

GME

# Position statement on laws and regulations concerning life-sustaining treatment, including artificial nutrition and hydration, for patients lacking decision-making capacity

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**Preamble.** The American Academy of Neurology (AAN), representing over 20,000 neurologists and neuroscience professionals, has long taken an active interest in scientific, ethical, and professional discussions regarding the provision and withdrawal of life-sustaining medical treatment for patients who lack decision-making capacity. Part of this interest stems from the role neurologists play in evaluating the cognitive capacity of patients for whom decisions to initiate, maintain, or discontinue life-sustaining interventions may be necessary. Neurologists share the concern of all physicians that decisions regarding the treatment of patients should be anchored in terms of each patient's own values, preferences, and goals of care, as best understood, which determine what is best for each patient. Respect for a patient's autonomy and wishes—whether those wishes are to continue or discontinue therapies—is essential.

**Relevant contemporary political and legal issues.** In the last 2 years in the United States, state and federal courts, legislators, and other elected officials have been involved in a national debate regarding the proper venues, standards of evidence, and presumptions to be employed when determining the wishes, values, and best interests of patients who are incapable of expressing their own views regarding their own medical care.

This debate particularly centers on decisions to

continue or withdraw artificial nutrition and hydration (ANH) when a patient is in a persistent vegetative state (PVS). This was exemplified most recently by the case of Theresa Schiavo, who had a cardiac arrest in 1990, was initially comatose, and then was in a persistent vegetative state. Her case was the subject of over 10 years of activity involving all branches of state and federal government, largely intended to overturn the initial rulings of a Florida judge who concluded by a clear and convincing standard of evidence that Mrs. Schiavo's wishes for care (which were determined through evaluation of her prior verbal statements) would have been to discontinue her ANH and that her husband, Michael Schiavo, was the appropriate decision maker for her. Once all legal and political maneuvers were exhausted, Mrs. Schiavo's feeding tube was removed in March 2005; she died 13 days later.

Soon after her death, and again in 2006, legislators in several states introduced bills that would create the presumption that any person who has been declared legally incompetent to make decisions affecting medical treatment or care would, in the absence of a carefully written advance directive that met specific statutory requirements, choose to receive ANH to sustain life. To withdraw ANH in these situations, the patient's surrogate would have to prove by a clear and convincing standard that the patient would have chosen to have ANH withdrawn

**Editorial, see page 1092**

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in the current circumstances. Furthermore, this proposed legislation would establish that elected officials, who in existing law have no legal standing as an “interested party” in such cases, would have the same right to challenge the administration or withdrawal of ANH as any true “interested party” (i.e., spouses, relatives) would. As of mid-February 2006, 20 bills, based upon model legislation from the National Right to Life Committee (NRLC), had been introduced in 13 states. Another 14 bills were modified to add additional restrictions.<sup>1</sup>

The presumptive nature of the model legislation regarding ANH would overturn more than 30 years of legal and ethical precedent because it would preclude patients’ fundamental right to make their own lawful medical decisions by proxy. Some bills (e.g., S.B. 1280 from the 2006 California legislative session and H.F. 3255 from the 2006 Minnesota legislative session) would have compounded this problem by requiring proof that the patient gave “express and informed consent” in the course of declaring their wishes or goals of care in the absence of written documentation, such as an advance directive. The definition of express and informed consent used in these bills would create an impossibly high threshold for surrogates or family to meet in demonstrating the patient’s intent on the basis of verbal communication. For example, the definition in the proposed Minnesota legislation would have required:

[C]onsent voluntarily given with sufficient knowledge of the subject matter involved, including a general understanding of the procedure, the medically acceptable alternative procedures or treatments, and the substantial risks and hazards inherent if the proposed treatment or procedures are carried out and if they are not carried out, to enable the person giving consent to make an understanding and enlightened decision without any element of force, fraud, deceit, duress, or other form of constraint or coercion.

Thus, under the terms of the proposed legislation, unless patients had previously described the exact circumstances leading to their need for a surrogate decision maker, and unless at the time of their previous statement they demonstrated a clear understanding of the consequences of their wishes, even a strong verbal statement by the patient in opposition to ANH that had been witnessed by multiple persons, or stated on multiple occasions, could be disregarded.

Such standards would increase the possibility that a patient’s advance directive could be successfully challenged in court and would increase the likelihood that an advance directive calling for the withdrawal of ANH would be overturned. Under the proposed legislation, a governor or attorney general, given status as “interested parties,” could file suit, claiming that the content of the patient’s advance directive did not match the patient’s specific medical circumstances, and thus would not be valid. This would place the burden upon the patient’s surrogate or family to prove clearly and convincingly that the ad-

vance directive addressed the patient’s exact current circumstances.

Less controversial legislation has also been introduced and passed in several states to make it easier for people to put a living will or advance directive to use. Legislative options in this area include the following: Educating the public about their advance directive options. Requiring medical professionals to give their patients an opportunity to develop an advance directive or similar document. Standardizing advance directive forms to increase their clarity and utility. Adding advance directive information to public ID cards. Creating advance directive registries to keep healthcare professionals and government agencies informed of patients’ preferences.

These legislative approaches appear to improve, rather than compromise, patients’ abilities to use advance directives and surrogate decision makers to exercise control over their medical care in situations when the patient lacks decision making capacity.

The Uniform Health-Care Decisions Act provides an example of a model law that could lend clarity to state laws across the country. The Act, which was proposed in 1993 by the National Conference of Commissioners on Uniform State Laws<sup>2</sup> and has been endorsed by the American Association of Retired Persons and the American Bar Association, helps to standardize and clarify state laws that govern advance health-care directives, health-care consent, and power-of-attorney provisions.<sup>3</sup> By creating clear and consistent rules and procedures for healthcare decision making in situations where patients are unable to speak for themselves, the language of the Act significantly reduces the medical and legal uncertainty that can emerge for all parties involved in making health-care decisions under difficult and perhaps unspecified circumstances. As a result, patients’ wishes are more likely to be understood and respected. Though only eight states have adopted the Act in its entirety, it has inspired several states to adopt similar laws.<sup>4</sup>

**Related positions taken by the AAN.** In 1988, the AAN issued a position statement, “Certain Aspects of the Care and Management of the Persistent Vegetative State Patient,” that set medical and ethical principles for physicians to consider when treating patients in PVS or similar states. The report describes the persistent vegetative state as “a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles, but at no time is the patient aware of himself or his environment. Neurologically, being awake, but unaware is the result of a functioning brainstem, and the total loss of cerebral cortical functioning.”<sup>5</sup> This loss of function also renders the patient unable to feel pain or suffer consciously, although reflex responses to painful stimuli may exist. Because the patient’s brainstem continues to function, there are alternating periods during which the eyes are either open or closed for sustained time

periods, giving the appearance of periods of sleep and wakefulness despite the absence of consciousness.

In assessing treatment options for patients with PVS, the AAN position statement noted that physicians should give consideration to three key factors:

A patient's right to self-determination is central to the medical, ethical and legal principles relevant to medical treatment decisions.

A physician must also attempt to promote the patient's well-being, either by relieving suffering or addressing or reversing a pathologic process. Where medical treatment fails to promote a patient's well-being, there is no longer an ethical obligation to provide it.

Treatments which provide no benefit to the patient or the family may be discontinued. . . . Medical treatment, including the medical provision of artificial nutrition and hydration, provide no benefit to patients in a persistent vegetative state, once the diagnosis has been established to a high degree of medical certainty.

The position statement concluded: "When a patient has been reliably diagnosed as being [in] a persistent vegetative state, when it is clear that the patient would not want further medical treatment, and the family agrees with the patient, all further medical treatment, including the artificial provision of nutrition and hydration, may be foregone."<sup>5</sup> Thus, the AAN position is that ANH may be withdrawn if a patient is in a PVS and it is determined that withdrawal of ANH is consistent with the patient's wishes. However, the AAN does not hold the position that ANH must be withdrawn for all patients in PVS, for to do so would override the autonomy of those persons who would wish ANH continued in such circumstances.

The AAN reaffirmed its support of these views when it introduced a resolution that was adopted at the 2005 American Medical Association (AMA) annual meeting opposing "all state and federal legislation that would presume to prescribe the patient's preferences for artificial hydration and nutrition in situations where the patient lacks an advance directive or living will."<sup>6</sup> The resolution anchored itself in existing AMA policies supporting a patient's right to self-determination, a limited role for judicial review in determining care options, and the appropriateness of withdrawing "life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis."<sup>7</sup>

**Statements from national professional medical organizations.** Several national professional medical organizations, including the American College of Physicians, the American Geriatrics Society, the American Nurses Association, and the American Osteopathic Association, have adopted similar position statements that reflect many of the same principles endorsed by the AAN. Whether drafted in response to the case of Mrs. Schiavo, or the case of Nancy Cruzan, whose family's appeal to the U.S. Supreme

Court for withdrawal of ANH became precedent setting, the positions reflect a strong concern that a patient's right to self-determination deserves deep respect and primary consideration in every health care situation. This same concern has been reflected in the majority of medical ethics articles on this topic.

**AAN position.** The AAN, representing over 19,000 neurologists and neuroscience professionals, has long taken an active interest in scientific, ethical and professional discussions regarding the provision and withdrawal of life-sustaining medical treatment for patients who lack decision-making capacity. Part of this interest stems from the role neurologists play in evaluating the cognitive capacity of patients for whom decisions to initiate, maintain or discontinue life-sustaining interventions may be necessary. Neurologists share the concern of all physicians that decisions regarding the treatment of patients should be anchored in terms of each patient's own values, preferences and goals of care, as best understood, which determine what is best for each patient. Respect for a patient's autonomy and wishes—whether those wishes are to continue or discontinue therapies—is essential.

The AAN has adopted the following principles regarding the determination of patient preferences for the provision and withdrawal of artificial nutrition and hydration: The AAN reaffirms its 1988 position statement titled "Certain Aspects of the Care and Management of the Persistent Vegetative State Patient." The AAN opposes all state and federal legislation that would presume to prescribe a patient's preferences for artificial hydration and nutrition. The AAN further opposes all state and federal legislation that limits the ability of patients to declare their preferences for health care through the use of living wills and advance directives or by discussion of their wishes with their families or surrogate decision makers. The AAN opposes all state and federal legislation that gives legal standing to elected officials (or their designees) to intercede in private decisions regarding the use of ANH. The AAN opposes all state and federal legislation that expands judicial intervention in a patient's decisions regarding the use of ANH. The AAN supports state and federal legislation that promotes a better understanding of patient preferences for medical care (including the development of advance directives, living wills, and durable power of attorney declarations; the creation of health care directive registries; and the indication of such information on official identification cards) in accordance with existing AAN policies. The AAN is committed to providing its members access to educational resources so that they can competently and sensitively discuss decisions regarding the provision of ANH with patients who are writing an advance directive, and with families or surrogate decision makers who are contemplating such decisions on behalf of patients.

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