Chapter Five

Artificial Nutrition
and Hydration

The consensus position of medical, ethical, legal, and religious bodies, together with public opinion, is clear on the subject of tube feeding: Artificially provided nutrition and hydration is a medical procedure that can be withheld or withdrawn like any other. ANH is not categorized as a treatment that must always be provided, and in coming to a decision about forgoing or continuing ANH, the patient's surrogates are allowed to either use their knowledge about the patient's desires and values or weigh the costs and benefits of tube feeding against the costs and benefits of waiving this treatment.

At the same time, Americans still have a good deal of anxiety about the prospect of discontinuing food and fluids, both for themselves and for their loved ones. This is one reason why there are approximately 1.5 million patients being tube fed in the United States today (Council 1992: 2229). Half of this group is over the age of sixty-five, and many if not most of these patients are severely and irreversibly demented (OTA 1987b: 293). The clinical reality is that tube feeding is often provided as a matter of course and that the choice of whether to tube feed or not is never fully explored. This situation contrasts markedly with the situation just a few decades ago.

Prior to the 1960s, when technological advances in artificial feeding made ANH a practical, widely accessible treatment,¹ the severe stage of dementia could also be considered the terminal phase: Patients simply stopped eating and drinking as the disease progressed, and in the end, they died. As Ronald Cranford (1991a: 18) writes, these patients died the way my great grand-mother died in 1958 at the age of 83. At that time, when she died at home, there were no CPR, no paramedics, and no intensive care units. The family never even gave a thought to putting her in a nursing home, and certainly no consideration was given to starting artificial nutrition and hydration, even though she was unable to eat or drink naturally as her condition worsened. We did have one thing back then that is unusual today: A family physician coming to the home almost daily to attend to his patient...
whom he had known for years, and finally to pronounce her dead, at home in her own bed. Back then, people died of old age. Even though a feeding tube was never started, she was never abandoned by her loving, caring family.

Today, the modus operandi of physicians and families is turned on its head. In past decades and centuries, family members provided around-the-clock palliative care in the home, and physicians occasionally stopped by to do what they could (which was usually little, if anything, given the lack of technology). Today, by contrast, caregivers provide various levels of technologically sophisticated care twenty-four hours a day, and family members drop by on occasion to do what they can (which is usually nothing, given the presence of technology). In the past, diseases were allowed to run their natural courses, largely because the technology had not been developed to accurately diagnose and treat mortal pathologies. Death was simply accepted as a natural and ultimate phase of living, an essential element of our humanity. Today, death tends to be regarded by many as a conquerable evil that must be resisted at all costs. With the widespread use of ANH and antibiotics, each of which can help to sustain the body in a vegetative or near-vegetative state for months and perhaps even years, dementia no longer has a terminal phase per se (Peck, Cohen, and Mulvihill 1990: 1195).2

A number of researchers have suggested that we return to the mind-set of the 1950s, when aggressive medical procedures (being scarce and costly, if available at all) were not blindly applied in the absence of thought about the ultimate goal of the intervention. Walshe and Leonard (1985: 1047) locate themselves squarely in this camp, arguing that “as in patients who develop the [vegetative] syndrome after acute injury, patients with progressive neurological disease should be treated without undue intervention to preserve a mindless life.”3 Mark Wicclair (1993: 60) advances the same position: “The severely demented elderly constitute another category of patients about whom it might be claimed that they will receive no benefit from life-prolonging measures. Although they are not unconscious, it is nevertheless arguable that their quality of life is so low that extended life is of no benefit to them.”

If only we knew a bit more about what tube feeding entails and what death after forgoing ANH was like, then ANH might become more than something we say we would forgo in response to a public opinion poll. It might instead become something we actually do forgo in real life, as Cranford, Walshe and Leonard, Wicclair, and others recommend.

Methods of ANH

Generally speaking, there are two kinds of ANH—enteral and parenteral. *Enteral* feeding (from the Greek term meaning intestines or entrails) delivers
a nutritional slurry directly into the gut through a plastic nasogastric tube, inserted through the nose and down through the throat or through a gastrostomy tube, inserted directly into the stomach or upper intestine. Parenteral feeding delivers fluid and nutrients through a needle inserted in the patient’s vein. This can be accomplished in one of two ways: intravenous feeding, using lines inserted into the veins of a patient’s limbs, or total parenteral nutrition (TPN), which uses lines inserted into the central veins in the neck and upper chest area. Enteral and parenteral feeding—like any medical procedures—both have their drawbacks and potential complications.

**Gastrostomies**

Gastrostomies, first practiced on humans in 1875 (Major 1989: 23), involve the surgical insertion of plastic tubes into the stomach under local anesthesia. Over time, a track forms between the skin and the stomach wall, much like the track that develops in the earlobe a few months after ordinary ear piercing. The tube can be relatively comfortable after the incision heals.

Though gastrostomy tubes are probably the preferred method of artificially feeding and hydrating patients over the long term, there are several possible complications associated with this method of enteral feeding. Some researchers have noted the prevalence of local infections and painful insertion sites (where the tube passes though the skin), inflammation of the stomach lining, hemorrhaging, and splitting open of the incision site in gastrostomy patients (Peck, Cohen, and Mulvihill 1990: 1198). The feeding formula may also be aspirated into the lungs, leading to pneumonia.

Often, demented patients have to be physically restrained to prevent them from inadvertently dislodging or purposefully pulling out their tubes. Patients who are at least partially conscious may be confused and irritated—physically, emotionally, or both—by the stomach tube and its associated apparatus.

**Nasogastric Feeding**

Nasogastric feeding is the most common mode of delivering enteral formulas to patients who need assistance in the short term. NG tubes can be placed by a trained health care professional without resorting to surgery, and for that reason, they are often considered to be “less invasive” than stomach tubes. Although consent is typically sought for the placement of a gastrostomy tube, NG tubes are often inserted without bothering to solicit approval from the patient or a surrogate decisionmaker; consent is generally thought to be implied when patients or their surrogates complete general “consent to treat” forms on admission to health care facilities.

The insertion of an NG tube involves passing a flexible plastic tube, lubricated with a tasteless jelly, up through the nostril, then down through
the back of the throat and into the stomach. The process can be quite uncomfortable and possibly painful, especially if the tube hits the upper nasal cavity and if the individual doing the insertion forces the tube to make the downward turn toward the throat. As the tube moves down past the esophagus, it often causes a gag reflex that can result in vomiting.

For confused patients, tube insertion can be frightening, requiring that they be physically restrained during the procedure. And once the tube is in place, it can be irritating and frightening to the demented patient; caregivers are sometimes forced to put the patient’s hands in mittens, which are tied to the sides of the bed or chair. Although there are few empirical data on the frequency of using restraints in demented patients, anecdotal evidence suggests that their use is widespread (OTA 1987b: 283).

If the NG tube becomes dislodged or if the patient continues to vomit, gastric contents can be aspirated into the lungs, leading to the development of aspiration pneumonia. If formula is introduced into the stomach too rapidly, diarrhea, regurgitation, aspiration, or vomiting can result. The average charges for enteral nutrition—delivered either through an NG tube or via a gastrostomy tube—run about $100 a day, or about $36,000 a year.5

Intravenous Feeding

The intravenous line is the most common method of delivering parenteral nutrition and hydration to patients over the short term. This method, first employed in the 1890s, can be used to supply a patient with water, saline, glucose solutions, and medications, infused through a needle inserted in the patient’s arm or leg.

Intravenous feeding is typically used over the long term only when the gastrointestinal tract is blocked or diseased to the point where absorption of food and fluids is compromised. The method cannot be used too long, however, because of the risk of infection at the site of the IV needle.

Intravenous feeding can become very expensive, running as much as $425 a day (over $155,000 per year, if it were ever employed for that length of time).6 As with NG tubes, the placement of IV lines is often considered part of routine care that is consented to on admission. Only rarely do hospitals require the specific consent of the patient or surrogate to begin IV feeding and hydration support (Hastings Center 1987). This practice only heightens the concern that may be raised regarding patient and surrogate autonomy (OTA 1987b: 320).

Total Parenteral Nutrition

Total parenteral nutrition, a process that was developed in the late 1960s and widely applied beginning in the 1970s, provides an alternative to the IV line for patients who need to be artificially fed over the long term but
cannot tolerate stomach (enteral) feeding. With TPN, formula is fed into the body through a catheter inserted into a large, central vein in the patient's chest or neck.

Although TPN is an improvement over IV feeding, it, too, has its drawbacks. TPN patients run a significant risk of catheter- and formula-related infections. Mechanical problems with insertion and maintenance of the catheter have also been noted (OTA 1987b: 284). As with any form of tube feeding, confused patients may have to be physically or chemically restrained to prevent them from tampering with the TPN line. Anecdotal evidence suggests that TPN is not regularly used for long-term demented and confused patients because of the costs and complications associated with this form of ANH. Total parenteral nutrition runs upwards of $200 a day, or more than $73,000 a year.

**General Drawbacks of ANH Summarized**

Whatever the method used, artificial feeding (particularly NG feeding) is likely to add to a dying patient's distress rather than alleviate it. This sentiment, expressed over twelve years ago by Dr. Judith Ahronheim, has been echoed among clinicians in more recent years (e.g., Enck 1994: 25; Cundiff 1992: 47–48). Perhaps even more disconcerting than the distress caused by tube feeding is the need to restrain patients who are uncooperative or confused and demented (Peck, Cohen, and Mulvihill 1990: 1197; Ahronheim 1984).

One study found that almost all of the fifty-two tube-fed patients in one skilled nursing facility required some form of continuous physical restraint to prevent self-extubation. Ninety percent of those patients with restraints had to have their hands enclosed in mittens, and 71 percent required some form of additional restraint (Peck, Cohen, and Mulvihill 1990). For patients who retain some level of awareness, restraints might be considered an affront to their dignity, and many patients who are aware of their situation tend to become depressed or angry over being tied down (Major 1989: 25). Restraints can also violate the dignity of demented and vegetative patients, for, legally, these individuals retain an interest in being cared for humanely (as opposed to being treated only as a biological entity) regardless of their mental state.

In addition to whatever indignity might be suffered, restraints can, over time, put the patient at increased risk for developing bedsores and pneumonia. According to one study, tube-fed patients were more than three times as likely to develop aspiration pneumonia (57 percent versus 15 percent in the control group). Restrained patients were also 50 percent more likely to suffer from painful decubitus ulcers (Peck, Cohen, and Mulvihill 1990: 1197; Ahronheim 1984). Tube feeding can also cause edema (swelling) in the abdomen and extremities. Accumulations of fluid in the upper respiratory tract can cause increased secretions, and accumulations in the lower tract can increase coughing and shortness of breath (Ahronheim 1984).
Artificially provided food and fluids may also precipitate psychological problems for friends, family members, and caregivers. The feeding tubes and their associated apparatus may serve as a barrier between relatives and the patient and may divert the attention of caregivers from tending to the patient to maintaining the equipment. Ultimately, the relief of the patient’s suffering, which should be the primary goal, can be overwhelmed by the drive to correct nutritional imbalances and restore electrolyte levels (Oliver 1984: 631; Sutcliffe 1994: 62; Peck, Cohen, and Mulvihill 1990: 1197). In addition, artificial feedings provided to hopelessly ill patients may give them (if they are conscious and aware), their friends, and members of the family a false sense of hope (Sutcliffe 1994: 62).

The Dehydration Alternative

There is a time-honored, foolproof alternative to tube feeding for terminally ill patients who are prepared to die: dehydration. The health care community is, of course, aware of this approach, but most members of that community are reluctant to speak openly about it—despite the fact that their professional journals are virtually brimming with evidence about the benefits of dehydration. Just as pneumonia was referred to as “the old person’s friend” years ago, before the development of antibiotics, a substantial body of literature indicates that dehydration might well be thought of as “the dying person’s friend” today.

When food and fluids are withheld or withdrawn, patients, in fact, die of dehydration, not starvation. The distinction is an important one that must be addressed before anything else about the subject of dehydration is considered.

Pathogenesis of Starvation

The word starvation inevitably conjures up gruesome images. Emaciated children in Third World countries come to mind, or one might recall the haggard visages of the ten Irish hunger strikers who fasted to death as part of a political protest in 1981. Whatever the vision, starvation seems to be anything but a satisfactory alternative for elderly demented patients at the end of life—and for good reason.

Death by starvation is a long, arduous process that can easily drag on for a number of weeks. The Irish nationalists who starved themselves to death in 1981 lived an average of sixty-two days after they stopped eating. This corresponds with the findings of Maurice Shils, James Olson, and Moshe Shike (1994: 938), who suggest that the length of survival without food for nonobese adults is sixty to seventy days.7

Starvation, involving drastic weight loss and body wasting, begins after feeding stops and the body has burned up all the readily available sugars in the blood. Thereafter, muscles and fatty deposits throughout the body are
metabolized as sources of energy. As the muscles are converted to fuel and begin to wither away, the limbs appear to shrink, taking on a sticklike appearance. Without fat to support it, the skin begins to sag and become wrinkled, sometimes giving even the youngest victims of starvation the withered, emaciated look of an old man. Other victims of starvation may suffer from kwashiorkor, a malnutritional deficiency that allows fluid to leak from blood vessels into the body. The primary symptom of kwashiorkor is severe edema, often manifested as a grotesquely swollen belly. Psychological changes such as apathy and irritability are common as well.

As the process of starvation wears on, bodily functions begin to shut down. One of the most critical functions that slows down is the reproduction of white blood cells. This weakens the immune system and leads to a sort of starvation-induced immunodeficiency. This condition is quite similar to AIDS, and it turns relatively common and typically benign infectious diseases into killers. Toward the end of the starvation process, the intestines begin to fail, leading to uncontrollable diarrhea. Finally, if the starvation victim has survived the ravages of infection by twist of fate or through good nursing care, the heart muscle, shrunken like all the other muscles in the body, gives out and the individual dies of cardiac arrest (Lemonick 1992: 36; Shils, Olson, and Shike 1994: 1460-1461).

Medical studies of political hunger strikers add gruesome details to this clinical picture. W. J. Kalk, M. Felix, E. R. Snoey, and Veriawa Yosuf (1993) reported that twenty-two of the thirty-one South African hunger strikers under observation had symptoms so severe (abdominal cramping, headaches, and clinical depression) that hospitalization was required. Dominique Fromme, Elisabeth Questiaux, Marth Gautier, and Leon Schwarzenberg (1984) reported that French hunger strikers opposing the nuclear arms race in 1983 agreed to begin the refeeding process about five and a half weeks into their fasting after severe nausea and abdominal cramps, bleeding gums, tremors, and tinnitus made continued fasting unbearable. Protesters in Ireland who carried their hunger strikes to the end suffered from vomiting so acute and so wrenching they could not even hold down springwater as they neared death (Cranford 1991a: 18-19).

There can be no doubt that starvation, planned or not, is a grim process. Obviously, it is not a death that most would wish for themselves and their loved ones.

Pathogenesis of Dehydration

Dehydration is entirely different from starvation. Whereas death by starvation is a drawn-out and unnatural process, dehydration is much more natural and common, and it leads to death relatively quickly and painlessly. It is for exactly this reason that political hunger strikers continue to take flu-
TABLE 5.1 The Hydration of Political Hunger Strikers

<table>
<thead>
<tr>
<th>Political Hunger Strikers</th>
<th>Fluid Intake</th>
<th>Source</th>
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<tbody>
<tr>
<td>800 South African political detainees in 1989</td>
<td>A teaspoon of sucrose dissolved in a jug of tap water daily, occasionally with a tablespoon of salt</td>
<td>Kalk et al 1993: 391</td>
</tr>
<tr>
<td>French hunger strikers opposing the nuclear arms race in 1983</td>
<td>1.5 liters of water daily</td>
<td>Fromme et al. 1984: 1451</td>
</tr>
<tr>
<td>10 Irish hunger strikers in 1981</td>
<td>Normal amounts of water as long as they could hold it down</td>
<td>Cranford 1991a: 18-19</td>
</tr>
</tbody>
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ids during their fasts; if they did not, they would die of dehydration with some dispatch. Death by dehydration is not nearly as politically effective as the death that results from the drawn-out and wrenching process of starvation (see Table 5.1).

Good, clinically based studies of death associated with dehydration are uncommon in the medical literature. This dearth of empirical studies can be explained, in part, by the reluctance of health care providers to intrude on dying patients and their families, for ethical and humanitarian reasons. In addition, many clinicians tend to treat the patient's lack of interest in eating and drinking toward the end of life as a problem requiring active intervention rather than a condition worthy of passive study.

Others, however, view dehydration in the elderly in historical (rather than technological) terms, as a naturally occurring phenomenon. According to Shils, Olson, and Shike (1994: 1460–1461), for example, prior to the development and popularization of tube-feeding techniques in recent years, dehydration tended to be the direct cause of all "natural" deaths (i.e., those not associated with violent trauma or acute infection) (see also Meares 1994: 10; Cranford 1991a: 18). Even today, it is generally accepted that food and fluid intake decreases naturally with age and that elderly people often report a decreased interest in eating and drinking (Justice 1995: 41; Ahronheim and Gasner 1990: 278). Similarly, Christopher Justice (1995: 42) argues that "cultural norms that allow either force-feeding or gentle encouragement of non-hungry, dying persons to eat—and which encourage the dying person, him or herself, to always continue eating—may act to 'unnaturally' extend the dying process."

The research that does exist on dehydration suggests that patients who stop taking in food and fluids slowly sink into unconsciousness and coma over a period of five to eight days and die peacefully several days after that. The transition from a fully hydrated state to unconsciousness is typically
made without complaint of pain or discomfort, as long as comfort care measures are continued (Sullivan 1993: 221; Ahronheim and Gasner 1990: 278). In the words of Dr. Robert J. Sullivan, a geriatric researcher and medical specialist, a review of the literature on this subject suggests that it is likely that prolonged dehydration and starvation induce no pain and only limited discomfort from dry mouth, which can be controlled. For individuals carrying an intolerable burden of illness and disability, or those who have no hope of ever again enjoying meaningful human interaction, the withdrawal of food and fluid may be considered without concern that it will add to the misery (Sullivan 1993: 222).

A few symptoms are associated with dehydration, but each is easily treated. One symptom, thirst, is experienced in only a small percentage of dehydrating patients at the end of life, and it is never hard to alleviate (Billings 1985: 810; Maillet and King 1993: 46–47; Hastings Center 1987: 59–60). In one study involving ninety-six hospice nurses, 73 percent indicated that dehydrated patients rarely complained of thirst (Andrews and Levine 1989: 31). Whatever thirst or mouth dryness that develops can easily be palliated with lip moisturizer, sips of water, ice chips, and hard candies (Schmitz and O’Brien 1989: 32; Printz 1988: 85; Andrews and Levine 1989: 31; McCann, Hall, and Grath-Junker 1994: 1265). In a small percentage of patients, electrolyte imbalance may lead to neuromuscular irritability and twitching, both of which are easily treated with antispasmodics and sedation (Schmitz and O’Brien 1989: 32; Sutcliffe 1994: 61). Nausea, another symptom of dehydration that emerges on occasion, is easily controlled with antiemetics (Printz 1988: 85). Bedbound patients may also report varying degrees of lethargy, drowsiness, and occasionally fatigue, but these symptoms are rarely a source of much distress (Billings 1985: 810).

Phyllis Schmitz and Merry O’Brien (1989: 36), two hospice nurses, write that “we have not seen evidence that dehydration occurring at the termination of life results in any pain or distressing experiences for the patient.” These conclusions are echoed in more general surveys of caregivers who are familiar with dehydration in dying patients: The vast majority of those experienced with treating patients at the end of life believe that dehydration is not painful.

There is also substantial evidence to suggest that dehydration carries some significant advantages. Schmitz and O’Brien (1989: 32) found that dehydration reduces nausea, vomiting, and abdominal pain. Sullivan (1993: 222) and Stephen Post (1990: 185) both reported that dehydration reduces the diarrhea that is often suffered by dying patients. Furthermore, the decreased urine output secondary to dehydration means fewer bedpans, precarious trips to the commode, catheterizations, and bed-wetting episodes (Schmitz and O’Brien 1989: 32; Andrews and Levine 1989: 31).
Pulmonary secretions also decrease with dehydration. This reduces coughing, congestion, gagging and choking, and shortness of breath. Often, in fact, the need to suction congesting secretions is completely eliminated (Schmitz and O'Brien 1989: 32; Sullivan 1993: 222; Post 1990: 185; Andrews and Levine 1989: 31).

Last and perhaps most interesting is the reduction of pain that some clinicians have linked to dehydration. Medical researchers report that terminally ill patients who become dehydrated tend to experience less discomfort than those receiving medical hydration, to the point where the dehydrated patients required less analgesia than the hydrated group (Printz 1988: 84, 1992: 698; Sutcliffe 1994: 61; Ahronheim and Gasner 1990: 278). "Indeed," writes Sullivan (1993: 222), "mild euphoria can be anticipated [with dehydration], accompanied by an increased toleration of pain." The slow but steady decrease in consciousness associated with advancing dehydration may serve as part of the protection against discomfort and suffering experienced by patients who are forgoing food and fluids (Post 1990: 185). Dehydration also reduces swelling in the body, improving a patient's overall sense of well-being. Reduced swelling also relieves pressure on any tumors that exist, and that, too, may relieve some discomfort (Andrews and Levine 1989: 31).

Clinical Attitudes About Dehydration

Unfortunately, there is little reliable evidence to indicate how—or how often—decisions are made to withhold artificially provided food and fluids from chronic, irreversibly demented elderly patients. There is, however, a fair amount of data on the attitudes of clinicians in these matters. One recent study by Candace Meares indicated that 95 percent of hospice nurses believe aggressive nutritional support does more harm than good (Meares 1994: 13). In another study conducted in 1994, 326 practicing internists who had personal experience with tube-fed patients were surveyed. Of this group, 84 percent opposed the initiation of tube feeding for a patient with advanced dementia when the patient’s wishes were not known (Hodges et al. 1994).13

Another study, involving 156 directors of nursing and 124 house physicians, revealed a bit more ambivalence. Respondents were asked to indicate their preferences on the tube feeding of demented patients on a scale of 1 (strongly favor tube feeding) to 8 (strongly oppose tube feeding) in various patient scenarios. An average score of 4.5 would indicate that, in the aggregate, the respondents were neither for nor against hydration. The registered nurses in the study leaned slightly in the dehydration direction; they had an average score of about 5 on the 8-point scale when asked about the tube feeding of old, confused, and seemingly unhappy patients. The physicians in the study, with an average score of about 6, appeared to lean a bit more
strongly in the direction of forgoing tube feeding for such patients (Watts, Cassel, and Hickam 1986: 607).

In a larger and more comprehensive study conducted by Daniel Luchins and Patricia Hanrahan (1993: 25–26), 1,408 members of the American Geriatric Society and members of the Alzheimer's Association (essentially, family members of individuals afflicted with DAT) were asked to recommend 1 of 5 levels of care for a patient with end-stage dementia, ranging from level 1 (do everything possible) to level 5 (provide comfort care measures only—no CPR, no respirators, no antibiotics, and no tube feeding). Sixty-one percent of the physicians, 55 percent of the other geriatrics health care professionals, and 71 percent of the family members in the survey indicated that they would opt for treatment level 5 (comfort care only, no tube feeding).

Dr. David Cundiff, a hospice physician and unabashed critic of euthanasia, is another caregiver who finds the tube-feeding option wanting. Cundiff states clearly that, as a rule, he does not recommend tube feeding for his terminally ill patients and that he recommends withdrawal of feeding tubes if they are in place. This sentiment was widely accepted among other clinicians as well, especially when physical restraints are required to keep patients from pulling out their feeding tubes or catheters (OTA 1987b: 315). At least two studies found that the more exposure a caregiver has to dehydration in dying patients, the more acceptable the dehydration option becomes (Andrews and Levine 1989: 31; Luchins and Hanrahan 1993: 25).

Overall, there is very little doubt that those experienced with death and dehydration believe the benefits of dehydration far outweigh the burdens for certain patients, namely, the terminally ill, the irreversibly unconscious, and the severely demented. This is not to say that the hopelessly ill should be forced to undergo dehydration against their expressed wishes. But when the vast majority of Americans say they would not want to be tube fed if irreversibly demented or vegetative (see Tables 3.2 and 4.4), when the consensus position holds that forgoing ANH is an entirely appropriate and ethical medical response to hopeless illness, when clerics formulate positions that sanction the forgoing of food and fluids if the benefits are outweighed by the burdens, and when clinicians explain the considerable drawbacks of tube feeding and the benefits of dehydration and express (through surveys) their solid support for the dehydration alternative, one can only wonder why any rational decisionmaker would choose long-term tube feeding at the end of life.

The dehydration alternative may also prove helpful to competent patients who are suffering from chronic and debilitating conditions and would like to have the option of physician-assisted suicide (PAS). Choosing dehydration overcomes many of the criticisms associated with PAS. More knowledge about the benefits of forgoing hydration might actually take some of the wind out of the sails of those who think physician-assisted suicide is the only or the best way to control one's end-of-life destiny. At the
Physician-assisted suicide (PAS) has been the subject of regular news coverage and has spawned much legal, ethical, and medical debate across the country. Given the interest and controversy that surround this subject, it seems curious that so little attention has been paid to the forgoing of fluids as a practical alternative for the seriously ill who seek to hasten death.

Dehydration, like PAS, provides a comfortable exit from life, and both processes shorten a dying process that might otherwise drag on interminably. Since the time of death is predictable with both dehydration and PAS, family members and friends can rearrange schedules and take the time to travel to the bedside of the loved one at the time of his or her passing. In both cases, the patient need not die alone, cared for only by strangers. Friends and family members can be there at the end to provide comfort care and give their support.

Dehydration also has some advantages that PAS does not:

• Dehydration provides control. Physician-assisted suicide involves having the patient breathe poison gas, take lethal injections, or swallow lethal amounts of pills, all of which begin processes that, for all practical purposes, are irreversible. In contrast, individuals who initiate death by dehydration have several days to change their minds.

• Dehydration requires no help. Patients who decide to use dehydration to hasten death are not forced to beg help from family, friends, or health care professionals, who may have moral qualms about PAS. Even the most debilitated patient can exercise his or her constitutional right to forgo hydration, allowing nature to take its course.

• Dehydration is natural. Physician-assisted suicide requires wrenching changes in medical ethics and practice that dehydration does not. Prior to the 1960s, dehydration was almost always present in the dying patient as either a direct or contributing cause of death. Just as pneumonia was once described as the sick person’s friend, dehydration was usually a close, amicable neighbor.

very least, dehydration provides another option for seriously ill patients who are intent on hastening death in an amenable way. (See Box 5.1.)

Why Is Tube Feeding So Common?

Empirical studies of tube feeding in clinical practice suggest that the use of artificially provided food and fluids in the severely ill is much more prevalent than one might expect, given the consensus position, public opinion, and caregiver experience. There is relatively clear and strong support for the legitimacy of forgoing ANH in the medical community (expressed via position statements of professional associations and the attitudes of bedside
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clinicians), in the lay community (in public opinion poll data), in the legal community (in judicial decisions at the state and federal levels), and in both the secular and religious ethics communities. But when push comes to shove, tube feeding is initiated and continued more often than not.

According to an international study by Thierry Collaud and Charles-Henri Rapin (1991), 28 percent of responding physicians said that they would recommend tube feeding, but 44 percent of them actually did recommend tube feeding in practice. Another study indicated that 54 percent of the physicians surveyed were concerned that ANH was used inappropriately in their critically ill and terminally ill patients, and 55 percent of the physicians responded affirmatively to the statement, “Sometimes I feel the treatments I offer my patient are overly burdensome” (Solomon et al. 1993: 14, 16). What is at the root of the dichotomy between clinical, public, and ethical sentiment—which accepts the notion of withdrawing tube feeding from seriously ill patients—and clinical reality—in which tube feeding is the norm?

The practices in nursing homes, where many elderly and infirm patients receive their care, provide a partial answer. Hand feeding patients is a time-consuming process, and it is regularly alleged that some hospitals and nursing homes use tube feeding because sufficient staff time cannot be allocated to hand feeding every patient who cannot feed him- or herself (OTA 1987b: 279). Some caregivers indicate they know of nursing homes that simply will not accept patients with eating problems unless tubes are in place at the time the patient is admitted to the facility. According to a study published by the New York State Task Force on Life and the Law (1992: 11), nursing homes may favor tube feeding because they receive a higher reimbursement for patients who are tube fed versus those who are fed by hand.

Caregiver anxiety about withdrawing food and fluids also comes into play, at least partly because of the important role that food plays in American culture. As R. A. Carson notes: “The simple act of offering to allay hunger and to slake thirst of a dying person is deemed across time and cultures not only right but good. Denying food and water for any reason seems the antithesis of expressing care and compassion” (cited in Sutcliffe 1994: 62). J. Andrew Billings (1985: 810) adds that “the decision to administer fluids to a dehydrated patient is often determined by the symbolic or emotional meaning of such measures to the patient, family, and caretakers.” It is not surprising, then, that when faced with a real-life decision, families often ask and physicians advise that tube feeding be provided.

The natural aversion to withholding and withdrawing food and fluids is understandable, especially when that aversion is compounded (mistakenly) by the thought that those who forgo ANH will be left to “starve” to death. In addition, providing food to those we love has always symbolized and expressed the essence of care and compassion. Dr. Joanne Lynn (1989: 47) notes that “there is a link made in the mind between feeding and
loving that is difficult to dismiss in the practice of making decisions for those who can no longer make decisions for themselves." Eating and drinking are associated with social interchange and the celebration of life, and providing others with food and drink is a common way of honoring them.

All of our holidays and social occasions, big and small, are marked by the provision of food and drink. All this, combined with the negative personal experiences people have with even relatively low levels of thirst and hunger and the horrific stories in the media about starvation in other parts of the world, often predispose family members to pursue tube feeding. There are also religious admonitions that pervade our culture regarding the duty to feed the hungry and provide drink to the thirsty. As a result, “tube feedings are often initiated to alleviate the anxiety of caregivers and families of patients,” and that is a response that cannot help but “cloud the real issues of providing comfort to the patient” (McCann, Hall, and Grath-Junker 1994: 1266).

Physicians also get caught up in the crosscurrents on feeding the hopelessly ill and demented patients in their care, especially when family members (and perhaps nurses) are imploring the physicians to “do something!” This external pressure, when combined with the influence of training that still regards infusions as the hallmark of serious treatment (Collaud and Rapin 1991: 238), may conspire to undermine the abstract clinical indications to forgo feeding tubes. The technological imperative, the sense that one needs to employ every means of technology available regardless of the costs or benefits of treatment, also drives physicians to act in ways that, in the abstract, may make little or no sense.

The preeminence of the technological imperative among clinicians may be rooted in medical schools where, according to James Lindgren, a doctor’s “instincts are well trained to intervene to prolong life. Indeed, physicians are rarely challenged for intervening but often criticized for ‘going slow.’ Physicians do not easily accept the conception that it may be best to do less, not more, for a patient. The decision to pull back is much more difficult to make than the decision to push ahead with aggressive support” (Lindgren 1993: 186). Continuing this line of thought, Ezekiel Emanuel writes that “whether it is positively affirmed, liberally espoused, or instinctively assumed, prolonging life becomes the ‘default’ response for physicians facing clinical decisions without clear guidelines on terminating care. As a result, aggressive medical treatment, without concern for the ‘whole’ patient—the physicalization of medicine—is the standard of care” (cited in Lindgren 1993: 186).

Mark Siegler and David Shiedermayer (1987: 34) have commented along these lines as well:

Many physicians believe the denial of fluids and nutrition would injure the therapeutic relationship and that continuing fluids and nutrition, even in the terminally ill, affirms the physician’s role as a caring professional. They con-
sider the provision of food and fluids to be both a form of treatment and a nurturing and symbolic act that avoids any appearance of abandoning the patient.

Of course, abandonment is exactly what physicians accomplish when they fuel false hopes with their symbolism and interpose a medical technology between the patient and the rest of the world. The predisposition on the part of physicians to tube feed is not shared universally, however. Ronald Cranford (1991a: 20) recounts that

on a recent trip to the Netherlands I spoke with health care professionals in nursing homes. One topic was the use of feeding tubes in profoundly demented patients. I asked some physicians what they do when patients become so profoundly demented they are unable to feed themselves naturally. Some didn’t seem to know how to respond to this question. One particular physician in a nursing home near Amsterdam kept repeating, “What do we do?” She didn’t seem to understand the question because the answer was so obvious to her. Finally she answered, “Well, we wait.” The idea of starting a feeding tube on a profoundly demented patient who has no chance of recovery is a truly “foreign” concept to the common sense and humane approach of many Dutch physicians and health care providers. When I told them of the common practice in the United States, they often stared at me in disbelief. Some asked “Why would you do that?” I didn’t have a very convincing answer.

Collaud and Rapin (1991: 238) argue against the American instincts the Dutch find so befuddling and suggest that “the therapeutic choice should be aimed at the patient’s well-being [e.g., best interests], and should not be aimed at relieving the anxiety of relatives or nursing staff.” Unfortunately, anxiety often overwhelms reason in these situations.

No doubt, some physicians are distracted by the writings of those who have argued that doctors should fight the impulse to accede to patient’s wishes when they express an interest in forgoing food and fluids because patients who choose this route are not thinking clearly, by definition. According to geriatrician John Morley (1989: 184), “Half of underweight older patients have abnormal attitudes toward eating.” He also reports that geriatricians commonly encounter older patients who, having lost their locus of control, use “food as a weapon in an attempt to manipulate the caregiver.”

There is also the physician’s fear of legal liability (Hodges et al. 1994: 1019), a fear that may, in part, be grounded in reality. Despite the widespread acceptance of ANH as a medical treatment that can be legitimately withheld at the end of life, some state statutes continue to treat ANH as a separate class of procedure that can only be forgone in very limited circumstances, if at all. In the Barber case in California, two physicians, Neil Barber and Robert Nejdl, were charged with murder by state prosecutors after they withdrew artificial nutrition and hydration from the irreversibly vegetative Clarence Herbert, at the behest of his family. Although the Barber
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In this case, like other similar cases, the very fact that the doctors were charged in the first place may leave physicians troubled by "the brooding presence of possible liability" (Kapp and Lo, cited in OTA 1987b: 72; also cited on 185, from Quinlan) when the issue of suspending ANH arises.

Research conducted by Dr. John Ely and his colleagues certainly brings this point home (Ely et al. 1992). The Ely team surveyed 439 members of the Missouri Academy of Family Physicians regarding a hypothetical case involving an eighty-nine-year-old stroke victim who had indicated a desire not to be tube fed. The researchers found that 66 percent of those physicians who said they would comply with the patient's legitimate wish to forgo tube feeding would reverse that decision and order artificial feeding if "pushed" to do so by members of the patient's family. The researchers explained this result in simple terms: It is the family, not the demented patient, who may initiate legal proceedings if treatment preferences are not honored. The family has the ability to sue, while the patient has none, and even if the physician wins his or her case after acceding to the patient's wishes not to be treated, the emotional and financial costs of legal proceedings may not be viewed as worth the effort.

In addition, there seems to be a fair amount of confusion among physicians about medical-ethical issues associated with ANH. For example, although many physicians apparently feel that tube feeding can be withdrawn from vegetative patients at the request of a surrogate, they are reluctant to do so, thinking that they would be violating professional norms (NYSTFLL 1992: 11) or that withdrawal would increase patient discomfort. A 1993 study by Mildred Solomon and colleagues revealed that 42 percent of 1,446 responding physicians and nurses thought ethical standards required that food and water always be continued (Solomon et al. 1993: 20). Many respondents also reported that they thought permission to withhold or withdraw treatment applied only to so-called heroic measures such as CPR, while "ordinary" measures such as tube feeding had to be continued in the absence of a court order. The same survey revealed that 12 percent of health care professionals in the study thought withholding tube feeding was tantamount to killing.

Follow-up interviews in the Solomon study revealed that one of the primary motivations for not wanting to withdraw ANH was a fear that to do so would cause discomfort in the patient, despite the stream of research on the subject that suggests that continued feeding and hydration can be much more problematic when it comes to pain and discomfort than forgoing this treatment. Other studies have found that most doctors who advocate the use of ANH for dying patients would use this treatment to ensure their patients' comfort (Sutcliffe 1994: 62; Andrews and Levine 1989: 31), even though studies of hospice nurses who have extensive experience with termi-
nal dehydration view dehydration as generally beneficial (Enck 1994: 27). In the end, a number of reasons conspire to yield a simple yet troubling reality, according to a study led by Sidney Wanzer (Wanzer et al. 1984): “Physicians worry too much about withholding treatment.”

Dr. Judith Ahronheim (1984) sums up the situation well:

Although potentially valuable and life saving in many situations, artificial nutrition and hydration do not provide comfort care for dying patients. Experience and available scientific evidence have shown that death without artificial nutrition and hydration is natural and pain free. . . . In contrast, tube feeding prolongs and often worsens the dying process. Terminally ill patients sometimes benefit from artificial feeding. But to assume that it must always be provided fails to consider the patients’ needs. Because we ourselves tend to see the provision of food and water as intrinsic to caring, we sometimes feel uncomfortable about withholding artificial nutrition and hydration. When we are entrusted with the decision for the dying, we need to broaden our understanding of caring so that we address the patient’s comfort, not our own (italics in original).

Antibiotics: Another End-of-Life Dilemma

Infection, like dehydration, is very common in the old and debilitated patient population. In one study of elderly nursing home residents, infections were found to account for 54 percent of all acute medical problems and 63 percent of all deaths (Mott and Barker 1988: 820).

Infections stem primarily from the incontinence and immobility that are so common in elderly patients. Immobility allows fluid to settle in the lungs, leading to the development of pneumonia, the most common of killer infections. Patients who are tube fed face the added risk of aspirating their feeding solutions even if the feeding tubes are properly placed. Meanwhile, incontinence leads to the increased risk of developing urinary tract infections (UTIs), the second most common terminal infection. In addition, incontinence, immobility, and low levels of blood protein in the elderly population lead to the development of another serious problem: bedsores. Sherwin Nuland graphically describes them as “ghastly to look at as they deepen to the point of exposing muscle, tendon, and even bone, coated in layers of dying tissue and pus” (Nuland 1994: 104). In the end, most patients whose dementia progresses to the vegetative point die of some sort of infection, whether treated or not. Consequently, Nuland (and others) suggest that it may be best to forgo the use of antibiotics and “let grim nature have its way” (Nuland 1994: 104).

Burdens of Antibiotics

The medical literature indicates that, like the use of artificial nutrition and hydration, the administration of antibiotics has costs as well as benefits.
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There can be no denying that, beginning with the development of sulfonamide in the 1930s, antibiotics have saved millions of lives and relieved an untold amount of suffering brought on by infections in otherwise potentially healthy individuals. At the same time, antibiotics—again, like artificial nutrition and hydration—should be used judiciously rather than reflexively, for such medical therapy can be excessively burdensome for some, especially those who are severely debilitated and chronically or terminally ill.

Sherwin Nuland is not alone in suggesting that we allow “grim nature to take its course” when infection strikes those who are already mortally ill. According to the Hastings Center’s Guidelines:

Although administering these drugs [antibiotics] can constitute a beneficial and welcome form of life-sustaining treatment for many patients, for others it can be disproportionately burdensome. ... [The] decision about using antibiotics and other life-sustaining medication, like decisions about other forms of life-sustaining treatment, requires patients and their surrogates to balance carefully the potential burdens of the treatment and the life it offers against the benefits. ... The patient or surrogate should be able to evaluate and forego antibiotics as they can other forms of treatment (Hastings Center 1987: 65–66).

According to William Osler’s Principles and Practice of Medicine, a medical textbook of 1,600 pages now in its twenty-first edition: “Pneumonia may well be called the friend of old age. Taken off by it in an acute, short, not often painful illness, the old escape those ‘cold gradations of decay’ that make the last stage of life all so distressing” (cited in Nuland 1994: 60). Dr. P. R. Katz (1993: 173), an internist and geriatric specialist, is another clinician who argues that antibiotics are not always desirable and should not always be used to address infection in nursing home patients. He recommends that physicians and nursing home administrators and staff work in concert to avoid inappropriate use of antibiotics, prescribing them only in situations in which clear benefit has been demonstrated. Beverly Volicer and colleagues (B. Volicer et al. 1993), writing specifically about DAT patients, suggest that increased use of hospice care for patients in this condition would have advantages for both the patient and for society (antibiotics are rarely used in hospices). According to Volicer, “Treatment of infections inflicts a burden on the DAT patient without proven benefit. Therefore, there is a need to compare the benefit and burden of the intervention to determine which are justified for an individual patient” (B. Volicer et al. 1993: 539, citations omitted; also see L. Volicer et al. 1986: 2213; Hurley et al. 1993: 21).

The potential burdens of antibiotic treatment begin with the diagnostic workup, which is required to identify the type of infection so that the appropriate course of antibiotic therapy can be prescribed. This workup can involve the sometimes painful harvesting of material for analysis from the site of the infection (B. Volicer et al. 1993: 539; Hastings Center 1987: 65–66). Transfer to an acute medical unit where clinicians who are unfamiliar to the
patient proceed with diagnostic testing and follow-up therapy, if required, can also prove frightening for a patient who may not fully comprehend the situation (B. Volicer et al. 1993: 539). The possibility of adverse drug reactions (B. Volicer et al. 1993: 539) and other complications secondary to the use of the antibiotics (Hastings Center 1987: 65–66) must also be weighed in the balance. The need for repeated injections and the problem of finding suitable injection sites in already compromised skin must also be considered (Nuland 1994: 104; Hastings Center 1987: 65–66).

Another negative factor involves the possible need to use physical or chemical restraints while administering antibiotic treatment (B. Volicer et al. 1993: 539). According to Greg Sachs and his colleagues,

> Even routine measures used to address intercurrent infections cause demented patients who cannot understand the purpose of the procedure to become agitated and combative, necessitating the use of physical restraints which only exacerbate the discomfort and agitation felt by the patient, while stirring feelings of guilt, helplessness, and despair in members of the patient’s family (Sachs et al. 1995: 558–559).

In many cases, no cause for the infection is identified, even though the patient has been subjected to burdensome diagnostic tests (B. Volicer et al. 1993: 539; Sachs et al. 1995: 558–559). And even when the proper diagnosis is made and therapy is started, patients who are noncommunicative and immobile often die in spite of the aggressive treatment they receive (Hurley et al. 1993; Sachs et al. 1995). In fact, research suggests that antibiotics do no better than a therapeutic course of analgesics and antipyretics (e.g., aspirin or acetaminophen to reduce fever) when treating infections in the severely demented patient (Hurley et al. 1993). In those whose illness is not as advanced, life may be prolonged, but suffering will be prolonged as well as one (or more likely several) underlying chronic pathologies continue on their course toward the inevitable death (Sachs et al. 1995: 558–559).

**Clinical Realities**

How has the medical community reacted to the ethical dilemma of treating infections aggressively in cases in which the treatment itself is burdensome? In one landmark study conducted in 1979, physician Norman K. Brown and medical researcher Thompson Donovan (Brown and Donovan 1979) found that antibiotics were regularly withheld from long-term care patients who had developed serious fevers (the primary symptom of infection). In reviewing 1,256 patient records from 9 Seattle-area institutions, Brown and Donovan found that although 190 patients developed serious fevers, only 109 were treated actively with antibiotics, hospitalization, or both. Antibiotics were withheld from 81 patients, of whom 48 (59 percent) died within
48 hours (mostly, the primary cause of death was pneumonia), and 13 more patients died within the next month. Thus, the total 1-month mortality rate in the untreated group was 75 percent. In summarizing the results of their study, Brown and Donovan stated: “We believe that most of the decisions not to actively treat these [infections] were part of an intentional plan by physicians and nurses. . . . The medical records of 23 untreated patients showed that grave illness would not be treated. Medical personnel undoubtedly took the same approach for [the] other [58] patients” (Brown and Donovan 1979: 1250).

Peter Mott and William Barker (1988) found similar patterns of practice in the late 1980s. These two authors, both physicians, placed each of the 110 nursing home patients in their study into 1 of 4 treatment categories, ranging from category 1 (51 patients for whom all care was to be provided, including hospitalization and intensive care, as necessary) to category 4 (12 patients who were to receive comfort care only and no antibiotics). After seven years of monitoring, Mott and Barker found that antibiotics were withheld in 14 percent of all cases and in 43 percent of the cases involving patients assigned to treatment category 3 (for whom antibiotics could be prescribed but who were not to be hospitalized) and category 4.

Perhaps more significant still, however, is the entire concept of assigning patients to a “comfort care only” category that involves withholding antibiotics. Apparently, given the straightforward way in which the categorization process was reported, withholding antibiotics is relatively routine and not particularly controversial. Although there is a fairly substantial body of literature on the benefits of withholding artificial nutrition and hydration from patients in the advanced stages of a mortal pathology, there is almost nothing written beyond what is cited here on the withholding of antibiotics. The few studies that have been published on the subject clearly indicate that withholding antibiotics is something of an open secret among health care professionals and that physicians who know the patient best are the ones most likely to do the withholding.

Summary

In the 1950s, patients were not typed with the classification DNR because the technology and know-how associated with modern cardiac resuscitation did not exist. Attempts at resuscitating heart attack patients became widespread only after the introduction of CPR and the development of electronic defibrillators in the mid-1960s. In the 1970s, physicians began “coding” patients on their own, realizing that, as important as CPR was, it did not make sense to attempt aggressive resuscitation for everyone who suffered a myocardial infarction (especially if the patient was already seriously or terminally ill). Shortly thereafter, patients gained the ability to sign
their own DNR orders. There were four phases in the evolution of CPR technology and the patient’s right to control that technology, moving from (1) a lack of technology to (2) the development, proliferation, and universal use of technology to (3) the selective use of technology and finally to (4) patient control. The evolutionary process took about fifteen years to complete (from 1960 to 1975).

Today, approximately 70 percent of patients who die in the hospital have DNR orders in place (Council 1991: 1869). Patients now have the right to execute such orders, and obviously, many of them exercise that right. In fact, a number of jurisdictions have expanded this right even further to include nonhospital DNR orders, allowing patients to carry DNR orders home with them whether they are seriously ill or not (in some cases). The fact that some patients have a relatively good chance to benefit from CPR does not diminish their right to have a DNR order. Likewise, the fact that CPR can be simple to employ (e.g., mouth-to-mouth resuscitation and external chest massage), requiring no invasive or technologically sophisticated equipment whatsoever (Capron 1989), does not impair the right to refuse such treatment. Clearly, patients or their surrogates are now in the driver’s seat. Virtually no one questions their right to sign DNR orders today.

We now may be in the throes of an evolution in thinking about tube feeding and antibiotic therapy that parallels—and lags by ten years—the evolution in thinking that has taken place regarding resuscitation. Perhaps “DNI” (do not intubate) orders will be available in the near future, just as DNR orders are today.

Prior to the 1960s, chronically ill patients who became dehydrated simply died. Then and over the history of civilization up to that time, dehydration was among the most common primary or secondary causes of death (Lynn 1989: 47). Only since the 1970s has tube feeding routinely been available to patients requiring long-term assistance with feeding and hydration. Then, in the early 1980s, physicians began to realize something about ANH that they had come to appreciate about CPR in the late 1960s and early 1970s: It simply does not make sense to treat every patient just because the treatment is available. Only then did certain physicians start to become comfortable with the unilateral decision not to offer tube feeding as an alternative to seriously ill patients who otherwise would have been candidates for the treatment.

In the early 1980s, the professional associations began revising their ethical codes to reflect the clinical reality that not all patients are suitable candidates for long-term intubation. Ten years later, around 1990 (the year the Supreme Court decision regarding Nancy Cruzan was handed down), the general public began to appreciate the futility of tube feeding for the mortally ill. If present trends and the parallel with the evolution of DNR orders continue, we should expect to see DNI orders being as commonly discussed, accepted, and employed in the very near future as DNR orders are today.
We might also see the popularization of “DNA” (do not use antibiotics) orders. Indeed, DNA orders may evolve more quickly than DNI orders even though the administration of antibiotics, either orally or intravenously, is much more straightforward and may involve fewer complications from a medical standpoint than the provision of artificial nutrition and hydration. The more important difference, from a cultural standpoint, is this: The provision of antibiotics is perceived as an entirely medical process and does not hold the same emotional and symbolic significance in our culture as the provision of food and drink does.

The popularization of DNI and DNA orders will result, sooner or later, from the slow but steady increase in the public’s understanding of the futility of using ANH and antibiotics in cases in which the costs of treatment so clearly outweigh the benefits. As long as no effective treatments exist to alter the course of serious, debilitating, dementing illnesses such as Alzheimer’s disease, tube feeding and antibiotics seem only to prolong and increase patient suffering, without providing significant benefits beyond the continuation of biological life.

When it is impossible to affect the pathogenesis of an ultimately—if not imminently—terminal disease such as Alzheimer’s, decisionmakers would be well advised to focus on providing comfort care without striving to maximize survival time (L. Volicer et al. 1986: 2210; Wanzer et al. 1984: 959). To take the opposite position and argue that a patient must be subjected to every possible medical intervention that holds out even the slightest hope of prolonging life reduces the patient to “a biological mechanism” or, as Lynn (1989a: 51) puts it, “an array of measurable variables.”

But what about the special place that the provision of food and drink has in our society? The aversion to forgoing ANH, however well fortified by culture and religion, does not constitute a moral imperative to provide tube feeding in every case. The presence of such an aversion simply means it is psychologically uncomfortable to forgo ANH. It does not render the action in question immoral by definition. As Lynn (1989a: 58) suggests, “The symbolic connection between care and nutrition or hydration adds useful caution to the decision making.” The symbolic connection—which creates the presumption that ANH should be used—is hardly sufficient to settle the matter, however. The presumption can be rebutted if there is evidence to suggest that the patient would choose to forgo ANH if he or she were able to express an opinion or if the burdens of continued treatment outweigh the benefits.

The fact that one may be maintained for a long time with ANH and antibiotics does not weaken the claim that both are morally optional treatments. The patient’s autonomy interest does not depend on the length of life that patient might have if the treatment was forced upon him or her (see Choice in Dying 1994b, Bouvia v. Super. Ct.). As a matter of fact, according to Norman Cantor (1989: 401), “the long prospective duration of a dying
process only enhances the importance of respecting a patient’s wishes. . . . Respect for the patient's decision is viewed instead as an affirmation of human dignity as embodied in the patient’s exercise of self determination.”

The situation parents face when children are about to leave home in their later teens or early twenties presents a useful analogy. The parents may be averse to seeing their children leave, but the existence of this aversion does not mean that allowing them to leave is an immoral choice. Indeed, it may be immoral to force the children to stay (assuming that could be done), even though allowing the children to leave is upsetting to the parents and may run counter to the parents’ nurturing and protecting instincts. Parents of grown children understand that there comes a time to let go, even if that means putting their children in harm’s way. The same could be said for caregivers, family members, and friends of patients who are at or near the end of life’s journey.

Some also worry about the deteriorating state of trust between patients and caregivers in our increasingly skeptical, litigious, and disconnected society. But the participation of health care professionals in forgoing treatment at the end of life does not jeopardize patient trust in those professionals. On the contrary, any failure to make the forgoing of life-sustaining medical treatment a fully appreciated option toward the end of life will only drive the wedge of distrust further between health care providers and family members. The key, it seems, is knowing when to shift the focus from curing to caring. Such a decision can often be made much earlier than it typically is today, when DNR orders are often drawn up only a few hours or days before death.

If we really care for those for whom we must make medical decisions near the end of life, we will think long and hard about whether to impose artificially provided nutrition and hydration. As Stephen Post (1990: 186, 190, citations omitted) suggests:

What could be less caring than artificially feeding a patient in the terminal stages of a dementing illness? It is far from evident that the provision of nutrition and hydration constitutes caring in all cases. . . . Such patients should not be forced to endure the burden and indignity of permanent artificial nutrition and hydration just to assuage the feelings of the health care professional or family members. To withhold or withdraw nutrition and hydration amounts to proper reverence for the wisdom of the body that knows the limits of restoration.