

MEDICALLY PROVIDED NUTRITION AND HYDRATION

Medically provided nutrition and hydration

In recent years there has been a lot of discussion around the issue of medically providing nutrition and hydration (food and fluid) at the end of life or when there is no hope of a return to health. These are sensitive and difficult issues.

Often there is added confusion and questions about how this discussion applies to children. The Ethics Committee of Children's Hospitals and Clinics began to discuss this issue in 1995 because of numerous questions, generally raised by parents, about the ethical issues involved in providing or forgoing medically provided nutrition and hydration.

As a result of that discussion, the Committee has developed a "Statement" regarding this topic. It was originally approved and distributed in January of 1996 and slightly revised in October of 1997. The Ethics Committee looked carefully at these issues and unanimously agreed to all the elements of this statement. This Statement does not suggest or require any particular decisions. It is meant to be used by caregiver, families, and, when appropriate, patients as an aid in thinking through the issues together.

The statement reflects the belief of the committee that a medical treatment is not by itself either good or bad. A treatment has meaning only in relationship to the condition of a particular patient. Any medical treatment should have a clear or potential benefit for the patient. The benefits or potential benefits of most treatments are clear. The Statement on Forgoing Medically Provided Nutrition and Hydration addresses situations where the benefits of the treatment are in question.

The document should be viewed as a whole. Individual statements, while numbered for ease of discussion, do not stand alone and should not be taken out of context. How the document applies to a specific patient should be carefully considered and discussed by the family and their advisors, the health care team, and, when appropriate, the patient.

Statement on Forgoing Medically Provided Nutrition and Hydration of the Children's Hospitals and Clinics of Minnesota Ethics Committee

The Ethics Committee of Children's Hospitals and Clinics of Minnesota has developed the following statement as a non-binding guide for families, health care providers, and occasionally patients themselves who are confronted with a tragic decision regarding the appropriateness of providing or not providing nutrition and hydration by medical means to pediatric patients. This statement should be viewed as a whole. The numbered, individual statements are identified for clarity, but should be considered in light of all other statements.

The Ethics Committee believes that providing nutrition and hydration is appropriate in most cases, but recognizes that circumstances exist in which the goals of treatment change and that providing nutrition and/or hydration may not be appropriate. This document is relevant to patients such as those with neurologic devastation or total irreversible intestinal failure and those for whom death from any cause is expected soon.

1. We recognize the offering of oral nutrition and hydration as a basic component of human interaction that in most instances provides sustenance and comfort. If oral nutrition and hydration would provide more harm than benefit to a patient, it can be permissible to discontinue offering them. The harms and benefits of oral nutrition and hydration should be specifically discussed in the context of decisions about and goals of medical treatments.
2. We believe decisions regarding medically providing nutrition and hydration should be placed in the context of all other treatment and life value decisions of the patient, and should be consistent with decisions about levels of other medical support, provision of comfort cares, and other experiences including social, educational, and familial needs.

3. We endorse the open communication of all involved in treatment planning about the issues of medical provision nutrition and hydration. The patient, family, and caregivers are encouraged to share any concerns or information regarding medically provided nutrition and hydration with the others most closely involved in the patient's care.
4. We believe decisions about medically providing nutrition and hydration should be made on the best available information. There are cases in which decisions must be delayed because of inadequate information. However it is also permissible in some cases to forgo medically provided nutrition and hydration even if there is some degree of uncertainty regarding prognosis or benefit.
5. We believe that the interests of the patient are the primary determinants of decisions, but that the interests of other family members and society may play a secondary role.
6. We believe that for most children the parents (or other legal guardians) are the primary decision-makers for the child, but that the decision to forgo medically provided nutrition and hydration requires the concurrence of the health care team most closely involved in the patient's care.
7. We endorse the inclusion of those who are important advisors to the parents (or legal guardians) in addressing these issues to the extent desired by the parents. This may include extended family or friends, spiritual advisors, or others as determined by the parents (or legal guardians). We believe, however, that like all medical decisions on behalf of the child, these are confidential and private matters in which third parties are involved at the invitation of the parents (or legal guardians).
8. We believe that children have the same rights as adults to have treatment provided or not provided based on how the treatment affects their interests. It is an emotionally difficult situation to make a decision about medically provided nutrition and hydration for another person, especially when that person is a child. It is ethically permissible for the person deciding for the child to choose among the full range of treatment decisions.
9. We believe provision of nutrition and hydration through any medical device is a medical treatment and is in a different category than oral nutrition and hydration. This includes nasogastric (NG) feedings and fluid, gastrostomy (GT) feedings and fluid, and intravenous (IV) fluid including total parenteral nutrition (TPN). These are medical treatments.
10. We believe that medical provision of nutrition and hydration may or may not be a comfort measure, and in some situations may in fact increase or prolong suffering.
11. We believe that, like all treatments, the use of medically provided nutrition and hydration is governed not by the nature of the treatment rather by whether or not the treatment advances the patient's interests and whether the benefits of providing the treatment outweigh the burdens of the treatment.
12. We believe that it can be ethically permissible to forgo medically provided nutrition and hydration when hope for recovery is low or nonexistent if the parents (or other legal guardians), with the concurrence of the health care team, believe that forgoing treatment is in the child's best interest.
13. We believe that it can be ethically permissible to continue to medically provide nutrition and hydration when hope for recovery is low or nonexistent if the parents (or legal guardians), with the concurrence of the health care team, believe that continued treatment is in the child's best interest.
14. We believe that there is no ethical obligation to continue a treatment which is no longer advancing the interests of the patient. It is therefore permissible in some cases to stop medically providing nutrition and hydration after it has been started.
15. We endorse the use of ethics consultation for further discussion and clarification of these issues if uncertainty or disagreement exists for the family or health care providers, but do not believe ethics consultation is required in every case.