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The controversy over artificial hydration and nutrition

James L. Bernat, MD; and H. Richard Beresford, MD, JD

The tragic case of Terri Schiavo raised to public consciousness the issue of whether a lawful surrogate is empowered to refuse artificial hydration and nutrition (AHN) on behalf of a patient in a persistent vegetative state (PVS) based on preferences she orally expressed while competent. Thoughtful commentators pointed out that decisions by surrogates in such cases are constrained by the accuracy of medical diagnosis and prognosis and by the degree of confidence that the surrogate is expressing the true wishes of the patient. However, some also raised the question of whether it is ever ethically acceptable for physicians to order withdrawal of AHN.

Medical practice standards, ethical guidelines, and law support the right of patients to refuse life-sustaining therapies in specified circumstances. This right was clearly articulated by the US Supreme Court in the Cruzan case in 1990. The justices determined that the choice of a person in a PVS to decline life support is a protected liberty interest under the 14th amendment to the federal constitution, and that this right is exercisable by a lawful surrogate.

Established ethical and legal standards provide guidance to surrogates in such situations. Surrogates first should determine what preferences patients have expressed, whether in the form of written advance directives or explicit oral statements. If these provide insufficient guidance, surrogates should attempt to determine as precisely as possible what choice patients would have made, taking into account patients’ values and expressed preferences about treatment. If such information is not available, surrogates should objectively weigh the benefits and burdens of proposed therapies and assert a choice that is in the best interests of the patients.

But should AHN be considered medical therapy that lawful surrogates can refuse on behalf of patients? Dissenters assert that AHN is simply a requirement for human life support, like oxygen. In this view, AHN is not a drug, a therapy, or a technology. Moreover, although some patients can survive without a respirator, penicillin, or prednisone, no one can survive without hydration or nutrition. Therefore, stopping AHN is tantamount to active euthanasia. Critics further argue that permitting physicians to withhold or stop AHN is a step on the slippery slope to euthanasia for devalued human lives.

Supporters of surrogate decisions to decline AHN for patients in PVS counter that AHN is medical treatment that must be administered by medical and nursing personnel, just as are other therapies. Maintaining hydration and nutrition for a patient in PVS requires surgical insertion of a feeding tube and medical orders to calculate nutritional and fluid requirements that must be implemented by nursing staff. Moreover, AHN via gastrostomy tube has complications. Therefore, AHN falls within the boundaries of medical treatment. Indeed, in the Cruzan case, the Supreme Court determined that a patient’s right to refuse life-sustaining medical therapy encompasses refusal of AHN. The Court held that death after surrogate refusal of AHN is neither euthanasia nor assisted suicide but is simply the natural consequence of the exercise of a patient’s constitutionally protected right to refuse an unwanted treatment.

Current medical practice guidelines permit physicians to withhold or stop AHN for neurologically impaired patients. For example, guidelines of the American Academy of Neurology and the American Medical Association, among others, allow physicians to withhold or withdraw AHN from terminally ill or permanently unconscious patients when it has been determined that patients or their surrogates have expressed informed refusals of AHN.

In this issue of Neurology, Larriviere and Bonnie provide an informative survey of state laws that ad-
dress withdrawals of AHN from patients in PVS. Importantly, they stress that, although *Cruzan* upheld a right to decline AHN, the Supreme Court also upheld the power of states to regulate exercise of this right to the extent of setting evidentiary standards that must be met before the right can be implemented. Therefore, the Court upheld a Missouri law that required “clear and convincing” proof of a patient’s intent to refuse AHN. In this context, the authors note that public debate about the Schiavo case apparently evoked efforts by some state legislators to enact laws that would require surrogates to produce evidence that a patient clearly and convincingly considered the matter of AHN and clearly and convincingly expressed the intent to refuse it.

The article by Larriviere and Bonnie is valuable to neurologists for at least three reasons. First, it illustrates why neurologists should understand how state laws regulate their medical practice. This is particularly important because a 1999 survey of neurologists uncovered a widespread lack of understanding of legal and ethical issues relating to stopping and withholding of life support. Second, it may stimulate neurologists to support state laws that protect the rights of patients to control their treatment after they have lost their capacity to consent or refuse. Finally, the article highlights how important it is for neurologists to encourage their patients to execute advance directives that clearly designate who will be their surrogates in the event of incapacity and specify what treatments they want or do not want, including AHN.

## References


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