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The Ethics of Artificial Nutrition and Hydration – A Practical Guide

by Muriel R. Gillick

Inside


Muriel R. Gillick

Artificial nutrition and hydration (ANH) were originally developed to provide short-term support to patients who were acutely ill. Whether delivered intravenously as total parenteral nutrition, or through the gastrointestinal tract via a tube, fluids and nutrients were traditionally administered with the expectation that the patient would recover from his disease and resume eating and drinking. Over time, these temporary measures have also come to be used as long-term treatment.

It is in these situations that ANH sometimes presents an ethical dilemma, analogous to the case of the respirator, which was seldom controversial when used on a temporary basis but which engendered ethical concerns when patients were sustained indefinitely on ventilators, with no prospect of recovery.

Ethical Framework

The conventional western biomedical approach to thinking about possible limitations of treatment begins with considering the autonomy of the individual patient. According to this model, a patient should decide whether he or she wants a proposed medical intervention.

In the case of ANH, relatively few patients are able to make informed decisions when they develop what is in all likelihood an indefinite compromise of their nutritional status.

> *"Factual information about what ANH can – and cannot – achieve is the first step in ethical decision making."*

Patients who are cognitively intact at the time they lose the ability to eat and drink, including many individuals with amyotrophic lateral sclerosis or metastatic cancer, can participate in the decision-making process. Treatment choices for patients who are cognitively impaired when the issue is raised are left to surrogate decision makers who are expected to use substituted judgment in determining how to proceed.

Occasionally, patient surrogates, or proxies, will have previously discussed with the patient his or her views on ANH or will have an advance directive available that specifically addresses nutritional support. In the absence of such guidance, proxies are expected to use their own judgment about what most people would want in comparable circumstances.

The legal standards for surrogate decision making vary from state to state, with restrictions on the authority of proxies to decide about ANH prevailing in a number of jurisdictions. In some cases, durable power of attorney for healthcare legislation includes a provision that proxies cannot withhold ANH unless the patient specifically delegated that authority (twelve states) or unless the patient had indicated

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CENTER FOR PRACTICAL BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

From the Contributing Editor

Seeking a Moral Compass — Decisions to Withhold or Withdraw Tube Feedings

Deciding to withhold or withdraw artificial nutrition and hydration has a visceral aspect to it that appears to set this decision apart from other critical care decisions. In truth, there is an unsettling and discomfiting element about any decision to withhold or withdraw life-prolonging treatment. The reasoning behind this flood of emotion is complex. We are expected to act with wisdom and passion, but we are also creatures of imperfect knowledge, and sometimes confuse our knowledge of an event with its cause: "I made the decision, so it's my fault he died."

Moreover, in medicine, the decision not to do something is almost antithetical to common sense. Although we admonish providers — doctors, nurses, and myriad other caregivers — "above all else, do no harm," we regularly bring our children, our spouses, our aging parents, and our friends to places where we know they will be prodded, probed, and prescribed to. In a word, we consent to, and allow, all manner of active and invasive treatment to preserve and protect life, often at great cost. And our confidence in technology increases with each new benefit.


John G. Carney

Today, we live longer, healthier lives than our forebears did just a century ago, but this longevity has its downside. We are not very good at embracing the inevitable, at allowing life to end in its often indelicate and untimely ways.

In this issue, we explore the sensitive and practical concerns surrounding artificial nutrition and hydration. What are our obligations to save, to treat, to care for, and protect those whose lives are at ebb tide? How do we value life, and simultaneously "let go" to honor the wishes of those who would forgo artificial nutrition and hydration? How do we determine the best interests of those who have not provided evidence of their healthcare wishes?

How do we affectively (not effectively) differentiate the symbolic acts of eating and drinking from medically assisted nutrition and hydration? Can we correctly weigh the benefits and burden of continued treatment or set limits to automony? Do we ask the same questions whether our loved one is a frail and elderly ninety-two-year-old or a strong-willed and struggling twenty-one-year-old with anorexia?

A few years ago, we were as conflicted about ventilators as we are now about feeding tubes, but that battle seemed to diminish once experience and evidence-based medicine predominated. The battle for or against the use of artificial nutrition and hydration seems tougher for a number of reasons – eating carries enormous symbolic weight, few patients can make informed decisions at this stage, and the special concerns of persons with disabilities must

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Ethics, Artificial Nutrition, and Anorexia Nervosa

by Sarah Breier-Mackie

Sarah Breier-Mackie

The incidence of tube feeding in vulnerable patient populations has never been more prevalent. Over the last ten years we have witnessed a tenfold increase in the incidence of feeding tube insertion (Janes, Price, and Khan, 2005) in vulnerable patient groups, primarily, the frail aged and those suffering with various types of dementia. One suggestion for this increase is the lowered threshold for insertion; it is commonly accepted that many patients in these vulnerable groups will receive feeding tubes more readily than ever before.

Another patient population that is starting to draw attention with regard to feeding tube insertion and artificial nutritional support is the "severe anorexic." Despite difficulties in obtaining correct prevalence data — many cases of eating disorders go unreported — it is estimated that, in the United States, the prevalence of anorexia nervosa is 1 percent. Some patients will become seriously ill and die from longstanding starvation or one of many comorbidities.

The case for and against aggressive enteral refeeding treatment in severe cases of anorexia nervosa should be carefully examined for each individual. I will offer a brief review of the ethical principles regarding the issue of tube feeding in this "new wave" of patients who are increasingly on the receiving end of artificial nutrition and hydration.

Understanding Anorexia Nervosa

Anorexia nervosa is a psychiatric illness with devastating consequences. Mortality rates from anorexia nervosa range from 3 percent to as much as 25 percent. Death usually occurs from suicide, emaciation, and electrolyte imbalances (O'Neill, Crowther, and Sampson, 1994).

The person with anorexia is plagued by a distorted body image and extreme fear of weight gain. Anorexia nervosa has been described as one of the most fatal psychiatric illnesses (Rosedale and Maher, 1993).

> ***"The management of severe anorexia nervosa opens a minefield of clinical, ethical and legal issues."***

The management of severe anorexia nervosa is extremely challenging because the treatment process and outcomes always directly conflict with the patient's wishes. Refeeding treatment is often necessary, but it is also resisted and often refused by the patient. Such noncompliance and sabotage of treatment occurs because the anorectic psychopathology is compounded by the negative impact of starvation on cognitive functioning (Kennedy and Schapiro, 1993).

Similarly, Tan (2003) contends that the anorexic patient's fear of weight gain and loss of control affects his or her mental capacity and ability to make valid autonomous decisions. Consequently, patients often refuse treatment, thus compounding the challenges that clinicians face and forcing them to negotiate the gray world between their duties to prevent harm and bring benefit and their patients' right to self-determination.

Persistent refusal to accept nutritional support may justify invasive procedural management such as the insertion of a feeding tube to prevent further physical deterioration and possible death. Clinical nutritional support via enteral or parenteral routes can be a life-saving measure, but it is no match for the underlying psychiatric illness that brings the controversy of patient autonomy and medical paternalism to the fore.

Consequently, the management of severe anorexia nervosa opens a minefield of clinical, ethical, and legal issues that tend to collide. It is this collision of issues that forces not only clinicians, but also patients and their families to weigh the benefit of treatment with the potential burden: the overriding freedom to preserve life. The following three dilemmas are often encountered in situations of treatment noncompliance by patients with life-threatening anorexia nervosa:

- Should patients with anorexia be allowed to refuse life-sustaining treatment when seriously ill? Or should they be forced to accept life-saving treatment, including a feeding tube?
- Should patients with anorexia be allowed to return home, either with physician approval or against medical advice? Or should they be involuntarily committed for inpatient treatment?
- Should the focus of treatment be shifted from curative to palliative when

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Ethics, Artificial Nutrition, and Anorexia Nervosa

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patients with anorexia are noncompliant? Or should aggressive treatment be forced on the unwilling patient with anorexia?

These dilemmas are predominantly ethical, that is, each of them is a conflict of values, for example, the right to autonomy versus the duty of beneficence. Nonmaleficence and justice also come into play.

> ***"Should patients with anorexia be allowed to refuse life-sustaining treatment when seriously ill?"***

Autonomy

Patients with anorexia often choose not to eat or drink and and strongly resist being fed by artificial means. Yet the ability of these patients to make autonomous decisions is often questioned because anorexia nervosa is a psychiatric illness, and because malnourishment affects one's cognitive abilities. The essential problem with anorexia nervosa and autonomy is that although patients have some difficulties with concentration as they become malnourished, they often appear to have a good understanding of the seriousness of their disorder and the risks involved in maintaining dangerously low weights.

At the same time, they may resist or refuse treatment that is judged to be not only beneficial, but life-saving (Tan, Hope, and Stewart 2003). This irrational or unreasonable behavior, in the context of a severe mental disorder, leads to debates about whether these patients truly understand the seriousness of their clinical situation, and whether or not they truly have decision-making capacity (Appelbaum and Rumpf, 1998). The question is stark: Should we allow these patients to choose to refuse treatment, when in some cases that means allowing them to choose to die (Draper, 2000)?

Beneficence and Nonmaleficence

Very serious harm will befall patients whose wish not to accept nourishment is respected. Death is the ultimate outcome, which could easily be ascribed to medical negligence. Patient abandonment could also be suspected, since other members of the treating team and the family may experience guilt for not having intervened to rescue the patient.

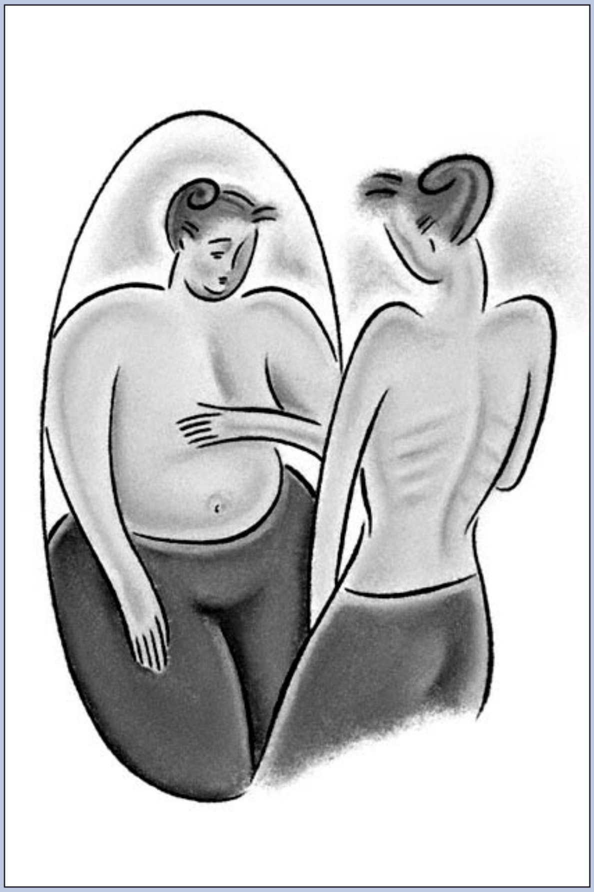
At this point, the "benefits versus burdens" equation needs careful and case-by-case analysis. On one hand, force-feeding may result in the patient feeling disempowered and embittered toward clinicians and the family, and these feelings may have a negative impact on future personal and therapeutic relationships. On the other hand, the patient may be rescued from certain death, thereby paving the way to future treatment of the underlying psychiatric illness.

Force-feeding is not, however, a simple task; and considerable discomfort may be associated with this treatment plan. Tube feeding can result in well-documented complications, especially if the more invasive percutaneous approach is used. Physical and chemical restraints may also be needed to prevent treatment sabotage. Still, the benefits of enforced feeding include saving the patient's life and restoring future autonomy. Conversely, not intervening with aggressive life-saving treatment (or delaying it) can result in the patient's death.

But death is a subject that also deserves further exploration. It raises the question of the focus of treatment and whether it should be changed from life-saving to end-of-life care. This question warrants an in-depth discussion that does not fit within the bounds of this paper. The palliative care option should be considered, however, in seeking practical alternatives to treatment in patients with life-threatening anorexia nervosa.

Justice

Long-standing anorexia nervosa is a chronic illness that requires ongoing care (including care that is often refused). Hospitalization



The person with anorexia is plagued by a distorted body image and extreme fear of weight gain.

and high acuity clinical management is very costly, yet patients are entitled to a fair share of healthcare resources. When resources are limited, the justification for imposing treatment on a noncompliant and severely ill patient who is overtly refusing intervention and has a poor prognosis may seem somewhat futile. However, justice demands that opportunities for life and health be preserved, even for those patients who are noncompliant and require extensive resources.

Justice also demands that these patients be cared for as individuals without prejudice — they must never be ignored or emotionally neglected.

> ***"Justice demands that opportunities for life and health be preserved, even for those patients who are noncompliant and require extensive resources."***

Although patient autonomy is a cornerstone of modern bioethics, clinicians will often be justified in pursuing aggressive life-sustaining interventions in severe anorexia nervosa — despite patient resistance and noncompliance.

A principlist approach can be used to tease out the obvious benefits-versus-burdens equation that exists in caring for the severe anorexia nervosa patient, but we must be careful to determine exactly what the perceived "good" and "harm" actually are. Artificial nutritional support for patients with severe anorexia nervosa should undergo the same rigorous clinical and ethical analysis prior to commencement as it does in other more common patient populations.

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the precise circumstances in which he or she would not want ANH (one state).[1]

In general, whether the patient is making this decision or whether a surrogate is deciding on the patient's behalf, the decision maker must weigh the benefits and burdens of intervention. Factual information about what ANH can — and cannot — achieve is the first step in ethical decision making.[2]

Benefits and Burdens

ANH is a form of medical therapy. Initiating treatment involves insertion of a central line (for total parenteral nutrition) or a surgical procedure (usually under endoscopic guidance) to place a feeding tube, whether via a gastrostomy (into the stomach) or a jejunostomy (into the small intestine). Occasionally, ANH is delivered via a nasogastric tube, but this is generally not a viable option for extended periods. Once ANH has been initiated, ongoing use requires prescribing the appropriate solution and monitoring its effects.

> ***"The various forms of ANH each have their own risks of side effects."***

The use of fluids alone, without protein and other key ingredients of nutrition, can be carried out for a short time (usually a matter of days), either intravenously or subcutaneously (via hypodermoclysis). Gradually, as serum protein levels fall, fluids will be drawn out of the intravascular space and will leak into the surrounding tissues. Continued provision of fluids at that juncture is counterproductive.

The various forms of ANH each have their own risk of side effects: total parenteral nutrition is associated with line sepsis, for example, and feeding tubes are associated with skin infections, diarrhea and, rarely, bowel perforation. Patients receiving these treatments who are conscious but cognitively impaired are often physically restrained

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to prevent them from pulling out the tube through which nutrition is delivered.

The potential benefits of ANH vary depending on the clinical scenario. For patients in a persistent vegetative state or with extreme short bowel syndrome, ANH prolongs life. It has been shown to improve quality of life in patients with the bulbar form of amyotrophic lateral sclerosis. Its benefits in patients with advanced dementia or advanced cancer are equivocal.

> ***"Terminally ill patients who refuse nutrition and hydration rarely experience discomfort."***

Another theoretical benefit of ANH is the prevention of suffering; however, determining whether patients are suffering and whether hunger or thirst play a role in their suffering is sometimes controversial. Patients who are dying of cancer associated with an inability to eat and who are alert do not report hunger in the absence of ANH. What little thirst they experience is typically alleviated with ice chips.[3] Terminally ill patients who refuse nutrition and hydration rarely experience discomfort, according to the reports of hospice nurses who care for them.[4]

Patients who are in a persistent vegetative state do not have the requisite cortical function to experience discomfort, according to the current neurologic understanding of these conditions. Patients who have advanced dementia and trouble swallowing cannot articulate discomfort, but indirect measures of distress indicate that while demented individuals who become acutely ill do experience discomfort from conditions such as fever or shortness of breath, they do not manifest any additional agitation or pain if ANH is withheld.[5]

Withdrawing Versus Withholding Treatment

Family members provide encouragement, reminders, and a pleasant evironment for eating.

Ethical issues surrounding ANH commonly arise at times when decisions are being made to initiate or withdraw treatment. Decisions to withdraw life-sustaining treatment are typically made when treatment is not providing the anticipated benefit or when its burdens outweigh its benefits, and decisions about withdrawing ANH are no different.

Legally and ethically, withdrawing and withholding treatment are indistinguishable, yet many patients, families, and physicians find removal to be more emotionally charged. Moreover, some religious traditions, such as Orthodox Judaism, distinguish between these categories and allow withholding (if treatment would cause suffering, or if death is imminent) but not withdrawing care.

The option of a limited trial of ANH may be particularly helpful in situations in which the prognosis is uncertain. A patient who has had a major stroke and cannot swallow, for example, could be maintained with ANH for a period of weeks to determine whether he or she will recover enough neurological function to eat or to want continued treatment.

Deciding on Treatment

Once the facts about ANH are clarified, the patient or proxy can in theory weigh its benefits and burdens and come to a conclusion about treatment. Often this balancing process gets hung up over disputes about the validity of seemingly counterintuitive studies which report no association between ANH and life-prolongation.

In the case of advanced dementia, for example, studies comparing patients who receive gastrostomy tubes with patients who do not fail to demonstrate any difference in life expectancy.[6] There have been no randomized, controlled trials, however, which raises the possibility that certain subsets of patients may have a survival advantage with a gastrostomy tube. This claim seems most plausible for patients who have ceased eating and drinking entirely.

> ***"Withdrawing and withholding treatment are indistinguishable, yet many find removal to be emotionally charged."***

Most individuals with advanced dementia, by contrast, do not take in enough by mouth to maintain their weight, but do take modest amounts of nutrition when hand fed. Accepting that such patients do not live longer with ANH requires recognizing that they have a terminal illness and, as with widely metastatic cancer or advanced AIDS, can be expected to die in the near future of their underlying disease.

Symbolic Value of ANH

Although understanding the evidence about the efficacy of ANH is important, the refusal of many people to believe the data suggests that patients and families have concerns about ANH that go beyond its scientifically measurable benefit. What matters to many people is the assurance that the patient is being cared for, and ANH symbolizes caring. At the heart of the debate about ANH is thus a question about the minimum standard of care for all persons.

> ***"At the heart of the debate about ANH is a question about the minimum standard of care for all persons."***

This minimum is fundamentally a matter of how a given society envisions its responsibilities for its most vulnerable members. Most people would presumably agree that basic components of respectful care include covering nakedness and keeping the person clean.

These views do not reflect a quantitative assessment of the effectiveness of such strategies on prolonging life nor are these actions likely to diminish the suffering of an unconscious or severely demented individual. Most people would likewise include offering food and drink to a person as part of basic, humane care. Although ANH is unlike conventional eating, just as delivering oxygen via a ventilator is dramatically different from ordinary respiration; it is often seen as nurturing.

A discussion of the attitudes toward initiating, withholding, or withdrawing ANH among different ethnic and religious groups is beyond the scope of this guide. It suffices to acknowledge that cultures vary in how they show respect for patients who have impaired eating or swallowing capacity. In general, however, religious traditions recognize human mortality and do not require interventions that produce suffering in dying patients. The Roman Catholic position on ANH, for instance, has been that "there should be a presumption in favor of providing nutrition and hydration for all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burden involved to the patient."[7]

The 2004 papal allocution indicating support for the use of ANH in individuals in a persistent vegetative state may well not apply to other clinical situations. Moreover, it hinges on the belief that patients in a persistent vegetative state have an uncertain prognosis and are capable of experiencing discomfort, which neurologists regard as incorrect assumptions.

> ***"A crucial strategy is to focus communication on what will be done to demonstrate respect for the patient, rather than on emphasizing what will be withdrawn or withheld."***

For some individuals, ANH will continue to be seen as a fundamental aspect of caring. To focus on the medical benefits of ANH in these cases is a vain attempt to turn a fundamentally symbolic question into a technical one. As with the futility debates of the 1990s, where conflict arose from discussions centering on the ineffectiveness of treatment rather than the goals of care, so too will ANH remain contentious as long as we focus exclusively on efficacy rather than meaning.

For the clinician at the bedside, a crucial strategy — in addition to clarifying misconceptions about the benefits of ANH — is to focus communication on what will be done to demonstrate respect for the patient, rather than on emphasizing what will be withdrawn or withheld.

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After Terri – An Ethics of Reciprocity

by Tarris D. Rosell

The tragic circumstances befalling a young woman in Florida more than sixteen years ago engulfed her family and all of us in an ongoing saga of biomedical ethics. Theresa Schindler Schiavo's situation polarized her husband against her parents, clinicians against family, the judiciary against legislative and executive branches, and some bioethicists against advocates for disability rights and the Religious Right.


Tarris Rosell

Few of us yet know exactly how to pronounce her married name, but "Terri" became known to millions of people because of controversies of which she herself had no knowledge. Months after the first anniversary of her death, we have no consensus on whether that death should have occurred. Thoughtful people of good will still disagree about what really happened or what ought to happen in similar cases.

But perhaps one moral mandate, on which there is near universal consensus, would tip the balance if applied to Schiavo or like cases. I refer and ultimately defer to the universal principle of reciprocity, or the Golden Rule.

Facts in Dispute

Terri Schiavo lost consciousness February 25, 1990, a twenty-six-year-old victim of sudden cardiac arrest. Cardiopulmonary resuscitation came too late to save cortical brain cells starved for oxygen. Her regular and court-appointed physicians diagnosed Terri's condition as entailing a persistent (or permanent) vegetative state (PVS). PVS is determined by neurological observation over many months, by reflex and response tests, and brain scans. It is a condition from which there is virtually no recovery.

> ***"Thoughtful people of good will still disagree about what really happened or what ought to happen in similar cases."***

Although the PVS diagnosis was disputed, what primarily polarized the discussion was whether or not to continue the daily treatments that were needed to maintain Schiavo's existence. Artificial nutrition and hydration – ANH, or "tube feeding" – is not particularly expensive or technically complicated; but neither is it "natural," and it frequently results in medical complications such as infection.

Is ANH a medical treatment or simply basic human care? Those who would lobby or legislate that ANH is simply care are ignoring sixteen years of near consensus on this issue. The 1986 case of quadriplegic Elizabeth Bouvia established the constitutional right of patients to refuse forced enteral feeding even if they are not imminently dying.

Earlier and later cases, respectively, of Karen Quinlan and Nancy Cruzan, pitted family surrogate decision makers against clinicians unwilling to "suffocate" or "starve" their patients unless such patients had stated their wishes regarding the use of breathing machines or feeding tubes. Both patients in these paradigm cases were permanently unconscious and without written advance directives. And the families of both these patients fought in court to withdraw life-support treatments standing between their loved one and a natural death.

Sensitized by those situations and their unsettling outcomes, Congress passed the Patient Self-Determination Act of 1990 (effective December 1991). Most states since, including Florida, have seen fit to include ANH in the short list of life-support treatments that may be withdrawn by request either of a patient or a patient's legal surrogate who is trusted to act in accord with "what the patient would have wanted." If the patient's wishes are unknown or seem conflicted, then the surrogate has a fiduciary responsibility to act in the patient's "best interests," that is, to decide the question on the basis of how "reasonable persons" in this situation would decide.

> ***"Patients have a constitutional right to refuse forced enteral feeding."***

In Terri Schiavo's case, her husband and legal surrogate said he knew both what his wife wanted done and what was in her best interests. Why then all the fuss?

It began as a private, family feud over interpretations of what the patient's wishes would have been and what was in her best interests.

It became a public fuss primarily among disability rights and "pro-life" activist groups, who had not been convinced by the Bouvia, Quinlan, and Cruzan outcomes

— and who were now reenergized by right-wing politics.

In addition, Terri Schiavo's family is Roman Catholic, and Pope John Paul II's allocution of March 20, 2004 (full text available on the Vatican website), added considerable fuel to the fires of ethical debate. In an address to the International Congress on "Life-Sustaining Treatments and Vegetative State," the pope acknowledged that persons said to be in a permanent vegetative state may "unfortunately remain prisoners of their condition even for long stretches of time."

Yet, in hope that even some of these might recover and "to reaffirm strongly the intrinsic value and personal dignity of every human being," the nonbinding allocution sought to obligate caregivers to continue artificial nutrition and hydration treatments indefinitely:

> "Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission."

Was it so in the case of Terri Schiavo? With Terri's parents, the late pope, and both secular and religious advocates for the disabled – Diane Coleman, Joni Eareckson Tada, and others – many of us affirm "the intrinsic value and personal dignity of every human being," and share a commitment to care for the most vulnerable among us.

Tube feeding is not expensive or technically complicated, but neither is it natural.

"[We] affirm the intrinsic value and personal dignity of every human being."

But what constitutes "care" in the case of Terri Schiavo, Nancy Cruzan, or others still languishing in states of permanently impaired consciousness? In particular, does interminable tube feeding and hydration respect a human's "intrinsic value and personal dignity"? Could it really have reflected Terri's wishes or best interests, or was this more likely a case of parental, religious, and politically misconstrued scruples?

The Case Is Decided

On September 23, 2004, the Florida Supreme Court upheld the lower court's ruling that "Terri's Law"— the Florida legislation that had restored Schiavo's feeding tube on October 22, 2003 — was an unconstitutional violation of the separation of powers between the judicial and executive branches of government. The U.S. Supreme Court ultimately upheld the state court rulings and declined to hear other appeals in this case.

The whole nation was galvanized by these and subsequent developments. On February 25, 2005, after reviewing and denying numerous other appeals by the Schindlers' lawyers, Pinellas County Probate Judge George Greer ordered the removal of Terri's feeding tube for the third time. This order was carried out on March 18, 2005, over the

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anguished objections of her parents and their supporters.

Hours later, the Schiavo case reached the U.S. Congress. Senate leader and former surgeon Bill Frist, having reviewed an hour of the Schindlers' home videos, disputed Terri's PVS diagnosis. He and other political conservatives called for erring on the side of caution and "life." Emergency legislation passed both houses for signature of the president and another round in court; but in the end, all political efforts to undo the judicial process failed, and hospice took over Terri's case and care. On March 31, 2005, Terri Schiavo died.

In the Aftermath

One of the earliest responses to Terri's death, was a renewed call for advance care planning, especially for appointing a durable power of attorney for healthcare decisions, and for families to talk about end-of-life decisions if only to avoid becoming another Schiavo case. That much surely is good.

> ***"One of the earliest responses to Terri's death was a renewed call for advance care planning."***

In another immediate response, state legislators began concocting bills that would put severe restrictions on withholding or withdrawing artificial nutrition and hydration. That may not be good; and, meanwhile, other patients like Terri remain in the liminality of their "prisoner" state. So where might we come down ethically on this sort of case situation?

From this distance and my ethics perspective, it seems most fitting to honor the request of a spouse or other legally designated surrogate and the recommendations of consulting clinicians. In Terri Schiavo's case, this request was to continue and maximize comfort care, but withdraw the feeding tube and discontinue the medical interventions that sustain life but also prolong dying.

"She isn't dying," protested the pro-lifers outside Terri's hospice room; yet surely her life was supported and sustained only by the continuation of what is otherwise considered a refusable medical treatment.

Nevertheless, I do not dismiss lightly any of the concerns that motivated the opposition. In the end, what convinced me more than anything about what should be done for Terri was reflection on what I want done for me in similar circumstances. In effect, I would settle this case and others like it in reference to the Golden Rule.

Although this rule is found in nearly all major religions and in many philosophies both ancient and modern, it is perhaps best known in its Christian version: "Do unto others as you would have them do unto you" (Matthew 7:12; Luke 6:31). Thomas Hobbes also popularized a version of this "ethics of reciprocity": "Do not that to another, which thou wouldst not have done to thyself" (Leviathan xv, 35).

It takes but a second or two for me to decide my own care plan should I be so unfortunate as to end up in Terri Schiavo's condition. Already I have told my family and future healthcare-givers, "Don't you dare force-feed me for fifteen years, or even fifteen days, should I sustain substantial brain damage and enter into anything remotely similar to a persistent vegetative state!" That is not the way I wish to live, nor would anyone else I know – not for the sake of thwarting death, and not for the sake of principle (even the sanctity of life).

If I am so adamantly opposed to the forced perpetuation of my own imagined future life by means of ANH; and if I hear virtually no one else – not even the most

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Is ANH a medical treatment or basic human care?

Artificial Food and Hydration – Defending a Tradition

by Rosemary Flanigan

Rosemary Flanigan

From the outset of the modern rise of bioethics, some religious traditions have been more influential than others, and my own Roman Catholic moral theology, which has a well-developed, written body of thought on medical-moral issues, has had considerable influence on prevailing attitudes, even among non-Catholics. For over 350 years, we have wrestled with end-of-life issues and have made some valuable distinctions that have made their way into bioethics literature.

With the furor over the Terry Schiavo case, I have seen some of that tradition questioned and even negated. In defense of the tradition, I write this essay.

Two theological presuppositions undergird our thinking about end-of-life:

- Divine sovereignty, namely, that God is the creator of life and that God alone retains ultimate sovereignty over it.
- Human stewardship, that God gives responsibility to us to care for that life, making us co-creators of our lives.

Now to be human means acting to fulfill one's needs, and there are four fundamental human needs:

- biological or physiological needs, which are satisfied by food and drink;
- psychological needs, which are satisfied through sense pleasures and sufficient rest and relaxation;
- social needs, which are satisfied through family, friends, and community; and
- creative or spiritual needs, which are satisfied through knowledge, truth, and love.

To fulfill these needs, we have four functions or powers: biological, emotional, social, and creative, and we have been given practical reason to help us fulfill these basic needs in a balanced way.

> ***"What might be ordinary means to preserve life under one set of circumstances might be viewed as extraordinary – or disproportionate – under another set of circumstances."***

Practical reason tells us that as we age, our needs will change. And as we near our dying, the change is even more remarkable.

Because through illness, accident, or aging, our human life can be irremediably altered, we have developed some basic distinctions to help us make decisions about choices yet to be made.

First, we recognize that not all treatments that prolong biological life are always humanly beneficial. We express this insight through the distinction between ordinary and extraordinary means, that is, we reason that it is appropriate to judge that what might be ordinary means to preserve life under one set of circumstances might be viewed as extraordinary — or disproportionate — under another set of circumstances.

Second, we hold that there is a moral difference — and that there ought to be a legal difference — between killing someone and allowing someone to die. In regard to my own life, there is a distinction between suicide and permitting nature to take its course.

And lastly, we recognize the right to decide these issues for ourselves.

Let me tell a story about my ninety-two-year-old uncle, a widower: I found him one afternoon feeling so poorly that I took him to St. Joseph Medical Center's emergency room. He was diagnosed with pneumonia, hospitalized, and treated. Six days later, the pneumonia was cured, but the toll taken on his ninety-two-year-old body by six days in bed left him weak and unable to go back home, so he was taken in a wheel chair to Carondelet Manor.

For the first few days he flourished; then the decline started. At first, he walked less, then talked less, and finally ended up in assisted feeding because he had no energy to lift fork and spoon. At first he was content to open his mouth and swallow his food. Then one Saturday noon, as the aide lifted a spoonful of food toward him, he raised his left hand in front of his mouth. She tried to offer it at an angle, and he moved his hand to forestall that route. She called her supervisor to say that her patient was not eating, and the supervisor simply instructed her to wheel my uncle back to his room and to try again at suppertime.

That evening, a new aide took over; the spoonful of food was offered to him

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Defending a Tradition

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and again his left hand came up blocking its route. Again she looked for wriggle room; again, his hand intervened. She called the supervisor who instructed the aide to return him to his room and she would call me. I was his durable power of attorney for healthcare decisions.

> ***"The gesture with his hand was eloquent communication that he saw that even swallowing food had become extraordinary means to keep him alive."***

The discussion that took place between the supervisor and me was almost a set-piece of Catholic teaching about end of life. We read through his advance directive in which he clearly stated that he did not want extraordinary measures to be taken when he entered his dying, and I was able to explain to her that though he was not using words anymore, the gesture with his hand was eloquent communication that he saw that even swallowing food had become extraordinary means to keep him alive, that he was ready to die and food no longer fulfilled a human need. We kept his mouth moist and he died several days later.

Can very ordinary means become disproportionate to the end for which they serve? Yes. Did he commit suicide? Of course not. He acknowledged the reality that he was dying and he was ready to let nature take its course. Not all deaths are so easy, and it is not always easy to use practical reason to make judgments that respect God's creative power and our own stewardship. But the tradition is there to help.

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Ethics of Reciprocity

(Continued from page 10)

adamant pro-lifer – expressing a desire for such prolonged "care," then it is nearly impossible for me to imagine Terri Schiavo having wished to be kept alive in that manner.

> ***"What do we advocate when advance directives, substituted judgment, and best interests end in conflict?"***

Granted, clinical ethicists do not usually appeal to this rule in their approach to end-of-life healthcare decision making. We much prefer to have decision makers act on the written or oral directives of the incompetent patient, or in the absence of such, to have designated surrogates with power of attorney decide on the basis of what the patient would want done.

When relevant wishes are unknown or when potential decision makers are conflicted, it is the "best interests" standard to which we appeal. We actually dissuade both clinicians and kin from projecting on to the patient's situation "what I would want done." But what do we advocate when all of the above—advance directives, substituted judgment, and best interests — fail to materialize or end in conflict?

In an online bioethics discussion of the Schiavo case, Dr. Robert Potter, then of the Center for Practical Bioethics, raised this question: "It probably is too much of a stretch to apply the Golden Rule here, but is there something compelling about doing unto others as you would have them do unto you?"

On further reflection, I make that stretch and respond in the affirmative. If no other moral, medical, or legal argument brings consensus on what constitutes appropriate care for a human sister or brother of ours, at least careful consideration of the Golden Rule or the ethics of reciprocity might do so. Do unto them as we would have done unto us.

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Is there something compelling about doing unto others as you would have them do unto you?

Honoring Ms. Burke's Wishes

Case Study and Discussion Questions

by Laura C. Hanson

Ophelia Burke was an older woman enjoying lively days of retirement. Though widowed, she lived in a community with a close circle of women friends. She had some difficulty with memory, which her physician had diagnosed as early dementia. Her forgetfulness worried her, but did not otherwise limit her rewarding volunteer work, her commitment to church activities, or her love of life.

At the early signs of dementia, her physician urged her to plan for future illness. He told Ms. Burke that she could help her children by writing a living will and discussing with them her wishes about life support and the goals of medical treatment.

Ms. Burke's ability to care for herself abruptly worsened when she suffered a major stroke. In the hospital, she was fed a liquid through a temporary feeding tube. During the first few weeks, she became more alert and began to eat soft foods offered by hand, so the feeding tube was removed. She had some trouble swallowing and occasionally choked on food. Still she seemed to enjoy mealtimes, and would light up with conversation and social activities.

In the months following this stroke, Ms. Burke had several episodes of infection – pneumonia and urinary tract infections. Her daughter noticed that with each acute illness she would stop eating temporarily, but begin enjoying food again once the infection was cured. Finally, there came a period of several weeks when Ms. Burke, now chair-bound and nonverbal, simply and consistently turned her head away from all offered foods.

Ms. Burke's physician sat down with her daughter. He told her that he had searched for anything treatable that could be interfering with eating – infection, a sore tooth, stomach pain, medication effects, or other problems – but all evaluations were normal. He knew Ms. Burke had a living will, but had she ever expressed strong opinions about artificial feeding?

Learning that Ms. Burke was a lifelong Catholic, he asked the daughter if she thought her mother's religious beliefs informed the kind of healthcare she would want in the setting of serious illness. Her daughter recalled that Ms. Burke had clearly stated that she did not want to have artificial feeding.

Together, daughter and physician decided to honor Ms. Burke's wishes, and to continue offering her favorite foods by hand. Her physician also informed her daughter that he thought this approach would not markedly change how long Ms. Burke lived.

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Questions for Discussion

Reflect on and discuss the following questions with your ethics committee or other colleagues. Dr. Hanson's commentary follows on page 14.

1. When should tube feeding be discussed?
2. How beneficial is tube feeding?
3. Are there other options when tube feeding is rejected?
4. What do families and patients weigh in making this decision?
5. What is the role of the physician?
6. How are decisions about tube feeding made in current practice?
7. Where do we go from here?

Case Studies are a regular feature of Practical Bioethics. *For more cases, visit www.practicalbioethics.org or ask about our online discussion group. Email your comments on this case or your request to join the discussion group to bioethic@practicalbioethics.org.*

Honoring Ms. Burke's Wishes – A Commentary

by Laura C. Hanson

Laura Hanson

Families and doctors discuss tube feeding when patients are seriously ill with diseases that affect awareness and swallowing. The most common diagnoses leading to tube feeding are dementia (29 to 35 percent), stroke (19 to 41 percent), and head and neck cancer (13 to 16 percent).[1] The use of tube feeding in patients with these diseases varies – among nursing home residents with dementia, rates of tube feeding range from 8 percent in Maine to 41 percent in Mississippi.[2]

> *"Ms. Burke was both prepared and fortunate, when this difficult decision became part of her medical care."*

Several problems make it difficult for sick people to eat – taste and smell dysfunction, acute illnesses, medications, or major depression may trigger loss of appetite. Illnesses that cause individuals to be confused or less alert will interfere with their ability to eat. People with advanced dementia or other neurologic diseases may forget how to eat. They may also have poorly coordinated swallowing, and seem uncomfortable because they choke on food and drink. As feeding problems result in poor intake, choking, or weight loss, they trigger decisions about tube feeding.

Tube feeding has limited medical benefit in terms of survival, risk of aspiration or pneumonia, and function. After a feeding tube is placed, patients have a thirty-day mortality risk ranging from 18 to 24 percent and a one-year mortality risk ranging from 50 to 63 percent.[3] Of patients who survive with a feeding tube, 70 percent have no improvement in function, but at six months about 20 percent will improve enough to begin eating on their own again.[4] Patients with stroke, younger age, and better baseline function have relatively better outcomes.

There are other options for some people. Individuals who can eat can choose assisted feeding. Family members or nursing aides provide encouragement, reminders, and a pleasant environment for eating. Changing the consistency of food and drink may help patients who have difficulty with choking.

Assisted feeding is not possible in the terminal phase of many illnesses, or if the patient is unconscious. Physicians are uncertain whether or not these patients feel hunger, but terminally ill patients who are alert say they do not experience much hunger or thirst, simply a loss of appetite.[5] Loss of the desire or ability to eat and drink may promote comfort during active dying.

Families make nearly all these decisions, and they express moral ambivalence as they struggle with cultural and religious meanings. Food is nurture, it symbolizes community, and is the basic source of health and well-being. For some surrogate decision makers, specific religious traditions within subgroups of Catholicism, Judaism, or evangelical Protestantism may frame tube feeding as morally obligated care. Other values may lead surrogates to perceive that

Shared decision making is the recommended approach for the decision about tube feeding.

> ***“Food is nurture, it symbolizes community, and is the basic source of health and well-being.”***

the personal interaction achieved by hand feeding and the familiar taste of favorite foods is essential to quality of life. Decision makers should acknowledge diverse values, and allow for values clarification.

In current clinical practice, tube feeding is often first discussed when a patient is hospitalized for stroke or other acute illness, dehydration, or aspiration pneumonia. Discussions are often perfunctory, without mention of treatment options or information on benefits and burdens. Surrogate decision makers are poorly informed, and they often feel they make the choice alone, with little physician discussion.

Shared decision making is the recommended approach for the decision about tube feeding. Shared decision making includes informing the patient and his or her surrogate about the patient’s condition and treatment options, inviting them to express their values regarding treatment and to participate in the decision at the level he or she feels comfortable. In this process, health professionals provide expert knowledge and make recommendations, while respecting the patient’s right to choose what happens to his or her own body.[6] State legislatures, regional courts, and the U.S. Supreme Court have explicitly recognized the right to forgo tube feeding as part of broader patients’ rights to control treatment near the end of life.

Conclusions

Ms. Burke was both prepared and fortunate, when this difficult decision became part of her medical care. She reflected and considered her treatment values, and communicated them to her children. In the hospital, she was given a temporary feeding tube right after her stroke, but it was not automatically replaced with a semi-permanent tube, allowing a trial of assisted feeding. Her daughter and physician were open to shared decision making, and able to reflect on Ms. Burke’s values and choose what she would have wanted. To improve shared decision making about feeding tubes, we will need to improve physicians’ awareness and communication skills and encourage more explicit advance care planning by the general population.

> ***“Health professionals provide expert knowledge and make recommendations while respecting the patient’s right to choose.”***

Notes

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Seeking a Moral Compass

(Continued from page 2)

be addressed. I refer our readers in particular to the **Statement of Common Principles on Life Sustaining Care and Treatment of People with Disabilities.** This statement, posted on the web at http://thechp.syr.edu/endorse/ was developed through a consensus process among leaders and advocates in the disabilities community. It addresses the rights and interests of people with disabilities, including the rights to life sustaining treatment and self-determination, and restates those rights in recognition of society's historical treatment of people with disabilities.

Decisions about artificial nutrition and hydration are similar to other medical decisions, and specious philosophical, theological, and political arguments about life's absolute beginnings and end must not be allowed to obscure our obligation always to care for and to act in the best interests of those entrusted to us.

It is true in modern medicine that not all that can be done should be done, for in recent times we have created "mechanical paths to death." It is also true that some people see and feel burdens that others do not. Most of us, for example, have imagined conditions in which we say, "I wouldn't want to live that way," only to find "that way" less intolerable than we expected it to be. What we reject in imagination may be more acceptable to us when we are actually standing on the brink. Or it may be that only then will we begin to understand our mothers' and grandfathers' wisdom in refusing to eat before they died.

Until then, and despite a cascade of questions, we must continue caring for one another and making decisions in good faith, with integrity and compassion, guided by a moral compass and ethical framework. Questions of nutrition and hydration are at the vortex of this principled construct. I invite you to explore what I hope will be a journey that leads to further illumination rather than deeper into an anxious abyss.

John G Carney

John G. Carney, *contributing editor for this issue of* Practical Bioethics, *is the Center's vice president for aging and end of life. For more information about our programming in this area, visit our website at www.practicalbioethics.org.*