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## A.S.P.E.N. Ethics Position Paper

Albert Barrocas

Cynthia Geppert

Sharon M. Durfee

Julie O'Sullivan Maillet

Cheryl Monturo

West Chester University of PA, [cmonturo@wcupa.edu](mailto:cmonturo@wcupa.edu)

*See next page for additional authors*

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**Authors**

Albert Barrocas, Cynthia Geppert, Sharon M. Durfee, Julie O'Sullivan Maillet, Cheryl Monturo, Charles Mueller, Kathleen Stratton, Christina Valentine, and A.S.P.E.N. Board of Directors

## **A.S.P.E.N. Ethics Position Paper**

*A.S.P.E.N. Ethics Position Paper Task Force: Albert Barrocas MD FACS Chair; Cynthia Geppert, MD, PhD, MPH, FAPM, DAAPM; Sharon M. Durfee, RPh, BCNSP; Julie O'Sullivan Maillet RD, PhD; Cheryl Monturo, PhD, APRN; Charles Mueller, PhD, RD, CNSD; Kathleen Stratton, JD, RD, LDN; Christina Valentine, MD, RD and the A.S.P.E.N. Board of Directors*

### **Introduction**

#### *Purpose*

Position papers provide the opinions, guidance and recommendations of a group or organization based on a consensus of evidence-based medicine (EBM), expert opinion, best practices, and clinical experience current at the time of development. This position paper's purpose is to provide a critical summary of the major ethical and legal issues related to the provision of artificial nutrition and hydration (ANH), to provide guidance for practitioners confronted with these dilemmas, and to direct readers to additional references for further study.

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is an organization comprised of healthcare professionals representing the disciplines of medicine, nursing, pharmacy, dietetics, and nutrition science. The mission of A.S.P.E.N. is to improve patient care by advancing the science and practice of nutrition support therapy. A.S.P.E.N. vigorously works to support quality patient care, education, and research in the fields of nutrition and metabolic support in all healthcare settings. Under the guidance of the A.S.P.E.N. Board of Directors, the Ethics Position Paper Task Force developed recommendations based upon general conclusions of experienced healthcare professionals and ethicists working in the field of nutrition support, and as an extension of previously published guidelines. The Task Force, in developing such a position, has balanced potential benefits to be derived from a particular mode of nutrition support therapy against inherent risks associated with such therapy

within an overall framework of ethical principles and values. The professional judgment of the attending health professional, however, is the primary component of quality health care. Because these recommendations cannot account for every variation in circumstances, the practitioners must always exercise professional judgment in their application. This position paper is intended to supplement, but not replace, professional training and judgment.

#### *Intended Audience and How to Use this Document*

While useful to a heterogeneous group of individuals, the intended users of this position paper are clinicians caring for patients and families faced with ethical and legal concerns involving ANH. The paper is not intended to be a full review of the clinical or even ethical and legal aspects of ANH or the medical disorders for which it is commonly utilized. This paper outlines the major ethical positions of A.S.P.E.N. regarding a variety of clinical situations concerning ANH. Extended discussions of particular areas and additional reference material are available on the A.S.P.E.N. website at [www.nutritioncare.org/ethics](http://www.nutritioncare.org/ethics).

#### **A.S.P.E.N. Ethics Position Paper Summary**

It is the position of A.S.P.E.N. that:

1. To the extent possible, decisions regarding ANH should be based on EBM, best practices, and clinical experience and judgment in discussion with the patient, family, or significant others. Page 5
2. From a scientific, ethical, and legal perspective there should be no differentiation between withholding and withdrawing of ANH, thus this paper employs the term “forgoing” for both, recognizing that withdrawing is more emotionally laden than withholding, especially within specific cultures. Page 5

3. Decisions regarding forgoing ANH should incorporate a benefit-risk-burden analysis based on EBM and best practices in discussion with the patient, family, or significant others. Page 6
4. Limited time trials are an acceptable alternative when the benefits of ANH are questionable and the trial nature of ANH is communicated and consented to by the patient and family prior to its initiation. Page 6
5. Scientific evidence on the physiology of patients with brain death, in a coma, or in a persistent vegetative state (PVS), indicates these patients do not experience thirst or hunger, and therefore are not likely to suffer. Page 6
6. ANH may not provide any benefit and may have associated risks in patients with severe dementia or in a PVS. Page 6-7
7. Artificial hydration of terminally ill patients can lead to discomfort due to fluid overload, pulmonary and generalized edema, shortness of breath, etc. and may be discontinued on clinical and ethical grounds provided such discontinuation is not in conflict with existing laws, institutional policies and consent/consensus of decision makers. Page 8-9
8. Forgoing ANH in infants and children at the end of life may be ethically acceptable when competent parents and the medical team concur that the intervention no longer confers a benefit to the child or creates a burden that cannot be justified. Page 9-11
9. The religious, cultural and ethnic background of patients and families need to be respected to the extent it is consistent with other ethical principles and duties. Page 8
10. Consent, respect, and preservation of dignity should be paramount during ethical and legal deliberations regarding ANH. Page 14
11. Many states in the U.S. require “clear and convincing evidence” to forgo ANH in decisionally incapacitated patients without documented ANH preferences. Page 16

12. Patients with decision-making capacity and authority should be the appropriate moral agents to make choices regarding ANH based on evidence-based information qualified practitioners present to them. Page 16
13. For patients lacking decision-making capacity, the health care professional has an ethical and legal obligation to reference an advance directive or discussion with the authorized surrogate decision maker, whether appointed through mechanisms of a durable power of attorney for health care directive, court or statutory processes. Page 16-17
14. Surrogate decision makers (including but not limited to family members and/or significant others) should be given the same considerations as individual patients with decision-making capacity. Page 16
15. Health care professionals should not be ethically obligated to offer ANH if in their clinical judgment there is not adequate evidence for the therapy, or the burden or risk of the intervention far outweighs its benefit. Page 12
16. The establishment of interdisciplinary teams and conferences with the patient and family is highly encouraged. Interdisciplinary ethics committees or panels should be consulted when the involved parties cannot resolve the ethical dilemma. Page 13
17. Care should continue until the conflict regarding ANH is resolved. If unable to resolve conflicts, even with an ethics consultation, orderly transfer of care assuring continuity of care is recommended to an equally qualified and willing practitioner and/or institution. At no time should patients or families feel abandoned. Page 13

## **Definitions**

Definitions of ethical terms can be found in a glossary on the ethics position portion of our website ([www.nutritioncare.org](http://www.nutritioncare.org)) and should be used in conjunction with the A.S.P.E.N.

*Definition of Terms, Style, and Conventions Used in A.S.P.E.N. Board of Directors-Approved Documents* which can also be found on the website ([www.nutritioncare.org](http://www.nutritioncare.org)).

### **The Ethics of ANH in Specific Patient Conditions**

There are many clinical conditions for which various types of ANH are utilized. While ethical issues can arise in the management of any of these disorders, they are most commonly encountered in the management of dementia, persistent/permanent vegetative states, and terminal illness. Shared decision-making about the use of ANH in these clinical situations should take into consideration ethical, legal, religious and cultural aspects discussed later in this paper. From a scientific, ethical, and legal perspective there should be no differentiation between withholding and withdrawing of ANH. Thus this paper employs the term “forgoing” for both, recognizing that withdrawing is more emotionally laden than withholding, especially within specific cultures. The decision to forgo ANH should be based on EBM, illness trajectory, the expected impact of the intervention on the disease/condition, expected clinical outcomes and the preferences and values of the patient or authorized surrogated decision-maker.

ANH is a viable and highly effective therapy to ameliorate the effects of temporary or chronic conditions for those unable to ingest food and fluids.<sup>1</sup> An ethical dilemma can be created when ANH treatment is not clinically indicated, ineffective or potentially harmful such as the risk of aspiration pneumonia with enteral nutrition for advanced dementia. Despite the clinical evidence, some patients and families believe that the forgoing of artificial nutrition is cruel, inhumane, or equivalent to starvation.<sup>2</sup> The basis for an ethically sound decision to forgo ANH should be based on the risk-benefit-burden analysis of ANH as well as the wishes of the patient and/or surrogate. In each of these conditions, limited time trials may be an acceptable alternative when the risk/burden-benefit ratio of ANH is uncertain or there is not consensus

among the involved practitioners. However, the trial nature of the intervention and the criteria and timeframe for reevaluation of the intervention should be clearly communicated to the patient and family prior to initiation of the trial.

**Persistent vegetative state (PVS)** is a state of prolonged unresponsiveness without awareness due to overwhelming dysfunction of cerebral hemispheres with preservation of brainstem function as evidenced by autonomic and motor reflexes- eye movements, yawning, involuntary movement to noxious stimulus and sleep/wake cycles.<sup>3</sup> PVS is characterized by wakefulness without awareness. It has a poor prognosis for recovery of awareness when present for more than a year in trauma patients and more than 3-months in all non trauma patients at which time it has a high probability of becoming a **permanent** vegetative state.<sup>4</sup>

Neuroscientific evidence suggests that patients who are comatose, or in a truly persistent vegetative state, do not experience suffering from thirst or hunger while patients in minimally responsive states or where some degree of consciousness is preserved do suffer. These distinctions have clinical ethics implications for risk-benefit-burden analysis. For instance, when the prognosis or cognitive state is uncertain such as early in the course of brain injury then a time-limited trial of ANH may be both clinically and ethically warranted provided the goals of such a trial are clearly understood and accepted by all parties involved. However, when the diagnosis has been determined with reasonable scientific certitude and the result of prior patient preferences or a process of shared decision making with family and/or the surrogate finds ANH to be excessively burdensome for that individual, then it can be forgone.<sup>5</sup>

**Advanced dementia** is a state of chronic, global, usually irreversible deterioration of cognition affecting primarily the elderly, although it can happen at an earlier age. Dementias may be primary neurodegenerative disorders, e.g. Alzheimer's disease, Parkinson's disease,

chronic alcohol abuse, infectious causes; or due to another condition such as vascular disease.<sup>3</sup> In advanced dementia, patients cannot feed, walk, or perform activities of daily living. They eventually become mute and often have dysphagia and cognitive deficits that impede normal intake making these patients candidates for nutrition support, specifically enteral (tube) nutrition since gastrointestinal function is not otherwise compromised. A survey of nursing home residents in the United States with advanced dementia found that 34% of 186,835 were tube fed.<sup>6</sup> In 1999 Finucane and colleagues noted in a review of the literature that enteral nutrition did not improve clinical outcome in advanced dementia.<sup>7</sup> In 2008 a Cochrane database and literature review concluded that there was insufficient evidence to suggest that enteral nutrition benefits patients with advanced dementia and that data on adverse events associated with enteral nutrition are lacking.<sup>6</sup> Both of these studies concluded that there is little efficacy for enteral nutrition in this population.

The American Dietetic Association recommends that the use of enteral nutrition in severe dementia may be justified by specific and limited goals. As the Association's position states, however, tube feeding can be ethically rejected when all involved understand the realistic outcomes of enteral nutrition.<sup>8</sup> Many patients, families and non-specialist clinicians misunderstand or overestimate the benefits of ANH in advanced dementia which can lead to ethical dilemmas that evidence based education and counseling may constructively address. In patients with advanced dementia, ANH has not been shown to promote the healing of pressure ulcers, reduce the risk of aspiration pneumonia, increase patient comfort, functional status or prolong survival when compared to hand-feeding. A review of 5266 nursing home residents with dysphagia failed to show benefit from placement of a feeding tube and found a higher 1-year mortality rate.<sup>7</sup>

Finally, it is important to note that some patients with advance dementia and the ability to consume food orally may receive ANH in lieu of hand feeding. This may be due to institutional culture<sup>9</sup>, reimbursement and regulatory considerations, or a lack of adequate staff<sup>10</sup>, or a neglect for the inherent meaning of food and the societal nature of mealtime, all of which have ethical implications.

### **End stage disease/terminal illness**

ANH is often initiated during the treatment phase of care and may be especially useful in patients with GI obstruction. When terminally ill patients progress to hospice care, the role of ANH, as with all interventions, needs to be re-evaluated in terms of the goals of comfort, relief of symptoms, and quality rather than quantity of life.<sup>11</sup> The majority of terminally ill patients will reach a point in their illness where they either refuse food or are unable to take nutrition orally. Families may feel a moral duty and emotional need to provide food and water to their dying loved ones. It is thus important to discuss with patients and families that loss of the desire to eat and drink is a natural part of the dying process. The risks, benefits, and burdens of ANH at the end-of-life along with relevant cultural and religious values and patient and family preferences and values must be weighed in each individual case.<sup>12</sup>

ANH in dying patients has been associated with increased nausea, vomiting, and diarrhea and repeated aspiration pneumonia,<sup>13</sup> while fluids may cause or exacerbate dyspnea, bronchial secretions, urinary frequency, bladder distention, pulmonary edema and effusions and ascites.<sup>14</sup> The administration of ANH often requires the need for additional interventions such as catheters, blood draws, restraints and medications to manage complications of nutrition and hydration, which may cause discomfort. Ironically ANH can prevent the ketosis and dehydration that are a protective mechanism against potentially painful symptoms of

dying. A study with terminally ill patients found that most did not experience hunger or that hunger was satisfied with small amounts of food. Feelings of thirst were relieved with sips of liquid and mouth care.<sup>15</sup> Hospice nurses working with dying patients reported that those who voluntarily refused both food and fluids experienced a good death within 2 weeks.<sup>16</sup> In a study in cancer patients undergoing hematopoietic stem cell transplantation, it was reported that patients receiving parenteral nutrition had lower oral intake and higher fevers and infections as compared to patients not receiving parenteral nutrition.<sup>17</sup> Research has not shown that ANH prolongs life in patients with certain specific serious and terminal conditions.<sup>18,19</sup>

### **Special Considerations for Infants and Children**

Legal authority to make life and death decisions for children generally<sup>20</sup> and for neonates specifically has historically been left to parents.<sup>21</sup> While there is specific federal legislation that applies in the case of infants, decisions for children are generally guided by the common law and statutes that will vary from state to state.<sup>20</sup> A clear understanding of clinical circumstances is vital to anticipate care for families.<sup>22</sup> Artificial support is a common practice as care decisions are being made in a terminally ill newborn. Each different clinical scenario requires a practitioner to evaluate the potential outcome in regard to the futility or realistic chance of improvement.<sup>23,24</sup> ANH is integral for the care of a newborn and difficult to forgo.<sup>25</sup> The forgoing of fluids and nutrition to a neonate can evoke strong emotional reactions since feeding is fundamental to infants, who possess no autonomy in the decision.<sup>26</sup>

The 1983 much publicized “Baby Doe” case involved an infant with Down’s syndrome and esophageal atresia in which the parents and physicians chose to defer surgery and nutrition support, with the infant subsequently dying 6 days afterward. This case prompted the Department of Health and Human Services to issue a federal ruling entitling anyone to report a

case whereupon “medical treatment or food was withheld from defective infants”.<sup>27</sup> Thereafter, in 1984, Congress amended the Child Abuse Prevention and Treatment Act (CAPTA) to include language intended to protect disabled infants from medical neglect.<sup>28</sup> The law defines medical neglect to include “the withholding of medically indicated treatment.”<sup>29</sup> Current federal regulations promulgated under the authority of CAPTA include nutrition and hydration within the definition of “medically indicated treatment” for disabled infants.<sup>30</sup> While CAPTA and the regulations do create an exception for when in a physician’s reasonable judgment an infant is “chronically and irreversibly comatose,” when treatment would “merely prolong dying,” or be “futile” or “inhumane,” it also excludes nutrition and hydration from this exception.

In a 2009 clinical report, the American Academy of Pediatrics (AAP) offered general principles designed to help practitioners decide when it is ethically permissible to forgo medically provided fluids and nutrition from infants, children, and adolescents.<sup>31</sup> The AAP report also addresses CAPTA, as it applies in the case of infants only.<sup>28,30</sup> In this report, the AAP also takes the position that although the language of CAPTA and the regulations “seem to advocate for the provision of appropriate fluids and nutrition in most cases,” forgoing ANH is ethically acceptable with competent parents when the intervention no longer confers a benefit to the child or creates a burden that cannot be justified.<sup>31</sup> The AAP also points out that while CAPTA makes states’ receipt of federal child abuse prevention program funding contingent upon having appropriate reporting mechanisms in place, there is no direct enforcement mechanism to the law. They therefore argue that CAPTA and the supporting regulations “were not intended as standards of physician or institutional liability.”<sup>31</sup> In an earlier report from 1994, the AAP Committee on Bioethics provided a framework for documentation of medical futility, discussions with parents of treatment options, corroborating statements from other physicians,

and the process of a bioethics committee review to help protect the infant but also to provide the most humane treatment.<sup>32</sup> Open communication with parents and realistic prognostic outlooks for their infant from the beginning is crucial to help avoid conflicts in providing or withdrawing care.<sup>33</sup>

## **Ethical Decision Making Background**

### *Bioethical theory*

Bioethics is a form of *normative ethics*: the branch of philosophical ethics concerned with formulating general standards or norms of ethical behavior and moral judgment. Ethical dilemmas are situations in which an individual is faced with two ethically acceptable courses of actions or decisions but it is not possible to fulfill both moral requirements. For example, a clinician may wish to respect a family's wishes that a dying patient receive ANH but also to honor his duty to avoid harming the patient through a burdensome treatment with complications. Ethical theories propose a set of coherent principles, obligations or virtues that can serve as the basis for evaluation of actions, decision-making and ethical reasoning. When these theories are used to analyze specific issues, such as forgoing of ANH in persons with advanced dementia, this is an example of *applied ethics*.<sup>34</sup> The three main groups of theories which are most relevant to the nutrition support clinician are: **deontological**, **consequentialist** theories, of which the most well known is utilitarianism, and **principlism**. **Deontology** derived from the philosopher Immanuel Kant, posits near absolute duties such as respect for the innate dignity of human beings. An action or decision is right when it fulfills and wrong when it abrogates these universal obligations. **Consequentialism** originating in the thought of John Stuart Mill is widely used in public health and health policy with the goal of obtaining the greatest good or happiness for the most people. Utilitarian theory would weigh the risks,

benefits, and burdens or calculate a cost/benefit analysis of a proposed nutrition support intervention for a particular patient and a population as a whole. **Principlism** grounds ethical decisions and formulates arguments through the specification and balancing of a set of core ethical principles: **autonomy, beneficence, nonmaleficence, and justice**.<sup>35</sup> These principles are further elaborated upon at [www.nutritioncare.org/ethics](http://www.nutritioncare.org/ethics).

### *Considerations and Models for Resolving Ethical Dilemmas*

Ethical dilemmas are situations in which nutrition support clinicians are commonly confronted with conflicts between clinical, legal and ethical obligations. Health care professionals should not be ethically obligated to offer ANH if in their clinical judgment there is not adequate evidence for the therapy, or the burden or risk of the intervention far outweighs its benefit. This recommendation should be considered even if families or patients request ANH be initiated or continued. The practitioner does have an ethical obligation to try and resolve the conflict.

The use of interdisciplinary teams and conferences with the family and patient can often resolve the conflicts through informal mechanisms. In addition several formal approaches to resolving ethical dilemmas are available to assist the practitioner in identifying, analyzing and resolving these dilemmas. The four-box method of Jonsen, Winslade and Siegler<sup>36</sup> analyzes clinical indications, patient preferences, quality of life and contextual features of each case to facilitate thought about difficult ethical issues. Barrocas has constructed conceptual templates entitled the “12Cs” of considerations important to nutrition support decisions.<sup>37</sup>

When ethical conflicts cannot be resolved through these approaches, then practitioners should consider consulting the facility ethics committee or ethics consultation service for assistance. The responsible practitioners should continue to provide care for the patient until

the conflict regarding ANH is resolved and at no time should the patient be abandoned. If even ethics consultation cannot develop a consensus among all parties, and a clinician feels that he cannot in conscience remain involved in the patient's care, then orderly transfer to an equally competent and willing practitioner or institution is ethically appropriate.

### *Cultural and Religious Considerations*

Cultural values and religious beliefs are far more powerful and pervasive factors in decisions regarding ANH than in those involving almost any other modern medical intervention. The associations of food/ feeding and fluids/drinking with care-giving, sustenance and survival carry an emotional valence for patients and families deserving practitioners' understanding and empathy.<sup>38</sup> Clinician's failure to identify and be responsive to these humanistic concerns can precipitate ethical conflicts. Recognizing that it is impossible to develop expertise regarding the beliefs and practices of the diverse faith and ethnic groups in our multicultural society, practitioners should endeavor to learn about the relevant religious positions and cultural attitudes comprising their patient population, learn the questions to ask and listen to the patients.<sup>39</sup> Clinicians should also be aware that the inherent culture of an institution, such as a nursing home, may also influence the decision to use ANH.<sup>9</sup>

Clinicians should show sensitivity and respect for the individual faith commitments and cultural preferences of patients regarding ANH even when they do not agree with them from a medical perspective. In some situations in which religious or culturally based treatment preferences for the continuation of ANH conflict with medical recommendations, respect for patient self-determination and dignity may outweigh clinical determinations recognizing that many aspects of risk-benefit-burden assessments are also value judgments. Practitioners confronted with these common and challenging dilemmas may want to work with the patient

and/or surrogate in consulting with faith leaders and the ethnic community to which the patient belongs as well as the institutional ethics committee. It is important to note that if these efforts do not resolve the issue, orderly transfer of care should be initiated so that the patient not be abandoned.

Catholic and Judaic viewpoints on ethical issues related to ANH have received considerable organizational and scholarly attention; however most other religious and cultural views are minimally represented in the U.S. medical literature. This discussion, therefore, is not intended to be comprehensive. There are three main issues that practitioners may encounter in clinical practice. First, while individual autonomy is the predominant force in Anglo-American decision-making, some members of Native American, Asian and Hispanic groups may exercise autonomy communally or through the family.<sup>40-42</sup>

Second, religious beliefs played a role in the *Schiavo* feeding tube controversy where a surrogate's request for tube removal was repeatedly challenged in court despite an established legal and ethical consensus supporting the decision. While this consensus was ultimately upheld, the media coverage and politicization of this case left many Roman Catholic patients and providers confused whether ANH can be withheld or withdrawn in a variety of conditions.<sup>43</sup> Similarly, the 2004 papal allocution suggesting an obligation to utilize ANH in persistent vegetative states<sup>44</sup> and the 2009 United States Conference of Catholic Bishops decision to revise the Ethical Directive on Nutrition and Hydration to contain a similar duty<sup>45</sup> illustrate the contemporary power of religious values to influence ANH decision making and the need for expert consultation.

Third, it is not only patients but also health care professionals whose religious beliefs and cultural values may conflict with clinically grounded recommendations to forgo ANH in

advanced dementia, PVS or at the end of life. State laws, professional codes of ethics, facility bylaws and institutional policies often contain conscience clauses that enable health care practitioners to be recused from the clinical treatment of a patient on moral or religious grounds if an equally qualified practitioner is available and willing to assume care of the patient.<sup>46</sup>

## **Legal Summary**

The law concerning ANH at the end of life is subject to the actions of state legislatures and courts and evolves over time as the public and legislators contemplate contested cases. Basic legal principles that courts rely on include the common law doctrine of informed consent, which is firmly entrenched in the law and includes the right of a competent person to refuse medical treatment.<sup>47</sup> Courts will also look to state statutes and constitutional authority for guidance. In the 1976 Quinlan case, the New Jersey Supreme Court relied on the constitutional right to privacy to allow cessation of medical treatment, in that case artificial ventilation.<sup>48</sup> Later, in the 1990 Cruzan case, the United States Supreme Court dealt directly with a case in which a guardian sought to stop ANH in a patient determined to be in a PVS.<sup>47</sup> Referring to the 14<sup>th</sup> Amendment Due Process clause, the Court stated that while a competent person has “a constitutionally protected right to refuse lifesaving hydration and nutrition,” the individual’s liberty interest must be balanced against relevant state interests, such as the preservation of life. The Court then held that a state (Missouri) could apply a “clear and convincing evidence standard” (a high legal standard) in looking for proof of the patient’s wishes concerning ANH in the end of life. A majority of state courts will apply the “clear and convincing” evidence standard but what type of evidence satisfies that standard can vary from state to state.<sup>49</sup>

Taking these basic principles into consideration, if a competent person is presented with a recommendation that ANH be initiated, care providers should educate that patient about the risks, benefits, and burdens of ANH so that the patient can make an informed decision about whether ANH is warranted. When a previously competent person, through accident or illness, suddenly becomes incapacitated and is unable to make health care decisions, health care providers must look to advance directives for previously expressed communication as to what type of life-sustaining treatment the patient desires, if at all. Surrogate decision makers (including but not limited to family members and/or significant others) should be given the same considerations as individual patients with decision-making capacity. Advance directives take different forms depending on the laws of the jurisdiction involved and the patient's wishes. These may include living wills (instructions for care) and/or a health care proxy (designates a person to carry out instructions), such as a durable power of attorney for health care, among other forms.<sup>50</sup> Some patients will have advanced directives prepared by attorneys as part of their end of life planning. Others might have prepared a living will by utilizing the help of their physician or an organization's website. Examples of websites that provide end of life planning guidance include Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO)<sup>51</sup> and Aging with Dignity, a national non-profit organization.<sup>52</sup>

However, a patient who is being considered for ANH may not have prepared an advance directive. A recently published study showed between 2000 and 2006, many elderly Americans needed decision making near the end of life at a time when most lacked the capacity to make decisions. Patients who had prepared advance directives (67.5% of this group) received care that was strongly associated with their preferences. These findings support the continued use of advance directives.<sup>53</sup> Legal conflicts may arise when a patient

who has not provided the health care team with an advance directive addressing ANH loses the capacity to speak for him or herself and conflicts between family members or caregivers arise. The 2005 Terry Schiavo case in Florida is one such example.<sup>54</sup> The same dilemma may arise if a patient is incompetent from the outset and there is no legal guardian or agent who has the legally appointed right/duty to make decisions on behalf of the patient. While established legal precedent guides the courts, each case has unique facts and state laws vary in how they protect patients' rights. While one state may allow oral substituted judgment of a patient's desires, another may require written evidence.<sup>50</sup> A practitioner must therefore be aware of the most current version of the laws at work protecting patients' rights in the particular state in which one practices. This includes state statutes, constitutions, and the legal precedent as set forth in the state's appellate court decisions.

## **Conclusion**

The purpose of this A.S.P.E.N. position paper is to provide a critical summary of the major ethical and legal issues related to the provision of artificial nutrition and hydration (ANH), to provide guidance for practitioners, patients, and families confronted with these dilemmas, and to direct readers to additional references for further study. This paper also outlines the major ethical position of A.S.P.E.N. regarding the use of ANH in three of the most commonly encountered and controversial clinical conditions: persistent vegetative states, advanced dementia, and terminal illness. The position paper also underscores the importance of religious beliefs and cultural values the decisions of patients and families regarding the provision of ANH. Finally, the position paper presents a summary of key legal cases and rulings, and outlines major ethical principles and theories, which provide the framework within contemporary clinical decisions about ANH are made. Effective communication amongst all

involved parties is of paramount importance in dealing with ethical and legal issues concerning ANH. It is hoped that the health care provider will be successful in achieving this goal with the aid of this position paper and the supporting documentation on the ASPEN Ethics website.

## References

1. Fine RL. Ethical issues in artificial nutrition and hydration. *Nutr Clin Pract.* 2006;21:118-125.
2. Andrews MR, Geppert CMA. Ethics. In : Gottschlich MM (ed.) *The A.S.P.E.N. Nutrition Support Core Curriculum: A Case-based Approach-The Adult Patient.* Silver Spring, MD:American Society for Parenteral and Enteral Nutrition, 2007:740-760.
3. Beers MH, ed. *The Merck Manual, 18<sup>th</sup> Ed.* Merck & Co., Inc. 2006:1811-1821.
4. Bernat JL. Chronic disorders of consciousness. *Lancet.* 2006;367:1181-1192.
5. Executive Board, American Academy of Neurology. Position of the American Academy of Neurology on certain aspects of the care and management of the persistent vegetative state patient. *Neurology.* 1989;39(1):125-126.
6. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev.* 2009 Apr 15;(2):CD007209.
7. Finucane TE, Christmas C, Travis K. Tube feeding with advanced dementia. A review of the evidence. *JAMA.* 1999;282:1365-1370.
8. O'Sullivan Maillet J. Position of the American Dietetic Association: Ethical and legal issues in nutrition, hydration, and feeding. *J Am Diet Assoc.* 2008;108:873-882.
9. Palan Lopez, R, Amella E J, Strumpf N, Teno J M, and Mitchell S L.. The influence of nursing home culture on the use of feeding tubes. *Arch Intern Med.* 2010;170: 83-88.
10. Post S. Tube feeding and advanced progressive dementia. *The Hastings Report.* 2001:Jan-Feb:36-42.
11. Fuhrman MP, Herrmann VM. Bridging the continuum: nutrition support in palliative and hospice care. *Nutr Clin Pract.* Apr 2006;21(2):134-141.
12. Hallenbeck J. Fast Facts and Concepts #11 Tube Feed or Not Tube Feed? 2nd ed: End-of-Life Physician Education Resource Center; August 2005.
13. Ciocon JO, Silverstone FA, Graver LM, Foley CJ. Tube feedings in elderly patients. Indications, benefits, and complications. *Arch Intern Med.* Feb 1988;148(2):429-433.
14. Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage.* 1995;10(3):192-197.
15. McCann RM, Hall WJ, Groth-Juncker A. Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA.* 1994;272(16):1263-1266.
16. Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med.* 2003;349(4):359-365.

17. Sheean PM, Braunschweig CA. Exploring the clinical characteristics of parenteral nutrition recipients admitted for initial hematopoietic stem cell transplantation. *J Am Diet Assoc.* 2007;107(8):1398-1403.
18. Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. *Lancet.* 1996;348(9039):1421-1424.
19. Rabeneck L, McCullough LB, Wray NP. Ethically justified, clinically comprehensive guidelines for percutaneous endoscopic gastrostomy tube placement. *Lancet.* 1997;349(9050):496-498.
20. Furrow BR, Greaney TL, Johnson SH, Jost TS, & Schwartz RL *Health Law*, (2d ed.), pp. 859-861, St. Paul MN: West.
21. Partridge JC, Dickey BJ. Decision-making in neonatal intensive care: Interventions on behalf of preterm infants. *NeoReviews.* 2009;10:e270-e279.
22. Porta N, Frader J. Withholding hydration and nutrition in newborns. *Theoretical Med and Bioethics.* 2007;28:443-451.
23. Singh J, Lantos J, Meadow W. End-of-life after birth: Death and dying in a neonatal intensive care unit. *Pediatrics.* 2004;114(6):1620-1626.
24. Chiswick M. Infants of borderline viability: Ethical and clinical considerations. *Fetal and Neonatal Medicine.* 2007;13:8-15.
25. Carter BS, Leuthner SR. The Ethics of withholding/withdrawing nutrition in the newborn. *Seminars in Perinatology.* 2003;27(6):480-487.
26. Bioethics Committee, American Academy of Pediatrics. Ethics and the care of critically ill infants and children. *Pediatrics.* 1996;98:149-152.
27. Federal Register. Nondiscrimination on the basis of a handicap. *Department of Health and Human Services: Interim Final.* 1983;48 Rule 45(CFR Part 84):9630.
28. 42 USC § 5101 et seq.
29. 42 USC § 5106g, 2006
30. 45 CFR § 1340.15 (b)(2) (10-1-08 Edition)
31. Diekema DS, Botkin JR. Clinical report--Forgoing medically provided nutrition and hydration in children. *Pediatrics.* Aug 2009;124(2):813-822.
32. Bioethics Committee, American Academy of Pediatrics. Guidelines on forgoing life-sustaining medical treatment. *Peds.* 1994;93:532-536.
33. Tripp J, McGregor D. Withholding and withdrawing of life sustaining treatment in the newborn. *Arch Dis Child Fetal Neonatal Ed.* 2005;91:F67-F71.
34. Fieser J. Ethics. In: Dowden B, ed. *The Internet Encyclopedia of Philosophy* 2006: <http://www.iep.utm.edu/e/ethics.htm>. Accessed June 4th, 2009.
35. Kuhse H, Singer P, eds. *A Companion to Bioethics*. Oxford: Blackwell; 2001.
36. Jonsen AR, Seigler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 6th ed. New York: McGraw-Hill, Inc.; 2006.

37. Barrocas A, Yarbrough G, Becnel PA, 3rd, Nelson JE. Ethical and legal issues in nutrition support of the geriatric patient: the can, should, and must of nutrition support. *Nutr Clin Pract.*2003;18(1):37-47.
38. Caspar R. Food and water: symbol and reality. *Health Prog.* May 1988;69(4):54-58.
39. Koenig HG. Spirituality in Patient Care Why, How, When and What.2<sup>nd</sup> ed. Templeton Press, 2007.
40. Fetters MD. The family in medical decision making: Japanese perspectives. *J Clin Ethics.* 1998;9(2):132-146.
41. Bedolla M. Patient Self-Determination Act: a Hispanic perspective. *Camb Q Healthc Ethics.* 1994;3(3):413-417.
42. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation. Benefit or harm? *JAMA.* 1995;274(10):826-829.
43. Sulmasy DP. Terri Schiavo and the Roman Catholic tradition of forgoing extraordinary means of care. *J Law Med Ethics.* Summer 2005;33(2):359-362.
44. Clark P. Tube feedings and persistent vegetative state patients: ordinary or extraordinary means? *Christ Bioeth.* Apr 2006;12(1):43-64.
45. Committee on Doctrine of the United States Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic health Care Services.* Washington, D.C. November 17 2009. Accessed March 15, 2010 [http://www.usccb.org/meetings/2009Fall/docs/ERDs\\_5th\\_ed\\_091118\\_FINAL.pdf](http://www.usccb.org/meetings/2009Fall/docs/ERDs_5th_ed_091118_FINAL.pdf)
46. Wicclair MR. Conscientious objection in medicine. *Bioethics.* Jul 2000;14(3):205-227.
47. *Cruzan v Director*, 497 U.S. 261 (1990)
48. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).
49. *Woods v Kentucky*, 142 S.W.3d 24 (Ky. 2004)
50. Krauskopf J, Brown R, Tokarz K & Bogutz A. (1993 and supp 2009). *Elderlaw: Advocacy for the Aging*, (2d ed.), pp. 487-523, St. Paul MN: Thomson Reuters/West.
51. National Hospice and Palliative Care Organization. Planning ahead. [www.caringinfo.org](http://www.caringinfo.org). Accessed April 29, 2010.
52. Aging with Dignity. Five Wishes. [www.agingwithdignity.org](http://www.agingwithdignity.org). Accessed April 29, 2010.
53. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010 Apr 1;362(13):1211-8.
54. *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla 2005, aff'd, 403 F.3d 1223 (11<sup>th</sup> Cir. 2005) and *In re Guardianship of Shiavo*, 916 So.2d 814 (Fa 2d DCA 2005).