Position of the American Dietetic Association: Ethical and Legal Issues in Nutrition, Hydration, and Feeding

ABSTRACT
It is the position of the American Dietetic Association that individuals have the right to request or refuse nutrition and hydration as medical treatment. Registered dietitians (RDs) should work collaboratively 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 lifespan. When patients choose to forgo any type of nutrition and hydration (natural or artificial) or when patients lack decision-making capacity and others must decide whether or not to provide artificial nutrition and hydration, the RD has an active and responsible professional role in the ethical deliberation around that decision. Across the lifespan, there are multiple instances when providing, withdrawing, or withholding nutrition and hydration creates ethical dilemmas. There is strong clinical, ethical, and legal support both for and against administration of food and water when issues arise regarding what is or is not wanted by the patient and what is or is not warranted by empirical clinical evidence. When a conflict arises, the decision to administer or withhold nutrition and hydration requires ethical deliberation. The RD’s understanding of nutrition and hydration within the context of nutritional requirements and cultural, social, psychological, and spiritual needs provides an essential basis for ethical deliberation on issues of nutrition and hydration. The RD, as a member of the health care team, has a responsibility to promote use of advanced directives and to identify the nutritional and hydration needs of each individual patient. The RD promotes the rights of the individual patient and helps the health care team implement appropriate therapy.


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

FRAMEWORK FOR INDIVIDUAL FEEDING RECOMMENDATIONS
Ethical Overview
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 within society. Technological and medical advances have created a conflict between the application of these moral principles and certain kinds of medical treatment. While the principle of autonomy is a strong cornerstone of American bioethics, this fundamental ethical principle is not absolute. Other ethical principles must be balanced along with autonomy.

Three major diverse ethical theories affect attitudes toward health care delivery and services: the utilitarian or consequentialist view; the formalist or deontological view; and the virtues view. The utilitarian viewpoint, as expressed by Mills, sees an ethical decision as that which produces the greatest positive balance of value over negative balance of value for all people 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 the central theme of the virtue ethics perspective is the character of the person.

This paper on nutrition and hydration affirms the patient’s right to self-determination as the overriding principle. American society highly values the right of individuals to govern themselves. The individual’s right to self-determination generally takes precedence over the beliefs of health care providers. Each patient approaches death with different cultural, religious, philosophical, and personal attitudes and values. For some people, every moment of life, no matter how painful and limited in quality, is of inestimable value. On the other hand, because of circumstances and their values, competent, informed patients may seek to forgo various medical procedures that may include nutrition support. Some patients may wish to forgo or withdraw aggressive medical care, such as use of antibiotics or ventilators, but may wish to continue nutrition or fluid hydration support.

The Hippocratic writings encourage physicians to recognize when medicine has reached its limit of usefulness. Plato emphasized the “inappropriateness of persisting with treatment which leaves the surviving patient with a useless life.” When there is disagreement over futility of care the question of benefit enters the discussion. Whether nutrition and hydration are morally obligatory or morally optional is a question. A common method of distinguishing between what is obligatory and what is optional is to consider the consequences, both positive and negative. Nutrition and hydration can be effective in that they maintain life, but by
themselves they cannot restore consciousness or prevent imminent death. Hence, in some circumstances, nutrition may be considered futile as a medical treatment as “the ultimate goal of any medical intervention should be improvement of the patient’s prognosis, comfort, well-being or general state of health” (6). On the other hand, one may be reluctant to withdraw feeding believing it to be morally obligatory and considering withdrawal of nutrition and hydration to be intentional killing (7).

Arguments that feeding is a benefit because of the sanctity of life are balanced with arguments about the dignity of death. If care providers decide that there is an obligation to feed the persistently unconscious patient, they may change the moral obligation to a moral option after the passing of time suggests that the patient’s state will be permanent.

While there is general agreement that patients 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 in the early stages and incomplete.

Another issue in the treatment of patients is the “need to ensure a just and fair allocation of scarce resources” (6). The question of whether cost should be a factor in clinical ethical decision making may intensify as resources become scarcer. The central question remains what the patient prefers, but allows for what providers consider worthwhile. This can be formulated into the key ethical discussion of what is wanted and what is warranted. What is wanted by the patient or family and warranted by evidence-based medicine. It may be that what is wanted is not warranted or what is not wanted is warranted. How to clarify and then resolve this conflict is the essence of the ethical deliberative process (see Figure 1).

The issue of justice and patient feeding may intensify, especially for the permanently unconscious. Legislative or social changes may be the solution (8). For instance, if the definition of death were changed to be the death of higher brain functions, the permanently unconscious patient might be considered dead. However, the lack of diagnostic certainty complicates this approach. In dealing with the rationing of health care debate, it could be required as a principle of justice that people who want to live in a permanently unconscious state purchase such insurance or pay for the care and feeding with the presumption that the permanently unconscious patient would not want to be alive in that state (8).

The distinction between physician assistance in dying and withdrawal or withholding of artificial nutrition and hydration is widely recognized. Withdrawing or withholding nutrition and hydration centers on the physician’s obligation to withhold or withdraw medically inappropriate treatment and/or to honor a patient’s refusal of life-sustaining treatment. Such a refusal requires the physician to carry out an action or omission. These acts and omissions are morally right because it is the patient’s right of refusal and the overriding value. Such acts and omissions are not defined as “physician aid in dying” because the physician has not provided the necessary medical means for the patient to commit suicide, nor is it the intent to hasten death. A position paper by the American College of Physicians recommends honoring “voluntary refusal of hydration and nutrition” in the case of terminal illness if the patient is competent to make his/her own decision (9). Health care providers must uphold the patient’s wishes whether they agree or disagree, or transfer the patient to another health care provider (8,10).

Legal Decisions
The past 30 years have provided landmark judicial decisions addressing the issue of withdrawing life-sustaining medical procedures, culminating with the United States Supreme Court decision in the Cruzan case. The following two cases explore some of the ethical, medical, and legal issues. Figure 2 highlights other key cases.

### Figure 1. Suggested ethical deliberative process in determining patient care dilemmas.

1. Clarify the moral question—the first statement of the moral problem
2. Recreate the context
   a. Gather data
   b. Relevant facts
   c. Relevant values
3. Name stakeholders and their relationships
4. Identify ways of ethical thinking used by the stakeholders
   a. Rules thinking—Ethics is about doing what is right by following the rules
   b. Roles thinking—Ethics is about being true to yourself and following your sense of virtue
   c. Goals thinking—Ethics is about producing good outcomes regardless of the rules and virtues
5. Practical limits to the situation: Policies, laws, standards, and codes
6. Center on balancing the patient’s known beliefs and preferences with the best interests of the patient
7. Respect advance directives
8. Assume the patient has decisional capacity
9. If decisional capacity is in question determine decisional incapacity and select substitute decision maker if necessary
10. Restate the ethical problem
11. Search for possible options
12. Test the various options
   a. Check through each option for:
      (1) Rules—Is it right?
      (2) Roles—Can I feel good about this?
      (3) Goals—What will it do?
   b. Keep asking: What is the fitting response?
13. Justify the option selected for recommendation
   a. Keep the patient’s best interest at the center of options
   b. Always provide a description of what will likely happen if this decision is made
   c. Goals thinking—Ethics is about producing good outcomes regardless of the rules and virtues
Figure 2. Other key legal cases on feeding patients. aANH = artificial nutrition hydration. bPVS = persistent vegetative state.

**Cruzan Case.** The Nancy Cruzan case provides the current legal framework for care of the permanently unconscious patient (15). Nancy Cruzan was involved in an auto accident at the age of 26. After Nancy had been in a persistent vegetative state (PVS) for 5 years, the Cruzan family requested removal of her feeding tube. The hospital employees refused to honor the request without a court order. The Missouri trial court found that Nancy had a fundamental right to “refuse or direct the withdrawal of death prolonging procedures” (16). The Supreme Court of Missouri reversed the decision because it was skeptical that the right to refuse treatment was applicable in this case and decided that the state’s policy to preserve life should govern because there was insufficient evidence to support the parents’ claim of Nancy’s wishes. The US Supreme Court agreed to “consider the question of whether Cruzan has a right under the United States Constitution which would require the hospital to withdraw life-sustaining treatment from her under these circumstances” (17). 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” in “proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state” (13). The definition of “clear and convincing evidence” is set by each state and could require oral substituted judgment or written evidence.

The Cruzan court defined artificial nutrition and hydration as medical treatment. In the majority opinion, the US Supreme Court states that the “principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions” and later states, “we assume that the United States Constitution would grant a competent person a Constitution-protected right to refuse lifesaving hydration and nutrition” (18). The various opinions also mentioned that the decision to prolong life or allow a natural death is a deeply personal issue.

The concurring opinion by Justice Sandra Day O’Connor states that the Cruzan decision “does not preclude a future determination that the Constitution requires the States to implement the decisions of a patient’s duly appointed surrogate” (18). Justice John Paul Stevens’ dissent states that “the best interests of the individual, especially when buttressed by the interests of all related third parties must prevail over any general state policy that simply ignores those interested. . . . To deny the importance of these consequences is in effect to deny that Nancy Cruzan has interests at all and thereby to deny her personhood in the name of preserving the sanctity of her life” (18).

Six months after the US Supreme Court decision, three new witnesses testified of Nancy’s desire not to continue with life-sustaining medical treatment. The Missouri court case was subsequently dismissed and the court granted permission for the feeding tube to be removed. The decision of the Court emphasizes the need for patients to have written advance directives and the use of health care proxies that would have made the court case unnecessary.

**Schiavo Case.** In 2005, the Terri Schiavo case captured the media of this country. In 1990, 26-year-old Terri Schiavo suffered severe hypoxia and lapsed into unconsciousness. Four months later her husband was appointed her legal guardian. Terri received extensive rehabilitation. Over time, her husband understood the permanence of the state but her parents disagreed. He asked the Florida court to assess the situation and decide on continuing or discontinuing her feeding tube. In 2000, the judge determined that the Florida standard of verbal clear and convincing evidence was satisfied and that Terri met the definition of permanently unconscious. Removal of the feeding tube was ordered by the court, but her parents appealed (19).

The decision went to the appellate court, which reaffirmed the original decision and tube feeding was halted in 2001. Feedings resumed 2 days later after Terri’s parents presented physician testimony to a different judge. Artificial nutrition and hydration was again stopped in 2003. Six days later, the Florida governor and Florida legislature passed “Terri’s Law,” which resumed “medical” nutrition treatment. In 2004, the Florida Supreme Court issued a decision that Terri’s Law was unconstitutional as a “violation of separations of powers” and a third date to stop the tube feeding was established. Despite the US Congress and President Bush trying to intervene, tube feeding was removed and Terri died on March 31,

The Schiavo case mirrored the 1990 Cruzan case, but with disagreement among the family. The family fought questions about the medical condition of Terri by those not aware of the physical responses of PVS patients, the medical interest, and the legislative intervention had the case back in court over a 5-year period. The argument of autonomy and liberty for the PVS patient prevailed as in the Nancy Beth Cruzan and the Karen Ann Quinlan cases (18,20).

Organizational and Regulatory Policy Changes

Guidelines on the ethical considerations to forgo or discontinue hydration and nutrition support have been written by numerous organizations, including the American Medical Society (21), the American Nurses Association (22), the American College of Physicians (9), the American Academy of Family Physicians Center (23), and the American Academy of Neurology (24), in addition to the American Dietetic Association.

The Patient Self-Determination Act, that took effect on December 1, 1991, requires all Medicare/Medicaid health care providers to inform patients of their right to prepare advance directives and to refuse treatment. It is based on a principle formulated 100 years earlier, in 1891, that “no right is held more sacred, or more carefully guarded by the common law, than the right of every individual to the possession and control of his person, free from all restraint or interference of others, unless by clear and unquestionable authority of the law” (25). The crucial ethical responsibility is to ensure that the patient, not the family or institutions, makes decisions about medical treatments, including nutrition and hydration. In 1986, an amyotrophic lateral sclerosis patient informed the hospital that when she lost her ability to swallow she did not want a feeding tube. The hospital disagreed and suggested she transfer. The court denied the hospital’s request, as it would subject the patient to emotional and psychological harm. The patient was allowed to refuse the tube feeding (26). However, the patient’s ethical and legal 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 personal liberty on the basis of several concepts: preservation of life, prevention of suicide, protection of innocent third parties, especially children, and protection of the ethical integrity of the health professional (27).

Meisel provides a comprehensive analysis of why forgoing nutrition and hydration in a nursing home, even with advance directives, is uncommon. Federal and state regulations that support patients are often assumed to require adequate nutrients, which can be in conflict with the patient’s right to forgo feeding. Based on the history of court rulings, the right to self-determine feeding takes precedence (28).

Citizen/Patient Attitudes

Establishing preferences for treatment or nontreatment of the legally “incompetent” patient is a difficult process. Surturing what the patient would have wanted can be done through a living will or durable power of attorney for health care or through family discussions. The legal weight of family decisions depends on the laws within each state.

Food and drink have both psychological and physical functions that often play special and central roles in patient care. Food has strong emotional and symbolic overtones that include maternal nurturing and religious, cultural, and social values. With certain cultures, autonomy is exercised by a family rather than the individual. Religious traditions may value life in any state and advocating sustaining life as a moral obligation. An argument is that if there is no benefit, the procedure cannot be obligatory. Hence the decision to omit nonobligatory care is to avoid burden for the patient.

One of the lessons learned from the Schiavo case is that public opinion is mixed on the issue of feeding. The suggested changes in state legislation after the Schiavo case suggest that attitudes toward acceptable practice and what is “personhood” are being questioned. The cornerstone of autonomy and a renewed emphasis on advanced directives is needed (24,29).

Figure 3 outlines the opinions of various religions. Much variation of opinion occurs within any given religion, as well as individuals practicing that religion. Patients should be asked about their beliefs, particularly on withdrawing nutrition and hydration.

<table>
<thead>
<tr>
<th>Culture/religion</th>
<th>Position</th>
<th>Reference</th>
</tr>
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<tbody>
<tr>
<td>Protestant</td>
<td>Life does not need to be prolonged when “it would be better for the patient to be allowed to die.” However, if patient believes being persistently unconscious is a God-mandated fate, patient may benefit by prolonged life.</td>
<td>8,30</td>
</tr>
<tr>
<td>Catholic</td>
<td>Not obliged to use extraordinary or disproportionate care when there is no hope. Moral obligation vs moral option and that the decision is individual, but presumes in favor of feeding. Vatican in 2007 said required in persistent vegetative state.</td>
<td>7,31</td>
</tr>
<tr>
<td>Orthodox Judaism</td>
<td>Belief that the soul is present in the comatose patient suggests need to maintain life.</td>
<td>32</td>
</tr>
<tr>
<td>Conservative Judaism</td>
<td>Rejects treatments that prolong suffering, but obligation to continue once treatments start.</td>
<td>33,34</td>
</tr>
<tr>
<td>Hindu</td>
<td>Prolonging life is not necessary.</td>
<td>35</td>
</tr>
<tr>
<td>Islamic</td>
<td>Life is sacred and should be prolonged.</td>
<td>35</td>
</tr>
</tbody>
</table>

Figure 3. Predominant position on withholding or withdrawing feeding in major religions.
Lifespan and Diagnostic Issues

Children. The goal of care decisions for children is to act in their best interests. The decision in the 1984 Baby Doe case was aimed at preventing child abuse. That case suggested that continuous aggressive treatment was essential. Some physicians are reluctant to discontinue nutrition because of this decision (36). However, since that time, the US Supreme Court has said that in most situations the parents have the decision-making prerogative (37). The courts in seven of eight cases affirmed the authority of the parents in care decisions (37). The guideline is to consider feeding the standard of care unless otherwise indicated by the parents.

Baby K was born in 1992 with anencephaly and placed on a respirator several times for life support. The Virginia district court judge ruled that the use of the ventilator was not futile and that it was the right of the parents to decide medical care for their children. It also ruled that when there is parental disagreement, the court should support the parent who is supporting maintenance of life. The court did not clearly deal with the issue of futility. In regard to nutrition, the circuit and appeals court agreed that anencephalic infants should be provided nutrition and hydration (38).

The Committee on Bioethics of the American Academy of Pediatrics has published guidelines and states that “limiting or stopping life support seems most appropriate, especially if treatment only preserves biological existence” and included “nutrition and hydration provided intravenously or by tube” in its definition of life-sustaining medical treatment (39). The American Academy of Pediatrics has issued a more recent position paper on palliative care for infants and children with terminal or life-threatening conditions, which states that respect for the opinion of the family is paramount (40).

Often, physicians and parents are reluctant to discontinue medically provided nutrition, yet are willing to forgo other forms of life-sustaining treatment. Three conditions are commonly recognized as justification for removal of nutrition and hydration: neurological devastation, proximate death from any pathology, and irreversible total intestinal failure (36). The aim is quality of life without rigid distinctions between curative and palliative care. The intent is not to hasten death, but to emphasize quality of life.

Children are incapable of independent decision making and usually have not expressed any wishes that their parents and health care providers can use when deciding about their medical treatment. Allowing parents to choose on a child’s behalf is more respectful of him or her as an individual than acting as if he or she has no interests.

The rights of minors to participate in medical decisions about their care have been the subject of intense deliberation at the American Academy of Pediatrics. The position of the Academy is that health care providers are ethically obligated to solicit the assent (not consent) of their minor patients who are capable of participating in treatment decision making but have not yet fully developed decisional capacity (40). Adolescent patients should be treated like young adults in their use of life-sustaining medical treatment. Court rulings on feeding the persistently unconscious minor are not known. There is no ethical reason not to treat the persistently unconscious child in the same manner as an adult.

Adults. A New York State Supreme Court justice ruled in February 1984 that an 85-year-old retired college president, who was alert but depressed, had the right to refuse to eat and to refuse surgery that would allow him to be fed artificially (41). A study of the decision-making process in a free-living elderly community for the insertion of the percutaneous endoscopic gastrostomy tube showed the physician was the predominant individual recommending percutaneous endoscopic gastrostomy tubes, not the patient or family. The major physician reasons for starting percutaneous endoscopic gastrostomy feeding were the eventual necessity of the feeding and the limited risk of the procedure (42).

In a Boston/Ottawa study, the reason for tube feeding in an elderly population was prolonging life (43). The study found that substitute decision makers generally (85%) did not know whether the patient had an advance directive, and only 48% were confident that the patient would want tube feeding. The study found that more patients with severe dementia received tube feedings in the United States and that the belief that it was a moral obligation to tube feed was higher in the United States (78% vs 52%). This study found a “lack of adequate advance directives, poor implementation of the principle of substituted judgment, and inadequate transfer of evidence-based knowledge between the health care team and the substitute decision maker” (43).

Advanced Dementia. Several authors have addressed the issue of tube feeding with patients suffering from advanced dementia who often have difficulty eating and show weight loss (44-48). For these patients, a review of the literature does not support 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. Patients with advanced dementia should be kept safe and comfortable in the least restrictive environment. Every effort should be made to remove dietary restrictions and let the patient’s preferences guide the type and amount of food provided. Use of hand feeding should be encouraged, as it is one of the pleasures available to patients with dementia (46). It is ethical to forgo tube feeding when all concerned understand what can and cannot be achieved with tube feeding. The decision to place a tube for feeding can be justified by specific and limited goals. If those goals are not being met, withdrawal of the tube can be justified (7).

A decision-making algorithm can be useful during the deliberation about feeding tube placement, but should not be used as a rigid prescription of approved decisions (49).

Persistent Vegetative State. Public values and standards of care for persistently unconscious patients will evolve (8). The Multi-Society Task Force on Persistent Vegetative State defines the persistent vegetative state as “a vegetative state present for at least one month after acute traumatic or nontraumatic brain injury or lasting for at least one month in patients with degenerative or metabolic disorders or developmental malformations” (50). The transition between a
The diagnosis of PVS and prognosis of a PVS is 12 months and 3 months, respectively (50).

In 2002, a condition called a “minimally conscious state” was defined and a diagnostic criteria set. The definition includes having “severely altered unconsciousness” with “minimal but definite behavioral evidence or environmental awareness” (51). The patients who make headlines after awakening years later are often in this state, but the distinction between vegetative state and minimally conscious state is not distinguished in
the media. In 2006, the Institute of Medicine convened a meeting and recommended criteria for differentiating the two and developing prognostic markers. It is estimated that the current error rate between these two sets of patients may be as high as 40% (51).

**Terminally Ill Patients.** Loss of appetite is common with terminally ill patients and does not reduce quality of life except for reducing the enjoyment of food. In a prospective study of 31 terminally ill cancer patients and one stroke patient in a comfort care unit, researchers tried to determine whether giving food and fluids only to the level requested by the patient affected the quality of their life. Diet restrictions were basically eliminated; patients were offered whatever they wanted for food. Patients were asked several times a day about hunger, thirst, and dry mouth. Two thirds of patients never experienced hunger, while the others had hunger initially and then lost their appetite (52). Thirst and dry mouth were more common with 21 patients initially and persisted until death in 12 patients. Fluids and comfort care, such as ice chips, lubricating the lips, and small amounts of food and water, reduced the thirst sensations from dehydration (52). Dehydration eventually results in hemoconcentration and hyperosmolality with subsequent azotemia, hypernatremia, and hypercalcemia. These metabolic changes are said to produce a sedative effect on the brain just before death. Withholding or minimizing hydration can have the desirable effect of reducing disturbing oral and bronchial secretions, need for frequent urination, and reduced cough from diminished pulmonary congestion. Withholding nutrition has been studied closely and the majority of reports indicate that physiological adaptation allows patients not to suffer from absence of food (52-55).

Each patient is unique, and the plan of care should be constantly reassessed for each individual. For the patient able to accept, and perhaps enjoy, oral intake, previous dietary restrictions should be minimized or eliminated, depending on the physical consequences. Registered dietitians (RDs) should work with the team to coordinate administration of pain medication to maximize enjoyment of food. Amelioration of symptoms such as nausea, vomiting, insomnia, and anxiety is an important objective. The actual or illusory source of strength, nurturing, comfort, and caring provided by food should be encouraged as well as family interaction and socialization.

**Summary Guidelines for Feeding**

The nutritional concept of “when in doubt, feed” is applicable to most patients. Feeding should start immediately upon being medically stable and continue until the treatment is futile. During feeding, it is essential to try to provide adequate nutrients and fluids to maintain or achieve a reasonable weight, maintain muscle mass, and achieve hydration. Feeding can be discontinued if is authorized by the patient or authorized surrogate, if the feeding is clinically contraindicated, or after the patient is diagnosed as permanently unconscious and the team has evidence of the patient’s wish to stop nutrition and hydration. In cases where the evidence in the case strongly suggests that feeding or hydration does not provide benefit, it is the responsibility of the team to explain this to the patient or authorized surrogate, but it is the patient or authorized surrogate that decides (7).

**GUIDELINES FOR COLLABORATIVE ETHICAL DELIBERATION**

**Roles and Responsibilities of the RD**

The RD has an active and responsible professional role in collaborative ethical deliberation informally or as a part of a formal committee (see Figure 1). When conflicts and dilemmas in treatment decisions arise, there is a need for ethical deliberation. It is the responsibility of each health care professional to have sufficient experience with clinical ethics to participate in or to facilitate deliberation. Figure 4 suggests a deliberative process regarding nutrition and hydration.

Constructive and substantial input from the RD is twofold. First, the RD is responsible for having sound technical judgment on a feeding strategy that will achieve the desired goals. The RD provides trustworthy information about the adequacy and acceptability of a variety of feeding methods. This responsibility can be summarized as “knowing how to achieve what is wanted.” If what is wanted is also warranted then it is generally appropriate.

The technical expertise of RDs can be shared with other members of the interdisciplinary team who also address nutrition and hydration issues with patients. The RD has a responsibility to provide education that can help others on the health care team to be more effective in dealing with difficult and delicate issues of nutrition and hydration. Where there is a formal ethics committee, including an RD as a member is highly valuable.

The second responsibility can be summarized as “knowing what is wanted” by the patient. RDs often have specific knowledge regarding the individual patient’s preference because they discuss feeding issues with the patient and family. Furthermore, RDs are in a position to contribute the most accurate and complete interpretation of nutritional value judgments based on knowledge of what patients generally prefer and how they tend to express preferences around feeding issues.

RDs should assume the responsibility of keeping the individual patient’s understanding of the options and outcomes at the center of the deliberation about feeding. RDs are in a position to ensure that adequate information has been shared with the patient and family so that they may make an informed judgment.

It is the responsibility of the RD to be certain that feeding issues are deliberated in such a way that all appropriate options are considered, rather than assuming that any strategy of feeding or not feeding is obligatory. This may require opening up the subject even after the principal decision makers have reached their conclusion. The situation may appear to make a feeding tube the only option, when, in fact, careful hand feeding may be as good, or better, an option for adequate nutrition.

It is the RD’s professional duty to understand and explain the position of the American Dietetic Association. The RD may have adopted a personal professional position that is in conflict with the American Dietetic Association position, which can create moral tension. The moral tension can be re-
General Ethical Assumptions

There are many ethical assumptions that form the basis of deliberation. Within clinical ethics, respect for the autonomy of the patient is of the utmost importance. Four assumptions provide strongly authorized guidance:

- Patient preferences guide the decision-making process.
- When the patient’s preference is not known a substitute decision maker is guided by the best interests of the patient.
- Informed and shared decision making is the best ethical practice.
- All stakeholders are encouraged to collaborate in the decision-making process.

Skills.

- Situation analysis—Evaluation of multiple sides of an issue and relevant factors that influence a situation is essential for ethical decision making. The word *discernment* is often used for the process of deciding what factors are important and how each factor will be interpreted.
- Critical thinking—This can refer to the entire process of making a decision or the evaluation of a specific argument. Many reasons for deciding one way or another are brought into a discussion, but some reasons are more reliable and important than others. The RD should use the best reasons for reaching a judgment in each case.
- Facilitation—The ability to keep a discussion focused on the goal of hearing all perspectives while searching for a decision that is acceptable to all parties can be developed by careful training and correction. When the discussion is not allowing all parties to be heard, or when the patient’s best interests are not the focus of concern, the RD can serve the ethical process by calling attention back to the goal.
- Negotiation—Conflicting positions usually can be changed if the parties are interested in reaching a mutually satisfactory middle ground rather than “winning.” The RD can serve the process and interests of the patient by carefully watching for signs of an acceptable consensus. Stating the possible consensus is often the action that brings the conflicted parties to a shared decision.
- Communication—The capacity to share one’s position and reasons for that position in clear, convincing, and concrete language is a skill for all health care professionals, as well as listening to the viewpoints of others.

Attitude.

- Empathy—The ability and willingness to experience the situation from the perspective of another person.
- Patience—This attitude requires taking whatever time is necessary to be certain that the patient understands the situation and has been able to grapple with whatever is most important from the perspective of the patient’s value system.
- Team approach—Ethics is a group effort and not the action of a single agent—all stakeholders are part of the team.
- Comfort with uncertainty—Clinical situations are often unpredictable. The ability to function within such ambiguity is necessary in order to allow a decision to be made without certainty about its correctness or its consequences.

Bioethical Principles.

- Autonomy—Respect for the autonomy of the individual is a very strong value in American culture. Adults with decisional capacity ought to be free to make their own choices. There is a limit to freedom, but that limit has to be defined with each situation and ought to strongly favor the individual.
- Nonmaleficence—This word means “do no harm.” This is a guide to action in clinical medicine. It is the warning to take care that whatever is done to help does not also hurt the patient. Basically, the balance of “help” and “hurt” must favor helping the patient.
- Beneficence—Doing good for patients is the goal of clinical decision making. Whateoever action is taken ought to be the right action to bring about the most good for the patient.
- Justice—Distributive justice is more difficult to apply in clinical medicine. Justice as “fairness” is the main formula used in clinical decision mak-
ing. The moral action is the fair action that treats each person as equal to all similar people in similar circumstances (1).

**Virtues of a Health Care Professional.** There are times when principles clash or do not resolve the moral conflict or dilemma. That is when the theory of moral virtues can be useful. This set of virtues was established by the American Board of Internal Medicine in 1984 as the definition of a virtuous clinician:

- **Integrity**—telling the truth, keeping promises, being able to do what one claims to be able to do.
- **Respect**—treating the other person as having worth and involving that person as a partner in the clinical encounter.
- **Compassion**—being able and willing to experience the suffering from the patient’s perspective and allowing that experience to guide the behavior of the health care provider (56).

**Goals of Health Care.** It is very difficult to state all the goals of health care. Multiple descriptions of health care have been attempted. The goals can be stated as a two-part summary:

- To maximize human flourishing is the goal of curative medicine that is focused on correcting the diagnosed disorder.
- To minimize physical, psychological or spiritual human suffering is the goal of palliative care.
- Balancing these two goals is the constant challenge of clinical intervention (57).

**Process for Collaborative Ethical Deliberation**

One can simplify ethics into two questions: “What is going on here?” and “What is the fitting response to what is going on here?” (58). The answer to the first question describes the situation and all the important stakeholders. It is the process of establishing the diagnosis. Discovering the nature of the conflict or dilemma is the main goal of the first question. To discover the problem, the context must be recreated. What are the medical facts, the decisions, the personal relationships, the strongly held beliefs, and the social forces that have influenced this situation? Many facts, values, relationships, and ways of ethical thinking are in dynamic interaction in even the most uncomplicated of life’s situations. Ethical deliberation must sort out the relevant features.

The most important idea in clinical ethics is to center on the patient. Constantly returning to the perspective of the patient and asking what is in the patient’s best interest is the most reliable guide to good ethical deliberation. If the patient has decisional capacity, then he or she ought to be involved in the deliberation. If it is determined that the patient lacks decisional capacity, selection of a substitute decision maker is necessary. If the patient has clarified preferences in an advance directive this document should be respectfully followed (36).

The ethical deliberative process identifies and clarifies the moral conflicts or dilemmas as preparation for considering possible options for action. This moves the process to answering the second question of ethics: “What is the fitting response?” This part of the process requires imagination and openness to accommodating conflicting values, while continuing to center on the patient’s wants and best interests.

Testing the fittingness of various options considers such questions as: “Is it right?” “Can I feel good about this?” and “What good will it do?” Justifying a particular option is the goal of ethical deliberation. Because the decision results in action and action results in consequences, special care must be taken in ethical deliberation.

**SUMMARY**

The health care team members, including the RD, must set treatment goals that are patient-centered and handled individually, respecting the unique values and personal decision of the patient. The patient’s expressed desire is the primary guide for determining the extent of nutrition and hydration received. Within the extent of the law, shared decision making within the family should occur when the patient’s preference is not stated. The health care team will need to discuss with the family the issues of ethics, values, religious guidelines, and referral for spiritual advice as needed. If the patient’s choice is feeding, the RD recommends the composition of the feeding that will meet nutritional health needs. If the patient’s choice is cessation of feeding, the RD should explain what is known about the duration of time between cessation and death. Sensitivity to the family’s needs and questions are imperative in both situations.

Within institutions, the ethics committee should assist in establishing and implementing defined written guidelines for feeding and hydration. The RD’s expertise is a valuable asset in development of institutional policy through active participation as a member or consultant to the ethics committee. The RD should provide education about nutrition and hydration to patients, families, and health care providers; serve as an advocate for patient and family; and participate in the legal and ethical issues regarding feeding.

**References**

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