

End of Life Nutrition and Hydration

Emerging research indicates that good oral care such as brushing teeth after each meal, daily tooth or denture care, and swabbing of the tongue or oral mucosa may be as important, or more important than other techniques for preventing aspiration (15).

Enteral Nutrition Near the End of Life

Artificial nutrition and hydration is highly effective in some situations, but an ethical dilemma is created when it is not clinically indicated, or when it is ineffective or potentially harmful (6). When an adult's lifespan is limited because of their advanced age, or there are medical problems or GI problems that may affect tolerance of the enteral feeding, there is little evidence to support the use of ANH to improve health or sustain life. Many long-term residents in nursing facilities are medically unstable, terminally ill, and/or cognitively impaired, so decisions regarding feeding tube placement become complicated and controversial (8). Patients with advanced, life-limiting illness often lose the ability to eat and drink and/or interest in food and fluids (2) and have minimal calorie demands (16). Declining food and fluid intake that leads to weight loss is a natural part of the dying process (4). Evidence shows that enteral feeding cannot restore consciousness, prevent imminent death, or increase a person's comfort (17). Tube feeding cannot improve the nutritional status of most terminally ill people and can result in medical complications (14).

Tube Feeding and Dementia

Dementia is considered a terminal illness; dementia patients are subject to the same declining appetite and interest in food, alterations in nutritional status, and potential for weight loss as those suffering from other terminal illnesses. Numerous studies have reported no evidence that tube feeding provides any benefit for individuals with advanced dementia in terms of survival time, mortality risk, quality of life, nutritional parameters, physical function, and improvement in, or reduction in, incidence of pressure injuries (3,18,19). Studies worldwide consistently demonstrate a very high mortality rate in older adults with advanced dementia who have feeding tubes (5,16). Taken together, the benefits and burdens do not support use of tube feeding in older adults with advanced dementia (1). However, this evidence does not always inform decisions regarding feeding tube placement in advanced dementia (6). This may be partially due to the emotional nature of the decision.

Considerations for Health Care Professionals

The decision to implement enteral feeding should be made carefully and thoughtfully, with input from the patient/resident and/or their surrogate and the IDT. Before recommending a feeding tube, the IDT should consider the treatment goal for a patient/resident and if that goal is appropriate given the individual's prognosis. The IDT should discuss expectations for improvement or survival if a feeding tube is placed (11). When all parties involved understand what can and cannot be achieved with EN, it is considered medically ethical to decline enteral feeding (3,12). The autonomy of the patient/resident or surrogate should be respected, and a final decision should be reached via a patient-centered approach (13).

Health care professionals should not be ethically obligated to offer ANH if (in their clinical judgement) there is not evidence for the therapy or if the burden or risk outweighs its benefits (6). PEG placement should not be offered in the absence of proven benefits (10). If the physician is not in agreement with an individual's decision for or against ANH, the individual should be transferred to another medical provider (6,20). If an institution has policies obligating the use of feeding tubes on religious or moral grounds and an individual does not desire feeding tube placement, they should be transferred to a facility that will honor those wishes (1,6).

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Despite the evidence outlining indications for use of tube feedings, some providers believe that giving tube feedings or IV therapy is a level of basic, humane care (16,21). Some believe that nutrition, similar to pain management and basic personal care, must be offered (17). When helping patients make end of life decisions, health care professionals should:

- Set aside personal and/or religious beliefs.
- Listen to patients/surrogates concerns and opinions.
- Rely on professional guidance regarding risk and benefits of tube feeding.
- Consider that each person is an individual with their own set of values regarding end of life care and inserting PEG tubes.
- Rely on professional guidance regarding the ethics of withholding or withdrawing PEG tubes.

In some cases, a patient and/or family may opt to discontinue tube feeding after it has been initiated. More information on this subject is found in Chapter 4.

References for Chapter 2: Determining Nutrition Care Plan at the End of Life

1. American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement: <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12924/pdf>.
2. American Academy of Hospice and Palliative Care. Statement on Artificial Nutrition and Hydration Near the End of Life. September 2013. <http://aahpm.org/positions/anh>. Accessed April 18, 2016.
3. Maillet JO, Swartz DB, Posthauer ME. Position of the Academy of Nutrition and Dietetics: Ethical and Legal Issues in Nutrition and Hydration. *J Acad Nutr Diet*. 2013;113:828-833. doi:10.1016/j.jand.2013.03.020. Accessed April 18, 2016.
4. Posthauer ME, Dorner B, Friedrich EK. Enteral nutrition for older adults in healthcare communities. *Nutr Clin Pract*. 2014;29(4):445-458.
5. Schwartz DB. Integrating patient-centered care and clinical ethics into nutrition practice. *Nutr Clin Pract*. 2013; 28(5):543-555.
6. Barrocas A, Geppert C, Durfee SM, et al. A.S.P.E.N. Ethics position paper. *Nutr Clin Pract*. 2010;25(6): 672-679.
7. Pew Research Center. Views on End of Life Medical Treatments. November 2013. Accessed April 18, 2016.
8. Kuo S, Rhodes RL, Mitchell SL, et al. Natural history of feeding tube use in nursing home residents with advanced dementia. *J Am Med Dir Assoc*. 2009;10:264-270.
9. Dorner, B. *Diet and Nutrition Care Manual: A Comprehensive Nutrition Care Guide*. Naples, FL: Becky Dorner & Associates, Inc.: 2016.
10. Cardin F. Special considerations for endoscopists on PET indications in older patients. International Scholarly Research Network. ISBN Gastroenterology. 2012. Article ID 607149. doi:10.5402/2012/607149.
11. Plonk WM. To PEG or not to PEG: nutrition issues in gastroenterology. In: Parrish CR, ed. *Practical Gastroenterology*; 2005;16-31. <http://www.practicalgastro.com/pdf/July05/July05Plonk.pdf>. Accessed May 9, 2016.
12. Angus F, Burakoff R. The percutaneous endoscopic gastrostomy tube: medical and ethical issues in placement. *Am J Gastroenterol*. 2003;98:272-277.
13. Schwartz DB, Barrocas A, Wesley JR, et al. Gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutr Clin Pract*. 2014;29(6):829-840. doi: 10.1177/0884533614546890.
14. Thomas D. Hard to swallow: management of dysphagia in nursing home residents. *JAMDA*. 2008; 455-458.