

BACKGROUND

Food and the enjoyment of eating play important social, religious, biological 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 with eating or loses the desire to eat. Those with advanced dementia generally experience eating difficulties, in conjunction with profound loss of memory, verbal, and functional abilities due to the underlying progressive neurodegenerative process. Patients 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 tube or PEG). This decision remains burdensome to family decision-makers given beliefs, culture, and lack of knowledge about the impact of tube feeding or the needs and comfort of an individual with advanced dementia.

Older adults with advanced dementia are bed-bound, unable to ambulate, and have limited, if any, ability to communicate verbally. Pneumonia, febrile episodes, and eating problems are frequent complications in patients with advanced dementia, and these complications have been linked with increased mortality.¹ When considering the use of tube feeding in older adults with advanced dementia, the preponderance of evidence does not support its use.² Ethical study design and methodology issues are significant barriers to research with this vulnerable population, and while a randomized controlled trial has not been conducted comparing the benefits and burdens of tube feeding versus hand feeding in persons with advanced dementia, current recommendations are based upon expert opinion and extensive observational data. Published empirical work using observational data remains highly consistent in finding a lack of efficacy in tube feeding in this population.²

Considerable variability in tube feeding use for residents in long-term care exists in the United States, which may reflect practices specific to nursing homes and/or hospitals rather than patient values or efficacy.³⁻⁵ As many as 34% of US 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 tube feeding decisions, and at times families feel pressure for its use.⁶ Nursing homes with low rates of tube feeding 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 caregivers⁷.

This guideline was first published in 1993 and reviewed in 2005. We are now revising this statement due to the publication of several sentinel studies further detailing burdens associated with tube feeding use in persons with advanced dementia.

POSITIONS

1. Percutaneous 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 patient comfort. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening 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 a very high mortality in older adults with advanced dementia who have feeding tubes.^{2,5,8-10} In observational studies, tube feeding has not been shown to prevent aspiration, heal pressure wounds, improve nutritional status, or decrease mortality in persons with advanced dementia.^{2,5,8-14} Additionally, tube feeding is associated with substantial patient burdens including recurrent and new onset aspiration, tube-associated and aspiration-related infection, increased oral secretions that are difficult to manage, discomfort, tube malfunction, pressure wounds, and the use of physical and chemical restraints.¹³⁻¹⁶ Moreover, studies have shown that nursing home residents with advanced dementia and a feeding tube frequently need to be transferred to the emergency room to address tube-related complications.^{5,17} Finally, increased levels of discomfort have not been observed in older adults with advanced dementia where, despite eating difficulties, a feeding tube was not placed.¹⁸

As with other medical therapies, the benefits and burdens of tube feeding should be discussed with patients' families or surrogate decision makers before the procedure is considered. There may be circumstances when short-term tube feeding would be appropriate¹⁹ and consistent with patients' previously expressed wishes and values. In these cases, clear goals of therapy should be decided upon before tube feeding is initiated and should be reviewed frequently. The benefits versus the burdens of tube feeding do not support its use in older adults with advanced dementia.

Therefore, it is essential that all options, including continued assisted oral feeding, be presented to surrogate decision-makers for patients with advanced dementia and persistent eating problems. In addition, for true informed consent to be obtained, the substantial treatment burdens associated with tube feeding need to be understood by decision-makers.

2. 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.

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.^{7,20-21} 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 as an accepted alternative to tube feeding.²² In addition, feeding tubes should never be viewed as a cheaper, more efficient way of feeding patients. When patients with advanced dementia develop a loss of appetite, weight loss, difficulty swallowing or aspiration, a discussion of feeding issues 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 can be declined or accepted by a patient's surrogate decision maker in accordance with advance directives, previously stated wishes, or what it is thought the patient 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.²³ When patients 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 a patient 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" while some like Missouri and New York use the "clear and convincing" standard. With few exceptions, the courts have upheld the rights of patients or their health care agents to refuse tube feeding.

4. It is the responsibility of all members of the health care team caring for residents in long-term care settings to understand any previously expressed wishes of the patient (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 a patient has exhibited a progressive decrease in oral intake and/or swallowing function. Though a thorough evaluation of reversible causes of these problems should be conducted, persistent eating difficulties are often the consequence of progression of the neurodegenerative process. Health care providers should be encouraged to discuss the future potential feeding issues 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 be delayed 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 number three, surrogate decision makers should use previously expressed value statements, wishes, and directives, to guide their substituted judgment to decide what the patient 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 patient preferences regarding tube feeding. They should not impose obligations or exert pressure on patients or providers to institute tube feeding.

Rationale: Patient 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.²⁴ 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 patients who are not eating and losing weight. Studies have not only revealed geographic variation in the use of tube feeding among nursing home residents with advanced dementia, they have identified institutional characteristics that are associated with increased 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 patients with advanced dementia, is a quality measure for US nursing homes that is closely monitored, used for evaluation purposes, and may serve as an impetus for feeding tube placement. Patient characteristics and choice should shape our institutions and drive clinical care. Institutions should not attempt to influence physicians or patients into providing or accepting care that is not effective or congruent with patient values and goals. If institutions, based on religious or moral grounds, have policies obligating the use of tube feeding, families and patients should be informed of them in advance. When a patient loses the ability to eat in such an institution, and does not desire tube feeding, the institution should transfer that patient to an establishment that will honor the patient's wishes.

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