

# To Feed or Not to Feed: Nutrition Considerations at the End of Life

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Most people hope for a respectful, peaceful death, one where they just slip away into the night. Unfortunately for many patients and their families, the end of life is not a single instant but rather a long complicated period fraught with agonizing decisions. The decision on whether to feed a loved one who is at the end of life is often excruciatingly painful. The media has played out several lengthy debates involving enteral or artificial feeding — patients Nancy Cruzan and Terri Schiavo became household names as their families battled about feeding issues regarding loved ones in a persistent vegetative state. These explosive media cases are infrequent but registered dietitians (RDs) and healthcare practitioners in home care, hospitals, and extended care facilities must deal with the question of feeding at the end of life on a daily basis.

## Dementia Study Results

The research on feeding patients with end-stage dementia is plentiful and growing. A search on PubMed using the keywords *tube feeding* and *dementia* found 282 articles published between 1980 and 2009. Many of these studies indicate that healthcare professionals are not adequately informed on the benefits versus the burdens of educating patients and families responsibly when no instructions on end-of-life feeding wishes pre-exist. Because our elderly population is expected to quadruple by 2050, patients with severe dementia and the accompanying nutrition and hydration problems will continue to increase, and we will need to become better prepared to provide education.<sup>1</sup> The evidence is sound that patients with terminal dementia, regardless of etiology, have difficulty eating, swallowing, or having food fed to them, resulting in unintended weight loss and/or aspiration, which eventually leads to death. Although it goes against commonly held beliefs, numerous studies have shown that aggressive enteral nutrition at the end of life does not necessarily extend life, increase body weight, reduce the incidence of pressure ulcers, or reduce the risk of aspiration.<sup>2</sup>

Despite the fact that up to one third of patients with severe dementia receive tube feedings (TFs), a recent *Cochrane Database Review*<sup>3</sup> suggested that TF may actually increase the death rate, increase the number of new illnesses, and reduce quality

of life. A recent study<sup>4</sup> of nursing home residents with dementia revealed mortality was 64.1% with a median survival of 56 days within 1 year following percutaneous endoscopic gastrostomy (PEG) insertion.

## Starvation Myths

Watching a loved one stop eating and/or drinking is difficult to bear, even when we know that it is that individual's wish. The situation is even more trying when family members and caregivers do not know the patient's terminal preference. The word *starvation* becomes top of mind and conjures up brutish images for most people. The phrase *dying of starvation* often is bandied about but is not technically accurate because the patient will likely expire from dehydration first. At the end of life, patients have a tendency to lose the desire to eat or drink because their appetite and thirst are minimized. Their metabolism changes, organ function slows, and the resultant elevated level of ketones produces a mild sense of euphoria. Starving people generally want food. Dying people do not. RDs and team members should help family members understand this change in metabolism and avoid the use of the word *starvation*.

We now also know that gradual dehydration is not painful; in fact, many patients report less discomfort as dehydration runs its course and have fewer requests for pain medication. Complaints of a dry mouth are treated more effectively by good mouth care along with ice chips, if the patient is alert. If the patient is not alert, mouth swabs are recommended rather than intravenous fluids. In reality, the administration of food and fluids to dying patients can extend their general discomfort and frustrate their desire to just let go and allow nature to take its course.<sup>5</sup>

## Tube Placement and Feeding

The healthcare team must clearly understand both the benefits and burdens of TF in order to fully relay this information to the patient and family members. The purpose of tube placement is to provide adequate nutrition and hydration when oral intake is not sufficient, safe, or feasible.<sup>6</sup> It is a lifeline for many individuals, such as stroke patients with good recovery potential or persons with diseases such as amyotrophic lateral sclerosis

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(ALS), when the ability to swallow sometimes is affected long before a person reaches the terminal phase of the disease.

PEG tube placement became common in 1979, providing a lower risk option to surgical placement of the traditional gastrostomy tube. However, even the PEG tube placement procedure itself is not without risks. Peristomal wound infections can range from 5% to 25%; thus, postoperative use of antibiotics is common.<sup>7-9</sup> Patients who are malnourished often have fragile skin, while patients with diabetes may have difficulty healing. These pre-existing concerns may put the patient at higher risk for post-PEG tube placement issues. Table 1 lists the major and minor complications encountered with PEG tube placement.<sup>6</sup>

The discussion of a patient's feeding wishes should take place long before a decision is needed. If aggressive support is desired, PEG placement should occur when it first becomes evident the patient can no longer consume adequate nutrition to avoid unintended weight loss. Often, PEG tubes are placed too late, making it impossible to regain the benefits that may have resulted from earlier placement.

When organ function is declining and lab values such as potassium, magnesium, and phosphorus are not monitored adequately, aggressive re-feeding of a malnourished patient is rife with risk. Additional PEG tube problems can include the need to restrain a patient's hands to avoid tube removal because of confusion, which can raise risk for skin damage; increased urination and stool output, which can worsen existing sacral pressure ulcers; and increased coughing and congestion from improved hydration. TF also deprives the patient from contact with staff if hand feeding is no longer provided, as well as the enjoyment of the taste of food, even if oral intake was previously minimal.<sup>10</sup>

### Education and Documentation

Communication with the patient and family is of utmost importance. Often the decision to insert a feeding tube is made inappropriately because of lack of information or misinformation provided by the healthcare team. This can create unrealistic expectations of the benefits a patient actually will receive from the TF and sometimes leads to litigation. Consider the loving daughter who testified that she refused a TF for her mother because the nurse posed the question in a leading manner. According to her testimony, the nurse flippantly asked, "You're not going to want a tube feeding, are you?" The daughter felt pressured to agree with the nurse's negative opinion of TF, but also felt uncomfortable that she was making life-and-death decisions without all the facts. After doing some research on her own, she decided she definitely wanted a TF and had her mother transferred to another facility where her mother received a PEG tube. Her mother's condition improved for a period of time, but she was still angered by this event and eventually sued the first facility. Another interesting point in her testimony was her comment that the discussion about TF took place in the hallway outside of her mother's room and lasted only 3 minutes.

**Table 1. Potential complications of PEG placement<sup>6</sup>**

Major	Minor
Aspiration	Tube leakage
Wound infection	Tube blockage
Peritonitis	
Hemorrhage	
Inadvertent removal of PEG	
Buried bumper syndrome	
Gastro-colocutaneous fistula	
Necrotizing fasciitis	

Often, patients and/or family members may not ask about their choices because they do not know that foregoing food and fluids is a legitimate option at the end of life. Both the person who is ill and the caregiver should complete an Advanced Health Care Directive to designate an official spokesperson to give caregivers the ability to speak for the individual who becomes too sick or too confused to make decisions. It is important that family members keep Advanced Health Care Directives where they can find them quickly and update them when necessary. If the healthcare surrogate listed has predeceased the patient, revision is essential. Family discussions on these directives are recommended so loved ones are clear on everyone's wishes and can honor them appropriately.

The moral and ethical uncertainty facing patients, healthcare surrogates, and physicians when confronted with the choice to withhold nutrition and hydration likely drives the decision to place PEG tubes in many patients who are unlikely to derive any benefit. It sometimes is difficult to put ethical and religious beliefs aside when assisting families to make uncomfortable end-of-life decisions. It is essential that healthcare team members know when to switch to palliative support versus curative care. However, it is uncertain whether interventions such as improved staff education about the limitations of PEG tubes to improve outcomes, increased use of palliative care teams, and increased use of Advanced Health Care Directives will help decrease in PEG tube placement in patients with end-stage illness.

### Practice Points

When nutrient intake is insufficient to meet physiologic needs, competition for the available nutrient substrate occurs. Wound healing is not the biological priority so do not be discouraged if the person has stagnant or worsening wounds.

If you do not feel comfortable addressing nutrition choices with a terminal patient's family, educate yourself and practice what you might say. Some guidance, including a script on this sensitive topic, is found at [www.RD411.com](http://www.RD411.com) in the Conversation Starters section. Also see Helpful Resources.

The healthcare team and family may decide to discontinue

weighing a patient after a decision is made to forego TF and all attempts to improve oral intake have failed. The act of weighing may disturb the sick patient, upset the family if significant weight loss occurs, and take time away from staff that is better spent elsewhere. The attending physician can provide an order to discontinue weight monitoring if the family and team members are all in agreement.

A medical care facility in Michigan found that providing a booklet<sup>11</sup> with their admission packet that outlines the process of withholding nutrition and hydration near the end of life is helpful in educating families early in the end-of-life decision process.

TF can continue once a patient is approved for hospice services; this should never deter families who wish to take advantage of the supportive and pain management services hospice can provide when life expectancy is less than 6 months.

When poor meal intake and unintended weight loss are first noticed, an aggressive care plan should be put in place, communicated to all involved parties, and documented in the medical record. Do not wait until patients have lost 10% or more of their usual body weight to begin interventions. Early identification and timely intervention is the key.

Set an example by taking stock of your own wishes for end of life care and complete the necessary paperwork now. This will give you and your family peace of mind.

## Final Word

Enteral nutrition surely has its role in medical care, but it is not a cure-all. As with every medical intervention, it is necessary to carefully weigh the risks and benefits. Death is not a comfortable topic in American culture but in order to provide the best care for our patients, healthcare practitioners must show the ability and willingness to tackle this topic. It is only with our guidance, compassion, and knowledge that we can help patients and families explore and contemplate all the options open to them, including the choice to feed or not to feed. ■

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## Helpful Resources for Further Exploration

Family Caregiver Alliance®: This alliance seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Fact sheets include End-of-Life Choices: Holding On and Letting Go and End-of-Life Choices: Feeding Tubes and Ventilators. Available at: [www.caregiver.org](http://www.caregiver.org) or (800) 445-8106.

Tube Feeding Options at the End of Life: A Consumer and Caregiver's Guide by James M. Hoefler, PhD: This guide provides specific details in the areas of medicine, ethics, law, and religion regarding end-of-life feeding. Available at: [www.dickinson.edu/endoflife/](http://www.dickinson.edu/endoflife/).

Alzheimer's Association: The Association provides a 28-page handout, *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Home: Phase 3 End-of-Life Care*. This is a project of the Alzheimer's Association Campaign for Quality Residential Care and provides a wealth of information for families and caretakers. Available at: [www.alz.org/national/documents/brochure\\_DCPRphase3.pdf](http://www.alz.org/national/documents/brochure_DCPRphase3.pdf) or (800) 272-3900.

Center to Improve Care of the Dying: The Palliative Care Policy Center offers expert support to hospitals, nursing homes, health systems, hospices, and other organizations that serve individuals nearing the end of life. Available at: [www.medicaring.org](http://www.medicaring.org).

National Hospice and Palliative Care Organization: This foundation provides state-specific Advanced Health Care Directive forms. Available at: [www.hospiceinfo.org](http://www.hospiceinfo.org) or (800) 338-8619.

Five Wishes®—Aging with Dignity: Five Wishes is a document that helps you express how you would like to be treated in the event that you become seriously ill and are unable to speak for yourself. Available at: [www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html) or (888) 5-WISHES.

How We Die: Reflections on Life's Final Chapter (1995) by Sherwin B. Nuland, MD: Available at: [www.amazon.com/How-We-Die-Reflections-Chapter/dp/0679742441/ref=sr\\_1\\_1?ie=UTF8&s=books&qid=1249911894&sr=8-1](http://www.amazon.com/How-We-Die-Reflections-Chapter/dp/0679742441/ref=sr_1_1?ie=UTF8&s=books&qid=1249911894&sr=8-1).

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