

## **Groundbreaking option in Washington state could let dementia patients refuse spoon-feeding**

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**A Washington state agency that advocates for medical aid-in-dying has created guidelines for dementia patients who fear losing control not only of their faculties but of their free will to live and die on their terms. By [JoNel Aleccia](#)**

*Kaiser Health News*

People who abhor the thought of being kept alive with feeding tubes or other types of artificial nutrition and hydration have, for years, had a way out.

They could document their wishes to halt such interventions —and have them honored — using advance directives.

That includes patients diagnosed with progressive dementia who are able to record crucial end-of-life decisions before the disease robs them of their mental capacity.

But the practice has rarely — hardly ever — included provisions to refuse food and fluids offered by hand. Until now.

A Washington state agency that advocates for medical aid-in-dying has created guidelines for dementia patients who don't want to be spoon-fed at the end of life.

The group [End of Life Washington](#), which assists people using the state's 2009 Death with Dignity Act, recently posted new "Instructions for Oral Feeding and Drinking" on its website.

Aimed at people with Alzheimer's disease and other progressive dementias, the document provides a two-page template for patients to instruct caregivers not to provide oral food or fluids under certain circumstances. There's another document explaining the do's and don'ts of using it.

The instructions — though not legally binding — are groundbreaking for patients who fear losing control not only of their faculties but of their free will to live and die on their terms, said Sally McLaughlin, executive director of End of Life Washington.

"We get calls from folks with concerns about dementia and concerns about the fact that loved ones with dementia feel like they're being force-fed," McLaughlin said. "Many, many folks understand that as they stop eating, they would like no one else to feed them."

Critics say the new document raises concerns about potential mistreatment of vulnerable patients, arguing that such “instructions” could be used essentially to starve the elderly or incapacitated.

“It really is troubling,” said Stephen Drake, research analyst for the disability-rights group Not Dead Yet.

He points to other so-called right-to-die efforts, such as the refusal of artificial nutrition and hydration, saying they started out narrowly defined, then became common practice.

“It really is a big game-changer in the number of people whose lives can be ended when they’re in vulnerable situations,” Drake said. “In legal situations, this is a door-opener.”

Proponents say the guidelines fill an information gap for people already interested in navigating the uncertain landscape at the end of life.

“What we are saying is that there are objective and somewhat subjective conditions in the future where you can say ‘I’m giving you instructions now to help you interpret my wishes,’” said Bob Free, a Seattle lawyer who helped draft the document. “We have never really seen a standard form or advance directive to govern this.”

The guidelines do not apply to people with dementia who still get hungry and thirsty and want to eat and drink, the authors note.

“If I accept food and drink (comfort feeding) when they’re offered to me, I want them,” the document states.

But if the person appears indifferent to eating, or shows other signs of not wanting food — turning away, not willingly opening their mouth, spitting food out, coughing or choking — the document says attempts to feed should be stopped.

And the guidelines tell caregivers to respect those actions.

“No matter what my condition appears to be, I do not want to be cajoled, harassed or forced to eat or drink,” the document states. It adds that the “reflexive opening” of the mouth should not be interpreted as consent to eating.

“An analogy is the difference between when a knee is tapped with a hammer and the reflexive response is a knee jerk and when a person voluntarily raises his or her knee,” said Free. “We think this is a fairly objective test, which in real life will be clear.”

The new guidelines won’t be binding — legally or ethically, experts say. Nearly two dozen states have laws that address assisted feeding, including many that prohibit withdrawing oral food and fluids from dying people.

“The hard part about advance directives is even though you put your wishes there, it doesn’t mean a medical professional will honor it — or that a facility will honor it,” said

Jonathan Patterson, staff attorney for Compassion and Choices, a group that supports medical aid-in-dying.

## “Much more specific”

The new forms follow two recent high-profile cases in which family members said dementia patients were kept alive with spoon-feeding by caregivers, despite written requests to stop.

Margot Bentley, 85, of British Columbia, died last year. She was a retired nurse who had cared for dementia patients before being diagnosed with Alzheimer’s in 1999. In 1991, she wrote a statement stipulating that she wanted no nourishment or liquids if she developed an incurable illness. However, the nursing home where she was a patient continued to spoon-feed her, despite her family’s protests. A court ruling upheld that action, saying food is basic care that cannot be withdrawn.

Nora Harris, 64, of Medford, Oregon, died Oct. 11 after an eight-year struggle with early-onset Alzheimer’s disease. More than a year earlier, her husband had [gone to court to stop caregivers from spoon-feeding](#) Harris, who had an advance directive that called for no artificial nourishment or hydration. A judge declined, siding with officials who said the state was required to feed vulnerable adults.

Such cases horrify people who fear the same fate. Nancy Christensen, 60, a Seattle nurse, said she updated her living will herself within days of reading about Harris.

“I thought, ‘Wow, I need to be much more specific,’ ” said Christensen, who appended notes saying she doesn’t want assisted feeding if she can no longer feed herself. “I don’t think anybody thinks about this until they’re too far into it.”

Free, 71, said he plans to fill out the new documents himself.

“It’s been a personal desire of mine to have a dignified death,” said the lawyer. “The idea that my sons would have to witness me in a deteriorated state is very frightening and demoralizing.”

## Document just a start?

Whether VSED, which stands for “voluntarily stopping eating and drinking,” can be authorized in advance by people diagnosed with dementia remains unclear. The question has gained traction in a nation where dementia cases in people 65 and older are projected to reach 7.1 million by 2025. Paul Menzel, a retired bioethicist at Pacific Lutheran University in Tacoma, said some people want to avoid the most debilitating stages of the disease.

“It’s not misery they’re afraid of,” he said. “They just don’t want years of withering.”

The End of Life Washington document is a novel tool, but it may not go far enough, said Judith Schwarz, clinical director for End of Life Choices New York, which advocates for medical aid-in-dying. The conditions it lists typically apply to the final stages of dementia, she said. Some patients want the right to refuse food earlier in the disease process in a deliberate effort to hasten death.

Until now, however, there have been few models for articulating those desires.

“It certainly is an improvement over no previous mention of hand-feeding,” Schwarz said. “Maybe this is where it must begin.”

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