

SUBJECT: GUIDELINES FOR FORGOING LIFE-SUSTAINING TREATMENT FOR POLICY NO. 352B

MINOR PATIENTS

CATEGORY: Provision of Care **EFFECTIVE DATE: 1/97 UPDATE/REVISION DATE: 11/21** POLICY CONTACT: Bonnie Rachman, MD REVIEWED BY COMMITTEE(S): Pediatric Acute and Critical Care Committee

PURPOSE:

To provide guidelines for physicians that address the forgoing of treatment, which includes withdrawal (terminating) as well as withholding (not beginning) treatment.

POLICY:

At Harbor-UCLA Medical Center, the medical treatment to minors must be provided in accordance with the principles of informed consent, including the right to refuse medical treatment. For unemancipated minors, decisions regarding forgoing treatment rest with the parent(s) or legal guardian, although the wishes of the patient should be taken into consideration. A parent or guardian generally has the right to decide to forgo medical treatment after having been fully informed about the benefits, risks and consequences of treatment alternatives, even when such decisions might result in shortening the minor's life.

Every patient less than 18 years of age is considered to be a minor unless the following circumstances apply: 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. In these cases, patients have the right to consent to or refuse medical treatment, and the principles relevant to medical decision-making for adults apply to them (See Policy 352A).

DEFINITIONS:

Treatment: Any procedure that is ordered by a physician, including nutrition and hydration.

Resident or Resident Physician: Any physician participating in an approved training program. Also includes the terms "intern" and "fellow".

Attending or Attending Physician: Physician of record who has the ultimate responsibility for all aspects of the care of the patient.

Mid-Level Practitioner: Certified Registered Nurse Anesthetists (CRNAs), Nurse Practitioners (NP), Physician Assistants (PA), Nurse Midwives.

Legal Guardian: Also, commonly referred to as legal custody, physical custody, or foster parents. These are legally appointed individual(s) that have physical custody of the minor, provide day-to-day care, and can make

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decisions about school, routine medical care, dental care, and vaccinations. This individual may or may not have the capacity to make decisions about all types of medical care. Commonly excluded medical decisions may include: HIV testing/treatment, psychotherapy, psychological testing/medications, procedures requiring general anesthesia, or blood transfusions/blood products. In these cases, legal guardianship documents should specify the rights granted to the guardian by the court.

Medical-Decision Maker: This includes biological parents, unless their parental rights have been terminated by the court, and adoptive parents. All other types of guardians should have legal paperwork to verify the extent of their medical decision-making rights granted to them by the court. Some legal guardians do have full medical decision-making rights but this is an exception and should be verified with the legal guardianship documents.

Adequate Information: The parent(s) or legal guardian should receive all information necessary to make a reasoned decision about withholding or withdrawing treatment. This should include the risks and benefits of treatment, alternative forms of treatment, and probable result of receiving no treatment. Information about burdens or risks should not be minimized or omitted simply because that might affect the decision.

GENERAL TREATMENT PRINCIPLES:

- 1. An Attending Physician should judge what treatments are medically appropriate for the patient.
- 2. There is a strong presumption that in exercising parental authority, parents are acting in the best interest of the minor patient. The parent(s) or legal guardian (and the minor, as appropriate) must be involved in all decision-making regarding forgoing treatment.
- 3. A treatment that is medically appropriate is one that is intended to reach any of the following goals of medicine: (a) Prolongation of meaningful life. (b) Preservation or restoration of function. (c) Relieving pain and suffering.
- 4. Treatment, even if life sustaining, need not be continued solely because it has been initiated. It may be appropriate in some cases to initiate a treatment to provide time for parent(s) or legal quardian to reach an appropriate decision.
- 5. Choices of the parent(s) or legal guardian to forgo or continue treatment shall be respected.
- 6. Consideration of the patient's "quality of life" should always be undertaken from the perspective of the patient.
- 7. Dignity, hygiene and comfort of the patient must be preserved in all circumstances even if specific life-sustaining treatment is withheld or withdrawn.
- 8. The pain and suffering of the minor patient should be a priority concern for all members of the health care team. Effective pain management and palliative care should be a primary goal in the care of all dying patients.
- 9. Medication should be given as indicated for pain or discomfort even if it may tend to hasten death, but should not be used with the primary intent to cause or hasten death.
- 10. Decisions to forgo medically administered nutrition and hydration (e.g. nasogastric tube) are extremely important. Because nutrition and hydration have a powerful symbolic significance, it is therefore particularly important that all members of the health care team fully understand the rationale for any order to forgo medically administered nutrition and hydration.
- 11. Accurate and complete documentation in the medical record of discussions with the parent(s) or legal guardian and minor (as appropriate) is required.
- 12. Physicians should discuss forgoing treatment with other members of the health care team.

II. ROLE OF THE ATTENDING PHYSICIAN:



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- 1. The Attending Physician is responsible for ensuring that the parent(s) or legal guardian receive adequate information to make treatment decisions.
- 2. The Attending Physician shall ensure that the parent(s) or legal guardian understand the choices that are available, including forgoing treatment. It is appropriate for the physician to provide advice concerning forgoing treatment and to make a recommendation to the parent(s) or legal guardian. When confusion or disagreement are present, the Attending Physician is responsible for leading efforts to resolve the situation through discussions with the parent(s) or legal guardian and other members of the health care team (such as Nurses, Mid-Level Practitioners, Social Workers, and Chaplains).
- 3. In keeping with recognized practices, physician-patient confidentiality must be respected in matters related to forgoing treatment.
- 4. When the Attending Physician has an objection of conscience to a forgoing treatment decision, s/he may decline to participate in that course of action. If another Attending Physician is willing to be guided by the parent(s)' or legal guardian's wishes and will accept responsibility for the patient, the care of the patient must be transferred to this Attending Physician. The Attending Physician declining to participate must cooperate in transferring care of the patient to the new physician. A decision to transfer the patient should be made only after diligent efforts have been made to reconcile the views of the physician and parent(s) or legal guardian, and after adequate notice has been given to the parent(s) or legal guardian that the Attending Physician will have to withdraw from the case. Other members of the health care team who have objections of conscience with respect to forgoing treatment decisions shall be accommodated.

III. PROCEDURE:

A. Documentation

The Resident or Attending Physician must document in the medical record the circumstances relating to forgoing treatment. Mid-level practitioners may not write this documentation note or orders to forgo treatment. Documentation must include:

- 1. Summary of the medical situation.
- 2. A statement summarizing outcome of consultations with the parent(s) or legal guardian and, where appropriate, the patient.
- 3. Documentation of discussion with and concurrence of the Attending Physician prior to forgoing treatment. Attending physician must enter a note or co-sign the Resident Physician's documentation.
- 4. The forgoing treatment decision must be reviewed as medically indicated. Documentation must reflect the continued re-evaluation of forgoing treatment status.

B. Notification of Administration of Decisions to Forgo Treatment

In special instances when a decision to forgo treatment involving life support, nutrition or hydration has been made, Administration should be notified. These instances should include the following circumstances:

- 1. When a patient is pregnant.
- 2. When the patient has sole custodial responsibility for the care or support of other minors.
- 3. When the patient is a ward of the court.
- 4. When the patient's condition may have resulted from possible criminal activity.
- 5. When there is a possibility medical treatment may have resulted in the patient's present condition.
- 6. When the parent(s) or legal guardian appear not to act in the best interest of the patient.



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C. Cancellation of Decisions to Forgo Treatment

- 1. The parent(s) or legal guardian may revoke an earlier decision to forgo treatment at any time.
- 2. The Attending physician must also be notified.
- The reasons for revoking an earlier decision must be documented in the progress notes by the Resident or Attending Physician and communicated directly to the Charge Nurse, who shall inform other involved staff immediately of the change in status.

D. Circumstances Under Which a Physician May Challenge a Parent's or Legal Guardian's Authority

- Authority of the parent(s) or guardian to make medical treatment decisions for the patient should not be recognized or relied upon by a physician in any one of the following circumstances:
 - When the parent(s) or legal guardian is not willing, or fails to act as a decision maker for the patient.
 - When the parent(s) or legal guardian appear(s) not to act in the best interest of the patient.
- 2. If, after diligent attempts to enhance communication with the parent(s) or guardian and after consideration of the principles outlined in this policy, a physician believes that a decision by the parent(s) or guardian to forgo life-sustaining treatment for a minor violates professional standards or clearly is not in the best interest of the patient, the physician is obligated to report the matter to the Department of Children and Family 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 parent(s) or legal 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 an agreement with the parent(s) or legal guardian regarding an appropriate course of treatment for the child.

E. The Child Abuse and Neglect Prevention and Treatment Act ("Baby Doe Regulations") The "Baby Doe" regulations are federal statutes that apply to (#1) minors less than one year of age, and (#2) minors older than one year who have been continuously hospitalized since birth, who were born extremely prematurely, or who have a long-term disability. Under these regulations, treatment may be withheld only when, in the treating physician's "reasonable medical judgment", any one of the following circumstances apply:

- 1. The infant is chronically and irreversibly comatose
- 2. The treatment would:
 - · Merely prolong dying, or
 - Not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or
 - Otherwise be futile with respect to the survival of the infant
- 3. The provision of such 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.

The decision to forgo treatment and documentation should be consistent with these



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regulations.

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