

Artificial Nutrition and the Public Guardian

ELIZABETH MENKIN, M.D.

CASE

AN 87-YEAR-OLD nursing home resident was discharged to a subacute skilled care center nursing home after hospital treatment for pneumonia. She had advanced Alzheimer's-type dementia and was bed-bound and nonverbal. The transfer summary reported she was not able to take oral medications so intravenous fluids and antibiotics were ordered. She had no family. Conservatorship had been given to the public guardian. It was clear that the public guardian had given consent for treatment with intravenous antibiotics and intravenous hydration but not clear whether a feeding tube would be required.

The patient appeared comfortable. On physical examination the patient was afebrile, with a blood pressure of 120/86, respiration rate of 22 (shallow and without use of accessory muscles), pulse 67 per minute and weak. She was not able to follow commands for the examination. There was 1+ edema bilaterally. Her left upper extremity was deformed at the elbow and held in a contracted, flexed position. Her right heel had a large posterior blister that was intact. Her left heel showed redness. Her coccyx was red and there were multiple red spots over the skin. She was completely nonverbal and required maximum assistance to move in bed. She did not open her eyes to voice or touch and she did not engage to social interaction at all. She responded to noxious stimuli with partial eye-opening and nonpurposeful movements.

A swallowing evaluation showed she was able to suck on a wet sponge swab, but coughed after a second aliquot of water was delivered by that method. When she was given juicy applesauce, she sucked the 1/2-teaspoon bolus off the spoon

and had a visible swallow. When she was given yogurt, she was able to take 1/2 teaspoon bites, some with double swallow stimulated by rubbing the spoon in her mouth a second time, with only one episode of brief cough.

Question: How do you discuss hospice care, the question of tube feeding, and withdrawal of parenteral hydration with the public guardian?

DISCUSSION

This case represents a common challenge for physicians practicing palliative medicine in nursing homes. There is little conflict when patients with decision-making capacity decline artificial hydration and nutrition for themselves (including through advance directives) or when valid, legal proxy decision-makers make those decisions on the patient's behalf. However, when a government-appointed conservator or guardian is involved, the decision to withhold or withdraw artificial hydration and nutrition can be complex.

In the state in which this case occurred, the public guardian is the court-appointed conservator, and is usually appointed with authority for both financial and medical decision-making powers for a demented patient who has no other family to oversee care. Medical decision-making by any surrogate decision-maker relies on a hierarchy of criteria. The first priority is to make decisions that are in accord with the patient's previously stated wishes, to the extent that those wishes are known. To the extent that the patient's wishes are unknown, the decisions are to be made in accordance with what the surrogate determines to be in the patient's best interest. In determining the patient's best interest, the surrogate

should consider the patient's personal values to the extent known to the surrogate.

Being court-appointed rather than chosen by the patient, the public guardian has no prior familiar relationship with the patient, and thus cannot rely on prior knowledge of the patient's values, goals, or wishes in making medical decisions. The only information immediately available in her prior medical records showed that the patient was a former director of a medical records department. Physician's notes at the time of her nursing home admission 12 years ago noted she had previously stated that she did not want a life ending in dementia. There was no medical directive and there were no acquaintances who could report her values and goals. The public guardian's office has no method or routine practice (or the staff available) to discover the patient's previously expressed wishes and values if they were not expressed in a statutory advance care planning document. Thus we could not apply the principle of substituted judgment.

Many public guardians, like most of the public, assume that tube feeding in the demented patient is important for comfort and is also beneficial. When faced with a choice whether to treat or not, they favor the default position of treat. Because the public guardian's office is a political one, they may reasonably fear the appearance of undertreatment of their conservatees.

There is increasing awareness of the need for better ways to handle the questions about tube feeding that come to the courts for adjudication. Some of these petitions to the court come with sparse discussion of the benefits and burdens of tube feeding.^a In this patient's case, at the prior nursing home the attending physician had discussed artificial nutrition and hydration with the public guardian in correspondence in 1992. The documents indicated the guardian held the opinion that tube feeding in the demented patient was important for comfort and would be beneficial.

Physicians are responsible for advocating for appropriate medical care, despite commonly held

misconceptions about benefits of tube feeding. Hence, there may be the potential for conflict with the public guardian. In order to do the best for patients, and avoid conflict with the public guardian's office, I have found the following approach to be helpful.

First, it helps to assume that the public guardian is trying to do the best for the patients under his or her care. It helps to get to know the public guardian and help him or her learn more about end-of-life care before there are specific cases in which you are asking for permission to withhold or withdraw interventions. In our county we have been successful in enrolling public guardians and a County Counsel in the EPEC course.

In Maryland, the Attorney General has said, "Ethical administration of a public guardianship program requires that guardians have an opportunity to become generally familiar with the clinical evidence that bears on their decision-making and that of the reviewing court. A public guardian who is confronted, for example, with the issue whether insertion of a feeding tube is in the best interest of a person with advanced Alzheimer dementia should be aware of the growing body of evidence about the questionable benefits and possible complications of this procedure.^{b,c} One can readily envision a case in which insertion of a tube would not be in the best interest of an AD patient."^d

In this case it helped to write a detailed letter to summarize all of the information about the patient that was germane to the decision as to whether continuing artificial nutrition and hydration was in the patient's best interest. While one might think the public guardian would have access to all of the records as well as be up-to-date on the latest medical information, they appreciate the 'one-stop shopping' that a detailed comprehensive letter provides. In this case, I sent the letter shown as Fig. 1:

^a"Cons'tee suffers from dysphagia and dementia and not able to eat. . . . Requesting placement of a percutaneous gastrostomy tube for chronic tube feeding and administration of medication. . . . The risk is minimal. . . . Based on medical advice, petitioner has in good faith determined that the procedure recommended is necessary." Case Summary P-256998-7, Alameda County Probate Examiners, 7/24/2003.

^bFinucane T, Christmas C, Travis K: Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA* 1999;282:1365-1370.

^cMeier D, Ahronheim J, Morris J, Baskin-Lyons S, Morrison RS: High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. *Arch Intern Med* 2001;161:594-599.

^dCurran JJ: Policy Study on Alzheimer's Disease Care. Chapter 3 Guardianship. <www.oag.state.md.us/Healthpol/alzchap3.pdf> (Last accessed May 12, 2004).

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Within 1 hour of faxing this letter to the Office of the Public Guardian, I received a faxed response from the on-call Public Guardian, who had attended the EPEC course. He granted permission to institute comfort feeding, to discontinue intravenous hydration, and to refer the patient for hospice care.

Address reprint requests to:
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Mr. John Jones
County of Somewhere
Office of the Public Guardian

Re: Patient Susan Smith

Dear Mr. Jones:

I have reviewed the 13 pages that you faxed to Long Term Care, Inc. on 1/14/2004 regarding the conservatorship of Susan Smith. Dr. Martin completed the application to withhold CPR and life support for this patient on 5/21/1992, more than eleven years ago. At that time the patient's dementia was "moderate," and she was able to talk spontaneously and make simple requests, but was disoriented to place, time and person, was easily confused, and was unable to answer simple questions. The patient was still able to feed herself some of the time, but needed to be fed by others about half the time.

In 1992, Dr. Martin recommended "No Life-Sustaining Intervention and No CPR," and on page 4 of the request the physician recommended against tube feeding. In the Deputy recommendation, Ms. R. wrote, "I agree with the physician's recommendation except that I feel the feeding tube should be provided if needed." She granted only the request for "No CPR."

In the last eleven years the patient's condition has changed dramatically. The patient is now completely nonverbal and totally bed-bound. She does not open her eyes to voice or touch and she does not engage to social interaction at all. She responds to noxious stimuli with partial eye-opening and nonpurposeful movements. She does respond to oral stimulation with primitive reflexive sucking and will swallow if small amounts of semi-solids such as yogurt are provided with this oral stimulation by spoon, but she only takes small amounts in this manner before beginning to cough and sound congested.

Since that time, research has shown that tube feeding for patients like Susan Smith does not improve comfort or prolong life. In the last eleven years there has been a large body of published research that refutes previously held assumptions about benefits of tube feeding for demented patients. A recent review of research on percutaneous gastrostomy procedures¹ (PEG tube placement, or gastric feeding tubes) listed many of these key findings. Despite the common assumption that PEG tubes decrease the risk of aspiration pneumonia, a frequent complication of advanced dementia, several studies suggest PEG tubes do not decrease the risk of aspiration pneumonia, and may actually lead to an increase.²⁻⁶ Similarly, a large percentage of physicians assume PEG tube placement with enteral feeding in advanced dementia improves nutritional status. However, the literature does not support this presupposition.^{2,4,7-9} Research shows an unpredictable and mostly unimproved response despite adequate caloric and vitamin supplementation. Also, PEG tubes in this population have not been shown to decrease the risk of pressure ulcers.^{2,9-11} although many people assume tube feeding will decrease this risk. Some are of the opinion that a PEG tube will improve functional status in advanced dementia, but studies fail to document improvement in functional status after PEG tube placement.^{7,8} Lastly, studies do not demonstrate a decrease in mortality after PEG tube placement compared to similar patients with chewing and swallowing disorders who do not receive a PEG tube.^{3,12,13} Even the assumption that those who cease to eat or drink suffer from hunger and thirst has been refuted. Intravenous fluids do not ameliorate a dry mouth. Moistening a dry mouth relieves the sense of thirst in the dying who are unable to tolerate food or drink. Extrapolating from the cancer literature or those who have participated in hunger strikes, experts think that hunger and thirst cease within days of stopping oral intake.¹⁴⁻¹⁶ As with patients with cancer, tube feeding in advanced dementia may even exacerbate hunger and thirst, as well as result in other unpleasant symptoms related to tube feedings.¹⁶

Considering the extensive medical literature on this topic published since 1992, I must conclude that placement of a feeding tube in Susan Smith will not benefit her comfort, function, or longevity. Further, data suggests her life expectancy is less than six months if her dementia follows its usual course. Therefore, I will not order tube feeding, but will continue to order "comfort feeding," slow and careful hand feeding with flavors, textures and consistencies of soft semi-solids that are easy to swallow. If she resists offers of food by spoon, we will try again later. If she begins to cough, we will suction her mouth as needed to remove matter that she has not swallowed, and clean her mouth with moist swabs to prevent dryness. I will ask the hospice program to become involved in her care.

Thank you for this opportunity to help you understand the medical issues that are relevant to the difficult decisions about the care of this unfortunate woman who has no involved loved ones.

Sincerely,

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¹Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA: Barriers to limiting the practice of feeding tube placement in advanced dementia. *J Pall Med* 2003;6:886-893.

²Finucane T, Christmas C, Travis K: Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA* 1999;282:1365-1370.

³Meier D, Ahronheim J, Morris J, Baskin-Lyons S, Morrison RS: High short-term mortality in hospitalized patients with advanced dementia: Lack of benefit of tube feeding. *Arch Intern Med* 2001;161:594-599.

⁴Gillick M: Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med* 2000;342:206-210.

⁵Kadackia S, Sullivan H, Starnes E: Percutaneous endoscopic gastrostomy or jejunostomy and the incidence of aspiration in 79 patients. *Am J Surg* 1992;164:114-118.

⁶Finucane T, Bynum J: Use of tube feeding to prevent aspiration pneumonia. *Lancet* 1996;248:1421-1424.

⁷Callahan C, Haag K, Weinberger M, Tierney WM, Buchanan NN, Shump TE, Nisi R: Outcomes of percutaneous endoscopic gastrostomy among older adults in a community setting. *J Am Geriatr Soc* 2000;48:1048-1054.

⁸Kaw M, Sekas G: Long-term follow-up of consequences of percutaneous endoscopic gastrostomy tubes in nursing home patients. *Dig Dis Sci* 1994;39:738-743.

⁹Henderson C, Trumbore L, Mobarhan S, Benya R, Miles TP: Prolonged tube feeding in long-term care: nutritional status and clinical outcomes. *J Am Coll Nutr* 1992;11:309-325.

¹⁰Finucane T: Malnutrition, tube feeding and pressure sores: Data are incomplete. *J Am Geriatr Soc* 1995;43:447-451.

¹¹Berlowitz D, Brandeis G, Anderson J, Brand HK: Predictors of pressure ulcer healing among long-term care residents. *J Am Geriatr Soc* 1997;45:30-33.

¹²Mitchell S, Kiely D, Lipsitz L: The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Intern Med* 1997;10:327-332.

¹³Sanders D, Carter M, D'Silva J, James G, Bolton RP, Bhardhan KD: Survival analysis in percutaneous endoscopic gastrostomy feeding: A worse outcome in patients with dementia. *Am J Gastroenterol* 2000;95:1472-1475.

¹⁴Sullivan R: Accepting death without artificial nutrition or hydration. *J Gen Intern Med* 1993;8:220-224.

¹⁵Billings J: Comfort measures for the terminally ill. *J Am Geriatr Soc* 1995;33:808-810.

¹⁶McCann R, Hall W, Groth-Juncker A: Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA* 1994;272:1263-1266.

FIG. 1. Public guardianship letter concerning the advisability of artificial nutrition and hydration.