



Feeding the Person With Late-Stage Alzheimer's Disease

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Families need guidance in making decisions on how to feed a loved one with late-stage Alzheimer's disease. Tube feedings have not been shown to extend life, improve nutritional status, or reduce pressure sores or aspiration and may have some negative effects on quality of life. Even so, they continue to be used widely. Assisted feeding may be an appropriate method when the therapeutic goal is comfort feeding. Resistance by health care professionals and surrogate decision makers to "withholding food" from a person with late dementia can be reduced with education. *Nutr Today*. 2011;46(2):75-79

An 84-year-old woman was admitted to a nursing home after hospitalization for aspiration pneumonia. Six years earlier, she had been diagnosed with Alzheimer's dementia (AD) and was now requiring help with dressing, toileting, grooming, and eating. She experiences dysphagia or difficulty in swallowing. Her diet had been liberalized. Despite good family support, she has lost 44 lb over the last year. Her current body mass index is 18.9 kg/m². She measures 5 ft 7 in. During feeding, she pockets food in her cheeks and spits it out. She often coughs when drinking liquids. The family has tried giving the patient her favorite foods, supplemental shakes, thickeners for liquids, and appetite-enhancing medications. She is considered a full code status but does not have advance directives or a Physician Orders for Life-Sustaining Treatment (POLST) outlining the end-of-life care she desired. Her family is asking about her prognosis and feeding options. In addition to their concern about their mother losing weight, they fear she may be experiencing the pain of hunger or thirst.

What's Going On

This older woman is coming to the end of her life, and eating problems with distressing symptoms have developed. Her family is facing a difficult decision

on how to have their mother fed. For many possible reasons, including attitudes of health care professionals and family members, regulatory scrutiny of weight loss in long-term-care facilities, and the time and labor intensity and outcomes of assisted feeding, feeding tubes are placed in people with late-stage AD. This article presents issues surrounding the decisions about feeding individuals with advanced AD including the risks and benefits of enteral tube feeding and assisted feeding in people with advanced AD. The effect of educating health care professionals and families is also described.

Malnutrition and AD

The dementia syndrome is defined by memory problems, at least 1 additional cognitive decline (aphasia, apraxia, agnosia, or executive function), and progressive decline that interferes with daily function and independence.¹ A recent analysis showed a mean survival of 6.7 years after the time of the dementia diagnosis in primary care setting for patients aged between 60 and 69.² There are several types of dementia, including AD, vascular, mixed, frontotemporal, Lewy body, and Parkinson's disease. Alzheimer's dementia is the most common type. As many as 5.1 million Americans may currently have AD, and it is projected to affect 19 million Americans by 2050.³

Malnutrition and unintentional weight loss are commonly observed in individuals with advanced AD. Over the course of an 18-month study, Mitchell and coworkers⁴ found that more than 86% of residents with advanced AD living in nursing homes experienced eating problems. Other complications such as pressure ulcers and aspiration also indicate advanced dementia with poor outcomes.^{4,5} Common types of feeding problems in AD are outlined in Table 1.

Tube Feeding in Patients With AD: What Are the Facts?

When feeding problems are observed and unintentional weight loss continues, a discussion regarding artificial

Table 1. Common Symptoms of Feeding Problems in Advanced Alzheimer's Dementia

Easily distracted while eating
Poor oral food and fluid intake
Pocketing food in cheeks or spitting out food
Decreased taste, smell, or appetite
Swallowing difficulties (ie, gagging, choking, coughing)
Aspiration of food or oral secretions
Loss of hand coordination for feeding, inability to use utensils
Chewing or eating objects generally not considered food by the individual or culture
Loss of weight

hydration and nutrition is often initiated by family or medical provider or nursing home staff. Tubes are typically placed when the patient cannot or will not eat and the gut is functional, allowing the individual to meet his/her nutrition needs by receiving liquid food into the stomach by either bolus or continuous infusion. Many health care professionals and families believe that tube feeding is undoubtedly beneficial to the patient. As a result, the use of enteral feeding tubes has become common in as many as 1 in 3 patients with advanced dementia with feeding problems,⁶ even though its risks and benefits have been debated since the 1990s.

When unintentional weight loss continues, a discussion regarding artificial hydration and feeding is often initiated by family or medical provider or nursing home staff.

Most authorities have concluded that percutaneous endoscopic gastrostomy or jejunostomy feedings do not improve mortality, pressure ulcers, aspiration pneumonia, nutritional status, or quality of life for people with advanced AD.⁶⁻⁹ In fact, many have observed that loss of lean muscle mass and weight continues despite tube feedings.

Certain patient and health care characteristics affect the rate of tube feeding in this population. In an analysis of 163 022 nursing home patients with advanced AD during the period 2000 to 2007, more than 12% of those patients had a feeding tube placement.¹⁰ Hospitals that placed more tubes were larger and for profit and provided higher rates of intensive care to chronically ill

individuals during the last 6 months of life. Also, black and Hispanic patients were also more likely to have tubes placed. For those patients with written directives, "Do Not Attempt Resuscitation" orders, and orders to forego artificial hydration and nutrition, the rate of tube placement was lower.

Feeding problems in advanced dementia indicate a very poor prognosis. In a recent prospective study of nursing home residents with advanced AD,⁴ the 6-month mortality rate for patients with eating problem was very high at 38.6%. Other conditions that indicated high 6-month mortality were pneumonia (46.7%) and febrile episode (44.5%). During the last 3 months of life, almost 8% received feeding tube, and more than 40% experienced burdensome interventions (hospitalization or emergency room visit, parenteral therapy, or tube feeding). This study⁴ also confirmed that the patients were 7 times less likely to receive all burdensome interventions in the last 3 months of life if the patients' decision makers understood the poor prognosis of advanced dementia and the associated complications. The discussion regarding the poor prognosis becomes essential to include when speaking with the family members regarding the various feeding options.

Many authors also suggest that the quality of life of a person with advanced AD is impaired with the placement of a tube.⁹ The existing literature suggests a medical complication rate of 32% to 70%.^{11, 12} Tube feedings in advanced AD patients have a potential for problems at the time of placement such as chronic nausea and vomiting, bleeding, and/or infection. There are ongoing issues such as dislodgement of tube, and some patients are potentially restrained physically to prevent the removal of feeding tubes. Others experience chronic discomfort or pain and skin erosion or ulceration around the tube site. The experts conclude that tube feeding neither worsens mortality nor provides a survival benefit when compared with withholding a tube.^{4,13} It is therefore appropriate to have a full discussion with the families regarding the lack of clear advantages of feeding tube and possible adverse outcomes.

If No Tube Feeding, Is Assisted Feeding Sufficient?

Assisted feeding is an interdisciplinary approach to feeding a patient with advanced AD and includes a coordinated effort from the various caregivers and professionals. The summary of assisted feeding methods is outlined in Table 2.

Families frequently wonder whether their loved one with AD is starving or suffering from their eating problems. Patients at this stage often refuse to eat or

Table 2. Assisted Feeding Methods

Assisted Feeding Methods	Interdisciplinary Team Members
• Calm environment	Families
• Meal groups	Certified nursing assistant
• Cueing	Dietitian
• Hand feeding	Nutritionist
• Adaptive utensils	Speech therapy
• High-calorie supplements	Physicians, nurse practitioner, physician assistant
• Favorite or family foods	Nursing staff
• Liberalizing diet	Occupational therapy
• Soft/pureed food	Hospice, home health agency
• Finger foods	

With the use of educational session, the researchers found that the surrogate’s knowledge about feeding options improved, and they had less expectation of benefit from tube feeding in dementia.

In summary, assisted feeding may be a viable alternative to tube feeding in these individuals; however, there have not been studies that directly compare outcomes from the 2 feeding approaches, and more research is needed in this area. The dietitian has a role in assessing and evaluating the need for nutrition interventions tailored to each person’s medical condition, needs, desires, and rights.¹⁷

drink, even though they are offered food. This is due to the patient’s sense of hunger and thirst diminishing as dementia advances. Once families realize that the patients with AD often do not experience hunger or thirst, they may be able to remove the guilt they feel associated with “starving them to death” and accept the natural progression of end-stage AD. It is also important to explain that patients with poor food and fluid intake who become dehydrated typically do not express pain or discomfort. It is generally believed that dehydration in end-stage dementia is not painful.

When helping a family decide if assisted feeding is the appropriate route to nourish an individual with advanced AD, it is important to clearly define the therapeutic goal. A variety of behaviors and conditions (Table 3) hinder a patient with advanced AD from obtaining appropriate nutrition. It is expected that assisted feeding may not meet the known nutrition and hydration needs of the person.¹⁴ It is crucial to clearly identify the goals of therapy, which include patient comfort, sense of normalcy, and enjoyment of food and feeding. The patients’ decision makers need to fully discuss the expectations and limitations of assisted feeding.

An ongoing support, education, and communication need to be provided to the decision makers to promote well-informed decisions regarding feeding options and assisted feeding. The educational interventions have been shown to decrease the overall decisional conflict and regret and increase the knowledge of feeding options in decision makers.^{15, 16} It is also clear that, in nursing facilities, the families mostly discuss the feeding issues and options with the staff members rather than with physicians (71% vs 17%, respectively).¹⁵ Therefore, educating all staff members in nursing homes and congregate living facilities becomes a vital role for dietitians and nutritionists.

Reducing the Rate of Burdensome Tube Placement

The actual number of Americans with AD who have documented wishes regarding artificial nutrition and

Table 3. Behaviors That Affect Individuals With Alzheimer’s Dementia Receiving Adequate Nutrition

Hindering
• May not recognize food
• Have decreased taste, smell, appetite
• Poor hand coordination
• Easily distracted
• Experience dysphagia and choking
• Spit food
Supporting
• Individuals with AD form relationships with their caregivers and feeders
• Providing a calm environment for eating
• Providing high-calorie supplements, favorite or family foods, soft or pureed or finger foods
• Giving verbal or touch cue
• Feeding with adaptive utensils or by hand
• Reorienting the person to the meal
• Hugging and kissing and/or maintaining touch between the feeder and the individual
• Giving reminders to swallow, encouraging a small cough between bites, and limiting bites to less than a tablespoon

Abbreviation: AD, Alzheimer’s dementia.
Adapted from Garrow et al⁷ and DiBartolo.²¹

hydration is unknown but is thought to be low. Dietitians and other health care professionals can play a role in alerting their patients/clients about the option to document their wishes in advance directives and health care power of attorney. Advance directives are available in each state and typically honored throughout the United States. Health care power of attorney is a legal document that designates a health care decision maker in case the patient herself is not capable of making medical decisions. This should be a person who is trusted with making decisions that are known to be the patient's wishes or understands the patient's values to make the best decision possible for her. Both of these documentation options require that the patient is capable of understanding and deciding the various options. Therefore, these documents must be drafted before the patient advanced in his/her dementia stage.

Where available, the dietitian may inform the family about POLST. A POLST is a medical order issued by a qualified health professional with the informed consent of the patient or patient representative that ensures a patient's wish for medical treatment at the end of life is known and honored. It is intended for patients who have an advanced chronic progressive illness and may have life expectancy less than 1 year. It includes preferences for artificial nutrition and hydration.^{18,19} The POLST can be drafted with a physician and the patient's legal decision maker, allowing for an advanced dementia patient's care to be documented when the patient is unlikely to be capable of making these medical choices. They are available in a small but growing number of states. An alternative to the use of the POLST model is for physician to write orders outlining specific patient or medical decision-maker wishes, such as "do not place feeding tube" or "do not hospitalize" after a full discussion and agreement on the future treatment plans.

For Health Care Professionals and Institutions

One hospital demonstrated that, by using interdisciplinary teamwork and focused education, it was possible to produce a rapid change in practice or culture shift on this issue.²⁰ With the creation of a palliative care consulting team and focused education on end-of-life care, the number of feeding tubes placed in patients was greatly reduced. They noted, however, that the number of tubes placed in patients with an advance directive refusing artificial nutrition was not significantly reduced. They reported that this highlighted the resistance by some doctors and surrogate decision makers to withhold this type of treatment. Some geriatric experts suggest that a way to reduce that resistance is to reframe the

discussion.¹⁴ They suggest creating a new order: "comfort feeding only." By that they mean to feed the individual as long as such feeding is not distressing. The goal is to feed for comfort, using the least invasive and potentially most satisfying way of attempting to maintain nutrition through careful hand feeding. The registered dietitian has a role in teaching other team members about the risks and benefits of nutritional interventions.

One hospital demonstrated that a culture shift regarding feeding options is possible and with interdisciplinary teamwork

The Case Revisited

The patient's family members had an initial discussion of the options available for feeding, the prognosis, and the goals of treatment for this patient with advanced dementia with the dietician, nursing supervisor, and the physician. During the meeting, the natural progression of AD, as well as the advantages and disadvantages of assisted feeding and tube feeding, was fully explained. Also, the poor prognosis was made clear, and the goals of therapy for the patient were explored. The family wanted foremost to ensure that the patient is comfortable and understood the poor prognosis regardless of the feeding options available for the patient. Subsequently, the family members decided to enroll the patient under hospice care and agreed to change her code status to "do not attempt resuscitation." They also expressed the desire that any painful procedures and hospital/emergency department transfers be minimized and consider only if the patient would benefit in maintaining comfort. They desired assisted feeding only, and no percutaneous endoscopic gastrostomy tube placement. The physician and the staff members at the nursing home continued to update and counsel the family members on the various interventions afterward. The patient continued to lose weight despite the interventions and died several months later of complications of aspiration pneumonia. The patient was managed at the nursing home with close collaboration between the nursing home staff and hospice. The family expressed high satisfaction with the care provided and thanked the various providers for their involvement.

Summary

Health care professionals including dietitians can help patients and families understand the dementia diagnosis

and prognosis and the advantages and disadvantages of each feeding option and to discuss and document personal wishes and the personal beliefs of the patient. Formulating an appropriate therapeutic goal is key.

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