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Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

Clinical Report—Forgoing Medically Provided Nutrition and Hydration in Children

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KEY WORDS
ethics, fluids, nutrition, withholding life-sustaining treatment, children, hydration, end-of-life decision-making

ABBREVIATIONS
AAP—American Academy of Pediatrics
CNS—central nervous system
CAPTA—Child Abuse Prevention and Treatment Act

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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abstract

There is broad consensus that withholding or withdrawing medical interventions is morally permissible when requested by competent patients or, in the case of patients without decision-making capacity, when the interventions no longer confer a benefit to the patient or when the burdens associated with the interventions outweigh the benefits received. The withdrawal or withholding of measures such as attempted resuscitation, ventilators, and critical care medications is common in the terminal care of adults and children. In the case of adults, a consensus has emerged in law and ethics that the medical administration of fluid and nutrition is not fundamentally different from other medical interventions such as use of ventilators; therefore, it can be forgone or withdrawn when a competent adult or legally authorized surrogate requests withdrawal or when the intervention no longer provides a net benefit to the patient. In pediatrics, forgoing or withdrawing medically administered fluids and nutrition has been more controversial because of the inability of children to make autonomous decisions and the emotional power of feeding as a basic element of the care of children. This statement reviews the medical, ethical, and legal issues relevant to the withholding or withdrawing of medically provided fluids and nutrition in children. The American Academy of Pediatrics concludes that the withdrawal of medically administered fluids and nutrition for pediatric patients is ethically acceptable in limited circumstances. Ethics consultation is strongly recommended when particularly difficult or controversial decisions are being considered. *Pediatrics* 2009;124:813–822

INTRODUCTION

Decisions to withhold or withdraw life-sustaining treatment from critically or terminally ill children are commonly made in US and Canadian hospitals.[1–4] Most children who die in American hospitals do so after critical care interventions are withheld or withdrawn.[5–8] The American Academy of Pediatrics (AAP) has stated that it supports allowing the withholding and withdrawing of a medical intervention when the projected burdens of the intervention outweigh the benefits to the child.[9] The AAP has also stated that treatment decisions regarding an infant should be based on the judgment that the infant will derive net benefit, concluding that medical treatment that is judged to be harmful, of no benefit, or "futile" is inappropriate and should not be offered or provided.[10] Although decisions about withholding or withdrawing treatments when death is at hand are difficult, a broad consensus has

emerged that decisions to withhold or withdraw medical interventions are ethically and legally acceptable in many circumstances, and these decisions fall within the authority of parents or guardians in consultation with the child's physician.[9] Nevertheless, the withholding or withdrawing of the medical provision of fluids and nutrition for children remains controversial, in large measure because of the strong emotional and social symbolism associated with feeding children. At the same time, there are situations in which medical provision of fluids and nutrition may fail to benefit a child or create a level of burden that cannot be justified by whatever benefit might accrue. In the treatment of adults, the President's Commission[11] and a number of professional organizations, including the American Medical Association,[12] the American Academy of Neurology,[13] the American Nurses Association,[14] the Hospice and Palliative Nurses Association,[15] and the American Academy of Hospice and Palliative Medicine,[16] support the authority of adult patients or their surrogate decision-makers to withhold or withdraw medically administered fluids and nutrition. The American College of Physicians has declared the medical administration of fluids and nutrition to be a medical intervention subject to the same principles of decision-making as all other medical interventions.[17] Appellate court decisions also consistently equate the decision-making process surrounding medically provided fluids and nutrition with other forms of medical treatment, supporting the authority of surrogates to forgo or withdraw medically provided fluids and nutrition when there is no longer net benefit to the patient.[18] The AAP statement on forgoing life-sustaining treatment mentions medically provided fluids and nutrition among interventions that can be withheld.[9] Nevertheless, pediatricians are often uncertain about the ethical and legal propriety of these decisions, the conditions under which such a decision would be appropriate, and how to communicate about this issue with families, colleagues, and staff. The purpose of this report is to review the medical, social, ethical, and legal issues involved in these decisions and to provide guidance to parents, guardians, and clinicians regarding the conditions under which medically provided fluids and nutrition can be withheld or withdrawn from infants, children, and adolescents who lack decision-making capacity.

USE OF TERMINOLOGY AND SCOPE OF REPORT

Medically provided fluids and nutrition are commonly used in pediatric practice for a wide variety of acute and chronic conditions. Fluids and nutrition provided through intravenous catheters and nasogastric, nasojejunal, and gastrostomy tubes have saved and maintained the lives of countless children. In this report, the provision of fluids and nutrition via medical devices is distinguished from the provision of food and drink to children who are capable of eating and drinking. The AAP considers it a fundamental principle that children who are hungry or thirsty, who are capable of oral intake, and for whom there are no medical contraindications to eating and drinking should be given food and fluids by mouth. The focus of this clinical report is children who depend on fluids and nutrition delivered through medical devices for their survival.

Given this focus, we will use the term "medically provided nutrition" rather than "food" and "withholding medically provided nutrition" rather than "starvation." The term "food" elicits images of eating, chewing, tasting, and swallowing along with the pleasures and social connotations that accompany those actions, failing to distinguish these from the technical process of delivering hydration and nutrition through medical devices. Receiving fluids and nutrition through a tube or intravenous catheter is not the same as eating a meal. Likewise, the term "starvation" fails to accurately characterize the experience of patients for whom medically provided fluids and nutrition are withheld, implying an element of suffering that is rarely present when medically provided nutrition is withdrawn.[19] When medically provided fluids and nutrition are withheld, death does not occur from starvation but as a result of dehydration and the patient's underlying condition. Reports on adult patients who have died after refusing nutrition and hydration have consistently shown that these patients do not appear to suffer but experience peaceful deaths.[20–23] In fact, before the development of medical means for providing nutrition or hydration, the cessation of eating and drinking frequently represented the means by which elderly individuals experienced a "natural" death from old age.[24]

ETHICAL DECISION-MAKING

The clear consensus that has emerged over the last few decades is that medical interventions can be withheld or withdrawn when refused by competent patients or by surrogate decision-makers on behalf of patients who lack decision-making capacity. Surrogate decision-makers are expected to base their decisions on what they believe the patient would have wanted or, in the absence of knowledge of the patient's wishes, a determination of the relative benefits and burdens.

The contemporary test in pediatrics for whether an intervention is ethically appropriate is the best-interest standard—a weighing of expected burdens and benefits of that intervention for a particular child. Although the

benefits, risks, and burdens to family, care providers, and society are relevant considerations in many cases, the primary focus should always be on the child's welfare. Other considerations may become determinative when the intervention offers minimal or no benefit to the child.

A number of commentators have argued that fluids and nutrition are different from other medical interventions, because they represent basic forms of care that can never be withheld or withdrawn, especially from children.[25–29] A mother's letdown reflex at the cry of her infant illustrates the deep and complex bond between parent and child and the importance of feeding offspring as an integral element of nurturing them. Food and water are essential to life, play an important role in social and cultural rituals, and are frequently used to reward, punish, or demonstrate love. For many people, having a well-fed child is a sign of a "good" parent, along with keeping their child warm, clean, and safe.[30,31]

Although the important symbolic meaning of feeding and eating is acknowledged, the provision of fluids and nutrition via medical technology is different in important ways from providing food or drink to a hungry or thirsty child.[23] Children who cannot eat and drink, cannot experience the pleasure of chewing and tasting, cannot enjoy the social aspects of sharing food and the social pleasures of mealtime, cannot detect hunger or thirst, or cannot experience nurturing through feeding have different needs that may or may not be met through the medical provision of fluids and nutrition. The medical provision of fluids and nutrition requires tubes, pumps, special formulas, monitoring for adverse effects and complications, and, frequently, surgical procedures.

Medically provided fluids and nutrition represent medical interventions. Similar to most other medical interventions, the medical provision of fluids and nutrition carries with it the potential for adverse effects and discomfort, including dyspnea, fluid overload, widespread edema with potential skin breakdown, systemic and local infection, fluid and electrolyte imbalance, thrombosis, pain, organ damage, and nutritional excesses and deficiencies. The rate of complications of enteral feeding can be as high as 76%.[32,33]

Similar to other medical interventions, medically provided fluids and nutrition may or may not be appropriate, depending on the goals of treatment.[34] Although the benefits of this technology commonly outweigh its risks when used temporarily as an aid to healing or to maintain a quality of life acceptable to patients and their families, the consideration of burdens and benefits remains the basis for determining the appropriateness of this and all other medical interventions. Therefore, medically provided fluids and nutrition can be withheld or withdrawn under the same 2 conditions that justify the withholding or withdrawing of other medical interventions:

- when a competent person has refused the intervention; or
- in the case of persons who have never possessed decision-making capacity or the absence of some indication of a previously competent patient's preferences, when a surrogate decision-maker, in consultation with the physician, has come to the conclusion that the expected burdens of the intervention to the patient exceed the potential benefit to the patient.

Any determination of relative burdens and benefits related to medically provided fluids and nutrition must occur within the context of other decisions about the appropriate level of medical support, provision of comfort care, and the goals of medical interventions given the patient's underlying condition. This report will not discuss the situation of the person with decision-making capacity who has chosen to forgo medically provided fluids and nutrition, because the response to that situation is clear, and it is infrequently encountered in pediatric practice. However, there are several situations in which medically provided fluids and nutrition might fail to provide a net benefit to the pediatric patient.

SITUATIONS IN WHICH THE BURDENS OF TREATMENT OUTWEIGH THE BENEFITS

The provision of medically provided fluids and nutrition is morally optional if it does not provide a net benefit to the child. This section will discuss several situations in which medically provided fluids and nutrition may not provide net benefit to a child. These situations are offered as examples and are not intended to encompass every possible scenario in which medically provided fluids and nutrition might fail to provide net benefit to a child. The argument that medically provided fluids and nutrition may be forgone in such children is not an argument that it should or must be forgone. In the absence of net benefit to the child, other considerations become relevant, and parents should be granted wide discretion in providing or withholding medically provided fluids and nutrition.

Some children may be unable to eat and drink permanently as the result of severe congenital or acquired central nervous system (CNS) injuries. For children with sufficient awareness to experience benefits from continued existence, long-term medically provided nutritional support might be potentially beneficial. However, for children who never possessed consciousness or fail to regain consciousness, questions may arise about whether long-

term medically provided nutrition and hydration ultimately benefit the child. Although medically provided fluids and nutrition may be beneficial while the diagnosis and prognosis remain uncertain and treatment is provided in hope of recovery, the decision to continue medically provided fluids and nutrition should be based on whether the child ultimately derives a net benefit from the continuation of treatment.[29]

Children who are rendered comatose from a severe CNS injury or disease may transition to a persistent vegetative state, "a clinical condition of complete unawareness of the self and environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brainstem autonomic functions," within several weeks.[35] A defining characteristic of individuals in a persistent vegetative state is the complete lack of awareness of themselves or their environment. Such patients are incapable of experiencing either pleasure or suffering and, thus, do not consciously experience any benefit from continued existence. Recent estimates suggest that there are between 14 000 and 35 000 adult and pediatric patients who are in a vegetative state.[36] Some individuals in a vegetative state may recover consciousness, although the probability decreases substantially over time, and most of the few patients who emerge from a vegetative state remain severely disabled.[37] The term "permanent vegetative state" describes patients who remain vegetative for 12 months after traumatic injury or 3 months after a nontraumatic injury, most commonly an anoxic-ischemic event.[38]

Because individuals in a persistent vegetative state are unaware of themselves and their environment, the provision of medically provided fluids and nutrition does not confer them benefit and may be withdrawn. Emerging social standards seem to support a decision to withhold or withdraw fluids and nutrition from a person in a persistent vegetative state. Population surveys suggest that most Americans would not want medically provided nutrition and hydration should they themselves be in a persistent vegetative state,[39–46] and most physicians knowledgeable in this domain support the option of withdrawing fluids and nutrition for those in a persistent vegetative state.[47] The application of a "reasonable-person" standard would suggest that a large majority of people would not want to be kept alive in a persistent vegetative state via any means, including medically provided fluids and nutrition, and that surrogate decision-makers should, therefore, be permitted to forgo such interventions on their behalf.[48–50] It would be a form of age discrimination to impose on children the burdens and quality of life rejected by the majority of adults merely because they had not achieved legally independent status before their catastrophic injury.

This rationale does not necessarily apply to children in a "minimally conscious state," a relatively new term for patients who have limited consciousness. In this condition, individuals have reproducible ability to respond to some limited environmental stimuli, sometimes exhibiting behaviors such as following a simple command, intelligible verbalization, appropriate smiling or crying, or reaching for an object. These patients have some intermittent awareness of themselves and their surroundings and presumably can experience pleasure and pain, although it may be impossible for observers to assess subjective experiences such as suffering.[51] It is difficult or impossible to understand the subjective experiences of individuals who exist in this condition, and it may be impossible to draw firm conclusions about long-term prognosis. Therefore, it is difficult to draw general conclusions about whether individuals in this state would or would not benefit from long-term technical support.[52] Because these individuals represent a group for whom it might be particularly difficult to assess level of awareness and determine prognosis, decisions regarding the withdrawal or withholding of medical interventions on their behalf should be made carefully, and caution must be exercised that judgments are not inappropriately influenced by prejudice regarding disability.

Infants with congenital CNS malformations or prenatal injury who never possessed the capacity to feed orally represent a third group of neurologically impaired children. Examples include infants with anencephaly, hydranencephaly, or profound perinatal asphyxia resulting in an inability to suck. Artificial fluids and nutrition may be essential to support many such infants until a diagnosis and prognosis are confirmed. If the diagnosis and prognosis indicate that the infant will never possess conscious awareness and the capacity to feed orally, some would argue that the risks and potential burdens of medically provided fluids and nutrition could easily outweigh what minimal benefit they would offer the child.[53]

In any of these groups of children with profound neurologic impairment, continued survival might be considered a benefit by the family members, and they may, therefore, choose to maintain their child's medically provided nutrition and hydration on that basis. Conversely, the mere physical existence of a child who will never recover consciousness or the ability to interact with his or her environment may produce great sorrow and suffering for some parents, siblings, and extended family without any perceived compensatory benefit. Therefore, medical provision of fluids and nutrition in these

circumstances cannot be said to benefit the child (who will never personally be capable of experiencing the benefit of existence) and may not promote the interests of the child's family. Therefore, it is not ethically mandatory to provide medically administered fluids and nutrition to a child in a permanent vegetative state or other condition that results in a permanent lack of conscious awareness. For individuals and parents who do not wish to forgo medically provided fluids and nutrition for ethical, religious, cultural, or medical reasons, a decision to maintain these support measures should be honored. Although a decision to forgo medically provided fluids and nutrition is ethically permissible in some circumstances, it would almost never be ethically required, and parents should be allowed wide discretion in making this decision.

Medically provided fluids and nutrition can also be withheld or withdrawn from children with other medical conditions when the burdens of such interventions are likely to exceed any potential benefits. In the final stages of the dying process, many individuals will lose their ability to take fluids or nutrition by mouth because of compromised mentation, sedation, and/or weakness. If a child is capable of experiencing thirst or hunger, fluids and nutrition can be an essential element of palliative care. However, anorexia is common at the end of life. A clear consensus has emerged on the basis of research and clinical reports that seriously ill or dying patients experience little if any discomfort on withdrawal of tube feedings, parenteral nutrition, or intravenous hydration.[54,55] In fact, the adult experience suggests that fasting, particularly in the setting of terminal illness, may carry significant benefits that include the release of endorphins and creating a feeling of well-being, ketone production leading to hunger reduction, and clearer thinking.[32]

Parents and care providers may wish to consider withholding fluids and nutrition in the setting of terminal illness when medically provided fluids and nutrition do not serve the goals of promoting comfort (eg, in some children with end-stage malignancies who are unable or unwilling to take oral fluids or food). In these circumstances, medically provided fluids and nutrition may not be comforting for the child and may only serve to prolong the dying process.[56] Indeed, providing fluids and nutrition in these circumstances may increase discomfort, and fasting might enhance the well-being of the patient through ketosis and endorphin production, decreasing symptoms such as nausea, vomiting, diarrhea, coughing, respiratory secretions, and urine output and decreasing the metabolic rate.[32] Furthermore, the provision of some forms of fluids and nutrition may be accompanied by other burdens such as ongoing hospitalization rather than home care and blood draws to monitor electrolyte balance, liver function, and evidence of sepsis. Palliative care measures to manage symptoms related to decreased oral intake, such as dry mouth or decreased oral hygiene, are well established and effective.[57]

Infants with a severe gastrointestinal malformation or a disease that is destructive to a large portion of the gastrointestinal tract leading to total intestinal failure represent another group for whom parents or legal guardians might be provided the option of withholding or withdrawing medically provided fluids and nutrition. Although administration of total parenteral nutrition may help such children live for years, long-term total parenteral nutrition, particularly in the absence of any bowel function, is associated with a high rate of complications such as infection and hepatic dysfunction.[58,59] More definitive treatments, such as bowel transplants, are currently associated with a significant rate of severe morbidity and mortality in young children.[60,61] Because in some cases the burdens may outweigh the benefits to the child, withdrawal of medically provided fluids and nutrition is an acceptable, although difficult, option to consider, particularly when technical complications, such as no further central line access sites, confront the caregivers.[29,58] For these patients, it is critical to ensure meticulous attention to prevention and treatment of discomfort.

Other conditions that are incompatible with long-term survival and for which significant burden is associated with continued existence or available treatment options might also create situations in which medically provided fluids and nutrition may ethically be withheld or withdrawn from a child. For example, some infants are born with heart defects that are ultimately incompatible with survival beyond a few months and for which transplant is the only therapeutic option. Parents may decide not to pursue the transplant, choosing instead to optimize their child's comfort during his or her short life. In these cases, medically provided fluids and nutrition may not serve the interests of the child. In particular, when congestive heart failure is present, medically provided fluids and nutrition can induce or worsen fluid overload, leading to dyspnea, uncomfortable abdominal distention and associated nausea and vomiting, chest pain, and massive edema with skin breakdown. Should parents and care providers choose to limit medically provided fluids and nutrition, a comprehensive palliative care regimen would be particularly important for minimizing the suffering of the child.

OTHER ETHICAL CONSIDERATIONS

Although withholding or withdrawing medically provided nutrition and hydration may be in a particular child's interests, children with disabilities must also be protected from discrimination. Many children benefit from medically provided fluids and nutrition. Some individuals and groups worry that "crossing a line" and permitting the withdrawal of medically provided fluids and nutrition in any cases will place these vulnerable children at risk of being neglected or devalued as social standards change. They are concerned that if it seems acceptable to withhold fluids and nutrition in children in a persistent vegetative state today, it may become acceptable in the future to withhold them from children with less severe conditions who might be considered burdensome to families or society. Although this "slippery slope" concern is important, it is not sufficiently weighty to preclude the withdrawal of fluids and nutrition in well-defined circumstances. Prohibiting the withdrawal of fluids and nutrition in all cases to ensure protection against discrimination would subject some children to unwanted and burdensome interventions. Because these difficult decisions to withdraw or withhold medically provided fluids and nutrition are explicitly justified on the basis of the welfare of the child, the risk of abuse is substantially reduced. Disability alone is not a sufficient reason to forgo medically provided fluids and nutrition. Decisions about medically provided fluids and nutrition should be made on the same basis that all other medical decisions are made—a determination that, ultimately, the patient would experience sufficient benefit from the intervention to justify any accompanying burdens. That is, it would not be ethically justifiable to withdraw fluids and nutrition from a child who was clearly benefiting from these measures to reduce burdens on the family, society, or the health care system.

One commonly expressed concern about the withdrawal of fluids and nutrition is that it might cause significant suffering. The clinical data (cited in the previous section) do not support this concern. For patients in a persistent vegetative state or with other conditions marked by the absence of conscious awareness, there can be no experience of suffering. For children in a terminal phase of illness, "forced" feedings or nutrition may cause more discomfort than their withdrawal, particularly when symptoms are carefully addressed through palliative measures.

A final ethical consideration concerns the role of parents or guardians in decision-making about the withdrawal of life-sustaining measures. Parents who are seeking their children's best interests are usually the best decision-makers for their children. Because of the value-laden nature of the decision to withdraw fluids and nutrition, this option should only be pursued with the full knowledge and support of a child's parents or legal guardian. Typically, decisions of this nature are not urgent, so parents, guardians, and care providers can wait to ensure the prognosis is correct and have time to fully consider all of the options and the ramifications of each available option. Parents may want to consult with others, including extended family, clergy, and friends. Parents also may want and should be encouraged to seek second or third opinions about the prognosis and the medical or ethical aspects of their options. Ethics consultation may help address the ethical issues and should be available to families. Decision-making in this situation should be accompanied by a discussion about limiting other interventions (such as cardiopulmonary resuscitation and routine blood draws), the practical aspects and logistics of withdrawing medically provided fluids and nutrition, and how comfort will be ensured for everyone involved. The decision to withhold or withdraw medically provided fluids or nutrition should be understood as an important entry point into a broader palliative care plan.[62–64]

It is also important to emphasize that care providers must work within their own ethical standards, and pediatricians and other health care providers should not be required to participate in treatment plans to which they have personal ethical objections. However, when such an option is legal and ethical by societal standards, parents must be made aware of the option and a referral must be made to caregivers who can assist them to further explore and carry out their wishes. On the other hand, although parental permission for the withdrawal of fluids and nutrition is essential, it is not sufficient if care providers do not believe such a choice is ethically permissible. Care providers may require support in understanding the reasons behind a parent's decision. Ethics consultation or ethics committee involvement may be valuable in these situations. In rare situations in which caregivers have a strong basis for believing that continuing or initiating medically provided fluids and nutrition would be, on balance, excessively burdensome to a child and parents do not support the withholding or withdrawing of medically provided fluids and nutrition, health care providers should seek the involvement of an ethics consultant or ethics committee. Difficult choices are best made when there is consensus between the parents and care providers about the best course of care, and the involvement of an ethics consultant, ethics committee, or palliative care consultant may be especially helpful when

there is disagreement surrounding the appropriateness of medically provided fluids and nutrition.

LEGAL CONSIDERATIONS

Most legal cases that have addressed the issue of withholding or withdrawing fluids and nutrition have involved adults, but several principles developed in these cases apply equally in the pediatric setting. One area of legal consensus is that medically provided nutrition and hydration are medical treatments and may be withheld or withdrawn under the same conditions as any other form of treatment.[65–67] Virtually every court case at the federal appellate level has concluded that provision of artificial nutrition and hydration is a medical procedure, that it may be forgone under appropriate circumstances as may any other procedure, and that the fact that it involves basic sustenance is not relevant to whether it must be administered or may be forgone.[65] In *Cruzan v Director, Missouri Department of Health*, for example, the US Supreme Court affirmed the view that medically provided fluids and nutrition are medical interventions that can be refused by a competent adult.[68] The court thus rejected the "exceptionalism" often afforded to medically provided fluids and nutrition.

Federal regulations relevant to this debate emerged after the public controversy over the case of "Baby Doe" in 1983. Baby Doe was an infant with trisomy 21 who died after the decision by his parents to withhold surgical repair of esophageal atresia. In response, Congress amended the Child Abuse Prevention and Treatment Act (CAPTA) in 1984 to include language requiring state child protective services agencies to have reporting mechanisms for the withholding of treatment from infants with severe disabilities.

The CAPTA stipulates that medical treatment need not be provided "other than appropriate nutrition, hydration, and medication" when, in the physicians' reasonable judgment, any of 3 circumstances apply: (1) the infant is chronically and irreversibly comatose; (2) the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or would be "futile" in terms of the infant's survival; or (3) the treatment would be "virtually futile" and "inhumane."[69] Although this language seems to advocate for the provision of appropriate fluids and nutrition in most cases, the AAP argues that medically provided nutrition and hydration are "appropriate" when they serve the interests of the child—in other words, when they are expected to offer a level of benefit to the child that exceeds the potential burden to the child. The purpose of this report is to define the appropriate use of medically provided fluids and nutrition, and in that sense, the CAPTA seems consistent with the guidelines provided in this report.[70] Furthermore, the Baby Doe regulations include no direct enforcement mechanism but make states' receipt of federal child abuse prevention program funds contingent on having a reporting mechanism in place. Therefore, the regulations are directed to state-funded child abuse prevention programs and were not intended as standards of physician or institutional liability.[29]

Although there is no federal prohibition of carefully made decisions to withhold or withdraw medically provided fluids and nutrition from children, individual states may have specific regulations or case law that address this issue. Physicians should be familiar with state laws that may influence their decisions regarding the withholding or withdrawing of medically provided fluids and nutrition (state AAP chapters, state medical associations, or the AAP Division of State Government Affairs can offer assistance in obtaining this information).

CONCLUSIONS

It is ethically permissible to withdraw medically provided fluids and nutrition from infants, children, and adolescents in selected circumstances. As a general rule, medically provided fluids and nutrition can be withheld or withdrawn from a child when there is consensus that the provision of fluids and nutrition do not confer a net benefit to the child. In addition, the AAP offers the following general principles:

1. Children capable of safely eating and drinking who show signs of wanting to eat or drink should be provided food and fluids.
2. Medically provided fluids and nutrition constitute a medical intervention that may be withheld or withdrawn for the same types of reasons that justify the medical withholding or withdrawing of other medical treatments.
3. Decisions about whether medical interventions should be provided to a child, including medically provided fluids and nutrition, should be based on whether the intervention provides net benefit to the child.
4. The primary focus in decision-making should be the interests of the child.
5. Although withholding or withdrawing medically provided fluids and nutrition may be morally permissible, it is not morally required.
6. Medically provided fluids and nutrition may be withdrawn from a child who permanently lacks awareness and the ability to interact with the environment. Examples of such children include children in a persistent vegetative state or children with anencephaly. The diagnosis and prognosis should be

confirmed by a qualified neurologist or other specialist with expertise in the evaluation of children with these conditions.

7. Medically provided fluids and nutrition can be withdrawn from children when such measures only prolong and add morbidity to the process of dying. In these situations, continued fluids and nutrition often provide very limited, if any, benefit and may cause substantial discomfort. Some examples of children in this group include those with terminal illnesses in the final stages of dying, infants born with heart defects that are ultimately incompatible with survival beyond a few months and for which transplant is the only therapeutic option, infants with renal agenesis, or infants with a severe gastrointestinal malformation or a disease that is destructive to a large portion of the gastrointestinal tract, leading to total intestinal failure, and whose parents have opted for palliative care rather than intestinal transplant.
8. Parents or guardians should be fully involved in shared decision-making with the physician and health care team and should support the decision to withhold or withdraw medically provided fluids and nutrition. Parents should be reassured that their child will be kept comfortable and should be informed about the likely course of events, including broad estimates of when the child's death is anticipated. Comprehensive palliative care measures for the child, including appropriate sedation and oral hygiene, should be provided in this situation.
9. Ethics consultation is strongly recommended when particularly difficult or controversial decisions are being considered.

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