



## End-of-life care

### Report offers guidance on the ethics of withholding fluids, nutrition delivered through medical devices

by **Sheryl Cash** • Correspondent

A new AAP clinical report provides ethical guidance for the sometimes difficult and controversial decision of whether to withhold medically provided nutrition and hydration for a terminally ill child.

In general, the decision to stop medical interventions for a child who no longer benefits from such care “is 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,” according to the report, *Forgoing Medically Provided Nutrition and Hydration in Children: Guidance for Ethical Decision Making* (*Pediatrics*. 2009;124:813-822). But the withholding of the medical provision of *fluids and nutrition* for children remains controversial because of the symbolism associated with feeding.

Pediatricians often are 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.

#### Expands existing guidelines

The clinical report concurs with and expands on a portion of the AAP policy statement, *Guidelines on Forgoing Life-Sustaining Medical Treatment* (*Pediatrics*. 1994;93:532-536).

The report concludes that the withdrawal of medically administered fluids and nutrition for pediatric patients is ethically acceptable in limited or selected circumstances.

Both statements recognize fluids and nutrition as life-sustaining medical treatment — the same as a ventilator, chest compressions or other life-saving care — for children who are incapable of eating and drinking on their own due to acute and chronic conditions, said Douglas S. Diekema, M.D., M.P.H., FAAP, chair of the AAP Committee on Bioethics and co-author of the new report.



**Dr. Diekema**

Yet while fluids and nutrition are medical interventions — administered through an intravenous catheter, or a nasogastric, nasojejunal or gastrostomy feeding tube — discontinuing such care “feels different than removing a ventilator” or other medical device, said Dr. Diekema. “While technically included in the earlier statement, the issue remained challenging for many (clinicians). There was still a perception — and we received many letters from physicians on this — that the

topic merited its own special statement.”

#### Considerations in the decision

The new clinical report states that the decision to continue or withhold medically provided nutrition for a child dependent on them for survival “should be based on whether or not the intervention provides net benefit to the child.”

Medically provided fluids and nutrition may be withdrawn from a child “permanently lacking awareness and the ability to interact with the environment, including children in a persistent vegetative state or children with anencephaly,” according to the report, and/or “when such measures only prolong and add morbidity to the process of dying.”

“If you have a child that is able to drink or eat without a tube, this statement does not say it’s OK to withdraw nutrition,” said Dr. Diekema. Children capable of safely eating and drinking who show signs of wanting to eat or drink should be provided food and fluids.

Most importantly, any decision pertaining to the withdrawal of medically provided, life-sustaining nutrition should be made with the consent and involvement of the child’s parent(s) or guardian(s), according to the report.



**Dr. Botkin**

“This would never be something considered without the full understanding and support of the parents,” said Jeffrey R. Botkin, M.D., M.P.H., FAAP, immediate past chair of the committee and co-author of the report. “This is the type of question that is not an emergency, and so you have the opportunity to think carefully about it and to encourage the parents to think carefully about the issues.”

#### Ethics consultation may help

In cases where the decision is particularly complex or controversial, the report strongly recommends ethics consultation for parents and clinicians.

Dr. Botkin recalled a case in which a 5-year-old who had nearly drowned and never recovered neurologically was living at home in the care of his parents and grandmother with medically provided nutrition.

“By that point, it was pretty clear that any hope for recovery was disappearing,” said Dr. Botkin, who worked with the ethics committee at Primary Children’s Medical Center in Salt Lake City to help the family explore their options, including discontinuing medically provided nutrition.

The report also states that while it “may be morally permissible, it is not morally required” to withdraw medical nutrition.

“We recognize that there are religious or cultural traditions where this would not be acceptable,” said Dr. Diekema. Therefore, the withdrawal of medically provided nutrition “is not mandatory, even if it is ethically appropriate. If religious beliefs are in conflict, then nutrition should be continued, not withheld or withdrawn.”

If the parents support withholding medical nutrition but the child’s

physician does not, options include transferring care to another physician who shares the parents’ view or obtaining an ethics consultation.

“Virtually every hospital has some sort of provision for ethics consultation support,” said Dr. Botkin. Clinicians and hospital staff should ensure that parents or guardians are made aware of such services if they exist.