Feeding Tubes for Nursing Home Residents with Advanced Dementia: How to Approach Feeding Tube Decisions

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You are making routine rounds at the nursing home on your long-time patient, Sally Smith, who has suffered from Alzheimer’s dementia for 8 years. She has resided in the dementia unit for the last 3 years. Her daughter Jane is, as usual, at the bedside trying to encourage her mother to finish the lunch tray in front of her. Sally has lost 12 pounds over the last year and appears frail and thin. You sit down with them and spend time talking things over with Jane who asks you what more she can do. You have taken care of Sally since she was in her early sixties, when she was a vibrant retiree who enjoyed daily Pilates classes, ballroom dancing, and playing cards at the community center. Sally no longer recognizes her daughter, spends most of her time in her room, and no longer ambulates. When hand-fed, she needs frequent cues, and often lets food pool in her cheeks without swallowing. Despite trials of antidepressants, appetite stimulants, careful hand feeding, and supplements, the weight loss has been steady. In addition, Sally was recently hospitalized due to the complications of aspiration pneumonia.

Sadly, Sally’s story is a commonly encountered one. Dementia is the fifth leading cause of death in the USA and it is estimated that 30% of feeding tubes are placed in patients with dementia. Families and physicians alike agonize over the right decision with regards to feeding in advanced cases of dementia. Feeding and swallowing difficulties are common with dementia. Dementia patients often cannot swallow, due to motor involvement and apraxia, and suffer complications including recurrent aspiration that leads to pneumonia, and weight loss. At the point where these symptoms and complications start to occur, patients are in the final stages of the disease trajectory. Most patients have months to a year of life remaining. Experts debate the long-term effects of artificial feeding and discuss whether it changes outcomes like nutritional state, pressure ulcer development or healing, and mortality. Emotion clouds the topic further, with distressed family members feeling that they could never “starve their loved one to death”. The decision to place a feeding tube is often made by loving caregivers who feel they would be neglectful if they did not “try everything” to save their loved one.

Having this conversation with families can be the hardest of all decision-making discussions. The common perception among families and practitioners is that tube-feeding is more comfortable for both patient and, can prolong life as well as improve overall nutritional status, thereby preventing the complications of malnutrition. The evidence base consists mostly of retrospective analyses, observational studies and review articles, as randomized control trials with well-defined control groups are challenging and difficult to perform. As a health care provider, there are several key questions that should inform this decision:

**What are the potential benefits of a feeding tube?**

For certain patients feeding tubes may be life-prolonging. For example, patients with Amyotrophic Lateral Sclerosis (ALS) may benefit from a feeding tube with a resultant longer life. However, such benefit has not been found in the systematic review of the literature to date with regards to dementia patients. Finucane and colleagues in 1999, in the first systematic review of the evidence, noted that a feeding tube inserted in a person with advanced dementia did not lead to prolonged survival, improved quality of life, prevention of aspiration pneumonia, or increased healing of pressure sores. This landmark review led to the strongest evidence that using tube feeding in patients with advanced dementia did not lead to the desired outcomes. A more recent review also found no clear support for the belief that tube feeding can improve pressure sores or prevent them. Finucane and colleagues’ review targeted aspiration pneumonia prevention, amelioration of the consequences of malnutrition, and survival rates. The authors searched MEDLINE from 1966 through 1999 but found no randomized control trials to include. The review supported the belief that tube feeding does not prevent aspiration pneumonias or pneumonitis, with the evidence available in the literature. Aspiration of oral secretions continued, as did reflux aspirations from the tube feedings themselves. Three case control studies described in the review demonstrated actual higher risks of aspiration pneumonia and death in tube fed patients. In addition, contrary to common perception, studies demonstrated that jejunostomy was not associated with lower risk than gastrostomy.

With regards to preventing the consequences of malnutrition, in several studies of tube-fed patients, markers of malnutrition did not improve with tube feeding. Weight loss, and muscle wasting persisted despite receiving appropriate calories and protein intake. Evidence suggests that the underlying effects of chronic disease, immobility, and inflammation overcome the effects of artificial nutrition. Finally, a feeding tube will not reverse the progression of dementia. So a key question is whether Mrs. Smith would want to live in a state where she is unaware and unable to interact with her surroundings. Would she have consented to a feeding tube, if she could talk to us today?

**What are the risks? When you forgo a feeding tube, are you starving someone to death?**

There is small risk of mortality with the procedure that has been greatly minimized with the use of endoscopic percutaneous gastrostomy tubes. However, complications include leaking around the tube, tubes being pulled out by confused or demented patients, blockage of tubes, and the necessitation of ER visits for replacement of the tubes due to blockage or displacement. Also, a more important concern is that for some, restraints need to be utilized to pre-
vent a nursing home resident from pulling out the tube.\(^2\) Additionally, survival analysis revealed unexpected results. Survival was poorer in the tube feed groups in various studies. Two large studies discussed in the review by Finucane and colleagues demonstrated median survival of tube fed patients was reduced.\(^1\) In one study the median survival of tube fed patients was 7.5 months; in the second, 63% of patients had died one year after placement of a feeding tube. On the flip side, studies demonstrated that carefully hand fed patients had similar survival rates, not lower, as initially expected. One study compared demented patients who required assistance eating to similar non-demented counterparts in a long-term care facility. The study followed patients for two years and the patients in the hand-fed program had similar survival to those who fed themselves.\(^3\) The literature review by Li reached similar conclusions.\(^2\)

**WHAT ARE THE ALTERNATIVES?**

The feeding-tube decision is often clouded by our cultural mores of showing love with food. To allow our loved one to refuse food, lose weight, and “waste away” is seen as neglectful and as the imposing of suffering. An important alternative to a feeding tube is to give a concerted trial of hand feeding, for those persons where feeding a modified diet is safe. With involvement of speech therapy to educate the staff, you may be able to forestall the need for a feeding tube. As noted above, carefully hand fed patients had similar survival to those who fed themselves.\(^2,3\) For those persons where feeding is not safe, a critical question is what is the experience of dying without food or water? If you were to stop all nutrition and fluid, the patient would die of dehydration. For most part, this will involve drifting off into a coma with evidence of dehydration being treated by assiduous mouth care. That sensation can only be inferred by studies of neuro-degenerative patients who choose to stop a feeding tube and in the terminally ill. The evidence indicates that the majority of symptoms were not severe. Approximately 75% of terminally ill patients retain the ability to report hunger and thirst, but comfort feeding (small amounts of food, ice chips, sips of liquids or mouth swabs) was able to satisfy these feelings.\(^2\) Though the comfort interventions did not provide adequate nutrition, they allowed the patient to remain free of hunger and thirst.

**IS IT LEGAL TO WITHHOLD OR DRAW A FEEDING TUBE IN RI?**

While considerable concern was generated with the Schiavo case, there is important case law from the Supreme Court in Cruzan vs. Director, Missouri Department of health, and state law in Gray vs. Romeo. Both cases noted that a feeding tube is an artificial means of life-sustaining treatment that a competent person may choose to withhold or withdraw. The Cruzan case noted that a state had a right to set higher standards of safety to ensure that the wishes are those of the patient. Grey vs. Romeo ruled that patients have the right to refuse medical treatment, including feeding tubes. The judge ruled that the feeding tube placed in Marcia Gray, a 49 year-old woman who suffered a cerebral hemorrhage and never regained consciousness, should be removed in line with her previously voiced wishes.\(^2\) Mrs. Gray had discussed her wish to not be kept alive by artificial means with her husband after the Quinlan case became public. Based on case law, a physician in RI, with consent of a duly appointed health care proxy, can legally withdraw or withhold a feeding tube.

You sit down with Jane now and explain to her that the best approach is to continue careful and patient hand-feeding, aiming for comfort. Sally should be given small amounts of food and drink, as she tolerates. However, aggressive feedings or tube feedings should be withheld, as they will not prolong her survival, or reverse her cachexia syndrome. The focus of care should change toward comfort. As physicians, we should assist families to make this difficult and emotionally charged decision. We should be willing to work with nursing home staff to find creative solutions to limited staffing for feeding, and with families to teach them how to support the staff in feeding their loved one. Caregivers need to be reminded that dementia is a terminal illness and tube feeding does not reverse the underlying process and can add to the suffering and complications. We should be comfortable discussing the trajectory of dementia and that death is approaching once these complications are noted.

Jane appreciates your honest discussion, and understands that she is not neglecting her mother or contributing to her death by withholding tube feeding. She asks you to consult hospice and to provide a plan for comfort feeding. The nursing staff and Jane coordinate a care plan that has divided responsibilities for feedings. Sally does not have any other aspiration pneumonias, but gradually continues along the course of her illness. Jane institutes a “do not hospitalize” order and Sally remains in the dementia unit until her death three months later. Her family was at her bedside, as were the nurses who had cared for her in her last few months. Sally had a peaceful death in the place she had called home for three years, and her family was grateful for the support of the medical team.

**REFERENCES**


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