game for Dementia

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The New Old Age

By **PAULA SPAN**

DEDHAM, Mass. — Jerome Medalie keeps his advance directive hanging in a plastic sleeve in his front hall closet, as his retirement community recommends. That’s where the paramedics will look if someone calls 911.

Like many such documents, it declares that if he is terminally ill, he declines cardiopulmonary resuscitation, a ventilator and a feeding tube.

But Mr. Medalie’s directive also specifies something more unusual: If he develops Alzheimer’s disease or another form of dementia, he refuses “ordinary means of nutrition and hydration.”

A retired lawyer with a proclivity for precision, he has listed 10 triggering conditions, including “I cannot recognize my loved ones” and “I cannot articulate coherent thoughts and sentences.”

If any three such disabilities persist for several weeks, he wants his health care proxy — his wife, Beth Lowd — to ensure that nobody tries to keep him alive by spoon-feeding or offering him liquids. VSED, short for “voluntarily stopping eating and drinking,” is not unheard-of as an end-of-life strategy, typically used by older adults who hope to hasten their decline from terminal conditions. But now ethicists, lawyers and older adults themselves have begun a quiet debate about whether people who develop dementia can use VSED to end their lives by including such instructions in an advance directive.

Experts know of just a handful of people with directives like Mr. Medalie’s. But

dementia rates and numbers have begun a steep ascent, already afflicting an estimated 30 percent of those older than 85. Baby boomers are receiving a firsthand view of the disease's devastation and burdens as they care for aging parents.

They may well prove receptive to the idea that they shouldn't be kept alive if they develop dementia themselves, predicted Alan Meisel, the director of the University of Pittsburgh's Center for Bioethics and Health Law.

"People in their 50s and 60s frequently say: 'I don't want to be in that situation. I don't want to put my family in that situation,'" he said. "And people will increasingly voice those views to others, sometimes in a formal way through advance directives."

Mr. Medalie, fierce-eyed at 88, has seen people close to him die lingering deaths from dementia and has already decided. His motto, pithy enough for a T-shirt: "If I'm not me, I don't want to be."

Dementia, though a terminal diagnosis, presents unique obstacles for those who want some control over the way they die. It generally kills slowly, over years, and "there is often no plug to pull," said Dr. Stanley Terman, a psychiatrist in Carlsbad, Calif., who specializes in end-of-life decision-making and estimates that several hundred people have requested copies of his Natural Dying Living Will. "There's no high-tech, life-sustaining treatment that can be withdrawn or withheld."

Even in the few states where physicians can legally prescribe lethal medication for the terminally ill, laws require that patients be mentally competent and able to ingest those drugs themselves. Mr. Medalie would prefer that option if he were to become demented, preferably with the barbiturates dissolved in "a little vodka."

But demented patients don't qualify for so-called death with dignity. VSED is a lawful way to hasten death for competent adults who find life with a progressive, irreversible disease unendurable. Several medical studies have reported that, with proper oral and palliative care, it can also be a comfortable way to die.

The question for proponents of VSED by advance directive is whether the practice can also provide a humane exit for those who, years later, no longer remember or understand why they wanted to use it.

Proponents of the approach acknowledge that dementia patients and their health care proxies will face great controversy if they try to cut off food and water; so will the professionals who care for them.

Nourishment carries connotations, from infancy, that make stopping it feel

different from rejecting medical machinery.

“It’s the rhetoric more than anything,” said Mr. Meisel, the author of the legal treatise “The Right to Die.” “You can apply the word ‘starvation.’”

If those opposed to removing patients from ventilators had thought to call it “suffocation,” he adds, the issue might be similarly contentious.

Moreover, the legal status of VSED by advance directive remains untested. In a recent article in *The Hastings Center Report*, two advocates argued that food and water should not be withdrawn until severe dementia has eroded the patient’s quality of life and “the self has withered.”

That approach would probably pass legal muster, said Paul Menzel, philosophy professor emeritus at Pacific Lutheran University, and an author of the piece.

Spoon-feeding may constitute basic care, however, more akin to changing sheets or bathing than to medical interventions.

“People get in trouble — nursing homes, even family members — for inadequate nutrition or letting someone dehydrate,” said Thaddeus Pope, the director of the Health Law Institute at Hamline University School of Law. “Neglecting basic human comfort care is a big source of elder abuse complaints and criminal prosecutions.” And if a patient demands that his basic care be withheld in the event of dementia? “Nobody from a legal perspective has really meaningfully grappled with that,” he said.

In several states, including New York, Wisconsin and New Hampshire, statutes have made it difficult to withdraw oral nutrition or hydration, sometimes even if that instruction is included in a directive.

A court case unfolding in British Columbia shows just how tricky these judgments can be.

Margo Bentley, 83, is a retired nurse with advanced Alzheimer’s disease. Her advance directive specified “no nourishment or liquids” if she became incapacitated.

When her husband and daughter attempted to honor her wishes, the care facility where she lived refused, sending the family to court.

Last February, a judge ruled that although a health care provider could legally honor such a directive, Ms. Bentley’s feeding should continue in part because she swallows food placed in her mouth. That constitutes consent, the judge ruled. The family has appealed.

If swallowing is all it takes to legally invalidate an advance directive, Mr. Pope

said, then patients will never be able to specify that they want for food and water to be withdrawn should they become demented.

The moral and ethical aspects are even more dizzying. Can one's current, competent self make decisions on behalf of one's future demented self — who may find modest pleasure, years later, in a life once deemed intolerable? What if that later self asks for, or points to, applesauce?

“I can imagine people saying, ‘You’re starving this vulnerable person who’s dependent on us for care when this person is willing to eat,’ ” said Rebecca Dresser, professor of law and medical ethics at Washington University in St. Louis.

At the other end of the ideological spectrum, Dena Davis, a Lehigh University bioethicist who has published articles on “pre-emptive suicide,” disputes the notion that withholding food should wait until the advance directive writer has reached a severe stage of dementia.

By that point, “you lost your dignity a long time ago; you’ve probably been a burden on your family for six or seven years,” she said. “It’s too little, too late for me.”

Religious organizations, disability groups and uneasy nursing home administrators will also surely weigh in if patients and families try to enforce VSED as detailed in advance directives. Catholic authorities, for example, have generally opposed removing terminally ill patients’ feeding tubes or IV fluids.

“We should not encourage people to think their life has no meaning or value because they’re in a fragile, vulnerable and terrible situation,” said John Brehany, a former executive director of the Catholic Medical Association. He predicted that Catholic-affiliated hospitals and nursing homes wouldn’t honor such directives.

None of this remotely dissuades Jerome Medalie. For now, “life is exceptionally good.” A veteran of bypass surgery, multiple angioplasties and two knee replacements, he exercises daily, canoes on the nearby Charles River with his grandchildren in summer, and uses a voice-controlled computer to counter the effects of macular degeneration.

His wife and children — and nearly everyone he has met in the last 20 years — are fully aware of his desires and instructions, however, and they are committed to carrying them out.

“I want to go out on my own terms,” he said. “I don’t want any church, the government, any doctor or hospital or even any member of my family to contradict

what I want for my death.”

But he hasn't persuaded everyone. Dr. Susan Mitchell, a Harvard Medical School geriatrician and researcher, has met Mr. Medalie and read his advance directive.

If she encountered a future Jerome Medalie, bed-bound and suffering from advanced dementia, she said, “I would not feel comfortable not gently offering him at least a sip of water and a spoonful of ice cream.”

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Correction: February 4, 2015

An article on Jan. 20 about people who want to draft advance directives allowing them to end their lives by voluntarily stopping eating and drinking, or VSED, if they eventually develop severe dementia referred incorrectly to the regulations governing the withdrawal of oral nutrition or hydration in three states and gave outdated information for a fourth state. In New York, Wisconsin and New Hampshire, it can be difficult for patients with dementia to end their lives by VSED because of state statutes, not because their legislatures have explicitly banned it. And in Minnesota, the statutes concerning the withdrawal of oral nutrition and hydration apply only to directives executed before Aug. 1, 1998, not to ones executed since then.

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