Position of the Academy of Nutrition and Dietetics: Ethical and Legal Issues in Feeding and Hydration

ABSTRACT
It is the position of the Academy of Nutrition and Dietetics that individuals have the right to request or refuse nutrition and hydration as medical treatment. Registered dietitians (RDs) should work collaboratively as part of the interprofessional team to make recommendations on providing, withdrawing, or withholding nutrition and hydration in individual cases and serve as active members of institutional ethics committees. RDs have an active role in determining the nutrition and hydration requirements for individuals throughout the life span. When individuals choose to forgo any type of nutrition and hydration (natural or artificial), or when individuals lack decision-making capacity and others must decide whether or not to provide artificial nutrition and hydration, RDs have a professional role in the ethical deliberation around those decisions. Across the life span, there are multiple instances when nutrition and hydration issues create ethical dilemmas. There is strong clinical, ethical, and legal support both for and against the administration of food and water when issues arise regarding what is or is not wanted by the individual and what is or is not warranted by empirical clinical evidence. When a conflict arises, the decision requires ethical deliberation. RDs’ understanding of nutrition and hydration within the context of nutritional requirements and cultural, social, psychological, and spiritual needs provide an essential basis for ethical deliberation. RDs, as health care team members, have the responsibility to promote use of advanced directives. RDs promote the rights of the individual and help the health care team implement appropriate therapy. This paper supports the “Practice Paper of the Academy of Nutrition and Dietetics: Ethical and Legal Issues of Feeding and Hydration” published on the Academy website at: www.eatright.org/positions.


POSITION STATEMENT
It is the position of the Academy of Nutrition and Dietetics that individuals have the right to request or refuse nutrition and hydration as medical treatment. Registered dietitians should work collaboratively as part of the interprofessional team to make recommendations on providing, withdrawing, or withholding nutrition and hydration in individual cases and serve as active members of institutional ethics committees.

HEALTH CARE PROFESSIONALS
have an ethical obligation to protect life and to relieve suffering. Respect of autonomy, nonmaleficence, beneficence, and justice are accepted moral principles governing the behavior of health care professionals, see definitions in the “Practice Paper of the Academy of Nutrition and Dietetics: Ethic and Legal Issues of Feeding and Hydration.” Health care professionals are considered to be working interprofessionally when two or more providers from different backgrounds work together to deliver high-quality care.

While the principle of autonomy is a cornerstone of American bioethics, this ethical principle is not absolute and must be balanced with other principles. Attitudes toward health care delivery, services, and values are influenced by three diverse ethical theories: the utilitarian/consequentialist view, the formalist/deontological view, and the virtues view. The utilitarian viewpoint, as expressed by Mill, sees an ethical decision as that which produces the greatest positive balance of value over negative balance of value for all persons affected. Kant’s deontological viewpoint of ethics states that some acts are wrong or right independent of their consequences. The virtue ethics connected with Aristotle says goals and rules are respected, but its central theme is the character of the person.

Ethics issues surrounding food and feeding are complex, as food and drink have both psychological and physiological functions that often play an essential role in total care. Food has strong emotional and symbolic overtones that include maternal nurturing and religious, cultural, and social values. The actual or illusory source of strength, nurturing, comfort, and caring provided by food should be encouraged as well as family interaction and socialization independent of feeding decisions.

MEDICAL—ETHICAL DECISION MAKING
This paper affirms that self-determination generally takes precedence over the beliefs of health care providers. It recognizes that each person approaches end of life with different cultural, religious, philosophical, and personal attitudes and values. For some people, every moment of life, no matter how painful and limited, is of inestimable value. Other people might seek to forgo various medical therapies that might include nutrition support. Yet others may wish to forgo or withdraw medical treatment, such as use of ventilators, but may wish to continue nutrition or hydration support. Religious and cultural traditions might assert that sustaining life is a moral obligation, with the counter ar-
argument that if there is no benefit, the procedure cannot be obligatory.

The Hippocratic writings encourage recognition of when medicine is not useful. Plato emphasized the inappropriateness of continuing treatment if the survivor will have a useless life. When there is disagreement about the futility of treatments, there is the question of when nutrition and hydration are morally obligatory or morally optional. A common method of distinguishing between what is obligatory and what is optional is to consider the consequences. Nutrition and hydration can be effective in that they maintain life, but by themselves they cannot restore consciousness or prevent imminent death.

While there is general agreement that individuals have the right to refuse treatment, the question is whether they have the right to demand treatment if it is nonbeneficial or medically contraindicated. The debate on the definition of futility is incomplete. Another issue in the individual’s treatment is the allocation of resources in a fair manner; whether cost should be a factor in clinical ethical decision making can intensify as resources become scarcer. The central question remains what the individual prefers, but allows for what providers consider worthwhile. This can be formulated into the ethical discussion of what is wanted and what is warranted; wanted by the individual/family and warranted by the evidence. If care providers decide that there is an obligation to feed the persistently unconscious individual, they may change the moral obligation to a moral option after the passing of time suggests that the individual’s state will be permanent. Health care providers must uphold the individual’s wishes whether they agree or disagree, or transfer the individual to another health care provider.

The issue of justice and individual feeding may intensify, especially for the permanently unconscious. For instance, if the legal definition of death was changed to be the death of higher brain functions, the permanently unconscious individual might be considered dead. The lack of diagnostic certainty complicates this approach. The rationing of health care debate could examine the principle of justice, suggesting that people who want to live in a permanently unconscious state purchase such insurance to pay for the care and feeding.

**LEGAL DECISIONS**

The past 30 years have provided landmark judicial decisions addressing the issue of withdrawing life-sustaining medical procedures—with Quinlan, the first case, and then the Cruzan and Schiavo cases, supporting the authority and liberty of the individual.

<table>
<thead>
<tr>
<th>Case</th>
<th>Year</th>
<th>Jurisdiction</th>
<th>Key finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanglie</td>
<td>1990</td>
<td>Minnesota District Court</td>
<td>Because patient died before decision, no ruling on whether a physician can withhold/withdraw ANH as futile care.</td>
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<td>Bland</td>
<td>1993</td>
<td>Great Britain</td>
<td>State health professional can start warranted treatment or curtail inappropriate treatment.</td>
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<td>Finn</td>
<td>2000</td>
<td>Commonwealth of Virginia</td>
<td>Governor stopped withdrawal of feeding tube of PVS patient as his duty to protect his public. Court rules that withdrawing ANH “merely permits the natural process of dying as not mercy killing or euthanasia.” Feeding stopped.</td>
</tr>
<tr>
<td>Wendland</td>
<td>2001</td>
<td>California</td>
<td>Wendland was neither competent nor PVS. Court decided that this individual required a higher standard of proof from a court-appointed conservator when this category of individual has left no advanced directive.</td>
</tr>
<tr>
<td>Baby Doe</td>
<td>1984</td>
<td>United States Supreme Court</td>
<td>Continual aggressive treatment essential. Later courts affirmed authority of individual in case.</td>
</tr>
<tr>
<td>Baby K</td>
<td>1992</td>
<td>Virginia</td>
<td>Right of parent to decide medical care; but support parent in life saving if disagreement and that anencephalic infants should be fed.</td>
</tr>
<tr>
<td>Quinlan</td>
<td>1976</td>
<td>New Jersey Supreme Court</td>
<td>Refusal of medical treatment allowable in PVS.</td>
</tr>
<tr>
<td>Cruzan</td>
<td>1988-1990</td>
<td>Maryland Supreme Court</td>
<td>State has right for “clear and convincing evidence” and that ANH is medical treatment.</td>
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<tr>
<td>Schiavo</td>
<td>2005</td>
<td>Florida Courts</td>
<td>Husband as legal guardian was allowed final decision to stop feeding despite protests from parents.</td>
</tr>
<tr>
<td>Golubchuk</td>
<td>2010</td>
<td>Manitoba, Canada</td>
<td>Converse of Wanglie, says physician can stop treatment when family values life and individual was not PVS.</td>
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**Figure 1.** Key legal cases commenting on feeding individuals. ANH = artificial nutrition hydration, PVS = permanent vegetative state.
FROM THE ACADEMY

highlights key cases14-25; for a more thorough explanation see Perry and colleagues.13,26

The Cruzan case provides the current legal framework for care of the permanently unconscious individual.11 The argument was the right to individual selection of treatment vs health professional obligation to sustain life. The argument traveled through a series of courts. Finally, the five-to-four decision of the US Supreme Court in 1990 affirmed the state’s right to determine its level “for clear and convincing evidence” (p 4) in when or where a guardian wishes to discontinue nutrition and hydration of a person in a permanently unconscious state.11 The US Supreme Court’s opinion states that to protect individual liberty “it is assumed that a competent person would have a constitutionally protected right to refuse lifesaving hydration and nutrition.”11 The Cruzan decision also defined artificial nutrition and hydration as medical treatment.

In 1990, Terri Schiavo had cardiac arrest. After 8 years of being permanently unconscious, there were a number of court hearings with feeding stopped and started because of an argument between her husband and her parents on the wishes of Schiavo and whether she was in a permanently unconscious state. In 2005, the Florida Court of Appeals upheld the US District Court for the Middle District of Florida that the husband, as legal guardian, could stop artificial nutrition and hydration.24

ORGANIZATIONAL AND REGULATORY POLICY VIEWS

Guidelines on the ethical considerations to forgo or discontinue hydration and nutrition support have been written by numerous organizations, including the American Medical Association,27 the American Nurses Association,28 the American College of Physicians,29 the American Academy of Neurology,30 American Academy of Pediatrics,31 and American Society of Parenteral and Enteral Nutrition,32 in addition to the Academy of Nutrition and Dietetics. State laws and regulations and institutional policies must also be considered.

The Patient Self-Determination Act, effective December 1991, requires all Medicare/Medicaid providers to inform individuals of their right to prepare advance directives and to refuse treatment. It is based on an 1891 principle that “no right is held more sacred . . . than the right of every individual to the possession and control of his person . . . unless by clear and unquestionable authority of the law.”33 The crucial responsibility is to ensure that the individual, not the family or institutions, makes the decision about medical treatments. However, within certain cultures, autonomy is exercised by a family rather than the individual (refer to the ethical and legal issues of feeding and hydration practice paper1). In addition, the individual’s right to self-determination as guaranteed by the informed consent doctrine is not absolute. The state, or other institutions, may exert powers to limit the right of liberty on the basis of several concepts, such as prevention of suicide, protection of innocent third parties, especially children, and protection of the ethical integrity of the health care professional.34

LIFE SPAN AND DIAGNOSTIC ISSUES

Stage within life span and physical condition of the individual impact the ethical deliberative process. Figure 1 summarizes some of the key legal cases. The Academy’s practice paper1 illustrates the issues in children and elderly, terminally ill, and persistently or permanently unconscious persons. A few highlights follow.

The Committee on Bioethics of the American Academy of Pediatrics states that limiting or stopping life support seems most appropriate when support only prolongs biological survival. Artificial nutrition and hydration are included in the definition of life-sustaining medical treatment.31 Providers should solicit the assent (not consent) of their minor patients who are capable of decision making31 with adolescent patients treated like young adults. While court rulings on feeding the persistently unconscious minor are unknown, ethically they should be treated in the same manner as an adult.

Many authors have addressed the issue of tube feeding with individuals suffering from advanced dementia.1 The evidence does not support the use of enteral feeding tubes to prolong survival, improve function, prevent aspiration pneumonia, reduce risk of pressure ulcers, reduce risk of infection, or provide palliation. Every effort should be made to remove dietary restrictions and let the individual’s preferences guide the type and amount of food provided.32,35 In fact, advanced dementia is being recognized as a terminal illness.36 A study of 323 nursing home residents found that 86% of near end-of-life patients had eating disorders; they suggest the eating problems are an end-of-life predictor.36 If possible, the use of hand feeding should be encouraged, as it is one of the few pleasures available to individuals with dementia.36

The Multi-Society Task Force on Persistent Vegetative State defined persistent as at least 4 weeks and permanent as 3 months after hypoxic-ischemia and metabolic causes and 12 months after traumatic brain injury.37 In 2002, a condition called a “minimally conscious state” was defined and a diagnostic criteria set. The definition includes a disorder of consciousness with at least one piece of behavioral evidence.38 Individuals who make headlines after awakening years later are often in a minimally conscious state. Neuroimaging and the Coma Recovery Scale are improving the diagnosis. Early nutrition treatment and reasonable rehabilitation are recommended.39

Loss of appetite is common with terminally ill individuals and it does not reduce quality of life except for reducing the enjoyment of food. Withholding or minimizing hydration can have the desirable effect of reducing disturbing oral and bronchial secretions, and reduced cough from diminished pulmonary congestion. Withholding nutrition has been studied closely and the majority of reports indicate that physiological adaptation allows individuals not to suffer from the absence of food.40,41

SUMMARY GUIDELINES FOR FEEDING

The nutritional concept of “when in doubt, feed” is applicable to most individuals. Feeding should start immediately upon being medically stable and continue until the treatment is futile. During feeding, the goals are to provide adequate nutrients to maintain or achieve a reasonable weight and muscle mass, and achieve hydration when possible. Feeding may be discontinued
if authorized by the individual or surrogate, if it is clinically contraindicated, or after the individual is diagnosed as permanently unconscious, with evidence of the individual’s wish to stop feeding. In cases where the evidence strongly suggests that feeding or hydration does not provide benefit, it is the responsibility of the interprofessional health care team to explain this to the individual or authorized surrogate, but it is the individual or authorized surrogate that decides.

RESPONSIBILITIES OF THE REGISTERED DIETITIAN

Registered dietitians should have an active role in collaborative ethical deliberation informally or as a part of a formal committee (see Figure 2). When dilemmas in treatment arise, it is the responsibility of each health care professional to have sufficient experience with clinical ethics to facilitate deliberation. The constructive input from RDs is twofold. First, RDs are responsible for having sound technical judgment on a feeding strategy that will achieve the desired goals. That expertise should be shared with the interprofessional and dietetics team, such as the dietetic technician, registered.

The second responsibility can be summarized as “knowing what is wanted” by the individual. RDs are in a position to contribute the most accurate interpretation of nutritional judgments based on knowledge of what clients and family generally want regarding feeding and nutrient needs. RDs should assume the responsibility of keeping the individual’s understanding of the options and outcomes at the center of the feeding deliberations and that all appropriate options are considered. The elements of collaborative ethical deliberation, knowledge, skills, and attitudes are further described in the practice paper.

SUMMARY

The health care team, including RDs, must set treatment goals that are client-centered, respecting their unique values and personal decisions. The individual’s desire is the primary guide for treatment. In compliance with the law, shared decision making within the family should occur when the individual’s preference is not available. The team needs to discuss with the family the issues of ethics, values, religious guidelines, and any referral options. If the choice is feeding, the RD recommends the composition and delivery method of the feeding to meet the individual’s nutritional needs. Sensitivity to the family’s needs and questions are imperative.

Within institutions, the ethics committee should assist in implementing defined written guidelines for feeding and hydration. RDs’ expertise is essential in policy development and implementation (see practice paper1). RDs should provide education about nutrition and hydration issues to individuals, families, and health care providers; serve as an advocate for client and family; and participate in the legal and ethical discussions and decisions regarding feeding.
References


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