

AMERICAN ACADEMY OF PEDIATRICS

Guidelines on Forgoing Life-Sustaining Medical Treatment

Committee on Bioethics

Most children who become ill, even those with life-threatening disorders, recover to lead satisfying lives. Nonetheless, the course of disease may at times cause health care professionals and families to consider whether continued treatment truly represents the best option. Sometimes limiting or stopping life support seems most appropriate, especially if treatment only preserves biological existence or if the overall goal of therapy has shifted to the maintenance of comfort. Based on the existing consensus in ethics and law, the following guidelines for professionals caring for children suggest elements in decisions to forgo life-sustaining medical treatment (LSMT).¹⁻⁴

Decisions to withhold or withdraw LSMT may seriously tax the intellectual and emotional reserves of all parties. Patients, families, physicians, and other members of the medical care team should have access to and feel free to use *ethics consultants* or *ethics committees* in addition to the other resources on which they usually rely.^{5,6}

PRELIMINARY NOTATIONS

Life-sustaining medical treatment encompasses all interventions that may prolong the life of patients. Although LSMT includes the dramatic measures of contemporary practice such as organ transplantation, respirators, kidney (dialysis) machines, and vasoactive drugs, it also includes less technically demanding measures such as antibiotics, insulin, chemotherapy, and nutrition and hydration provided intravenously or by tube.⁷

The term "forgo" refers to both stopping a treatment already begun as well as not starting a treatment. Although many health care professionals feel reluctant to discontinue life-sustaining treatments, most philosophical and legal commentators find no important ethical or legal distinction between not instituting a treatment and discontinuing treatment already initiated. Fear about stopping therapy may keep clinicians from beginning treatments that may help some patients, particularly when great uncertainty prevails. A better course often includes initiating interventions that, if they later prove unhelpful, may be stopped. Continuing nonbeneficial treatment harms many patients and may constitute a legal, as

well as moral, wrong. Those who feel culpable and emotionally strained when faced with withdrawing treatment deserve sympathy and one should be sensitive to those upset by decisions to stop therapy. However, ethical theory and legal practice provide reasons to start or stop treatments based primarily on the relative benefits and burdens for the patient.⁸

Generally, parents give permission for the treatment of children who cannot do so themselves. (See "Decision Making for Patients Who Lack Decision-Making Capacity.") However, the American Academy of Pediatrics emphasizes that physicians and parents should give great weight to clearly expressed views of child patients regarding LSMT, regardless of the legal particulars.

For such serious matters as LSMT, the medical plan usually should conform to the values and choices of the patient and his or her family. In some circumstances, only one parent will be reasonably available before some decisions must be implemented. In other situations, although only a single parent will have actual guardianship or legal responsibility, the clinician may have moral and psychological reasons to consider the views of the other biological parent. In yet other instances, surrogates besides the parents will have decision-making authority; these may include other family members appointed guardians by a court, guardians *ad litem*, or representatives of child protective agencies maintaining custody of the child.

Decision-making capacity and the legal term "competency" refer to the ability of a person to make decisions at particular times under particular circumstances. One formulation of this overall capacity involves three essential elements: (1) the ability to understand and communicate information relevant to a decision; (2) the ability to reason and deliberate concerning the decision; and (3) the ability to apply a set of values to a decision that may involve conflicting elements.⁹ Each potential decision maker regarding LSMT should manifest these abilities. However, children should have the opportunity to participate in decisions about LSMT to whatever extent their abilities allow.

Many decisions regarding life support for children call for the use of the "best interests" standard. This involves weighing the benefits and burdens of LSMT. The benefits may include prolongation of life (understanding that the continuation of biological existence without consciousness may not be a benefit); improved quality of life after the LSMT has been applied (including reduction of pain or disability); and increased "physical pleasure, emotional enjoyment,

This statement has been approved by the Council on Child and Adolescent Health.

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

PEDIATRICS (ISSN 0031 4005). Copyright © 1994 by the American Academy of Pediatrics.

and intellectual satisfaction" (as cited in a ruling by the New Jersey Supreme Court).^{10,p295}

The burdens of LSMT may include intractable pain; irremediable disability or helplessness; emotional suffering; invasive and/or inhumane interventions designed to sustain life; or other activities that severely detract from the patient's quality of life. (The phrase "quality of life" refers to the experience of life as viewed by the patient, ie, how the patient, not the parents or health care providers, perceives or evaluates his or her existence. The American Academy of Pediatrics specifically rejects attempts to equate quality of life with the notion of "social worth" as judged by others. Such equations have unfortunately tainted discussions of limiting LSMT for children. Avoidance of the term quality of life would, however, ignore its widespread use.)

STATEMENT OF GENERAL PRINCIPLES

Presumption in Favor of Treatment

The American Academy of Pediatrics believes that physicians should provide life-sustaining medical care in conformity with current medical, ethical, and legal norms. Physicians should remember that two broad principles guide the implementation of therapy. First, *beneficence* suggests that clinicians justify the use of treatments based on the benefits they provide, not simply on the ability to employ them. The related notion of *nonmaleficence* reminds physicians to consider potential harm to patients. Harm includes obvious physical problems such as pain but may also include psychological, social, and economic consequences. Second, self-determination or *autonomy* accepts the likelihood that different persons may judge benefits differently. Our social system generally grants patients and families wide discretion in making their own decisions about health care and in continuing, limiting, declining, or discontinuing treatment, whether life-sustaining or otherwise. Medical professionals should seek to override family wishes only when those views clearly conflict with the interests of the child.

Right to Decide and To Be Informed

Whether they are child patients, parents, or other surrogates, health care decision makers have the ethical and legal right to adequate information about reasonably available diagnostic and therapeutic options (including risks, benefits, nature, and purpose of the options).

Right to Refuse Treatment

As a general rule, children who meet statutory criteria for emancipation and those who have been judged mature for purposes of medical decisions may refuse unwanted medical intervention. Most courts that have considered the issue also recognize that incompetent patients, including children, need not receive all possible treatments in each case.¹⁰ As noted previously, society generally presumes that parents should exercise the right to refuse medical treatment when nonautonomous children cannot do so for themselves.

Decisions to Forgo Are Particular to Specific Treatment

A decision to limit, decline, discontinue, or otherwise forgo a particular treatment or procedure applies specifically to that treatment or procedure. Such decisions do not imply that any other procedures or treatments are to be forgone, without a specific decision to do so. Thus, the decision to forgo use of antibiotics in the case of suspected infection does not mean that the patient should not receive oxygen, analgesics, or range-of-motion therapy aimed at providing comfort. Similarly, a do-not-resuscitate order should never signal the abandonment of a patient. When doubts exist regarding the appropriateness of particular treatments, the parties should ask themselves if the therapies of concern further the overall treatment plan. Such a plan should encompass the general goals of treatment, including its scope and limits, and the means suited to achieving those goals.

Preservation of Respect for the Patient

The needs of the child must remain primary, and measures necessary to assure comfort must be maintained at all times. Comfort measures include appropriate nursing and hygienic care as well as analgesics.

Physicians' Obligations

Individual physicians who generally decline to participate in the limitation or withdrawal of therapy should communicate their position to patients and families as soon as that information becomes relevant. When physicians do not wish to participate in forgoing LSMT, they have a legal duty to arrange for care by another physician before removing themselves from the relationship.

Availability of Guidelines to Patients and/or Families

Educational material with substantially the same message as these guidelines should be made available, whenever relevant, to patients and/or their families.

Presumption Against Judicial Review

Families and health care professionals should work together to make decisions for patients who lack decision-making capacity. Recourse to the courts should be reserved for occasions when adjudication is clearly required by law or when concerned parties have disagreements that they cannot resolve, despite appropriate consultation, concerning matters of substantial importance.¹¹

GUIDES FOR DECISION MAKING

Informing for Decision Making

Physicians have the responsibility to provide the patient, parents, or other appropriate decision makers with adequate information about applicable therapeutic and diagnostic options.

This information should include the risks, discomforts, side effects, and estimated financial and other costs of treatment alternatives, the potential benefits, and the likelihood, if known, of whether the treatment will succeed.

The physician should also provide advice about which option(s) to choose. That is, physicians should do more than offer a “menu” of choices—they should recommend what they believe is the best option for the patient under the circumstances and give any reasons, based on medical, experiential, or moral factors, for such judgments. However, physicians should remind families that they may accept or reject the physician’s recommendations.

The physician should elicit questions; provide truthful and complete answers to such questions; attempt to ascertain whether or not the decision maker understands the information and advice provided; and attempt to enhance understanding as needed.

The understanding of options by patients, parents, or other decision makers will often increase over time. Therefore, decision making should be treated as a process, rather than as an event. This implies, in part, that patients and/or their surrogates may change their minds as they develop an appreciation of the clinical situation and its meaning for their lives.

Withholding of Information From Patients, Parents, or Other Decision Makers

There is a strong presumption that all information needed to make an appropriate decision about health care (including a decision to forgo LSMT) should be provided to the patient, parents, or surrogates. Experience and study suggest that most patients, family members, or other decision makers want to hear the reality of their situation.^{12,13} Open and honest communication reduces tension in the physician-patient relationship.

Information may not be withheld on the grounds that it might cause the patient or surrogate to decline a recommended treatment or to choose a treatment that the physician does not wish to provide. Nor may information be withheld because its disclosure might upset the patient, parents, or other decision maker.

Physicians may withhold information when a competent patient clearly indicates that he or she does not wish to have the information provided, and the physician has previously offered to provide such information. Some commentators believe that parents or other surrogates do not have the same prerogative to refuse information or decline participation in decision making.¹⁴

Physicians may withhold information if they believe the information would pose an immediate and/or serious threat to a patient’s or surrogate’s health or life. *These circumstances will occur rarely, if ever.* A physician who withholds information assumes the burden of supporting the decision not to make customary disclosures. The physician should withhold only the specific information that might produce a threat. Even when immediate full disclosure may produce harm, the physician may succeed in providing partial information gradually, until full disclosure has occurred.

When the physician purposely limits disclosure, he or she should document the reasons in the medical record.

Collaborative Physician-Patient (or Physician-Surrogate) Decision Making

When the attending physician believes the treatment no longer confers a benefit and should be forgone, the patient, parents, or other surrogate should be so informed. Children, even those of early school years, often appreciate their medical situations far better than their family members, guardians, or health care providers believe.¹⁵ In many cases, young children deserve to hear the general conclusions of decisions that will affect their continued survival. Children should not be deprived of opportunities to say goodbyes to loved ones. Well-meaning attempts to shield children from this information may result in the breakdown of open communication and trust between patients and those caring for them.

Under some circumstances, child patients and their parents will not agree on the best plan of action. Such situations defy easy rules-of-thumb. The parties must consider, among other concerns, the facts and gravity of the situation; the maturity, knowledge, and intelligence of the child; and the reasons for and strength of the feelings of other family members. The parties should consider seeking consultative help from the following: (1) child psychiatrists, family therapists, or similar professionals skilled in behavioral assessment and counseling; (2) ethics consultants or an ethics committee; (3) other sources of family support, including religious advisers; and, if necessary, (4) the courts.

Physician-Patient (or Physician-Surrogate) Disputes

Patients or surrogates may not compel a physician to provide any treatment that, in the professional judgment of that physician, is unlikely to benefit the patient.¹⁶ However, physicians should not use their views that a treatment provides no benefit (one that they therefore do not wish to offer) as a reason for circumventing possibly difficult discussions with patients. For example, the medical judgment that cardiopulmonary resuscitation will not succeed (that resuscitation is “futile”) in a patient with severely injured lungs from bronchopulmonary dysplasia or necrotizing bronchiolitis should not serve as an excuse to avoid talking about do-not-resuscitate orders. Hospitals should have policies addressing intractable differences between staff and patients or families.

If the patient or surrogate makes a decision that the physician cannot accept in good conscience, the physician should arrange transfer of the patient’s care to another physician or hospital willing to accept the decision.

If the physician can make no such arrangements, action by the physician to continue or forgo treatment without extensive consultation seems unwise. Such disputes deserve careful consideration of their ethical, legal, and administrative implications. Only in the rare situations in which extended counseling efforts fail, and no physician or facility will accept the patient, should physicians or hospitals refer these cases to the courts.

Consultation With Family

Professionals who care for children should strongly encourage their patients to discuss LSMT with their families and with other close friends and advisers well in advance of the need for decisions. However, when requested to do so, medical professionals should respect the privacy and confidentiality of patients legally entitled to make their own decisions (emancipated minors or those judged mature), including decisions about LSMT. Physicians should honor the desire of patients and parents to prevent disclosure of medically related information to members of the extended family in all but the most unusual circumstances.

DECISION MAKING FOR PATIENTS WHO LACK DECISION-MAKING CAPACITY

The following sections delineate concerns about decision-making capacity and standards to be applied when patients lack such capacity. Many medical professionals who care for children, as a matter of course, take the views of the children about treatment seriously. However, the gravity of decisions about LSMT requires careful, *explicit* attention to the wishes and feelings of the children, regardless of the legal status of the patients.

Definitions

The definition of *emancipated minor* varies somewhat from state to state. Generally, legislation defines emancipated minors as those who have graduated from high school, members of the armed forces, those who are married, those who are pregnant or parents, or those who live apart and are financially independent from their parents.

The legal notion of *mature minor* varies even more. Many courts and some legislatures recognize that individual children, beginning at approximately age 14 years, may be assessed sufficiently mature to make decisions, including some medical ones, for themselves.

The *substituted judgment standard* refers to situations in which surrogates can make inferences about the preferences of previously competent patients. When such a patient's wishes are known or can be deduced, surrogates should replicate the decision that the patient would have made under the circumstances. Thus, this legal standard applies for children who are emancipated or considered mature.

Presumption of Capacity:

Decision-Making Capacity in General

In the case of conscious and alert emancipated minors or those judged mature minors, the ethical and legal presumption of capacity should govern, unless countervailing evidence arises to call the presumption into question.

The professional staff may question a patient's capacity if they suspect or diagnose conditions such as delirium, dementia, depression, mental retardation, psychosis, intoxication, stupor, or coma. Lack of decision-making capacity can be transient and specific to a particular decision. Therefore, patients who

suffer from any of these conditions may not lack capacity at all times for all purposes, and the staff may need to reassess decision-making capacity from time to time.

Refusal of specific treatment that most patients would agree to does not alone mean the patient lacks decision-making capacity, but such refusals may serve as a basis for inquiring into the patient's decision-making capacity.

Standards for Decision Making for Patients Lacking Decision-Making Capacity

A surrogate must make health care decisions for patients who lack decision-making capacity.

The substituted judgment standard should be used for children who are emancipated or mature when their wishes are known or may be deduced.

The best interests standard serves as the basis for decisions for patients who have never achieved decision-making capacity, including infants and young children. This standard does not easily apply to patients in whom a permanently unconscious state has been reliably diagnosed. It is difficult to claim that their continued life benefits them, although we cannot say with certainty that they suffer any burden. Physicians and families should also consider whether continued treatment conforms with respect for the meaning of human life and accords with the interests of others, such as family members and other loved ones.

Formal Assessment of Capacity

As a rule, the attending physician should assess and document the capacity of a patient to make or assist in making decisions about forgoing treatment. Formal developmental, psychiatric, or other consultation may help determine the patient's abilities and the appropriateness of the child's participation in making decisions.

Advance Directives

Legal uncertainty surrounds the status of "living wills" or durable power-of-attorney documents executed by minors, even those recognized as emancipated or mature. Thus, in most situations, children will not have formal advance directive documents even under the Federal Patient Self-Determination Act.¹⁷ However, physicians and others should accord considerable weight to the feelings minor children may have expressed before losing the capacity to communicate clearly regarding LSMT. If the patient has executed a living will or any other form of advance directive for health care, that document should serve as strong evidence of the patient's wishes.

Pediatricians should encourage parents of dying children to plan alternatives to calling emergency medical personnel if the family does not desire resuscitation.

DOCUMENTATION OF DECISIONS AND ENTRY OF ORDERS

The American Academy of Pediatrics recommends explicit documentation, in the form of clear orders

and explanatory progress notes in the medical record, to encourage involved health care providers to adhere closely to the goals of treatment agreed on by the patient, parents, or other decision maker, and the patient's physician.

Orders

Physicians should encourage hospitals to develop and maintain written policies permitting the forgoing of life-supporting treatment of patients, including children, in appropriate circumstances. Such policies should state that when it has been determined that a particular LSMT is to be forgone, the attending physician or a designee must write an order in the patient's medical record. Telephone orders alone are not acceptable under most circumstances. The attending physician has the responsibility to elicit and consider the views of other members of the professional staff regarding treatment limitations before entering orders limiting LSMT. He or she should discuss the meaning of any order limiting treatment with the staff and ensure that all involved understand such orders and their implications.

Progress Notes

At the time an order limiting LSMT is written, the attending physician should write a companion entry in the progress notes including the following information: diagnosis, prognosis, patient's or other decision-maker's wishes, the content of discussions with involved parties, any disagreements or unresolved issues, and the recommendations of the treating team and consultants.

Acceptable Orders

Each situation deserves individual consideration. This usually requires detailed orders appropriate to the specific case. However, physicians may indicate the following orders to facilitate communication.

No Specified Limits on Therapy These patients will receive all medically appropriate interventions, including treatment of cardiopulmonary arrest. All patients are assumed to be in this category unless it is otherwise noted in the patient's orders and explained in progress notes.

Limited Therapy These patients receive medically indicated treatment but have specific interventions, diagnostic or therapeutic, forgone as noted in the patient's orders and explained in progress notes. For example, one may omit cardiopulmonary resuscitation, provide all reasonable therapies for respiratory disease, but forgo tracheal intubation and/or mechanical ventilation, or provide "comfort measures only," such as nursing care plus appropriate analgesia and sedation. Interventions already begun may be withdrawn. Forgoing specific measures does not preclude initiation or continuation of other indicated diagnostic tests or therapies.

ACKNOWLEDGMENTS

This document draws extensively on a framework developed by Meisel and others.¹ The American Academy of Pediatrics state-

ment focuses on the special issues that pertain to children and clarification of substantive matters beyond the largely procedural approach in that article.

COMMITTEE ON BIOETHICS, 1992 to 1994

Arthur Kohrman, MD, Chair
Ellen Wright Clayton, JD, MD
Joel E. Frader, MD
Michael A. Grodin, MD
Ian H. Porter, MD
Virginia M. Wagner, MD

LIAISON REPRESENTATIVES

Robert C. Cefalo, MD, PhD
Elena A. Gates, MD
American College of Obstetricians
and Gynecologists
Nuala P. Kenny, MD
Serge Melancon, MD
Canadian Paediatric Society

SECTION LIAISON

Anthony Shaw, MD, Section on
Surgery

CONSULTANT

Rebecca Dresser, JD

REFERENCES

1. Meisel A, Grenvik A, Pinkus RL, Snyder JV. Hospital guidelines for deciding about life-sustaining treatment: dealing with health "limbo." *Crit Care Med.* 1986;14:239-246
2. The Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment the Care of the Dying.* Briarcliff Manor, NY: The Hastings Center; 1987
3. Task Force on Ethics of the Society of Critical Care Medicine. Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. *Crit Care Med.* 1990;18:1435-1439
4. American Thoracic Society Bioethics Task Force. Withholding and withdrawing life-sustaining therapy. *Ann Intern Med.* 1991;115:478-485
5. Grodin MA, Markley WS, McDonald AE. Use of an institutional ethics team on a pediatric service. *Qual Rev Bull.* 1985;11:16-19
6. La Puma J, Stocking CB, Silverstein MD, DiMartini A, Siegler M. An ethics consultation service in a teaching hospital: utilization and evaluation. *JAMA.* 1988;260:808-811
7. Lynn J, ed. *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food Water.* Bloomington, IN: Indiana University Press; 1989
8. Wanzer SH, Federman DD, Adelstein SJ, et al. The physician's responsibility toward hopelessly ill patients: a second look. *N Engl J Med.* 1989;320:844-849
9. Brock DW. Children's competence for health care decision-making. In: Kopelman LM, Moskop JC, eds. *Children Health Care. Moral and Social Issues.* Dordrecht, The Netherlands: Kluwer Academic Publishers; 1989
10. Meisel A. *The Right to Die.* New York, NY: Wiley Law Publications; 1989
11. Armstrong CJ. Judicial involvement in treatment decisions: the emerging consensus. In: Civetta JM, Taylor RW, Kirby RR, eds. *Critical Care.* Philadelphia, PA: J. B. Lippincott Co; 1988
12. Waitzkin H. Doctor-patient communication: clinical implications of social scientific research. *JAMA.* 1984;252:2441-2446
13. Myers BA. The informing interview: enabling parents to "hear" and cope with bad news. *AJDC.* 1983;137:572-577
14. Veatch RM. Limits of guardian treatment refusal: a reasonableness standard. *Am J Law Med.* 1984;9:427-468
15. Bluebond-Langner M. *The Private Worlds of Dying Children.* Princeton, NJ: Princeton University Press; 1978
16. Council on Ethical Judicial Affairs of the American Medical Association. Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA.* 1991;265:1868-1871
17. Sahler OJZ, Greenlaw J. Pediatrics and the patient self-determination act. *Pediatrics.* 1992;90:999-1001