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**Abstract**
A surrogate decision maker may conclude that efforts to mechanically provide liquid nourishment would cause considerable suffering in return for little gain. But such a decision is unquestionably one that can produce great conflict for families and for medical caregivers. Assessment must be made of each patient's situation and of the benefits and burdens that will result if tube feeding is withheld or withdrawn. It may well be, however, that in some cases, the most humane and compassionate treatment for a patient is the withdrawal of all technological interventions, including those that supply nourishment.

**Keywords**
biomedical ethics, healthcare, euthanasia, living wills, substituted judgment, Karen Ann Quinlan

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FEEDING THE PERMANENTLY UNCONSCIOUS OR DYING IS NOT ALWAYS COMPASSION

By Phebe S. Haugen

On March 3 Governor Rudy Perpich signed into law the Adult Health Care Decisions Act, making Minnesota the 39th state to adopt a Living Will law. The statute permits individuals to declare in advance what medical treatment they would like in the event they become incapable of communication their preferences, and permits the designation of a proxy to make healthcare decisions for a declarant.

The battle over the proposed law was waged for six years. While a number of provisions fueled the debate, none was as controversial as the proposal to permit a proxy decision to withdraw artificially administered nutrition and hydration from an incompetent patient. The specter of patients who could no longer speak for themselves being “starved to death” caused bitter opposition to the law. Special interest groups lobbied tirelessly against what they viewed as the first step down the slippery slope to active euthanasia.

Despite the opposition, the bill arrived on the governor’s desk with its basic provisions, including those permitting the withdrawal of tube feeding, relatively unencumbered by qualifications. Its critics vowed to return another day to try to protect the most vulnerable from what they are certain represents an inhumane abdication of society’s responsibility to give basic care to the hopelessly ill.

Are these opponents of the living will law correct in their understanding of what it means to permit the withdrawal of artificially administered nutrition and hydration? Many think not, although the subject is not without controversy, even among doctors. Where did it all start?

In 1976 the parents of Karen Ann Quinlan went to court seeking permission to remove the respirator that everyone believed was keeping her alive. The publicity generated by the Quinlans’ agonizing claim to the right to speak on their daughter’s behalf brought to the public’s attention the question of how much treatment is enough for a patient in a hopeless condition, and who decides for someone who can no longer speak for herself?

Before the Quinlans brought the issue to the front pages of the world’s newspapers, such questions were rarely considered by anyone other than a patient’s family in consultation with her doctor. But it was not unknown for a doctor and the family of a hopelessly ill patient to meet, talk quietly together, and determine that for their patient, resuscitation would be withheld in the event of cardiac arrest, mechanical ventilation would not be employed to assist breathing, and if pneumonia developed, no antibiotics would be administered to defeat it.

After several months of litigation, the New Jersey Supreme Court granted the Quinlans’ petition and affirmed strongly that patients and their families, not the courts, should make medical treatment decisions. In the 13 years since the Quinlan decision, many other courts have struggled with similar questions, and certain principles have been firmly settled: A competent adult has the right to refuse medical treatment. Any medical intervention may be refused, no matter how necessary to the patient’s survival. Thus, a patient with no kidney function can refuse further dialysis treatments, and a quadriplegic can insist on removal of the ventilator that enables her to breathe and the gastrostomy tube that supplies her nutrition and hydration. This right of autonomous decision is grounded in the constitutional right to privacy and the common law right to bodily self-determination.

A patient who lacks the ability to make decisions has the same right as the competent patient to refuse treatment. In this situation, the patient’s family or guardian exercises the right on the patient’s behalf, and the decision is made on either a substituted-judgment or a best-interests standard. When substituted judgment is employed, the decision maker tries to ascertain what the patient would have wanted. If that is not possible, an effort is made to determine the best interests of the patient by balancing the burdens of continuing treatment against the benefits to be gained by the intervention, and the likelihood that the patient can return to cognitive existence.

Despite problems with the application of those standards, in virtually every case where a family’s decision to end treatment has reached the courts, that decision has been upheld. It has become commonplace to disconnect mechanical ventilators from the hopelessly ill. But what if what is sought is the withdrawal of artificially administered nutrition and hydration? What has become so clear in the case of respirators is far less certain for tube feeding.

As recently as 20 years ago, patient malnutrition inevitably followed from illnesses that made normal digestion difficult or impossible. Today’s technol-
In summation

...ories make it possible to give patients thousands of calories per day of liquid nutrients administered through plastic tubing. Since we can keep patients alive by these means, must we always do so?

Though most courts that have grappled with this question have ultimately upheld the decision of a surrogate to discontinue tube feedings, they have done so on differing theories and without clear guidelines. Why is this such a difficult issue? For many, the provision of liquid nutrition is ordinary care, while mechanical ventilation, sophisticated cardio-pulmonary resuscitation techniques, and even antibiotics are viewed as extraordinary and therefore not mandatory.

Others see these latter interventions as medical treatment, which may be foregone if they are not beneficial or are unduly burdensome for the patient, while they view the provision of nutrition and hydration as basic care which must always be maintained.

The American Medical Association's Council on Ethical and Judicial Affairs declared in its opinion on “withholding or withdrawing life-prolonging medical treatment,” issued in 1986, that artificially or technologically supplied nutrition and hydration are life prolonging medical treatment and as such may be discontinued in proper cases. The Minnesota Medical Association has agreed. Still, the issue remains troubling and unsettled, even among doctors.

The provision of food and water is of great symbolic importance. For many it carries religious significance as well. When we share a meal, says author Frederick Buechner, we meet at the level of our most basic need. Joanne Lynn and James F. Childress note in “Must Patients Always Be Given Food and Water?” (13 Hastings Center Report 17, October 1983) that the act of feeding communicates our values in a profound way. We demonstrate love, compassion, and concern when we give food and drink to another. Feeding the newborn is our first and most important act to nurture both the new life and the relationship we have with it. It remains the primary means by which we comfort and sustain the very young and vulnerable.

Still, the mechanical provision of nutrition and hydration has little in common with the symbol-laden act of sharing food and water. There are two basic systems through which such sustenance is provided. In one, liquids are administered through a naso-gastric tube from the nose into the stomach or through a tube surgically inserted into the stomach or intestine (gastrostomy or jejunostomy). In the other, the fluids are delivered intravenously by peripheral catheter or through a larger catheter inserted directly into a major vein in the chest. In all its forms, the procedures are intrusive, often uncomfortable, and carry some risks.

It is a fundamental ethical principle in medicine that interventions that would provide no benefit to a patient may be withheld, and that if they have been begun, they may be withdrawn at the point when they no longer help. Are there any situations in which we can say that the mechanical provision of nutrition and hydration is of no real benefit to a patient? Lynn and Childress, among others, argue that there are three situations when it is ethically permissible to forego this intervention: when the procedure would be futile to accomplish its goals, when a patient is permanently unconscious, and when the procedures would be disproportionately burdensome.

Sometimes procedures for providing food and drink simply do more harm than good.

In the first case, patients with certain conditions, such as serious absorption diseases, intestinal cancers, advanced congestive heart failure, or severe and extensive burns will die of their conditions no matter what is done. Efforts to provide them with nutrients and liquids through any of the means described above will likely not be effective and may well cause added suffering without any benefit.

The second case, that of permanently unconscious patients, raises deep philosophic questions for most commentators. The medical reality is that when cognitive, sapient life is not possible, interventions that will maintain biological life can be of no benefit to the patient. There are, however, two lingering questions. Can we be certain that the unconsciousness really is permanent, and will these patients suffer pain if their nutrition and hydration are withdrawn? Although the accurate diagnosis of permanent unconsciousness, and particularly of the persistent vegetative state is a complicated and sophisticated problem, a skilled neurologist can make the diagnosis quite reliably today. New diagnostic tools have added to the certainty with which the condition can be identified. As to the problem of pain, the American Academy of Neurology has taken the unequivocal position that the experience of pain is a function of consciousness and is not possible without the integrated functioning of the cerebral cortex and the brain stem, functioning that is absent in the permanently unconscious patient. (See Amicus Curiae Brief, American Academy of Neurology, filed in Brophy v. New England Sinai Hospital, Inc., 39 Mass 417, 497 N.E. 2d 626, 1986).

The third and perhaps the most difficult case in which it has been argued that tube feedings are of no benefit to a patient is when the procedures would be disproportionately burdensome. Sometimes they simply do more harm than good. For the severely demented patient who must be restrained to be “fed” in this way, the whole process can be so terrifying as to be cruel. For the end-stage cancer patient, there is considerable evidence in the nursing and hospice literature that withdrawal of fluids may actually be beneficial. (See, for example, Zerwekh, “The Dehydration Question” 13 Nursing 47, January 1983). It often results in less nausea, less pulmonary edema and less confusion. This can mean far greater comfort for the patient, especially when good nursing care and adequate pain control are maintained. The deaths that follow in these situations, usually within a few days, have been reported by families to be peaceful.

In any of these situations, a surrogate decisionmaker may well conclude that efforts to mechanically provide liquid nourishment would cause considerable suffering in return for little gain. But such a decision is unquestionably one that can produce great conflict for families and for medical caregivers. Assessment must be made of each patient's situation and of the benefits and burdens that will result if tube feeding is withheld or withdrawn. It may well be, however, that in some cases, the most humane and compassionate treatment for a patient is the withdrawal of all technological interventions, including those that supply nourishment.