

American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement

American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee

When eating difficulties arise, feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered because hand feeding has been shown to be as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Moreover, tube feeding is associated with agitation, greater use of physical and chemical restraints, healthcare use due to tube-related complications, and development of new pressure ulcers. Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be part of usual care for older adults with advanced dementia. Tube feeding is a medical therapy that an individual's surrogate decision-maker can decline or accept in accordance with advance directives, previously stated wishes, or what it is thought the individual would want. It is the responsibility of all members of the healthcare team caring for residents in long-term care settings to understand any previously expressed wishes of the individuals (through review of advance directives and with surrogate caregivers) regarding tube feeding and to incorporate these wishes into the care plan. Institutions such as hospitals, nursing homes, and other care settings should promote choice, endorse shared and informed decision-making, and honor preferences regarding tube feeding. They should not impose obligations or exert pressure on individuals or providers to institute tube feeding. *J Am Geriatr Soc* 2014.

Key words: feeding tubes; advanced dementia; position statement; AGS guidelines

Food and the enjoyment of eating play important social, religious, and symbolic roles in most cultures. Given these diverse roles, it is not surprising that great concern

often arises when a person begins to have difficulty eating or loses the desire to eat. People with advanced dementia often experience eating difficulties in conjunction with profound loss of cognitive, verbal, and functional abilities due to the progressive neurodegenerative process. Eating difficulties are considered a natural part of the disease process and, when persistent, characterize the end stage of dementia. In the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study,¹ a recent landmark study that followed individuals with advanced dementia over 18 months, more than 85% of the study cohort experienced eating difficulties, with subsequent 6-month mortality approaching 50%.

Individuals with advanced dementia are dependent on others for all aspects of their care and must rely on others to make decisions about the types of care they receive. Once persistent eating difficulties arise, family caregivers are often confronted with difficult decisions that typically include whether to continue hand feeding or initiate tube feeding (through placement of a percutaneous endoscopic gastrostomy (PEG) or feeding tube). This decision can be difficult for family and surrogate decision-makers given the interplay of cultural and religious beliefs, potential misperceptions about the natural progression of dementia, and lack of awareness of the evidence surrounding the benefits, risks, and burdens of tube feeding. Shared decision-making between healthcare providers and family members or surrogate decision-makers facilitates an evidence-based approach, while providing ongoing guidance and support, so that care plans reflect the individual's needs and goals.

Older adults with advanced dementia are usually bed-bound and unable to ambulate and have limited, if any, ability to communicate verbally. Pneumonia, febrile episodes, and eating problems represent a natural progression of the disease process and indicate a transition from advanced dementia to end of life, with each of these "complications" having a 6-month mortality that approaches 50%.¹ The preponderance of evidence does not support the use of tube feeding to avoid eating difficulties in older adults with advanced dementia.² A randomized controlled trial comparing the benefits and burdens of tube feeding with those of hand feeding in persons with advanced dementia has not been conducted because of concern

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surrounding ethically appropriate study design and methodology in part because of the vulnerability of the population. Current recommendations are based on expert opinion and highly consistent empirical work using observational data adjusted for potential confounders and selection bias.²

Considerable variability in feeding tube use for residents in long-term care exists in the United States, which may reflect practices specific to nursing homes and hospitals rather than individuals' values or efficacy.³⁻⁵ As many as 34% of U.S. nursing home residents with advanced dementia have feeding tubes, two-thirds of which are inserted during an acute hospital stay.³⁻⁵ Caregivers report little conversation surrounding feeding tube decisions (more than half of caregivers report no conversation or one that lasts less than 15 minutes), and at times, families feel pressure for their use.⁶ Nursing homes with low rates of feeding tube use have environments that promote the enjoyment of food and administrative support and empowerment of staff to promote hand feeding, along with practices that foster shared decision-making among surrogate caregivers.⁷

This guideline was first published in 1993 and reviewed in 2005. This statement is now updated and revised because of the publication of several sentinel studies further detailing the natural history of eating difficulties and burdens associated with tube feeding use in persons with advanced dementia.

POSITIONS

1. Feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Tube feeding is associated with agitation, greater use of physical and chemical restraints, greater healthcare use due to tube-related complications, and development of new pressure ulcers.

Rationale

The current scientific evidence suggests that the potential benefits of tube feeding do not outweigh substantial associated treatment burdens in persons with advanced dementia. Studies consistently demonstrate high mortality in older adults with advanced dementia, and survival is not better in those who are tube fed than in those who are not.^{2,5,8-10} In observational studies, tube feeding has not been shown to prevent aspiration, heal pressure ulcers, improve nutritional status, or decrease mortality in persons with advanced dementia.^{2,5,8-13} Tube feeding is also associated with substantial burden, including recurrent and new-onset aspiration, tube-associated and aspiration-related infection, oral secretions that are difficult to manage, discomfort, tube malfunction, use of physical and chemical restraints, and pressure ulcers.¹³⁻¹⁵ The relationship between being tube fed and pressure ulcers in advanced dementia is particularly striking, with tube feeding not improving pressure ulcer healing and being associated with a greater likelihood of new pressure ulcer

development.¹² Moreover, studies have shown that nursing home residents with advanced dementia and a feeding tube frequently need to be transferred to the emergency department to address tube-related complications such as blockage and dislodgement.^{5,16} Finally, greater levels of discomfort have not been observed in older adults with advanced dementia in whom, despite eating difficulties, a feeding tube was not placed.¹⁷ Taken together, the benefits and burdens of tube feeding do not support its use in older adults with advanced dementia.

Ideally, families and surrogate decision-makers should receive ongoing education about the natural progression of dementia, which includes eating difficulties near the end of life. Using this approach, decisions regarding feeding options (tube or assisted oral feeding) could be delineated proactively rather than reactively. When a feeding tube decision occurs, providers and families or surrogate decision-makers should engage in shared decision-making to further delineate the goals of care. Prognosis should be discussed (most often in months), along with a review of the evidence demonstrating no clinical benefit and substantial treatment burdens associated with tube use. If after careful counseling the proxy elects to insert a feeding tube, the goals of the medical treatment should be documented and reviewed at regular intervals. As with any medical treatment, cessation and not initiating a treatment are considered ethically equivalent, so stopping tube feeding when care goals are not met is appropriate.¹⁸

2. Efforts to enhance oral feeding by altering the environment and creating individual-centered approaches to feeding should be part of usual care for older adults with advanced dementia.

Rationale

Oral feeding may be one of few remaining pleasures and a time for socialization for a person with advanced dementia. Mealtime must be regarded as an event of importance, instead of a task that needs to be completed as soon as possible. Environments with less noise and clutter are more conducive to eating than chaotic ones. In nursing homes, nurse training and staff education improves feeding strategies in residents with dementia.^{7,19,20} Diets should be liberalized based on resident preference, and adequate fluids should be given with feedings to enhance the taste of foods. Continued careful hand feeding should be considered to be an accepted alternative to tube feeding.²¹ In addition, feeding tubes should never be viewed as a cheaper, more-efficient way of feeding. When individuals with advanced dementia develop a loss of appetite, weight loss, difficulty swallowing, or aspiration, a discussion of feeding should occur without delay. This should involve a multidisciplinary assessment of reversible causes of not eating and discussions with family about the plan of care in relation to the stage of dementia.

3. Tube feeding is a medical therapy that an individual's surrogate decision-maker can decline or accept in accordance with advance directives, previously stated wishes, or what it is thought the individual would want.

Rationale

Since 1990, when the Supreme Court ruled on the Nancy Cruzan case, artificial feeding was deemed to be “medical therapy” and, like any other medical therapy, could be started and stopped based on a person’s wishes and values.²² When individuals lose their capacity to consent to treatments, their previously expressed directives, wishes, or values should be used to guide surrogate decision-makers. The court ruled that individual states could define the level of evidence required to substantiate that an individual would not want have wanted artificial feeding. Thus, Missouri was permitted to set this standard of evidence at the level of “clear and convincing.” Many states have adopted a standard of “reasonable evidence,” whereas some like Missouri and New York use the “clear and convincing” standard. With few exceptions, the courts have upheld the rights of individuals or their healthcare agents to refuse tube feeding.

4. It is the responsibility of all members of the healthcare team caring for residents in long-term care settings to understand any previously expressed wishes of the individual (through review of advance directives and with surrogate caregivers) regarding tube feeding and incorporate these wishes into the care plan.

Rationale

In most cases of advanced dementia, there is opportunity, often over a period of months, to observe that an individual has exhibited a progressive decrease in oral intake or swallowing function. Although a thorough evaluation of reversible causes of these problems should be conducted, persistent eating difficulties may be the consequence of progression of the neurodegenerative process. Healthcare providers should be encouraged to discuss the future potential feeding problems and functional losses that accompany dementia with caregivers as a way of providing education about the disease process. Discussion of advance directives regarding feeding support should begin early in the course of illness and should not wait until a crisis develops. Early discussion and planning is important given that percutaneous feeding tubes are usually placed during an inpatient hospitalization,⁵ often in the setting of acute illness and prognostic uncertainty. This does not allow family members time to prepare to make a potentially difficult decision. As noted in position statement 3, surrogate decision-makers should use previously expressed value statements, wishes, and directives to guide their substituted judgment to decide what the individual would want under the present circumstances.

Practitioners should recognize the concept of (personal) autonomy. Although it is considered the bedrock of Western ethical principles, it may not be as important to people from other cultures or specific religious traditions. It is important that practitioners articulate the concept of autonomy—what the person would want—while acknowledging cultural expectations, religious beliefs, and family traditions. In the United States, informed consent requires a review of the benefits and burdens of tube feeding.

5. Institutions such as hospitals, nursing homes, and other care settings should promote choice, endorse shared and informed decision-making, and honor individuals’ preferences regarding tube feeding. They should not impose obligations or exert pressure on individuals, or providers to institute tube feeding.

Rationale

Individual values, goals, prognosis, and efficacy of treatment should be the determinant of any medical therapy, including tube feeding. Institutions such as nursing homes should develop policies to ensure that residents with remediable causes of weight loss are evaluated and treated appropriately and that tube feeding is not regarded as the only treatment choice. Decision aids about feeding options in advanced dementia have been shown to improve the quality of decision-making for surrogates and their frequency of communication with medical providers.²³ Institutions should employ these tools in combination with high-quality communication to ensure that families are making informed treatment choices. Clinical conditions such as constipation, depression, medication side effects, and xerostomia are among several conditions that should be considered in individuals who are not eating and are losing weight. Studies have not only revealed geographic variation in the use of tube feeding in nursing home residents with advanced dementia, but have also identified institutional characteristics that are associated with greater use of tube feeding in nursing homes, including larger nursing homes, lack of dementia care units, no on-site midlevel providers, and for-profit status.³ Additionally, weight loss, a common occurrence in individuals with advanced dementia, is a quality measure for U.S. nursing homes that is closely monitored, is used for evaluation purposes, and may serve as an impetus for feeding tube placement. Individual characteristics and choice should shape institutions and drive clinical care. Institutions should not attempt to influence physicians or individuals into providing or accepting care that is not effective or congruent with individual values and goals. If institutions, based on religious or moral grounds, have policies obligating the use of feeding tubes, families and residents should be informed of them in advance. When an individual loses the ability to eat in such an institution and does not desire feeding tube placement, the institution should transfer that individual to an establishment that will honor his or her wishes.

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REFERENCES

- Mitchell SL, Teno JM, Kiely DK et al. The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538.
- Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev* 2009;CD007209.
- Mitchell SL, Teno JM, Roy J et al. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 2003;290:73–80.
- Teno JM, Mitchell SL, Gozalo PL et al. Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. *JAMA* 2010;303:544–550.
- 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.
- Teno JM, Mitchell SL, Kuo SK et al. Decision-making and outcome of feeding tube insertion: A five-state study. *J Am Geriatr Soc* 2011;59:881–886.
- Lopez RP, Amelia EJ, Strumpf NE et al. The influence of nursing home culture on the use of feeding tubes. *Arch Intern Med* 2010;170:83–88.
- Meier DE, Ahronheim JC, Morris J et al. High short-term mortality in hospitalized patients with advanced dementia: A lack of benefit of tube feeding. *Arch Intern Med* 2001;161:594–599.
- Sanders DS, Carter MJ, D'Silva J et al. Survival analysis in percutaneous endoscopic gastrostomy feeding: A worse outcome in patients with dementia. *Am J Gastroenterol* 2000;95:1472–1475.
- Mitchell SL, Kiely DK, Lipsitz LA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Intern Med* 1997;157:327–332.
- Teno JM, Gozalo PL, Mitchell SL et al. Does feeding tube insertion and its timing improve survival? *J Am Geriatr Soc* 2012;60:1918–1921.
- Teno JM, Gozalo P, Mitchell SL et al. Feeding tubes and the prevention or healing of pressure ulcers. *J Am Geriatr Soc* 2012;60:697–701.
- Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. *Lancet* 1996;348:1421–1424.
- Ciocon JO, Silverstone FA, Graver LM et al. Tube feedings in elderly patients. Indications, benefits, and complications. *Arch Intern Med* 1988;148:429–433.
- Odom SR, Barone JE, Docimo S et al. Emergency department visits by demented patients with malfunctioning feeding tubes. *Surg Endosc* 2003;17:651–653.
- Givens JL, Selby K, Goldfeld KS et al. Hospital transfers of nursing home residents with advanced dementia. *J Am Geriatr Soc* 2012;60:905–909.
- Pasman HR, Onwuteaka-Philipsen BD, Kriegsman DM et al. Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is forgone. *Arch Intern Med* 2005;165:1729–1735.
- Naik AD, Abraham NS, Roche VM et al. Predicting which patients can resume oral nutrition after percutaneous endoscopic gastrostomy tube placement. *Aliment Pharmacol Ther* 2005;21:1155–1161.
- McGillivray T, Marland GR. Assisting demented patients with feeding: Problems in a ward environment. A review of the literature. *J Adv Nurs* 1999;29:608–614.
- Lopez RP, Amelia EJ, Mitchell SL et al. Nurses' perspectives on feeding decisions for nursing home residents with advanced dementia. *J Clin Nurs* 2010;19:632–638.
- Hanson LC, Ersek M, Gilliam R et al. Oral feeding options for people with dementia: A systematic review. *J Am Geriatr Soc* 2011;59:463–472.
- Orentlicher D. From the Office of the General Counsel. *Cruzan v Director of Missouri Department of Health*: An ethical and legal perspective. *JAMA* 1989;262:2928–2930.
- Hanson LC, Carey TS, Caprio AJ et al. Improving decision-making for feeding options in advanced dementia: A randomized, controlled trial. *J Am Geriatr Soc* 2011;59:2009–2016.