

**ADDENDUM: Guidelines for Forgoing Life-Sustaining Treatment
for Minor Patients¹**

Approved by:
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1. Rights of Minor Patients and Parents

a. Medical treatment to minors must be provided in accordance with the principles of informed consent.

b. Minors who (1) have received a declaration of emancipation from the court, (2) are living apart from their parents and are self-supporting, (3) are in the Armed Forces, or (4) are married or were previously married, have the right to consent to or refuse medical treatment, and the principles relevant to medical decision making for adults apply to them.²

c. For minors other than those identified in Section 1.b. of this Addendum, parents generally have the right to consent to, or refuse, medical treatment.

d. Parents have a constitutionally protected right to raise their children as they see fit, and may generally do so in accordance with diverse lifestyles, cultural traditions and religious beliefs; however, the rights of the parents are not unlimited. The State may intervene³ to protect a minor child from parental decisions that expose the child to an unreasonable risk of harm, even when those decisions are based upon religious beliefs.

e. Parents making decisions regarding life-sustaining treatment for their children must be given the information necessary for them to make informed choices. This information should include, among other things, alternatives, risks, discomforts, side effects, estimated financial and other costs of treatment alternatives, potential benefits, the likelihood of successful treatment and the potential effects of nontreatment.

2. Principles for Decision-Making

a. PRINCIPLE: There is a strong presumption that in exercising parental authority, parents are in fact acting in the best interest of the minor patient.

¹ We consider the *Guidelines on Forgoing Life-Sustaining Medical Treatment* published by the Committee on Bioethics of the American Academy of Pediatrics (the "AAP Guidelines") and the *Guidelines for Neonates at the Threshold of Viability* adopted in February, 1996 by the California Association of Neonatologists (the "Neonatology Guidelines") to be compatible with these Guidelines, and recommend them to readers interested in further discussion of the issues raised herein. The AAP Guidelines are published at 93 PEDIATRICS pp. 532-36 (March 1994). The Neonatology Guidelines may be obtained by calling the LACMA/LACBA Joint Committee on Biomedical Ethics office at 213/630-1139.

² See LACMA-LACBA Joint Committee on Biomedical Ethics, *Guidelines for Forgoing Life-Sustaining Treatment for Adult Patients*, regarding principles to be applied to minors who are authorized to make their own medical decisions. See the CONSENT MANUAL, published periodically by the California Healthcare Association, for a listing of other health care decisions which minors may be permitted to make for themselves.

³ Such intervention is accomplished through the exercise of jurisdiction by the juvenile dependency court, as discussed in Section 4 of this Addendum.

COMMENT: The parental decision to forgo life-sustaining treatment for minor children should be followed unless there is **strong evidence** that the parents are not acting in the best interest of the minor patient. Physicians should resist substituting their own judgment of what constitutes the minor patient's best interest except in those circumstances where the parents are clearly acting against that interest. For example, where the treatment decision is outside the current range of treatment practices for the circumstances, the physician must discuss that decision with the parents, exploring their understanding of the child's medical status and the reasons for the decision. Consultation with a bioethics committee may be helpful in this regard, as discussed in more detail in Section 5.d of this Addendum.

b. PRINCIPLE: The minor should be a part of the decision-making process to whatever extent his/her abilities allow.

COMMENT: California court opinions and statutes suggest that "mature" minors will typically include at least minors 14 years of age or older. Other minors may also be considered mature based upon the evaluation of the parents and the physician. The more mature the individual, the greater the weight to be given to his/her opinion.

c. PRINCIPLE: Consideration of the minor patient's "quality of life" should always be undertaken from the perspective of the minor child.⁴

COMMENT: Discerning this perspective is admittedly difficult, but should be attempted. The desirability of a minor's life, as determined by others, should not be judged by the value that such a life might have in society.

d. PRINCIPLE: The pain and suffering of the minor patient should be a priority concern for physicians. Effective pain management and palliative care should be a primary goal in the care of the dying minor patient.

COMMENT: The principles and rules that govern the provision of pain management and palliative care in adult patients apply equally well to minor patients. For the dying minor patient, aggressive pain management is justified even if the aggressive management of the minor patient's pain and suffering has the unintended side effect of hastening the dying patient's moment of death.

3. The Communication Process

When a child is very ill, clear and appropriate communication between parents and the health care team is essential. However, it can be difficult to achieve due to the inherent stress of the circumstances and the unverified assumptions and unstated expectations of both health care providers and parents. Nonetheless, a great majority of the difficult issues arising from the treatment of minor patients are basically communication problems, and can be resolved by focusing on communication and interpersonal skills.

Every effort should be made to clarify and maintain open communication between parents of minor patients and physicians. Some communications pitfalls and potentially helpful approaches are described below, but physicians should use their creativity and enlist the parents' involvement to craft communication approaches which best fit individual circumstances.

a. Physicians need to be aware of their own emotional needs, especially when they are distressed over their inability to cure a child, and should seek support from their peers or other resources, not from the parents.

⁴ "The phrase 'quality of life' refers to the experience of life as viewed by the patient, i.e., how the patient, not the parents or the health care providers, perceives or evaluates his or her existence." *AAP Guidelines, id.* at footnote 1, p. 533.

b. Parents who appear to be making unreasonable treatment decisions for their child may be basing those decisions on inconsistent communications from the health care team. To avoid or resolve this problem, there must first be a mechanism for communication between members of the health care team regarding the child's clinical status, potentially appropriate therapies and their predicted outcomes. If differences of opinion between treating physicians on these issues come to light, the physicians should attempt to resolve those differences with or without the assistance of available institutional processes.

If differences of opinion between treating physicians remain unresolved, the physicians should discuss those different opinions, with their rationale, with the parents in a meeting. This meeting will give the parents the opportunity to ask questions of each of the physicians, thereby helping the parents to eventually reach their own conclusions regarding appropriate care for their child.

If the treating physicians are in agreement regarding the child's clinical status, potentially appropriate therapies and their predicted outcomes, such information should be communicated to the parents clearly, should be updated as necessary and should be reinforced often. One physician should be designated to have primary responsibility for ongoing communication with the parents. In having these conversations, physicians should be sensitive to the family's cultural background and religious beliefs.

c. The treating physician should clearly document in the medical record the minor patient's clinical status, the goals of treatment (as those goals are ultimately determined by the parents and, as appropriate, the minor patient, in consultation with the physician), and the physician's treatment orders. Any limitations on treatment should be described in the detail necessary for members of the treatment team to administer or withhold specific treatment measures. In addition, the physician is responsible for clearly communicating to the hospital staff that comfort care is to be consistently provided regardless of the medical interventions provided or withheld. Comfort care includes maintaining warmth and cleanliness and providing careful handling, human contact and, when appropriate, analgesics. In addition, parents should be encouraged to hold, touch, interact with and participate in the care of their child.

d. When there is disagreement between the physician and the parents, between the parents, or between the parents and the minor patient regarding the appropriate course of treatment, a bioethics committee and/or patient advocate of the institution can be excellent resources and should be fully utilized. Professional mediators are also generally skilled in facilitating communication, and their involvement could be considered under these circumstances.

4. Circumstances under which the Presumption of Parental Authority May Be Challenged

Parental authority to make medical treatment decisions for their minor child should not be recognized or relied upon by a physician in the following circumstances:

a. when parents or a guardian are not willing or available, or fail, to act as surrogate decision makers for a minor;

b. when the parents refuse to authorize life-sustaining treatment where it will have significant benefit to the child in terms of quality and quantity of life; or

c. when the parents' decision regarding life-sustaining treatment for their minor child clearly violates professional practice standards.

In these circumstances, the physician should utilize the Communication Process described in Section 3 as appropriate. It is important for the physician to establish a close, supportive relationship with the parents in order to understand the parents' views. If the physician ultimately decides not to follow the parents' decision, the physician should discuss the reasons with the parents. If the difficulty is not resolved through the Communication

Process, the physician should refer the matter to the county agency responsible for children's services⁵ for the appointment through the Juvenile Court of an appropriate surrogate. The Juvenile Court has authority to remove from the parents the right to make health care decisions for the minor, where the inaction or proposed decision by the parents unreasonably exposes the minor to death or serious harm. Both when deciding whether to refer a matter to the county agency, and after making such a referral, the physician should be sensitive to the family's cultural background and religious beliefs and should provide appropriate emotional support for the parents and the child.

5. Circumstances under which the Presumption of Parental Authority Should Be Considered Further

a. Whenever the physician is concerned that the parents' decision to forgo life-sustaining treatment for their minor child might not be appropriate even though that decision does not clearly violate professional standards or clearly go against the minor patient's best interests, the physician should attempt to resolve those concerns by using the Communication Process described in Section 3 of this Addendum.

b. If, after diligent efforts to enhance communication with the parents, the physician resolves his or her previous concerns by determining that the parents' decision clearly violates professional standards or clearly goes against the minor patients' best interests, the physician should refer the matter to the county agency responsible for children's services for the appointment through the Juvenile Court of an appropriate surrogate. Both when deciding whether to refer a matter to the county agency, and after making such a referral, the physician should be sensitive to the family's cultural background and religious beliefs and should provide appropriate emotional support for the parents and the child.

c. If, after diligent efforts to enhance communication with the parents, either the physician's concerns are resolved in favor of the parents' decision or the physician remains concerned but *is not convinced* that the parents' decision to forgo life-sustaining treatment either clearly violates professional standards or clearly goes against the minor patient's best interests, the physician should either proceed to implement the parents' decision or transfer the care of the child to another physician.

6. The Federal Baby Doe Regulations and Their Effect

For (1) minors less than one year of age, and (2) minors older than one year who have been "continuously hospitalized since birth and who were born extremely prematurely or who have a long term disability", special definitions of child abuse have been created by federal statute and regulations ("Baby Doe Regulations")⁶ which may affect treatment decisions in states which have agreed to accept federal funds for their state child abuse programs. For example, California accepts such funds, and the California Department of Social Services has incorporated the provisions of the Baby Doe Regulations into its operating manual. The Baby Doe Regulations are therefore used by the California Department of Social Services to determine whether certain actions must be reported as child abuse/medical neglect.

The Baby Doe Regulations prohibit the "withholding of medically indicated treatment," which is defined as "failure to respond to the infant's life threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions" Treatment may be withheld under the Regulations where, in the treating physician's "reasonable medical judgment":

- (a) the infant is chronically and irreversibly comatose;

⁵ In Los Angeles County, the agency is known as the Department of Children and Family Services.

⁶ 42 United States Code §§5106a-5106g and 45 Code of Federal Regulations Part 1340.

- (b) the treatment would
 - (i) merely prolong dying,
 - (ii) not effectively ameliorate or correct all of the infant's life threatening conditions, or
 - (iii) otherwise be futile with respect to the infant's survival; or
- (c) the provision of treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.

Even in such circumstances, the Regulations do not permit withholding or withdrawing of "*appropriate* nutrition, hydration or medication" (emphasis added).

The phrase, "*appropriate* nutrition, hydration and medication," is not defined. However, since the drafters of the Baby Doe Regulations chose to use the word, "appropriate," it seems reasonable to assume that circumstances exist where parents, in consultation with the treating physician, can decide to forgo nutrition and/or hydration when such treatment would be inappropriate for the infant's condition.

7. Reporting Requirements Regarding Minors Applicable to Physicians

If, after consideration of the Principles described in Section 2 of this Addendum (particularly Principles 2.a and 2.b) and after diligent attempts to enhance communication with the parents, a physician believes that a decision by a parent or guardian to forgo life-sustaining treatment for a minor violates professional standards or clearly goes against the minor patient's best interests, the physician is obligated to report the matter to the county agency responsible for children's services, so that appropriate application may be made by that agency to the court for an order protecting the child and authorizing appropriate medical care. The physician should first explain to the parents or guardian what the law requires of the physician, and advise them of the intent to make the required report. Throughout this dialogue, the physician should continue to attempt to reach agreement with the parents or guardian regarding an appropriate course of treatment for the child.