Guidelines for Treatment and Life-Support Decision Making for (Minor) Patients

I. Introduction

A. Function and limits of these guidelines

These guidelines are intended to apply only to patients who are minors. Though no set guidelines will anticipate all dilemmas that arise during the care of seriously ill patients, the following guidelines respect the privacy and autonomy of patients and families, encourage care that is in the best interest of minor patients, and assure humane and beneficial treatment.

B. Definitions

The following definitions apply to these guidelines:

1. "Attending Physician" means the staff or faculty physician who has ultimate responsibility for a patient's treatment and care.

2. "Competent Person" means an individual possessing the ability, based on reasonable medical judgment, to participate in treatment discussions and to understand and appreciate the nature and consequences of a treatment decision. Persons under 18 years of age may be competent if they have been emancipated by judicial decree, or if they have been married.

   Note: A person who is pregnant, regardless of age, can make treatment decisions.

   State law also authorizes a minor's consent to treatment if the minor:
   (a) is on active duty with the armed services, or
   (b) is 16 years of age or older residing apart from his/her parents and managing his/her own financial affairs, or
   (c) consents to diagnosis and treatment of any infectious disease, or
   (d) is unmarried and pregnant and consents to treatment, other than abortion, related to her pregnancy, or
   (e) consents to treatment for any condition relating to chemical use or;
   (f) consents to counseling in conjunction with treatment for sexual abuse, physical abuse, suicide prevention, or chemical use.

   In case of doubt about a minor's legal right to make treatment decisions, a decision maker should contact legal counsel.

Parents, regardless of their age, can make treatment decisions for their children.

3. “Decision Maker(s)” means parents, legal guardians, or others legally authorized to make medical decisions for patients, including the Child Protective Services Program of the Texas Department of Protective and Regulatory Services (CPS).

4. “Emancipated Minor” has the meaning it has in state law, which currently is a minor who has received a judicial decree removing the disabilities of minority for general purposes or for limited purposes if one of the limited purposes is to consent to medical treatment. In case of doubt, a decision maker should contact legal counsel.

5. “Incompetent Person” means an individual lacking the ability, based on reasonable medical judgment, to participate in treatment discussions and to understand and appreciate the nature and consequences of a treatment decision. While a child under 18 years of age is normally considered incompetent, a patient’s participation in medical decisions, as may be appropriate given the patient’s age, maturity, and condition, should be encouraged.

6. "Irreversible condition" means a condition, injury, or illness (a) that may be treated but is never cured or eliminated, (b) that leaves a person unable to care for or make decisions for himself or herself, and (c) that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.

7. “Life Support” means a medical or surgical procedure or intervention (including, but not limited to, the provision of nutrition or hydration, dialysis, medication and resuscitation) that uses mechanical or other artificial means to sustain, restore or supplant a vital function and without which the patient will die.

8. "Minor” has the meaning it has in state law, which currently is a person under 18 years of age who has never been married, or who has not had the disabilities of minority removed for general purposes. In case of doubt, a decision maker should contact legal counsel.

9. “Physician” refers to the designated physician to be contacted in case of a patient emergency.

10. “Resuscitation” means cardiopulmonary resuscitation or other techniques (such as defibrillation or the administration of anti-arrhythmic or other drugs)

that are used with the intent to reverse the sudden loss of function of the cardiac or pulmonary system.

11. "Terminal Illness" means an incurable condition caused by injury, disease or illness, which, even with the application of life support would, within reasonable medical judgment, produce death within six months, and where the application of life support serves only to postpone the death of the patient.

C. Presumption in Favor of Life
In case of doubt, or until appropriate consultation has been obtained, treatment decisions should be made toward preserving life.

D. The Physician's Responsibility
It is the physician's responsibility to initiate the dialogue regarding treatment, although the patient or family also may initiate the treatment dialogue. In addition, before an order to withhold or withdraw life support is written, the concurrence of the attending physician as to the appropriateness of the order should be obtained. These guidelines are offered to assist the physician in acting within the best standards of the profession and the dictates of conscience.

E. Involving Ethics or Legal Counsel
In cases that are unclear legally or ethically or in which there may be disagreement between the various parties involved, including physicians, nurses, family, chaplains, and others, the Institutional Ethics Committee and legal consultation are available for either prospective counsel or retrospective consideration.

If any participants conclude that a decision would constitute neglect or abuse of the patient, legal counsel should be consulted immediately.

F. Role of Other Members of the Health Care Team
"Do Not Resuscitate," "Discontinuing Life Support" and "Refusal of Treatment" questions are by necessity spiritual, emotional and interactional. Pastoral Care and other patient support services can be utilized by patients, their families or surrogates, nurses and physicians during the decision making process. Adequate confidence in the accuracy of the diagnosis and prognosis should be assured. There should be general agreement within the health care team regarding these factors before important treatment decisions are made.

G. Physician Documentation
In all cases to which these guidelines apply, the physician will complete an "Order Form for Withholding and Withdrawing Life Support" to communicate this decision to other health care providers. A progress note documenting the discussion between a physician and the patient, the patient's family, or the patient's surrogate should also be entered in the patient's medical chart. The

progress note should also include identification of participants in the discussion, a description of the decision making procedures and decision agreed upon.

H. Relationship to the Texas Advance Directives Act
These guidelines are to be interpreted consistent with the Texas Advance Directives Act. The guidelines also apply to situations not covered by that Act. Both that statute and these guidelines are to be applied with compassion and sensitivity.

II. Refusal of Medical Treatment

A. The patient's attending physician shall become involved as expeditiously as possible with any case involving refusal of treatment.

B. The physician must inform the competent decision maker(s) of: (1) the relevant consequences of their refusal of treatment, (2) alternative therapies available, (3) actions that may be taken in the event of life-threatening emergency, (4) physician and institutional transfer options and (5) other pertinent information.

C. The competent decision maker's refusal of a medical treatment may, in the medical judgment of the patient's physician in light of the known circumstances at the time of refusal, render certain other care inappropriate or useless.

D. The refusal of any or all medical treatment by a patient or competent decision maker will in no way compromise or diminish care that benefits or respects the dignity of the patient.

E. A patient's pregnancy does not affect the application of these guidelines.

F. If a patient has no competent decision maker, the Child Protective Services Program of the Texas Department of Protective and Regulatory Services (CPS) should be consulted.

G. The Institutional Ethics Committee may be consulted in any case in which a patient or competent decision maker refuses treatment.

III. Withholding and Withdrawing Life Support

A. General

1. Doubt resolved in favor of treatment
If the physician, patient, family members or other competent decision makers disagree on the matter of whether or not to discontinue life support, the life support should be continued until the disagreement is resolved or the procedures described in Part IV of these guidelines have been completed.

2. Nontreatment of patient who is dead
   A patient whose status is described as dead by the Texas Determination of Death Statute should be removed from life support.

3. Role of physician
   a) As appropriate, the decision to withhold or withdraw life support should be made in consultation with the attending physician or the attending physician's designee.
   b) Life support should be withheld or withdrawn by the patient's physician, not by other medical caregivers.
   c) A physician involved in obtaining organs for transplant patient should not be the person who pronounces death or who discontinues life support.

4. Documentation
   a) When a decision is made to withhold or withdraw life support, the patient's physician should complete the "Order form for Withholding and Withdrawing Life Support" and enter a progress note on the patient's medical chart that:
      1) describes the patient's diagnosis and prognosis,
      2) identifies the persons with whom the consequences of and the alternatives to the decision were discussed and that describes that discussion;
      3) lists the reasons for deciding against life support, and
      4) confirms the agreement of the appropriate person or persons.

   b) A "Do Not Resuscitate" order must be in writing, unless the patient's physician is present during the cardiopulmonary arrest.

5. Continuation of Other Care
   Even though life support is discontinued or withheld, that should in no way compromise or diminish other treatments and care that provide physical and psychological comfort or respect the dignity of the patient.

6. Resuscitation
   a) In the absence of a written "Do Not Resuscitate" order signed by the patient's physician, all patients will receive full resuscitation for cardiac or respiratory arrest. The preceding sentence does not apply if a valid "Out-of-Hospital Do-Not-Resuscitate Order" has been executed on behalf of the patient and the patient is in the Emergency Department or in an out-patient setting. When the patient's physician is present, a written order is not required.
   b) Once resuscitation has been initiated, it should be stopped only by the patient's physician. If the patient's physician is not available,

resuscitation can be stopped when the physician directing the resuscitative efforts decides that resuscitation is unsuccessful.

c) A "Do Not Resuscitate" order should be reviewed by the patient's physician at least every three days, but remains in effect until it is canceled by the patient's physician. If changing clinical status makes such an order inappropriate, it should be canceled.

d) All "Do Not Resuscitate" orders and/or Advance Directives are suspended while in the operative suite unless special circumstances are discussed prior to surgery on an individual-case basis by the surgeon, the anesthesiologist, and the patient or competent decision maker and documented in the patient's chart.

B. <u>Withholding and Withdrawing Life Support</u>

1. If the physician, family members, and other competent decision makers agree~~s~~ whether or not to discontinue life support, that decision should be respected. A patient's participation in the decision, as may be appropriate given the patient's age, maturity, and condition, should be encouraged. The family members or other competent decision makers, and patient, if appropriate, should be fully informed of the nature of the illness, the prognosis, and the consequences of a decision whether or not to discontinue life support.

2. When the patient's participation in the decision is appropriate, if the patient and the patient's family disagree with each other on the matter of withholding or withdrawing life support, consultation may be sought with the IEC.

3. If the competent decision makers refuse life support, and that decision would not constitute medical abuse or neglect of the patient, but the patient's physician disagrees with that decision, whenever possible, the physician should identify other possible physicians to whom the care of the patient may be transferred. If a reasonable effort to arrange a transfer is unsuccessful, the procedures described in Part IV of these guidelines should be followed.

4. If the patient is terminally ill or has an irreversible condition and the patient's physician and family or other competent decision makers agree~~s~~ that the continuation of life support offers only the prolongation of dying without proportionate benefits, then life support should be discontinued.

5. If a patient who is terminally ill or has an irreversible condition has no family or competent decision maker available and the patient's physician judges that further treatment would be useless and burdensome to the patient, the Child Protective Services Program of the Texas Department of Protective and Regulatory Services (CPS) should be consulted.

IV. Refusal to Honor an Advance Directive or Treatment Decision

Physicians sometimes disagree with an advance directive or a surrogate decision maker's treatment decision to withhold or withdraw life support. In addition, because of continual and rapid progress in medical knowledge, patients or families may occasionally request or demand treatments that are without benefit from the physician's perspective. No physician should be forced to withhold or withdraw life support when doing so would be contrary to the physician's conscience or professional judgment. Similarly, no physician has a duty to provide useless or futile treatment, but often what constitutes useless or futile treatment is controversial among physicians as well. It is with these principles in mind that the following guidelines are offered. These guidelines are intended to ensure that only reasonably effective medical treatments are given, yet allow patient/family choice when physicians are divided in their opinion regarding therapeutic efficacy.

If a family or other competent decision maker, or patient in appropriate circumstances, requests or refuses a "life-saving" or "life-preserving" treatment, and the physician refuses to honor the treatment decision or the advance directive upon which it is based, the following procedures should be followed. Steps A through E are required by Texas law as a precondition for immunity from civil and criminal liability and professional discipline:

A. The attending physician (or a designee of the attending physician) shall request a consultation with the Institutional Ethics Committee.
B. The patient's surrogate decision maker shall be notified of the time and place of the consultation at least 48 hours before the meeting is to occur, unless the time period is waived by mutual consent. The surrogate shall be offered the opportunity to attend the consultation. If reasonable efforts to locate a surrogate decision maker fail, the Institutional Ethics Committee shall be consulted.
C. After the consultation is completed, one of the co-chairs of the Institutional Ethics Committee shall prepare a summary of the meeting in a format that has been approved in advance by the Institutional Ethics Committee. The summary shall be given to the surrogate and copies both placed in the patient's medical record and retained by the Institutional Ethics Committee.
D. Additional requirements apply if (i) the surrogate has requested life support that the physician deems to be useless and without benefit and (ii) the Institutional Ethics Committee does not disagree with the physician's conclusion. Life support shall be continued for at least ten days, starting on the date a summary of the Institutional Ethics Committee consultation is delivered to the patient or the surrogate decision maker. The Texas Advance Directives Act provides that the physician should not indicate in the patient's medical record that the disputed treatment is medically unnecessary until the expiration of this ten-day period. If the physician or patient's surrogate does not agree with the decision reached during the consultation, a reasonable attempt shall be made to transfer the patient to another physician, another care setting within the hospital, or another facility.

E. If the physician believes the procedures described in subparagraphs (A) through (D) should not be followed, life support should be continued and both the Institutional Ethics Committee and the legal department should be consulted.
F. If life support that is required by these procedures can be provided to the patient only by denying life support to another patient, the physician should contact the Institutional Ethics Committee.
G. If for some reason the conditions in A through F above have not or cannot be met, the disputed treatment should be administered until these conditions have been met.
H. Providing or denying a disputed treatment should not affect the provision of other treatments that benefit the patient.

V. Out-of-Hospital "Do-Not-Resuscitate Order"

A. Definition: The physician and the parent(s), guardian, or managing conservator of a minor patient who is discharged from an acute care setting may desire that a do-not-resuscitate order be written. When properly executed this procedure permits Emergency Medical Services, Emergency Department, and out-patient personnel to withhold resuscitation efforts if called to assist this patient. Out-of-hospital DNR Orders executed in other states are valid in Texas.

B. Procedures
1. The patient's physician obtains a package of material from the Pastoral Care Department. This package will include the state form (the original cannot be photocopied prior to execution), the patient's bracelet, and information concerning the form. Chaplains will be trained to assist in the technical details of completing the form as such assistance is required.
2. The form must be signed by the patient's parent, legal guardian, or managing conservator and by the patient's physician.

3. Two witnesses, at least one of whom is not involved in the patient's health care and is not related to the patient, must witness the signature(s).

4. The original of the form is to remain in the possession of the patient or with the patient's parent, legal guardian, or managing conservator. One copy of the form is placed in the patient's medical record. Other copies may be distributed to family members as the patient or patient's surrogate desires.

5. An identifying bracelet will be placed on the patient's arm which must be worn at all times or the Out-of-Hospital DNR form (either the original signed form or a photocopy) must be immediately available to the responding healthcare professional.

Reference: Board of Managers Policy Manual Section V