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**AMERICAN ACADEMY OF NEUROLOGY**

**POSITION STATEMENT ON LAWS AND REGULATIONS  
CONCERNING LIFE-SUSTAINING TREATMENT,  
INCLUDING ARTIFICIAL NUTRITION AND HYDRATION,  
FOR PATIENTS LACKING DECISION-MAKING CAPACITY**

**June 2006**

**Preamble**

The American Academy of Neurology (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.

**Relevant contemporary political and legal issues**

In the past two 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 ten 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 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>

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<sup>1</sup> MergerWatch: “Summary of State Bills Restricting End-of-Life Choices Introduced in 2005 and 2006.” March 28, 2006. Available online at [http://www.mergerwatch.org/pdfs/fs\\_end\\_of\\_life\\_legislation.pdf](http://www.mergerwatch.org/pdfs/fs_end_of_life_legislation.pdf)

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

10  
11 [C]onsent voluntarily given with sufficient knowledge of the subject matter involved,  
12 including a general understanding of the procedure, the medically acceptable alternative  
13 procedures or treatments, and the substantial risks and hazards inherent if the proposed  
14 treatment or procedures are carried out and if they are not carried out, to enable the  
15 person giving consent to make an understanding and enlightened decision without any  
16 element of force, fraud, deceit, duress, or other form of constraint or coercion.  
17

18 Thus, under the terms of the proposed legislation, unless patients had previously described the exact  
19 circumstances leading to their need for a surrogate decision maker, and unless at the time of their previous  
20 statement they demonstrated a clear understanding of the consequences of their wishes, even a strong  
21 verbal statement by the patient in opposition to ANH that had been witnessed by multiple persons, or  
22 stated on multiple occasions, could be disregarded.  
23

24 Such standards would increase the possibility that a patient's advance directive could be successfully  
25 challenged in court and would increase the likelihood that an advance directive calling for the withdrawal  
26 of ANH would be overturned. Under the proposed legislation, a governor or attorney general, given status  
27 as "interested parties," could file suit, claiming that the content of the patient's advance directive did not  
28 match the patient's specific medical circumstances, and thus would not be valid. This would place the  
29 burden upon the patient's surrogate or family to prove clearly and convincingly that the advance directive  
30 addressed the patient's exact current circumstances.  
31

32 Less controversial legislation has also been introduced and passed in several states to make it easier for  
33 people to put a living will or advance directive to use. Legislative options in this area include:  
34

- 35 - Educating the public about their advance directive options
- 36 - Requiring medical professionals to give their patients an opportunity to develop an advance  
37 directive or similar document
- 38 - Standardizing advance directive forms to increase their clarity and utility
- 39 - Adding advance directive information to public ID cards
- 40 - Creating advance directive registries to keep healthcare professionals and government  
41 agencies informed of patients' preferences.  
42

43 These legislative approaches appear to improve, rather than compromise, patients' abilities to use advance  
44 directives and surrogate decision makers to exercise control over their medical care in situations when the  
45 patient lacks decision making capacity.  
46

47 The Uniform Health-Care Decisions Act provides an example of a model law that could lend clarity to  
48 state laws across the country. The Act, which was proposed in 1993 by the National Conference of

1 Commissioners on Uniform State Laws<sup>2</sup> and has been endorsed by the AARP and the American Bar  
2 Association (ABA), helps to standardize and clarify state laws that govern advance health-care directives,  
3 health-care consent and power-of-attorney provisions.<sup>3</sup> By creating clear and consistent rules and  
4 procedures for healthcare decision-making in situations where patients are unable to speak for themselves,  
5 the language of the Act significantly reduces the medical and legal uncertainty that can emerge for all  
6 parties involved in making health-care decisions under difficult and perhaps unspecified circumstances.  
7 As a result, patients' wishes are more likely to be understood and respected. Though only eight states  
8 have adopted the Act in its entirety, it has inspired several states to adopt similar laws.<sup>4</sup>  
9

## 11 **Related positions taken by the AAN**

13 In 1988, the AAN issued a position statement, *Certain Aspects of the Care and Management of the*  
14 *Persistent Vegetative State Patient*, that set medical and ethical principles for physicians to consider when  
15 treating patients in PVS or similar states. The report describes the persistent vegetative state as "a form of  
16 eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic  
17 sleep/wake cycles, but at no time is the patient aware of himself or his environment. Neurologically,  
18 being awake, but unaware is the result of a functioning brainstem, and the total loss of cerebral cortical  
19 functioning."<sup>5</sup> This loss of function also renders the patient unable to feel pain or suffer consciously,  
20 although reflex responses to painful stimuli may exist. Because the patient's brain stem continues to  
21 function, there are alternating periods during which the eyes are either open or closed for sustained time  
22 periods, giving the appearance of periods of sleep and wakefulness despite the absence of consciousness.  
23

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

- 27 - "A patient's right to self-determination is central to the medical, ethical and legal principles  
28 relevant to medical treatment decisions."
- 29 - "A physician must also attempt to promote the patient's well-being, either by relieving  
30 suffering or addressing or reversing a pathological process. Where medical treatment fails to  
31 promote a patient's well-being, there is no longer an ethical obligation to provide it."
- 32 - "Treatments which provide no benefit to the patient or the family may be discontinued. ...  
33 Medical treatment, including the medical provision of artificial nutrition and hydration,  
34 provide no benefit to patients in a persistent vegetative state, once the diagnosis has been  
35 established to a high degree of medical certainty."

37 The position statement concluded: "When a patient has been reliably diagnosed as being (in) a persistent  
38 vegetative state, when it is clear that the patient would not want further medical treatment, and the family  
39 agrees with the patient, all further medical treatment, including the artificial provision of nutrition and

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<sup>2</sup> David Casarett, M.D., Jennifer Kapo, M.D., and Arthur Caplan, Ph.D. "Appropriate Use of Artificial Nutrition and Hydration — Fundamental Principles and Recommendations." *New England Journal of Medicine*, December 15, 2005. 353:24; P. 2607-2612. Available online at <http://www.bioethics.upenn.edu/nutrition/images/v353p2607.pdf>.

<sup>3</sup> "A Few Facts about The Uniform Health-Care Decisions Act." Available online at [http://www.nccusl.org/Update/uniformact\\_factsheets/uniformacts-fs-uhcda.asp](http://www.nccusl.org/Update/uniformact_factsheets/uniformacts-fs-uhcda.asp). The model Act is presaged in some respects by the Patient Self-Determination Act (PSDA), a federal law passed in 1990 that requires providers to inform all adult patients about their right to create an "advance directive" and to accept or refuse medical treatment.

<sup>4</sup> "Patient Rights: Encyclopedia of Everyday Law." *Gale Encyclopedia of Everyday Law*. Ed. Shirelle Phelps. Gale Group, 2003. eNotes.com. Available online at <http://law.enotes.com/everyday-law-encyclopedia/introduction>.

<sup>5</sup> "Certain Aspects of the Care and Management of the Persistent Vegetative State Patient." AAN position statement adopted on April 21, 1988. Available online at <http://www.aan.com/about/ethics/109556.pdf>.

1 hydration, may be foregone.”<sup>6</sup> Thus, the AAN position is that ANH *may* be withdrawn if a patient is in a  
2 PVS and it is determined that withdrawal of ANH is consistent with the patient’s wishes. However, the  
3 AAN does not hold the position that ANH *must* be withdrawn for all patients in PVS, for to do so would  
4 override the autonomy of those persons who would wish ANH continued in such circumstances.  
5

6 The AAN reaffirmed its support of these views when it introduced a resolution that was adopted at the  
7 2005 American Medical Association (AMA) annual meeting opposing “all state and federal legislation  
8 that would presume to prescribe the patient’s preferences for artificial hydration and nutrition in situations  
9 where the patient lacks an advance directive or living will....”<sup>7</sup> The resolution anchored itself in existing  
10 AMA policies supporting a patient’s right to self-determination, a limited role for judicial review in  
11 determining care options, and the appropriateness of withdrawing “life-sustaining medical treatment in  
12 accordance with a proper substituted judgment or best interests analysis.”<sup>8</sup>  
13

#### 14 **Statements from national professional medical organizations**

15 Several national professional medical organizations, including the American College of  
16 Physicians, the American Geriatrics Society, the American Nurses Association, and the American  
17 Osteopathic Association, have adopted similar position statements that reflect many of the same  
18 principles endorsed by the AAN. Whether drafted in response to the case of Mrs. Schiavo, or the  
19 case of Nancy Cruzan, whose family’s appeal to the U.S. Supreme Court for withdrawal of ANH  
20 became precedent-setting, the positions reflect a strong concern that a patient’s right to self-  
21 determination deserves deep respect and primary consideration in every health care situation.  
22 This same concern has been reflected in the majority of medical ethics articles on this topic.

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<sup>6</sup> Ibid.

<sup>7</sup> AMA-YPS Delegate’s Report, AMA Annual Meeting, June 17 – 22, 2005, Chicago, Illinois. Available online at <http://www.ama-assn.org/ama1/pub/upload/mm/17/a05delegatesreport.pdf>.

<sup>8</sup> Resolution 209 (A-05), as introduced at the 2005 Annual Meeting of the American Medical Association. Available online at <http://www.ama-assn.org/meetings/public/annual05/209a05.doc>.

1 **AAN Position**  
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3 The American Academy of Neurology (AAN), representing over 19,000 neurologists and neuroscience  
4 professionals, has long taken an active interest in scientific, ethical and professional discussions regarding  
5 the provision and withdrawal of life-sustaining medical treatment for patients who lack decision-making  
6 capacity. Part of this interest stems from the role neurologists play in evaluating the cognitive capacity of  
7 patients for whom decisions to initiate, maintain or discontinue life-sustaining interventions may be  
8 necessary. Neurologists share the concern of all physicians that decisions regarding the treatment of  
9 patients should be anchored in terms of each patient’s own values, preferences and goals of care, as best  
10 understood, which determine what is best for each patient. Respect for a patient’s autonomy and wishes—  
11 whether those wishes are to continue or discontinue therapies—is essential.  
12

13 The AAN has adopted the following principles regarding the determination of patient preferences for the  
14 provision and withdrawal of artificial nutrition and hydration:  
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- 16 - The AAN reaffirms its 1988 position statement titled “Certain Aspects of the Care and  
17 Management of the Persistent Vegetative State Patient.”  
18
- 19 - The AAN opposes all state and federal legislation that would presume to prescribe a patient’s  
20 preferences for artificial hydration and nutrition.  
21
- 22 - The AAN further opposes all state and federal legislation that limits the ability of patients to  
23 declare their preferences for health care through the use of living wills and advance  
24 directives, or by discussion of their wishes with their families or surrogate decision makers.  
25
- 26 - The AAN opposes all state and federal legislation that gives legal standing to elected officials  
27 (or their designees) to intercede in private decisions regarding the use of ANH.  
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- 29 - The AAN opposes all state and federal legislation that expands judicial intervention in a  
30 patient’s decisions regarding the use of ANH.  
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- 32 - The AAN supports state and federal legislation that promotes a better understanding of  
33 patient preferences for medical care (including the development of advance directives, living  
34 wills, and durable power of attorney declarations; the creation of health care directive  
35 registries; and the indication of such information on official identification cards) in  
36 accordance with existing AAN policies.  
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- 38 - The AAN is committed to providing its members access to educational resources so that they  
39 can competently and sensitively discuss decisions regarding the provision of ANH with  
40 patients who are writing an advance directive, and with families or surrogate decision makers  
41 who are contemplating such decisions on behalf of patients.  
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43 Approved  
44 Ethics, Law and Humanities Committee ~ June 13, 2006  
45 State Affairs Committee ~ June 8, 2006  
46 Board of Directors ~ June 24, 2006