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Feeding Dementia Patients With Dignity

By RONI CARYN RABIN

First [Alzheimer's disease](#) stole Rosemary DeFelice's speech, mobility and independence. Then, at 75, she lost the ability to eat.

She would chew away at her food, coughing and sputtering and spitting up but swallowing very little, said her daughter, Cyndy Viveiros. And like many relatives caring for patients with advanced [dementia](#), Ms. Viveiros had to decide whether or not to have a gastric feeding tube inserted.

This quandary — which usually arises near the end, when Alzheimer's begins to destroy the part of the brain that controls eating — is often presented as a stark choice between providing nourishment and withholding it.

But social workers advising Ms. Viveiros suggested another option: continuing to have her mother carefully fed by hand, giving her only as much as she wanted and stopping if she started [choking](#) or became agitated.

"I had this realization — wow — that no matter what we did, Mom was never going to get better," Ms. Viveiros said. "We were just prolonging the inevitable, and potentially causing more suffering.

"Mom was already dying. Alzheimer's is a terminal disease. There's no stopping it," she said.

Mrs. DeFelice, of Providence, R.I., died about eight months later.

Doctors are calling this new option in palliative care "comfort feeding only." In a recent paper in *The Journal of the American Geriatrics Society*, the authors argue that feeding tubes do not necessarily prolong life in patients with advanced dementia, and that surveys indicate that a vast majority of nursing home residents say they would rather die than live with a feeding tube.

But medical orders like “no artificial hydration and **nutrition**” — used to indicate that the patient should not be given a feeding tube — are often interpreted as “do not feed.” And few people can tolerate the idea that a loved one may be starving to death.

Comfort feeding offers another alternative.

“We believe careful hand-feeding is a much more humane way of taking care of these people, and preserves the patient’s dignity,” said an author of the paper, Dr. Joan Teno, a professor of community health at **Brown University**’s medical school. “They can still have that human interaction and intimate contact that comes with being fed.

“Just imagine someone interacting with the patient, talking to them, cueing them into eating,” Dr. Teno said, “as opposed to someone walking to the bedside and pouring a bottle of Ensure down the feeding tube.”

Nancy Berlinger, a bioethics research scholar at the Hastings Center, a research institute in Garrison, N.Y., said the feeding-tube dilemma was “not a choice people tend to want to face with reference to their mother, who probably fed them at an earlier age.”

Eating is a pleasurable activity, and feeding is associated with love and nurturing, Dr. Berlinger went on, so the question “Should we put a feeding tube in, or do you want to stop feeding her?” is almost like asking, “Do you love your mother or not?”

Feeding tubes are used in about a third of all nursing home residents with advanced dementia, in part because the homes worry they could face regulatory scrutiny if their patients are losing weight. Hand-feeding can also be time-consuming and labor-intensive. In addition, the **United States Conference of Catholic Bishops** issued a directive last year stating that Catholic health facilities have “an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally.”

Yet studies suggest that the tubes do not necessarily prolong survival. Nor do they always prevent aspiration in people who have trouble swallowing, since they are at risk of aspirating their own saliva.

Moreover, the tubes can be very uncomfortable, and people with dementia must often be physically restrained or sedated to prevent them from yanking the tubes out.

As many as 5.1 million Americans have Alzheimer’s disease, the most common cause of dementia, and the number is expected to rise as the baby boom generation ages. The disease is progressive and terminal, though it may take years to run its course; it is the sixth leading

cause of death in the United States, killing more than 71,000 a year, a figure many experts think is understated.

Sometimes the ability to eat is lost in the early stages of Alzheimer's, not toward the end. Seymour Geffner says it was one of the first signs that something was wrong with Blossom, his wife of 63 years.

He started feeding her four years ago, while she went through a series of tests to figure out what was wrong. Now that she lives at Schervier Nursing Care Center in Riverdale, in the Bronx, he spends every day there, hand-feeding her lunch and dinner.

Each feeding takes 45 minutes to an hour, said Mr. Geffner, 86.

"Some days are better than others," he said. "The food is puréed, and she doesn't eat a full meal. But I always give her at least half a banana every day, and strawberries in season."

"The bottom line is she doesn't go hungry," he said. "She looks good."