

SUBJECT
LIFE SUSTAINING TREATMENT, INITIATION OF
ORDER TO FOREGO OR DISCONTINUE

APPROVED BY

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INTRODUCTION

At the core of the clinical mission at Childrens Hospital Los Angeles has always been a commitment to providing the highest quality, most compassionate family-centered care to children with serious illness.

At no time is this commitment more significant than at the end of life. Most patients receiving care at Childrens Hospital recover fully from their acute illnesses or enter a stable chronic state consistent with a productive life outside of the hospital. However, some patients, despite the best of efforts, experience progression of underlying acute or chronic illnesses such that the inevitable outcome is death. In such situations, the foregoing of life-sustaining treatments is an acceptable option among potential management plans for these patients.

The process of maintaining dialogue about clinical care between patient, family and health care team is no where so important as in the context of the management of the dying process. In an effort to facilitate the implementation of this dialogue, the Ethics Resource Committee of Childrens Hospital has compiled the following group of documents. These documents are designed to provide guidelines for the members of the medical professional staff, the medical house staff, and the allied health professional staff in initiating discussions with patients and families about the issues surrounding impending death and in carrying out any advance directives which may result from these discussions.

A substantial proportion of patients hospitalized at CHLA who require consideration for foregoing of life-sustaining treatments have either acutely or chronically been receiving some forms of advanced supportive treatment (e.g. chronic ventilatory assistance, in ICU on inotropic agents, on dialysis, etc.). Therefore, in order to alleviate some of the confusion on the part of healthcare providers re implementation of these policies in different clinical contexts, we have provided guidelines for three clinical settings: 1) Non-critical care medical/surgical setting; 2) Non-ICU chronic ventilator setting; 3) Critical Care setting (PICU, CT ICU, NICU).

Although we would strongly encourage all medical and allied health professional staff to peruse the documents in entirety, the table of contents and topics index should allow ready access to pertinent material for specific clinical situations.

These documents represent the management policies surrounding the end of life which are currently in effect in this hospital. Any questions, concerns or problems with interpretation are to be directed to the Ethics Resource Committee, which may be contacted through the Medical Staff Office, x2270 during regular business hours, or through the Administrator of the Day, after hours.

PROCEDURE

Non-ICU General Medical-Surgical Patient Care Units:

MAKING THE DECISION

When a patient's prognosis, in the best opinion of the healthcare providers, has become irreversibly poor, the treatment of choice may be to forego advanced life-sustaining treatment. Life-sustaining procedures are defined as any medical procedures or interventions which utilize mechanical or artificial means to sustain, restore, or supplant a vital function and which would only serve to prolong the process of dying. In some very limited circumstances, this definition will also include artificial feeding. Decisions should be made after assessing whether the treatment is proportionate or

disproportionate. (See glossary)

There is no ethical or legal distinction between discontinuing and never initiating advanced life support measures.

Every necessary procedure should be performed to relieve the patient's suffering and to maintain the patient's comfort, hygiene and intrinsic human dignity.

PROCEDURES FOR ISSUING ORDERS

A. WHO MUST BE CONSULTED

Before writing a "Accept Natural Death (AND)" order, the primary attending physician will need to confer with the patient's family, the patient (in certain circumstances), and appropriate members of the healthcare team, including consulting physicians, nurses, and social workers. For further discussion and review of the circumstances when a child may be included in the discussions refer to Appendix D, Medical-Legal Issues.

A consultation with the ERC is always available to help clarify ethical issues surrounding a particular situation. This consultation is encouraged in those situations where there are medical contraindications to pursuing further treatment but patient and family disagree., or vice-versa (if there is conflict regarding a planned course of action)

The intensivist for the appropriate unit should be consulted if the patient is in or will be transferred to an Intensive Care Unit (BMT, NICU, PICU or Cardiothoracic ICU). Institution of an "AND" order does not preclude the beginning or continuation of other therapies which may require ICU care. (See Section below for Critical Care Units.)

B. DOCUMENTATION

All orders to withhold or withdraw life-sustaining treatment must be documented in the Physician Order Sheet in the electronic medical record (EMR) by the primary attending physician or another attending designated by the primary attending. The physician must also verbally inform the nursing staff that such an order has been given.

The orders must be re-evaluated at least every 96 hours, and more often when medically indicated. All reviews must be documented in the "Notes" section of the patient's EMR. The order does not expire, however, and does not need to be rewritten.

In the event that the management plan changes and resuscitation efforts are once again included, an order must be written to rescind the "AND" status. Progress notes should be written accordingly.

At the time of consideration to forego or discontinue life-sustaining treatment, the medical team should discuss whether to continue other treatment the patient is receiving. (See Appendix B, Concurrent Care Issues). The primary attending physician must document in the progress notes all the circumstances surrounding the orders. The note shall include a synopsis of:

The patient's medical situation including the diagnosis, prognosis, mental status and test results; all risks and possible complications of treatment that can be provided, as well as their potential benefits and burdens.

Consultations with other physicians and other healthcare team members.

Discussion with the patient and/or specifically identified decision-maker (s) including what information was given and the decision of the patient and/or decision-makers. (See Appendix D, Medical-Legal Issues for guidelines regarding the definition of adult and minor patients with respect to the "AND" consent process.)

Discussion with the pertinent healthcare team members, patients, parents, family and any other interested and involved parties.

In the event of disagreement, see Appendix F, Communication.

C. VERBAL ORDERS

Verbal orders are acceptable when the following conditions are met:

Verbal orders for AND will be accepted if, and only if, a prior AND status has been established, written, and signed by the attending physician prior to the need for verbal orders for AND (i.e., as an outpatient or during a previous admission).

When a patient well known to CHLA as an AND patient arrives in the ER or is a direct admission to the hospital, the patient's primary attending physician will be contacted by telephone and asked about the AND status. If the patient remains an AND patient, the attending physician may give the verbal AND order by telephone.

The telephone conversation with the primary attending physician must be verified by two individuals-- RNs or MDs--and an appropriate dated and timed entry made in the chart documenting the nature of the conversation. Both individuals who listen to the conversation must sign the progress note.

A verbal AND order must be verified in the patient's EMR by the attending physician within 24 hours of the order having been authorized.

D. PARTIAL "AND"

Cardiopulmonary resuscitation (CPR) will be initiated for cardiac or respiratory arrest, unless an "AND" order is written. Hospital policy specifically forbids the issuance of partial "AND" Orders. An "Accept Natural Death" order implies that neither basic nor advanced life support measures will be initiated.

CPR was developed as a means to reverse cardiorespiratory arrest in a patient whose death was not expected. If CPR is to be initiated, it should be with the express intent of preserving life. Limited resuscitation (i.e., manual ventilation, but not intubation or "cardiac compression but do not use resuscitation drugs," or "walk slowly to the arrest," or "slow code," etc.) does not employ the technique and therapies used in CPR in a manner most likely to avoid the death of a patient. Such orders represent an inappropriate application of this mode of medical therapy and should not be written.

E. SPECIAL CIRCUMSTANCES

In a situation where the patient is already on advanced life support (a ventilator, ECMO, etc.) an "AND" order may still be appropriate. This order shall indicate withholding of cardiac massage and foregoing escalation of advanced life support modalities. (See sections below for Non-ICU Ventilator unit and Critical Care Units.)

Clinical research - All ethical and legal principles apply equally to patients who are participating in clinical research.

Operating Room

An "Accept Natural Death" order will be automatically suspended when the patient is taken to the Operating Room. The order will remain suspended while the patient is in the operating room and the recovery room. This information must be communicated to the patient's surgeon, as well as the patient's family and other interested parties. The "AND" order will be reactivated when the patient is transferred out of the recovery room, unless the surgeon orders otherwise. The surgeon may order continued suspension of the "AND" order for up to twenty (20) hours after the time the patient leaves the recovery room. The surgeon's order shall be in writing. The "AND" order will thereafter be reactivated unless the patient's attending physician specifically discontinues the "AND" order.

"AND"/No Code Orders in O.R. - Operating Room

The current policy of suspension of "AND"/No Code orders for patients with such an existing advanced directive will continue to be the norm. However, consideration of the following should be made and documented appropriately in the Medical Record in the Informed Consent note:

The clear indications for the surgical procedure in the context of a terminally ill patient, i.e. for palliation, for improved comfort/quality of life, for an achievable therapeutic though perhaps short term goal.

The patient/family has been directly informed that usual custom and practice is for suspension of "AND"/No Code orders occur during the time the patient is in the operating room/recovery area, but that the orders will be reinstated thereafter. The patient/family must have the opportunity to understand the implications of their decision to proceed with the planned surgical procedure. In some situations, it is conceivable that a patient/family may choose instead to forego the surgical procedure. It is the responsibility of the attending surgeon (with the assistance of the primary physician, if not the same person) to assist the family in balancing the potential benefits vs. the potential burdens of the proposed surgical procedure.

Under ideal conditions, both the Attending Surgeon (and primary physician if not the same as the surgeon) and Attending Anesthesiologist will have conferred with the patient/family together such that the decision to proceed represents a true consensus. Nevertheless, at minimum, the Attending Surgeon/Primary Physician should be the direct participant in discussions with the patient/family under these circumstances.

Under very rare and exceptional circumstances, a consensus might be reached that foregoing "CPR" in event of abrupt circulatory arrest would be appropriate in the operating room/recovery area. The following conditions should be met and documented appropriately in the Informed Consent Note for such plan to be implemented:

The cardiac arrest is not a result of an easily reversible effect of anesthesia but to the progression of the underlying disease process (e.g. intractable sepsis/DC associated with widespread bowel necrosis).

Circulatory and respiratory support is carried out according to the usual standard of care in the operating room and that "pre-arrest" conditions are treated in the usual fashion.

The proposed surgical procedure is clearly indicated, i.e. for the purposes of establishing a more certain prognosis, or for curtailing a rapidly progressive lethal condition such as progressive bowel infarction and other similar situations.

The patient/family understand and accept that death from the underlying disease process is likely in the immediate short-term and might coincide with the needed surgical procedure.

The Attending Surgeon (and Primary Physician if not he same as the Surgeon) and Attending Anesthesiologist and agree that resuscitation may be foregone and have both discussed this issue with the patient/family and secured their assent.

III. The patient's primary attending physician shall be responsible for determining the circumstances surrounding the discontinuance of mechanical life support system.

Non-ICU Ventilator Care Unit:

Patients who are on chronic ventilator assistance either at home or in a subacute care residential facility may be hospitalized acutely in the Non-ICU Ventilator Care Unit at CHLA. Some of these patients will experience significant decline in status and prognosis such that discontinuation of assisted ventilation and/or foregoing of circulatory support (i.e. inotropic agents or cardiac massage) and further resuscitative becomes appropriate. In those cases, the procedure described above should be followed. However, there will likely be two scenarios:

Discontinuation of assisted ventilation, foregoing of CPR. Pain management as appropriate. Chronically implanted devices, such as tracheostomy tubes, will be retained and undisturbed. Continuation of assisted ventilation, but in event of either respiratory decline and/or circulatory insufficiency, no escalation of ventilation and foregoing of circulatory assistance (cardiac massage and inotropic agents.) In this circumstance, continuing assisted ventilation DOES NOT constitute a partial "AND".

Critical Care Units

Most patients admitted to any of the critical care units are already receiving some form of advanced life-sustaining treatment. In some patients, the intensity of therapy could be defined as "continuously resuscitative." When, in the medical judgment of the treating attending physician, the patient no longer derives benefit from the therapy, particularly if the therapy has been advanced to "toxic" levels, then an appropriate management plan includes either foregoing continued therapy or at least reduction of therapy to "sub-toxic" levels. In addition, the provision of cardiac resuscitation (e.g. cardiac massage) may be futile and can be withheld. In critically ill patients who demonstrate poor or non-response to treatment and where the ongoing care constitutes continuous resuscitation, the foregoing of further ineffective treatment or of potentially harmful (toxic) treatment resides within the attending physician's judgment re appropriate levels of beneficial management. Patients/families should always be closely informed, but cognitive dissonance on the part of families is expected and may often result in significant disputes between the healthcare team and the family. The Ethics Resource Committee should be consulted for evaluation of the situation in cases where the dispute seems intractable.

In the Critical Care Units, when foregoing of life-sustaining treatment is considered, the policies listed above should be followed.

Three likely scenarios may result:

Discontinuation of assisted ventilation as well as circulatory support with foregoing of any further or additional resuscitative measures.

Continuation of assisted ventilation, but with continuation of current levels of support. In event of respiratory decline and/or circulatory decompensation, no additional resuscitative efforts will be made and there will be no Escalation of Care (EOC). This DOES NOT constitute a partial "AND".

Continuation of assisted ventilation, but with curtailment of circulatory support (i.e. inotropic agents), curtailment or foregoing of other supportive technologies (e.g. dialysis). In event of respiratory decline and/or circulatory decompensation, no additional resuscitative efforts will be made. This DOES NOT constitute a partial "AND".

APPENDIX A - ETHICAL CONSIDERATIONS

The central principle most commonly used at present in contemporary American Society as the ethical foundation for foregoing life-sustaining treatment is that of Respect for Autonomy as expressed by Patient Self Determination. For the pediatric patient, this means that health care professionals have obligations to discern and respect the wishes of their patients and families (frequently acting in the capacity of surrogate decision-makers) concerning willingness to undergo or forego treatment. The respect for autonomy pervades the entire professional-patient relationship and is most readily visible in the informed consent process, in itself an expression of the principle of Fidelity or obligation for Truth-telling. Obligations to respect autonomy and provide sufficient information about clinical status, likely effectiveness of proposed treatments and prognosis for patients is especially important in situations where the inevitable outcome is death and where potential treatments are unlikely to be of significant benefit in forestalling the outcome. [See Appendix G, Guidelines For Obtaining Informed Consent.]

Health care professionals also have obligations to act towards their patients under the principle of Beneficence, that is, the positive obligation to do good. It is this ethical principle which could be said to be the cornerstone of the so-called Virtue Ethics and is also the most frequently cited justification for potentially misguided paternalistic behavior on the part of health care professionals towards patients and their families. The presumption in the case of minor and/or incompetent children, is that their family caregivers act on behalf of the best interests of those children and that those best interests assessments are shared by the health care professionals involved. Most frequently, these obligations are carried out in the form of providing, rather than discontinuing treatments. Therefore, inherent conflicts may seem to exist between this principle and that of Respect for Autonomy in the context of foregoing life-sustaining treatments, since preservation and sustaining of life are often regarded as goods in and of themselves. The potential discordance between patient-family views and those of health care professionals on the Goods of either continuing or discontinuing treatments is often the basis for ethical disagreements and dilemmas embedded in the management plans for pediatric patients. Discordance results from the difficulties of defining Best Interests for individual patients.

All persons exist within a context of relationships with others. This is, of course, particularly true of pediatric patients, most of whom have a well defined context of family or other caretakers. For these patients, there is also the context of relationship with the health care professionals involved in treatment. The so-called Ethic of Care describes such relationships as transcending the roles of rights and obligations which might be active in the therapeutic relationship. In other words, both family/caretakers and health care professionals are likely to be impelled to act on behalf of patients, not only because the patients have rights to be treated and that there are obligations to provide treatment, but also because family/caretakers and health care professionals have attachments to patients. These attachments can be seen as expressions of empathy and identification such that impulses either for or against continued treatment are based on substituted judgment; i.e. "What I will choose for my loved one or my patient is what I would choose for myself." Divergent values about the goods of accepting or refusing treatments between patient and family and health care professionals may lead to ethical disagreements and dilemmas.

Competing ethical principles and contexts are often the basis for significant disagreements as to the course of right-action in the management of pediatric patients. Given the grave nature of the clinical outcomes in situations of foregoing life-sustaining treatment, it is particularly important to develop a coherent and consistent basis for managing treatment at the end of life. Appeals to specific ethical principles or ethical systems are often unsatisfactory in attempts to reconcile divergent views on the proper course of action because of the divergent Value Systems inherent in those divergent views which result in differing rankings in primacy of those ethical principles. A more satisfactory and successful approach to developing patient management plans within an ethical context has been articulated recently: this is the notion of Balancing Benefits (of treatment) vs. Potential Burdens (associated with

treatment). Where the burdens exceed the benefits, there is no ethical obligation to provide or continue treatment. Furthermore, there may be a positive obligation to discontinue or withhold the particular treatment under consideration. The global nature of this equation allows for considerations of the greater family context and may provide additional justifications beyond the strictly medical ones for both continuing or discontinuing treatment based on patient-centered and determined quality of life issues. Implicit in these obligations, and less often articulated, is the obligation to maintain respect for the autonomy of individual health care providers. Consensus as to the most appropriate management plan for each patient is often imperfect. Under such circumstances minority dissenters whose value systems will not permit accommodation of a management plan may choose to be Conscientious Objectors and be excused from further participation in the plan. (See CHLA P&P MHR 47.0, Staff Rights)

The need to provide and/or continue Measures for Comfort or Pain for all patients cuts across all of the cited systems of ethical principles. The minimizing of pain empowers patients and their families to quell suffering, to participate more fully in achieving the goals of their remaining lives, ensures a positive balance of benefits vs. burdens of continued life, and clearly fulfills the obligations to do good, or to act beneficently. Therefore, regardless of the approach to management of the dying patient, a cornerstone of any plan is the Management of Pain and Suffering. (See CHLA P&P COP 12.0, Management of Pain in Infants, Children, Adolescents and Young Adults)

In summary, given the complex nature of values assessments between patient-family and health care providers in the clinical context near the end of life, the recommended approach by the Ethics Resource Committee to the discernment of right-action is that of Balancing Benefits vs. Burdens.

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2. Nolan K: Ethical issues in pediatric pain management. In **Pain in Infants, Children, and Adolescents**. Williams & Wilkins, 1993. Pp. 123-132.
3. Gunderman RB: Medicine and the question of suffering. **Second Opinion**, Volume 14, 1990. Pp. 15-25.

APPENDIX B - CONCURRENT CARE ISSUES

The decision to obtain an "Accept Natural Death (AND)" order on a patient often eclipses the complex and emotionally difficult issues which must be addressed in order to support the patient and the patient's family. The following guidelines will promote comprehensive management of the dying patient. The physician who writes an "AND" order is accountable for the documentation that all appropriate issues have been addressed within twenty-four (24) hours of the "AND" decision. This documentation will communicate to all caregivers the patient and family decisions which may be crucial to certain medical decisions to be made during the process of dying.

The role of the family (or established surrogates) during the ordeal of a child's dying is essential and legally protected. It is the policy of this institution to promote the family's involvement in difficult decisions. Given the nature of the parent-child relation, all due respect must be paid to the family's wishes. In order for these wishes to be well-informed and in order to diminish regret which families may suffer as a result of the difficult decisions they make, we require involvement of the family at every step of the way, and promote respect for their decisions. In investigating options, physicians and families should be sensitive to the issues of the benefits of an action versus the burdens which the action may precipitate. The physician has a responsibility to offer only feasible options which have a reasonable chance of returning the child to a condition of comfort and sentient life. In the case of a dependent child, the family must participate in the definition of burden. If, in any case, a family makes a decision with which a physician or other healthcare-giver is at odds, the caregiver may consider delegating the responsibility for the child to a caregiver in concert with the family.

The case of an older, cognitively developed child is especially difficult. The degree to which these children participate in the decisions regarding the management of dying must be determined on an individual basis. But, in general, the same principles as above should be followed: families should have the final say in how to involve an older child in the decision-making process. We may advise, but we must defer to their decisions, keeping in mind the best interests of the patient. (See Appendix D, Medical-Legal Concerns for guidelines as to minors' rights to consent to medical treatment, and CHLA P&P ETH 20, Assent)

In this tertiary care institution, most patients will accumulate a team of highly specialized and skilled physicians. Identifying and making the difficult decisions regarding the management of dying may be complicated by dissent amongst the members of this team. Usually, a primary attending is identifiable, even when the patient has entered the ICU. It is the policy of this institution to promote the identification of the team leader when issues of dying are involved, and whenever possible, to allow the primary attending physician to orchestrate the formalities. It is essential that the primary attending physician work closely with all other healthcare team members, including staff in the intensive care units, as decisions are discussed and made. (See Appendix F, Communication)

Nursing Staff and social workers familiar with the case must be involved at each step of the way. They are ultimately responsible for the implementation of the orders and decisions, and have a perspective on the situation which is unique to their professions and essential to the process of making effective decisions. What follows is a list of concerns for caregivers to use in the formulation of a management plan for any patient for whom an "AND" order is written. The weight of importance for each issue will vary according to the clinical picture, but each issue would be addressed, even if briefly. Spiritual needs and pain management needs must always be addressed, and the plan for meeting those needs must be clearly documented in the chart.

- 1. Assisted Ventilation:** If the child is intubated, under what conditions would the family wish for extubation? The family should be well-informed as to the physical and emotional consequences of extubation. Before extubation, consideration must be given to the presence of neuromuscular

blockades. In most cases additional pain medication is given to ensure comfort during extubation/discontinuance of ventilatory support.

2. Dialysis: If renal failure is likely, the patient's family must understand the risks and benefits of dialysis. Particularly difficult will be those situations where dialysis will prolong life in a burdensome way. We should try to inform families sufficiently to enable them to make a decision in concert with their deepest values.

3. Blood Products Support: Families need to be aware of the benefits versus the burdens of blood products support so that they may make decisions regarding various options. In most cases, such support should be offered when it primarily promotes comfort. For example, platelets which help control bleeding may prevent the discomfort of bleeding while packed cells might inadvertently prolong the dying process.

4. Antibiotics/Chemotherapy: At some point, antibiotics may become a last barrier between life and death where death is inevitable. In this case, antibiotics could be defined as futile care. The family and the healthcare team must be alert to this issue so that a decision to discontinue antibiotics may be addressed, especially where antibiotics such as amphotericin or certain chemotherapies cause great discomfort to the patient.

5. Pressor Drugs: In general, these drugs should not be started in the presence of an "AND" order as this action would represent a "partial code." In fact, pressor drugs may, in some cases, need to be discontinued where their sole action will be to prolong life in a burdensome way. There may be circumstance where a patient is on pressor drugs before issuance of the "AN" order; in this case, a decision may be made to continue but not to escalate care.

6. Vital Sign Frequency/Non-invasive Monitoring: When a patient is dying, the purpose of monitoring changes. The use of monitors or other assessments of vital signs should be used primarily to promote comfort and minimize disturbance. The need for documentation of vital signs will usually decrease.

7. Nutrition and Hydration: Controversies abound surrounding the appropriateness of withdrawing nutritional and hydration support. In some cases, nonetheless, it will be appropriate to provide aggressive support, especially when families' religious values dictate this. Caregivers should keep this inevitable controversy in mind, however, when total parenteral nutrition is discussed. It may be emotionally easier to forego than to discontinue. In cases where withdrawal of nutrition or hydration is being considered, the Ethics Resource Committee (ERC) shall be consulted to protect the patient, the family, and the staff regarding ethical liabilities. Risk Management and the Hospital's Legal Counsel serve on the ERC to assist in identifying institutional liability exposures. (Refer to CHLA P&P MHR 47.0, Staff Rights)

8. Invasive Monitoring: The healthcare team should refrain from invasive techniques on a patient who is dying except when the invasion can be justified for refining a pain management plan.

9. Diagnostic Tests: At the point where caretakers and family agree that the dying is inevitable, certain invasive diagnostic tests should be foregone except where comfort measures may be improved by the clarification of a clinical finding.

10. Pain Management: In all cases where an "AND" order has been written, the pain management plan must be clearly indicated in the chart within twenty-four (24) hours. The difficult issues of the perceived conflict between comfort and promotion of death must be made clear, to all healthcare providers and to the family and the patient where appropriate. (See Appendix C, Comfort Measures)

- 11. Spiritual Needs:** Especially in our community where cultural diversity is profound, understanding and acceptance for ritual which may differ from one's own must be promoted. The family should be encouraged to articulate their spiritual preferences regarding life, death, and dying as early in the process as possible. These preferences then must be well documented in the chart and communicated to caregivers. All effort should be made to allow for the expression of these spiritual values, within guidelines for safety and health of all. (See Appendix K, Spiritual Needs)
- 12. ICU Transfers:** In general, patients with an "AND" order should remain on the patient care unit where staff knows them best, so that comfort and privacy may be provided. In some cases, where management is complex, ICU transfer may be necessary. This likelihood should be described to the family in advance whenever possible, to minimize the emotional trauma of connecting with new staff at this difficult moment.
- 13. Discharge Planning, Hospice Planning:** A large percentage of patients with an "AND" order, especially in the pediatric population, may actually survive to discharge. Some families may request assistance in planning for comfortable dying in the home. Explicit provision should be made for documentation of the "AND" status for caretakers who may encounter the patient on an outpatient basis. (See Appendix H, Sample "AND" Letters, CMA form)) Every effort should be made to give a realistic picture of the benefits and difficulties of managing a death at home. Clinicians should contact our institutional resources for planning and providing for hospice care as soon as discharge looks likely as this planning is complicated and detailed.

APPENDIX C - GUIDELINES FOR PROVIDING COMFORT MEASURES

A. What Do We Mean By Dying? The question of who is to be considered terminal may provoke uncertainty within the healthcare team when making treatment decisions. Cohen (1982) provides an insightful report of one medical center's ethics committee's conclusions as follows: "...to expect what cannot reasonably be expected is to deny medicine any basis whatsoever in science and rationality, and also to risk a miserable death for a great number. A patient is considered to be terminally ill if it is medically determined that he or she suffers from an irreversible disease process (or combination of these) that bears a reasonable probability of directly causing the death of the patient in the foreseeable future."

B. The Dilemma: Pain control touches the heart of clinical practice as the twin goals of health care (prolonging life and reducing suffering) come dramatically into conflict (Lisson, 1987). Physicians and nurses may have different perspectives regarding the definition of "dying." Nurses are less reluctant to classify a patient as dying and more readily turn the focus of care from a "cure" to "comfort orientation, as their education has prepared them for. "The dying person, who can no longer benefit from aggressive curative therapy, represents a defeat of medicine's goals. It is the obligation of both professions to recognize these differences...and understand when they result in interprofessional conflict about ethical dilemmas" (Muller and Koenig, 1988). Physicians, however, most often have been steadily trained to focus on "cure". A patient's death may represent a failure of all that the physician has strived for.

C. Common Misconceptions and the Facts

1. Misconception: Providing adequate pain relief through the use of opioids may shorten a patient's life by depressing respiratory effort and thus be akin to euthanasia.

Fact: The incidence of serious respiratory depression in patients who receive opioids is low providing that the drug is given by experts on timing, dosage, method of administration and indications and technique for reversal. Less than 1% of patients who receive opioids for pain develop serious respiratory depression (Angell, 1982). The depressive effect is easily reversed, however, by administration of appropriate dosages of naloxone. Tolerance to the respiratory depressant affects of narcotics usually occurs along with tolerance to the analgesic effects (Jaffe and Martin, 1990).

2. Misconception: Other side effects of opioids, which may be used for pain control (such as decreased bowel motility, nausea and vomiting) outweigh the benefits and preclude their use.

Fact: Concerns about the side effects in the terminal patient should be secondary to the relief of pain. However, many side effects can be controlled or avoided altogether by a careful review of pharmacological agents.

3. Misconception: Malpractice could be alleged if a patient died while being treated for pain as it could be argued that the treatment caused respiratory failure and hastened death.

Fact: In fact, the opposite is true. Healthcare professionals have been successfully prosecuted for failure to provide adequate pain relief for a dying patient (James vs. Guardian and Hillhaven Corp., 1990).

On 3/21/83, the President's Commission for the Study of Health Care and Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report on "Deciding to Forego Life-Sustaining Treatment." The Commission concluded that, while deliberate ending of a life is

absolutely morally forbidden, nothing prevents a physician from ordering pain-relieving drugs in sufficient dosages to control unbearable pain (Cushin, 1983).

The "doctrine of double effect" provides guidance when considering these difficult issues.

This Catholic medico-ethical principle holds that an action which may have at least one bad and one good effect is morally permissible if four conditions are met: (1) the act itself must be morally good or neutral (for example, administering a pain-killer); (2) only the good consequences of the action must be intended (such as relief of the patient's suffering); (3) the good effect must not be produced by means of the evil effect (the relief of suffering must not be produced by the patient's death); and, (4) there must be some weighty reason for permitting the evil (the relief of great suffering, which can only be achieved through a high risk of death).

{President's Commission, 1983}.

California Senate Bill No. 1802 states that "no physician or surgeon shall be subject to disciplinary action by the Board for prescribing or administering controlled substances in the course of treatment of a person for intractable pain. Intractable pain means a pain state in which the course of the pain cannot be removed or otherwise treated and which in the generally accepted course of medical practice no relief or cure of the cause of the pain is possible or none has been found after reasonable efforts including, but not limited to, evaluation by the attending physician and surgeon and one or more physicians specializing in the treatment of the area, system, or organ of the body perceived as the source of the pain." The real moral issue to be considered is whether or not the decision-makers have taken into account "the full range of foreseeable affects, have knowingly accepted whatever risk of death is entailed, and have found the risk to be justified in light of the paucity and undesirability of other options." (President's Commission, 1983). The Hastings Center defines the central role in caring for the dying as mitigation of pain and suffering; "thus the health care professional who does so is acting in accord with the fundamental professional requirement to promote the patient's good."

D. Ethical Considerations: "Pain is dehumanizing. As it becomes more severe it consumes one's consciousness until all one can think about is pain. In it's extreme, pain destroys the soul itself and all the will to live." (Lisson, 1987). Healthcare professionals have an obligation to control distressing symptoms in dying patients. Suffering can result not only from physical causes, but from emotional, social and spiritual ones as well. Total care requires professionals to attend to all these potential sources of distress. (Hastings Center, 1987)

Pain is most poorly managed for those most vulnerable - children. A child's developmental level may preclude the ability to articulate the presence or degree of pain. A child may also not be able to understand cause and effect in relation to the pain. This inherently dictates an even greater responsibility on the part of the pediatric healthcare professional to use every method appropriate and available to ensure the management of this pain. The patient has the right to have a statement of pain (or hurting) believed and pain recognized as a problem. Pain relief should be perceived by the healthcare team as a priority. "The increasing titration of medication to achieve symptom control, even at the expense of life, thus hastening death secondarily, is ethically justified." (ANA, 1992)

E. Documentation: Careful documentation of the healthcare team's efforts and intents toward providing comfort is critical. Nursing notes should show that the patient was closely monitored regarding pain level and severe respiratory depression. Daily physician progress notes should include assessment of pain level and goals of treatment; i.e., "around-the-clock" administration of medication for the purpose of prevention rather than abatement of pain. Each time dosage is increased, progress notes should indicate rationale. The intent to relieve pain and the patient's response to the analgesic should be fully documented in both medical and nursing records. (Cushin, 1983)

Caring for the terminally ill patient poses a great challenge for healthcare givers. As we shift our focus from cure to comfort, the issue of optimal pain management becomes critical. As Albert Schweitzer said, "We all must die. But that I can save (a person) from days of torture, that is what I feel is my great and even new privilege. Pain is a more terrible lord of mankind than even death himself." (Lisson, 1987)

For recommended pain management regimens for the terminally ill patient, the MAGIK Pain Service is available for consultation.

APPENDIX D - MEDICAL-LEGAL CONCERNS

I. DEFINITION OF ADULT AND MINOR PATIENTS WITH RESPECT TO THE "AND" CONSENT PROCESS

A. When the patient is 18 years of age or older and competent. Upon admission, patients 18 years or older will have been given information concerning advanced directives (refer to Sections II and III below for further information regarding advanced directives.) It is recommended that the healthcare provider confer with the patient and/or patient's family as to whether an advanced directive was executed. If so, a copy of the signed and witnessed directive should be placed in the patient's medical chart.

Where the validity of an executed directive is in doubt, it is recommended that Risk Management (X14527) or the Hospital's General Counsel be consulted.

Surrogate decision-maker in the event the patient is 18 years of age or older but deemed incapable of deciding for himself/herself because of his/her medical and/or mental condition.

B. Where the patient is under the age of 18 years, a surrogate decision-maker shall be identified and consulted.

1. Parental Consent: If the patient is a minor, his/her parents have the legal capacity to consent to medical treatment for their child. The parents' informed consent must be obtained before proceeding to withhold and/or withdraw life sustaining measures from a patient.

Documentation of the informed consent discussion(s) shall be documented in the medical chart as dated and timed progress note(s). The progress note(s) shall also include the identity of the persons present during the discussion(s).

2. "Competent" Minor Patient: Informed assent should be sought from a cognitively mature minor--that is, where the patient is able to understand the nature of his/her diagnoses, prognosis and the consequences of a decision to forgo life sustaining treatment. (See Appendix G, Guidelines for Obtaining Informed Consent).

3. Special Circumstances Involving Minor Patients

(a) Minor With Divorced Parents: Regardless of the custody situation, it is recommended that the consent of both parents be obtained.

The parent who has legal custody has final authority in cases where reasonable attempts to resolve conflicts between parents have been tried and failed. A copy of the court order regarding legal custody should be carefully reviewed and a copy placed in the patient's medical chart.

If the parents have joint custody or joint legal custody, generally, either parent has the right and responsibility to make health care decisions unless the court has specified, in its court order, that the consent of both parents is required. A copy of the court order regarding legal custody should be carefully reviewed and a copy placed in the patient's medical chart.

(b) Minor Born Out of Wedlock: The natural mother has the legal capacity to consent to medical treatment of her child.

The natural father also has the legal capacity to consent to medical treatment for his child. Where the natural father disagrees with the natural mother in a decision to withhold and/or withdraw life sustaining treatment, it is recommended that consultation with Risk Management (X14527) or the Hospital's General Counsel be obtained.

(c) Minors Who Have Legal Guardians Or Who Are Wards Of the Court Or Are In Foster Homes

Although the patient's parents usually have the legal capacity to consent to medical treatment, their legal right may have been temporarily or permanently removed. In such instances, a surrogate decision-maker must be identified and consulted.

The extent to which a surrogate decision-maker for a minor may authorize/consent to medical treatment is determined by the court. In cases involving a surrogate decision-maker, it is strongly recommended that:

- (1) A Social Worker be called into the case;
- (2) Copies of any court documents concerning guardianship, foster placement, etc., be obtained and carefully scrutinized to determine the extent to which the surrogate decision-maker may consent to medical treatment;
- (3) Attempts shall be made and documented to locate and confer with the patient's natural parent(s) regarding his/her (their) wishes;
- (4) Risk Management (X14527) be called

In certain cases, it may be necessary to request a Court Order to withhold and/or withdraw life sustaining measures. In such instances, Risk Management shall be contacted as soon as practicable to assist in the coordination of medical-legal activity between the healthcare providers and legal counsels.

II. SPECIAL CONSIDERATIONS PERTAINING TO INFANTS

Unique considerations affect decisions pertaining to infants. In accordance with accepted community practice, infants should receive all therapies that are clearly beneficial to them. Life sustaining treatment should not be withheld or withdrawn on the basis of considerations such as infant's anticipated or actual limited potential or the present or future lack of available community resources.

It is, however, legally and ethically appropriate to withhold medical and surgical procedures which are clearly futile and will only prolong the act of dying. In all cases, basic, humane and dignified care should be provided to ensure the infant's comfort. If it is unclear whether treatment should be provided, the generally accepted standard requires a presumption in favor of treatment.

III. CALIFORNIA'S REVISED NATURAL DEATH ACT (1992)

The California Natural Death Act was originally enacted by the California Legislature in 1976. The Act established statutory procedures which allowed an adult person of sound mind to declare, in writing, his/her wish that his/her physician withhold and/or withdraw life-sustaining treatment under certain conditions. Substantial revisions were made effective January 1, 1992. [Health and Safety Code § 7185-7194.5]

It is important to note that the Natural Death Act specifically recognized the patient's right to control decisions relating to withholding and/or withdrawing life sustaining procedures "in instances of a terminal condition," which is broader than the right created by the Act to make a declaration. Furthermore, the Act explicitly states that it is not intended to set up the exclusive method by which life support systems or other treatment can be withheld or withdrawn.

The absence of a valid and binding declaration as defined by the statutes does not prohibit a patient or physician from authorizing the withholding and/or withdrawing of life sustaining treatment when the patient or physician is exercising an independent legal right or legal responsibility in a lawful manner.

A. Prerequisites for a Valid Declaration (See CHLA P&P ETH 13.0, Patient Self-Determination Act, and CHLA CHEX Learning Module, PSDA)

1. The patient must be an adult and of sound mind. If a person is not legally competent, he/she cannot execute a valid declaration. A declaration may not be executed on behalf of the patient by his or her legal representative.

2. The declaration's form and wording must comply with the statute. The appropriate wording for a declaration is statutorily prescribed. [Health and Safety Code § 7186.5(b). Call Risk Management or the Hospital's General Counsel for further information.]

3. The declaration must be signed voluntarily by the patient in the presence of two (2) adults who personally know the patient and who: (a) are not related to the patient by blood or marriage; (b) are not mentioned in the patient's will; or (c) would not have a claim on the patient's estate.

B. Term and Revocation

A valid declaration remains effective indefinitely unless it is revoked. A declaration may be revoked at any time and in any manner by the patient without regard to his or her mental or physical condition. A revocation is effective upon its communication to the Attending Physician or other healthcare provider by the patient or by a witness to the revocation. If a patient informs a hospital employee that the patient wishes to revoke the directive, the employee should contact the patient's nurse. The nurse shall note document the communication in the patient's medical record and immediately notify the Attending Physician.

C. Operative Effect of a Declaration

A declaration becomes "operative" when: (a) it is communicated to the patient's Attending Physician, and (b) the patient is diagnosed and certified in writing by the patient's Attending Physician and a second physician who has personally examined the patient to be in a terminal condition or a permanent unconscious condition, and is no longer able to make decisions regarding the administration of life sustaining treatment.

When the declaration becomes operative, the Attending Physician and other healthcare providers must follow the declaration's provisions or transfer care of the patient to another physician or healthcare provider who is willing to do so.

(1) Once it is determined that the patient is in a terminal condition or a permanent unconscious condition, the Attending Physician who knows of the declaration shall record the determination and the terms of the declaration in the patient's medical chart along with placing a copy of the declaration in the chart.

(2) If the Attending Physician or other health care provider is unwilling to comply with the declaration, "all reasonable steps as promptly as practical" must be taken to transfer the care of the patient to another Attending Physician or healthcare provider who is willing to do so.

(3) A Durable Power of Attorney for Health Care (Refer to next Section) shall prevail over a declaration executed pursuant to the Natural Death Act unless expressly provided for in the Durable Power of Attorney for Health Care. If any inconsistencies exist, Risk Management or the Hospital's General Counsel should be consulted.

(4) Instruments Executed in Other States
Natural Death Act "Directives" executed pre-1992 may also be valid instruments for conveying an adult patient's wishes regarding the withholding and/or withdrawing of life sustaining treatment. Instruments governing the withholding and/or withdrawing of life sustaining treatment executed in another state in compliance with the law of that state or of this state may be valid in California.

(5) The wishes of the members of the patient's family (for example, family members opposed to the patient's directive) have no effect on the declaration.

(6) Pregnancy
If the patient is known to the physician to be pregnant, the declaration has no force or effect as long as the patient is pregnant.

References: Consent Manual 1992 Edition, Chapter 5, Health and Safety Code §7185 et seq.

IV. DURABLE POWER OF ATTORNEY FOR HEALTH CARE (DPA-HC) [California Civil Code §2430-2444 and §2500]

An in-depth description and discussion of the DPA-HC is contained in Chapter 2 of the Consent Manual published by the California Association of Hospital and Health Systems. Highlights of that Chapter follow.

Through the execution of a DPA-HC, an adult patient authorizes an "attorney-in-fact" to make healthcare decisions on his/her behalf. The "attorney-in-fact" may also, in limited situations, authorize the withholding and/or withdrawing of life-sustaining treatment, to permit the natural process of dying.

Patients who indicate that they have executed a DPA-HC and persons indicating they have been designated as a patient's attorney-in-fact should be asked to give a copy of the properly executed DPA-HC for placement in the medical chart.

A. The DPA-HC should be reviewed to assure that it meets statutory prerequisites. Risk Management or the Hospital's General Counsel are available for assistance in determining whether a DPA is valid.

B. Any limitations or special instructions should be noted and implemented.

C. A copy of the DPA-HC shall be placed in the patient's medical chart.

D. If patients indicate a desire to appoint an attorney-in-fact, or to have a person make healthcare decisions on their behalf, a call should be made to Patient and Family Services which maintains information which can be given to the patient.

Note: Patients who need further clarification regarding the DPA-HC should be directed to call their attorney or the County or State Bar Association for a referral.

V. LIVING WILL

A living will is any written statement in which the patient states what treatment is desired or rejected at some future time. It may apply to a wide range of circumstances and treatments not addressed by a Natural Death Act Declaration and permit more personalized statement of the patient's wishes. There is no prescribed format for such documents, although some organizations distribute printed formats for the documents.

Although living wills are not recognized by statute in California, the courts have generally treated them as significant evidence of the patient's desires. If the physician becomes aware that the patient has signed a living will, contact Risk Management or the Hospital's General Counsel for consultation.

VI. FEDERAL CHILD ABUSE AMENDMENTS OF 1984

(The following is excerpted from Chapter 5 of the 1992 Edition of the Consent Manual)

In the Child Abuse Amendments of 1984, Congress attempted to address the perceived problem of discriminatory denial of medical care for infants with disabling conditions. The amendment required each state to adopt systems for responding to reports of medical neglect of children by enacting a very restrictive definition of what constitutes medical neglect. This legislation required the Department of Health and Human Services to adopt regulations to implement the new requirements and model guidelines to encourage the establishment of hospital committees to deal with questions regarding the provisions of medical care for handicapped infants.

The legislation required state child protective agencies to develop and maintain mechanisms for responding to reports of medical neglect of children, including instances of "withholding of medically-indicated treatment" from disabled infants who have life-threatening conditions. This requirement is consistent with California's child abuse reporting statute, which requires the reporting of "medical neglect" which is defined as the willful or negligent failure of any person responsible for the child to provide adequate medical care.

California's definition of "medical neglect" further provides that "an informed and appropriate medical decision made by the parent or guardian after consultation with a physician or physicians who have examined the child does not constitute neglect." While this provision allows for an interpretation of what constitutes "an informed and appropriate decision," it does seem to require the physician or other health care provider to file a report where the decision of the child's parent or guardian is not consistent with the child's best interest.

The federal law is inconsistent with the state child abuse reporting requirements in that the law defines prohibited "withholding of medically-indicated treatment" in a very restrictive manner. Federal definition includes the failure to respond to an infant's life-threatening conditions by providing treatment which, in the treating physician's reasonable judgment, is most likely to be effective in ameliorating or correcting all life-threatening conditions. The only exceptions, under the federal definition, in which life-sustaining medical treatment may be withheld are when, in the treating physician's reasonable judgment: (a) the infant is chronically and irreversibly comatose; (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. But, even in the exceptional circumstances in which treatment may be withheld or discontinued, the federal law does not permit withholding or withdrawal of appropriate nutrition, hydration or medication.

VII. SPECIAL CIRCUMSTANCES REQUIRING CONSULTATIONS WITH RISK MANAGEMENT OR THE HOSPITAL'S GENERAL COUNSEL:

- (a) The patient's condition resulted from an injury which appears to have been inflicted by a criminal act; or
- (b) The patient's injury or condition was created or aggravated by a medical accident;
- (c) The patient is pregnant; or
- (d) The patient is a parent with custody or responsibility for the care and support of young children; or
- (e) The patient's parent is under 18 years old.

For separate discussion on organ transplantation, See Hospital Policy and Procedures, ETH-10.

APPENDIX E - DECISIONS SURROUNDING THE END-OF-LIFE

(The following is from a November 11, 1992 memo addressed to the members of the Medical Staff from Gerald I. Lubin, MD, Chairman of the Ethics Resource Committee)

The practice of Pediatric Medicine has traditionally been, for all of us, a unique opportunity to provide family-centered, integrated care of children, often with chronic illness, during the most dynamic, formative portion of the human life cycle. A substantial part of the gratification for pediatric healthcare providers is the positive impact that good, continuing care of children with long term illness can have on survival, restoration of function, and limitation of disability. Nevertheless, some children will ultimately die of their acute or chronic conditions. Recognition, acknowledgement and planning for an inevitable demise in such cases remains a substantial challenge to all pediatric healthcare providers. This challenge, however, if managed well, may result in the richness of human experience that can surround a good death, the resolution of feelings, and acceptance by patients and family members, as well as the healthcare team.

Perhaps because, outside of majority tertiary, inpatient pediatric centers, childhood death remains relatively rare, we often find it difficult to acknowledge that death may be the short term end to our relationships with certain patients. In the wake of such a failure of recognition decisions about the approach to medical management and care, including aggressivity of treatment, specific levels of appropriate care and resuscitation, in the final phases of illness may become the burden of strangers. That is, healthcare professionals, without prior acquaintance, in emergency rooms, urgent care centers, at the bedside on an inpatient service, must address these decisions and attempt to render compassionate, sensitive care under the least optimal conditions. It should be no surprise then that many patients and families, not having been previously counseled and solicited for their preferences, may not be prepared to articulate their feelings about these issues in what now becomes a crisis. Clearly, the anguish and suffering over looming death for patients and their families, as well as the various healthcare providers, is magnified many fold. And there is little opportunity for the resolution of relationships, the goodbyes, the tying up of loose ends.

The enactment of the Patient Self-Determination Act (PSDA) at the Federal level has brought the timely and regular engagement of patient dialogue about issues regarding ultimate decision-making to the forefront of public concern. While the PSDA is directed towards decision-making by adult patients before they become cognitively incapacitated, consideration of the implementation issues of the PSDA provides pediatric healthcare givers with an occasion for reminding ourselves of our own obligations to engage our patients and families in discussions of such issues on a timely basis.

Attached you will find a brief set of guidelines, sampler drafts of advanced directives which may be helpful for our pediatric patients, information about the PSDA and, for those interested, a list of readings relating to the end-of-life decisions. In addition, the Ethics Resource Committee remains an active advisory body whose members are available for consultation and assistance about individual cases. We hope that you will consider these materials and take advantage of our advisory group for further assistance. Our sincere and best wishes for your continuing success in rendering the finest and most compassionate care to the children who are your patients.

Members of the Ethics Resource Committee
(signed by Gerald I. Lubin, MD)

GUIDELINES: For Dialogue re: Approaches to Management, Including Decisions About the End-of-Life

Specific Time Points	Actions	Involved Parties
Identification: Patient with acute and/or long term potentially life threatening illness.	Establish pattern of communication, i.e., continuing dialogue surrounding the prognosis associated with various recommended treatment options. Aggressivity of treatment may be appropriate for discussion here.	Primary care physician, in concert with consultant physicians, and extended healthcare team.*
Interim follow-up, patient's condition relatively stable	Continuing, regular re-assessment of patient's treatment preferences, attitudes, values history as well as health status. The efficacy and appropriateness of the medical management plan should be evaluated. Aggressivity of treatment may be appropriate for discussion here. Discussion of End-of-Life decisions may be appropriate in some situations.	As above
Unexpected, acute exacerbation of condition, which may or may not lead to a fatal deterioration	Emergency reassessment of patient's treatment preferences, attitudes, values history as well as medical status and, perhaps, consideration of End-of-life decision.** Aggressivity of treatment should be discussed here.	As Above.
Patient enter what might be termed a "subterminal" phase, that is, a phase where one might anticipate demise from an interval event or progressive decline within 6 months.	Careful reassessment of the patient's treatment preferences, attitudes, values history as well as medical status, determination of whether a change in direction or intensity of medical care may afford a re-establishment of previous plane of function or not. Aggressivity of treatment should be discussed here. End-of-Life decisions should be discussed here. Written Advanced Directives should be formulated at this time and distributed to family members and potential caregivers.	As above.
Patient enters what might be termed a "terminal" phase.	As above. Formal written Advanced Directives should have been formulated by this time and made available to potential emergency care-givers.	As above.

* - Desirable that an individual be designated to be the primary "communicator" for the patient. This necessitates continuing dialogue among the members of the healthcare team as well as the patient.

** - It should be understood that End-of-life decisions do not necessarily equate to "Accept Natural Death" status, but rather to care as a generic issue. Some patients and families have profound religious, cultural and ethical basis for decisions to request full and aggressive continued care even in the face of what appears to be a severely diminished likelihood of survival. In these rare instances, it is the position of the Ethics Resource Committee to encourage a Respect for such directives and to afford

appropriate time-limited trials of resuscitation. It is also the position of the Ethics Resource Committee that "AND" does not equate to "Do Not Provide Care For," nor does it preclude aggressive or even escalated medical care in other respects. Finally, in every instance where a patient nears death, that the elements of Care must be sharply focused towards the patient and family.

REFERENCE LIST

1. Guidelines for Providing Comfort Measures to the Dying Patient, CHLA
 2. Hastings Center: Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. The Hastings Center, New York, 1987
 3. Kecker, NS: Knowing when to stop: the Limits of Medicine. Hastings Center Report, May-June, 1991, pp: 5-8.
 4. Chervenak FA and LB McCullough: Justified limits on refusing intervention. Hastings Center Report, March-April, 1991, pp: 12-18.
- Scofield GR: Is consent useful when resuscitation isn't? Hastings Center Report, November-December, 1991, pp: 28-36.
6. Callahan D: Medical Futility, Medical Necessity - The-Problem-Without-A-Name. Hastings Center Report, July-August, 1991, pp: 30-35.
 7. The Care of the Dying - A Symposium on the Case of Betty Wright. Law, Medicine and Health Care. 17: 207-233, 1989.

APPENDIX F - HEALTHCARE TEAM COMMUNICATION/DISPUTE RESOLUTION

DISPUTE RESOLUTION:

1. A case conference should be initiated by any member of the healthcare team when questions arise as to the appropriateness of orders to forego or discontinue treatment. Until resolution is reached, life-sustaining treatment should be provided and disputed "AND" orders suspended, if any, unless the best interest of the child is threatened.
2. The managerial hierarchy should be initially contacted to resolve any conflict.
3. The Ethics Resource Committee (ERC) shall be involved as early as possible in resolving problems. The Committee may be accessed by calling the Medical Staff Office at 213/669-2270 (X12270) or by calling the Administrator on Duty.
4. If the bedside nurse or any other healthcare team member feels uncomfortable in participating in the plan, he/she may request to be replaced. He/she may also request consultation with the Ethics Resource Consultative Sub-Committee. (See CHLA P&P MHR 47, Staff Rights)

Except in situations governed by the Revised Natural Death Act or Durable Power of Attorney for Health Care, the Ethics Resource Committee may not direct the issuance of an order to forego or discontinue life-sustaining treatment. The ERC acts to advise a physician when it believes such action may be appropriate.

When a qualified patient has properly executed a valid declaration pursuant to the Revised Natural Death Act or Durable Power of Attorney for Health Care and death is imminent (e.g., expected to occur within the next four weeks) regardless of the application of life-sustaining measures, the ERC may recommend to the patient's primary attending to withhold life-sustaining procedures or to transfer the responsibility for the patient's care to another qualified physician who will comply with the declaration or directive.

APPENDIX G - GUIDELINES FOR OBTAINING INFORMED CONSENT

The matter of informed consent, the physician's and nurse's roles and responsibilities, and the concept of the child's consent is outlined as a guideline for all concerned with patient care. Beyond the legal implications are moral and ethical issues involved in caring for patients. These include the need for a continuing dialogue with the parents and child in a timely and appropriate manner in order to insure true understanding of the nature of the problems and the comprehensive plane of care.

LEGAL ISSUES OF CONSENT

Hospital's Responsibility in the Informed Consent Process

In reviewing the legal issues of consent, the following must be considered: Title 22, California Administrative Code, Patient's Rights Section, particularly rights: #3: To know the name of the physician with primary responsibility for coordinating care, and the names of the other physicians and non-physicians who will see the patient; #4: To receive information about the illness, course of treatment, and prospects for recovery in terms the patient can understand; #5: To receive as much information about any treatment or procedure as the patient may need to give informed consent or to refuse treatment; #6: To participate actively in decisions regarding medical care.

The Hospital's role is verification that the patient's informed consent has been obtained before the physician is to perform the medical procedure. The hospital's responsible employee should serve as a witness. If it appears, at the time the hospital's surgical, diagnostic, therapeutic consent form is presented, that the decision-maker has significant questions about the nature, benefits, or risks, or voluntarily indicates doubt or confusion, the physician should be contacted. The hospital employee should not attempt to obtain consent in such a situation. It is the treating physician's responsibility to obtain informed consent. (See Hosp P&P #2103)

The Physician's Responsibility in the Informed Consent Process

The doctrine of informed consent is the law's recognition that a patient is an autonomous individual who is free to authorize or refuse the administration of medical treatment. The doctrine of informed consent encompasses two elements: (1) The physician's duty to disclose information; and, (2) the obtaining of permission or consent of the patient or a surrogate decision-maker for the proposed treatment. (See Appendix D, Medical-Legal Concerns)

The duty of disclosure is the obligation of the physician to reveal:

- a) The nature of the recommended therapy
- b) The expected benefits
- c) Any serious risks or side-effects of the proposed therapy
- d) Alternative modalities of treatment and their associated risks and complication, including the consequences of no treatment.
- e) Any personal interest, economic or research, the physician may have in recommending the treatment
- f) Any circumstances as a matter of good medical practice.

To assist the physician communicate information to the patient, the physician may consider utilizing pre-printed written material, audio cassettes, videos, drawings, slides, etc. Whether or not any audio-visual aides are used to assist in providing information, a personal explanation should always be incorporated into the process. This discussion is required in the legal doctrine of "informed consent" to give the patient or the patient's surrogate decision-maker the opportunity to receive information and ask questions.

A patient has the right to decide on medical treatment. If the patient is incompetent by reason of age or condition, a surrogate decision-maker should be identified to make decisions on the patient's behalf. For minors, parents or guardians are almost always the proper persons to consult although minors ages 14 through 17 should be involved in the informed consent process. (See Appendix D, Medical-Legal Concerns) Physicians should confirm that surrogate decision-makers are acting in the patient's best interest.

A physician may be liable for not securing an informed consent. However, beyond the legal aspects lie the moral and ethical responsibilities to ensure that the child and parents or surrogate decision-makers truly understand, on an ongoing basis, the nature of the diagnoses, diagnostic procedures and therapeutic interventions necessary for care.

Physician guideline for documenting informed consent discussion:

Date and time of medical record entry. I spoke with (names of consenting party and others involved), who is responsible for deciding whether to authorize medical care. I have summarized the patient's condition, the plans for treatment, the procedure to be undertaken. I have also discussed the alternatives, their attendant risks and complications as well as the consequences if no action is taken. In addition, I have discussed the risks, including the serious risk of death. The special circumstances of this patient's condition have been included in the discussion. (Name of the consenting party) agrees to proceed as recommended.

The Nurse's Responsibility in the Informed Consent Process

Nursing today is firmly grounded in the concept of patient advocacy, as is mandated by the American Nurses' Association's Code for Nurses and the California Board of Registered Nursing in its regulations.

In fact, the regulations speak specifically to the nurse's responsibility to give the client the opportunity to make informed decisions about healthcare before it is provided.

(Title 11, California Code of Regulations, Section 1443.5.) Thus, the issue becomes one of licensure, as well as one of ethical dimensions.

Nursing ethics recognizes the importance of respect for patient autonomy as the right to self-determination, which is legally and ethically implemented in practice by the procedure of informed consent. It follows, then, that the nurse must be familiar with the conditions which contribute to a consent's validity, i.e., that the patient must have the decision-making capacity to make choices; that the patient must be given the necessary information to make an intelligent decision; and, that the consent must be freely given.

Nurses, acting as patient advocates, should be involved in the process to the extent of giving the decision-maker the opportunity to make informed decisions and to understand the entire plan of treatment as well as proposed isolated procedures. In the case of medical or surgical treatment, that would mean facilitating communication between the decision-maker and the physician when there is doubt or confusion regarding the proposed treatment. The nurse's signature as witness to a consent attests to the identity and capacity to give consent of the consenting party. At the same time, the nurse should verify that the decision-maker understands the information that is being given.

ASSENT Refer to new CHLA "ASSENT POLICY" - ETH-20.0 (New: 6/18/03)

APPENDIX H - SAMPLE "AND" LETTERS

Sample letters which the attending physician may use in the event that a patient with an "Accept Natural Death " order is discharged are offered. A hard copy of the CMA" Pre-Hospital Do Not Resuscitate" form is available at the end of this section where hard-copy CHLA P&P manuals are kept. The letter provides the family with the benefit of being easily produced at any ER or other medical setting thereby minimizing any hesitancy on the part of the medical staff who may not be familiar with the patient. In the event that the patient is readmitted at night or on the weekends, such a letter may also assist the staff in clarifying the "AND" status without the presence of the attending physician.

Additionally, AB3000 provides a voluntary, legally recognized form intended to help health care givers understand and honor an individual's wishes regarding life-sustaining care (POLST-Physician Orders for Life-sustaining Treatment). This form includes patient wishes for cardiopulmonary resuscitation, antibiotic use, artificially administered nutrition and other medical interventions. In practice, the POLST form takes the individual's wishes regarding life-sustaining treatment and converts those wishes into a medical order that applies across care settings.

POLST forms are completed by health care professionals based on patient preferences and medical indications, and must be signed by a physician and the patient or his/her legally recognized health care decision-maker. The form remains with the patient as he/she is transferred between care settings. The POLST is not an advance directive. Therefore hospitals are not required to provide patients information about POLST pursuant to the Patient Self-determination Act. The POLST form is available on-line at www.finalchoices.calhealth.org/polst-hcp.html.

(SAMPLE LETTER #1)

June 10, 1993

To Whom It May Concern:

This patient, (Patient's Name), has been under my medical supervision and care at Childrens Hospital Los Angeles. He/She has a terminal illness, which is:

(Insert diagnosis) and no reasonable possibility of recovering from this condition. After carefully reviewing the available treatment options and the patient's diagnosis and prognosis, his/her parents (or legal guardians) decided to withhold all resuscitation efforts. Thus, a "Accept Natural Death" or "No Code" order was issued. The documentation supporting the order is in the Childrens Hospital of Los Angeles electronic medical record, in the progress notes of (Insert dates)

The persons authorized to make this decision are the patient's parents or legal guardians, who are:

Names:

They retain the right to withdraw consent for the "AND" order, but you may assume that they have not done so if they present this letter to you. This letter constitutes a request that you abide by the "AND" order which has been issued, and specifically that you provide no resuscitative efforts in the event the patient suffers a cardiac or respiratory arrest. The documentation supporting this order is in the chart, as noted above. Treatment to control pain should be provided and any other life-sustaining treatment that might be considered should be discussed with me and the parents/legal guardians prior to initiating them.

In order to verify that the order remains valid, you may wish to confirm with the parents/legal guardians or representatives who are present with the child that their decision is unchanged.

If you have any questions regarding the order, please call me through my office/exchange. The telephone number(s) is(are):

Office #

Exchange #

Sincerely,

(Physician's Signature)

(Physician's Printed Name), MD

(SAMPLE LETTER #2)

June 10, 1993

RE: Patient: Doe, Jane
CHLA MR#: 123456
Date of Birth: 6/7/92

To Whom It May Concern:

The above named patient carries the following diagnosis:

1. Severe static encephalopathy (essential persistent vegetative state).
2. Infarction of cerebral nuclei.

Because of the extremely poor prognosis and absence of any likelihood of significant neurological recovery, the family and the Health Care Team have chosen **NO RESUSCITATION IN THE EVENT OF CARDIO-RESPIRATORY ARREST.”(Accept Natural Death)”**

The infant is being cared for at home by the parents as a hospice patient. Should this infant present to any Emergency Room facilities or Urgent Care facilities, we would appreciate it if the examining healthcare providers reconfirm that the family still wishes “AN” STATUS and that we be notified.

During regular business hours, please call _____ of the Division of Neonatology & Pediatric Pulmonology at 213/669-2287. After hours and on weekends, please call 213/660-2450 and ask for the Attending Neonatologist or Attending Pediatric Pulmonologist on-call.

Thank you for your compassionate assistance,

Cheryl D. Lew, MD
Associate Professor of Pediatrics

APPENDIX I - DETERMINATION AND PRONOUNCEMENT OF BRAIN DEATH PURSUANT TO THE UNIFORM DETERMINATION OF DEATH ACT

POLICY

A physician shall pronounce a patient dead if he/she determines, in accordance with accepted medical standards, that the patient has sustained either:

- (1) Irreversible cessation of circulatory and respiratory functions; and,
- (2) irreversible cessation of all functions of the entire brain, including the brain stem.

(California Health and Safety Code §7180)

When death is pronounced on the basis of irreversible cessation of all functions of the entire brain, the following procedures shall be followed.

PROCEDURE:

A. DETERMINATION OF BRAIN DEATH:

1. The patient's primary attending physician shall pronounce a patient dead if he/she determines that the patient has suffered an irreversible cessation of all functions of the entire brain, including the brain stem.

2. The determination that all functions of the entire brain, including the brain stem, have irreversibly ceased is a medical judgment. The determination shall be made in accordance with the guidelines developed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Guidelines for Determination of Death." JAMA, 1981, 246:2184-2186, and the Task Force on Brain Death in Children," Pediatrics, 1987 80:298-299.

3. The standards to be used do not allow a diagnosis of brain death for an infant younger than seven days.

B. INDEPENDENT CONFIRMATION

A second attending staff physician shall independently confirm all functions of the patient's entire brain, including the brain stem, have irreversibly ceased. At least one of the physicians involved in diagnosing brain death shall be a neurologist or neurosurgeon.

C. PROHIBITION AGAINST PHYSICIANS WHO PRONOUNCE DEATH PARTICIPATING IN TRANSPLANTATION

If a deceased patient is to be a donor pursuant to the Uniform Anatomical Gift Act, neither the physician who determines the brain death has occurred nor the physician who independently confirms that brain death has occurred may participate in the procedure for removing or transplanting a part.

D. DOCUMENTATION IN THE MEDICAL RECORD

The physicians who, independently, determine and confirm that brain death has occurred shall both document in the patient's medical record:

1. The procedure used to determine death; and,
2. The factual basis for the determination of death.

E. COMPLETION OF DEATH CERTIFICATE

1. Unless the case is a coroner's case, the physician who was last in attendance at the patient's death shall complete the death certificate, in accordance with the Hospital policy and procedure. (See Policy 2122, Exhibit "A")

2. The time of death shall be the date, time, and hour that the physician pronounced the patient dead pursuant to the Uniform Determination of Death Act. Death will be pronounced after the confirmation and prior to the termination of medical treatment, such as a ventilator.

F. INFORMING THE PATIENT'S FAMILY, SURROGATE DECISION-MAKER AND LEGAL REPRESENTATIVES

The patient's attending physician should explain to the patient's family, other surrogate decision-makers and legal representatives, if any, that the patient has sustained an irreversible cessation of all functions of the entire brain, including the brain stem, that this fact has been independently verified by a second qualified physician, and that, therefore, death will be pronounced and all forms of medical intervention will be discontinued. CHLA will provide the family or next of kin with a reasonably brief period (defined as the amount of time afforded to gather family or next of kin at the patient's bedside) of accommodation, from the time that the patient is declared dead by reason of irreversible cessation of all functions of the entire brain, including the brain stem, through discontinuation of cardiopulmonary support for the patient. During this reasonably brief time, a hospital is required to continue only previously ordered cardiopulmonary support. No other medical intervention is required. In addition, the attending physician should explain to the patient's family, other surrogate decision-makers and legal representatives, if any, that the patient's cardiac and/or respiratory activities may not immediately cease when the mechanical devices are removed from the body.

"The hospital shall provide the patient's legally recognized health care decision maker, if any, or the patient's family or next of kin, if available, with a written copy of this policy upon request, no later than shortly after the treating physician has determined that the potential for brain death is imminent". (AB2747)

1. If the patient's family, legally recognized health care decision maker, or next of kin voices any special religious or cultural practices and concerns of the patient or the patient's family surrounding death by reason of irreversible cessation of all functions of the entire brain of the patient, the hospital shall make reasonable efforts to accommodate those religious and cultural practices and concerns.
2. If the patient's family, or other surrogate decision-maker or legal representative objects to the discontinuance of all medical intervention on the basis that they believe that the diagnosis is mistaken or was not made in accordance with accepted medical standards, they should have a reasonable opportunity to request an additional confirmation of the neurological determination of death by a qualified physician of their choice. Should the patient's family, other surrogate decision-maker or legal representative fail to obtain a

consultation within a reasonable period, death will be pronounced and all forms of medical intervention will be discontinued. In the rare instance where the physician requested by the patient's family, other surrogate decision-maker or legal representative fails to confirm the neurological determination of death, an attempt should be made to resolve the dispute within the hospital. If this fails, judicial review will be necessary. Consultation with Risk Management (X14527) or the Hospital's General Counsel (X12425) is recommended.

3. For purposes of this section, in determining what is reasonable, a hospital shall consider the needs of other patients and prospective patients in urgent need of care.

4. When appropriate, the attending physician should explain to the family, other surrogate decision-maker or legal representative that treatment will be continued for a short time for the sole purpose of maintaining the viability of organs or parts that are to be transplanted.

G. DISCONTINUING TREATMENT

1. Except in those cases in which the life support equipment should be continued in order to preserve the viability of the organs that are to be transplanted, after the family, other surrogate decision-maker or legal representative have concurred with the determination of treatment and the physician or his/her designee, shall be responsible for disconnecting the ventilator, IV's, and all other forms of treatment.

2. Upon cessation of all cardiac and respiratory activity, the patient's remains shall be transferred to the Hospital's morgue in accordance with Hospital policy and procedure. (Refer to Policy CCR-02.)

APPENDIX J - PERSISTENT VEGETATIVE STATE

Persistent vegetative state (PVS) in infants and children may be diagnosed based on the appropriate neurological examination for age, knowledge of the insult causing brain injury, and an appropriate period of observation depending on the age of the patient and nature of the insult. A neurological consult is required to assist in the determination of this diagnosis.

Between the newborn period and 2 years of age, the diagnosis is difficult and controversial. Most neurologists agree that a reliable diagnosis can be made in children over two years of age. In all cases, a period of three to six months is believed to be the minimum observation period before a diagnosis of PVS can be made, with longer observation periods required for younger patients.

While a definition of PVS in adults is commonly used and generally accepted, differences of opinion persist in the community of pediatrics (See Table 1 below). In general, child neurologists define PVS in infants and children in terms of the persistent loss of higher cortical functions rather than the persistence of vegetative functions.

Opinions regarding appropriate support, including placement of a G-tube, placement of a tracheostomy, pain management, the role of artificial nutrition and hydration, vary widely. As a consequence, confusion and dissent may be present when PVS is being investigated. All effort should be made to communicate opinions clearly, between professionals and with the family.

Resource: Ashwal, et. al., The persistent vegetative state in children: "Report of the Child Neurology Society Ethics Committee," Annals of Neurology, Vol. 32, No. 4, October 1992, pp. 570-576.

Table 1. Definition of PVS in Infants and Children

	Apply (%)	Supportive (%)	Necessary (%)	
1. Wakefulness without awareness	95	16	84	
2. Eyes-open unconsciousness	94	33	67	
3. No "voluntary" action or behavior	91	23	77	
4. No "cognitive" response	90	22	78	
5. No "voluntary" language	84	29	71	
6. Inability to follow commands	83	22	78	
7. Spontaneous eye movements but no sustained tracking	83	47	53	
8. Intact brainstem reflexes and sleep-wake cycles	75	53	47	
9. Spontaneous breathing, but chewing & swallowing impaired	75	65	35	
10. Bowel and bladder incontinence	53	53	47	

Data given as a percentage of respondents (n = 250)
PVS = persistent vegetative state.

From: Issues in Clinical Neuroscience: Ashwal, et al.: Persistent Vegetative State

Appendix K – Spiritual Issues and Concerns

Family-centered, holistic, and culturally sensitive care involves the assessment of spiritual values and the provision for meeting spiritual needs of CHLA patients and families.

As the spiritual care provider within the interdisciplinary team, the chaplain should be involved *as early as possible* in the patient's care. Involvement well before the family is faced with the end-of-life decision allows the chaplain to develop trust and a caring relationship with the family.

A referral to the chaplain can be made by family members as well as by any member of the interdisciplinary team.

Chaplains respect the diverse religious traditions of CHLA patients and families and provide spiritual support through **spiritual assessment**:
of spiritual resources that help families to cope
of spiritual concerns that may cause stress, anxiety and compound the end-of-life crisis
of values, beliefs, and attitudes as they affect the end-of-life decisions of families

Chaplains respect the diverse religious traditions of CHLA patients and families and provide spiritual support through **spiritual care interventions**:
Reflective listening, assisting families in clarifying their concerns
Provide comforting presence and support
Contact diverse religious communities if desired
Make referrals to other members of the healthcare team as appropriate (social work, for example, for psychosocial and emotional issues)
Facilitate end-of-life rituals that assist the grieving process and may promote the resolution of feelings and thus help families cope
Communicate spiritual assessment and spiritual care in the medical record

APPENDIX L – RESOLVING CONFLICTS OVER ISSUES OF FUTILITY

Physician initiated orders to forego further resuscitation in the context of an acute crisis requiring ongoing resuscitation

An attending physician may write or give a verbal order to forego further resuscitative efforts during an ongoing resuscitation attempt if in his/her medical judgment the patient is not responding to therapies and there are no further therapies to offer that would be effective in saving the patient's life. Otherwise stated, the physician believes that any further treatment will fail to reverse a physiologic disturbance that will lead to the child's proximate death. In this case the family does not need to be asked for informed consent to forego further resuscitation, but informed that resuscitation has not been successful and that the patient is dying despite all appropriate medical therapies.

Resolving Conflicts over Possibly Inappropriate or Harmful Life-Sustaining Therapies

I. INTRODUCTION

II. The goal of medicine is to benefit the patient. Conflicts may arise when clinicians disagree with patients and families over whether initiation or continuation of life-sustaining therapies has a reasonable chance of providing benefit. As the technological possibilities for medical intervention continue to multiply, clinicians and patients alike have an increasingly difficult time determining whether the application of these technologies is likely to benefit the patient or merely delay the inevitability of death.

As recently as forty years ago, the discontinuation of a life-sustaining treatment under any circumstances was regarded as both unethical and illegal. Since then, however, a consensus has emerged in law and bioethics that competent adult patients may refuse any unwanted medical therapy, even if their clinicians disagree. More recently, the question has arisen in reverse: when may clinicians refuse to provide life-sustaining treatments that are desired by patients and families when the clinicians believe that their use is inappropriate or harmful? At the present time there is no consensus about this more recent question, with ambiguities in both the law and current bioethical opinion. (*Please refer to the Addendum for a discussion of case law and legal issues.*) However, it is well recognized that there is no ethical or legal obligation to provide treatments that are of no short or long-term benefit and it is inappropriate for healthcare professionals to abrogate this standard of care on the basis of parental preference.

Clinicians are only rarely unable to resolve differing views with patients and families about the appropriate use of life-sustaining technology. While members of the care team may disagree with each other and with the patient or family, the vast majority of these conflicts can be resolved through a process of discussions, team meetings, and with the assistance of clergy, social workers, ethics consultants, or other mediators. On rare occasions, however, disagreements between the care team and the patient or family over the initiation or continued use of life-sustaining therapy may become intractable. The motivations for insistence upon treatment that is inappropriate or harmful are often complex: clinicians may regard the death of the patient as a personal failure and therefore insist upon treatment indefinitely; families may be unable to accept the impending death of a loved one and desire postponement of the inevitable for as long as possible, even at the expense of the comfort and dignity of

the patient. When the disagreement is intractable, a process is necessary to ensure fairness to patients and their families and which will lead to resolution of the conflict.

Steps of the approach are as follows:

Identification of conflicts:

Conflicts may involve disagreements between the care team and a patient, and/or a patient's parents or legal guardians over initiation or continuation of life-sustaining treatment. It may be the case that (1) the patient/family wish to forego either initiation or continuation of life-sustaining treatment recommended by physicians, or (2) The patient/family wish to initiate or continue treatment that is seen as inappropriate or harmful by physicians or other health care practitioners. In either case, a fair process is needed to lead to resolution of the conflict. This process will be invoked only if the usual mechanisms for decision-making (informal discussions, team and family meetings, assistance of social workers, clergy, or ethics consultants) have proven ineffective at resolving the conflict. Patients' families will be informed about this process by the primary attending physician or his/her designee. Patients and families as well as clinicians will have access to consultation about the process as well as the opportunity to initiate the process through the Ethics Resource Committee.

For these purposes, treatments are defined as inappropriate when they provide no reasonable possibility of extended life or other benefit for the patient, and treatments are defined as harmful when the additional suffering or other harm inflicted (burdens) is grossly disproportionate to any possibility of benefit. (These definitions are adapted from: Tomlinson T, Czlonka D. Futility and Hospital Policy. Hastings Center Report 1995;25:28-35.) Benefit is defined as that which is valuable to the patient as perceived by the patient or family. Burdens of medical treatment refer to any physical, emotional or social costs imposed on the patient by the medical treatment. For additional discussion of balancing benefits vs. potential burdens as well as other ethical terms and issues please refer to Appendices A and M.

If the physicians are insisting upon the use of a life-sustaining therapy against the wishes of the patient and/or patient's family, their recommendation should be based upon the expected benefits and burdens of the therapy in the context of the relevant clinical information. Often consensus can be reached by focusing on a time-limited trial of therapy, with the understanding that the treatment will be discontinued if certain goals are not met within a defined period of time. If the need for life-sustaining therapy is in the context of an emergency situation, and it is believed by physicians that the parents' decision is not in the best interests of the child, it is recommended (and the law allows) for the physicians to proceed with the treatment on an emergent basis, but then proceed with steps outlined below.

If the physicians believe that a life-sustaining therapy desired by the patient and/or patient's family is either inappropriate or harmful, then they must justify this view on the basis of the expected benefits and burdens of the therapy. Under these circumstances, the physicians should emphasize that limiting the use of life-sustaining treatments will not lead to abandonment, nor to neglect of the patient's need for symptom control or emotional support. In particular, the availability of comfort care, consultation from palliative care specialists, and psychosocial and spiritual support should be discussed and offered whenever possible.

If these measures fail to resolve the disagreement, then the primary attending physician(s) should proceed with the following steps: 1) The physician should seek a second opinion from another board certified specialist in the appropriate discipline. The family should have an opportunity to meet with this consultant. 2) If the conflict is still not resolved, the physician should contact Ethics Resource Committee for consultation. Any other concerned healthcare provider may also request the consultation. If a

conflict is identified by a resident, a nurse or other non-physician healthcare provider, and cannot be resolved with discussions with the primary attending physician(s), it is recommended that the ERC be consulted directly by the healthcare provider who identifies the conflict.

ERC Consultation Process:

Once a case is identified as outlined above (usually by referral from the healthcare team or possibly from the patient/family), the Medical Staff Coordinator for the Ethics Resource Committee informs the Chair of the committee (or designee) who will arrange for formal evaluation before the Committee.

Parties involved in the process include:

Members of the Committee.

Members of the care team: These should include the attending physician(s), nurse or nurses, members of the house staff, social workers, therapists, and spiritual care staff. Consultants to the team may also be involved.

The patient's family and/or legal guardians, and supporting individuals that the family has requested to be involved. Where possible the patient should be included in the ERC evaluation.

Some families may decline to meet with the Committee. Nevertheless, their choice not to meet with the Committee should neither be seen as undermining the integrity of the process nor invalidating the Committee's recommendations when good faith efforts have been made to include the patient and family in the process.

The purpose of the evaluation is for the ERC to make recommendations for action on the part of the healthcare team which increase the potential for resolution of the conflict. Recommendations may include whether or not further use of life-sustaining treatment is obligatory, appropriate or harmful. The Committee undertakes this determination through a synthesis of both the medical facts as well as the broader and unique circumstances of the case itself. In making its recommendations, the Committee considers the well-being and moral integrity of the patient and family, as well as those of the clinicians and the institution. Analyses of the benefits vs. burdens of specific therapies for individual patients form the basis for the ethical considerations in each evaluation. Therefore, ERC recommendations to continue, discontinue, or forego specific treatments including cardiopulmonary resuscitation are based on whether the treatments in question are likely to result in net and sustained benefit for the patient.

The Chair of the Committee (or designee) will write a formal consultation report for the Medical Record. The consultation report includes a summary of the salient features of the case, a discussion of the ethical dimensions and the recommendations of the ERC based on the ethical ramifications. The Chair of the ERC communicates the recommendations of the ERC to the attending physician and provides copies of the written report to the healthcare team and to the family.

Occasionally, the ERC is unable to agree on the recommendations and may choose to provide alternative recommendations to the healthcare team and family. Consensus on the part of the ERC is not required for the process of deliberation to lead to new insights and strategies for the healthcare team to achieve resolution. Ultimately, if ERC recommendations do not result in a resolution of the patient's situation, the ERC will usually recommend that the health care team involved the Legal Affairs Department for further assistance. This latter circumstance would likely involve action by the Hospital Administration and possibly court adjudication.

Usually, the ERC does agree on recommendations:

Family does not want life-sustaining treatment recommended by physicians, ERC supports the family's position

If the Committee supports the view of the patient's parents or legal guardians that further use of life-sustaining therapy is inappropriate or harmful, then the attending physician(s) may:

Agree to withhold or withdraw the unwanted life-sustaining therapy: In some cases, the process of deliberation may lead the physicians to see the situation in a different light and be willing to discontinue further use of the life-sustaining treatment.

Seek transfer of care to another physician or another institution: If the responsible physician continues to believe that it is not ethical to withhold or withdraw the unwanted therapy, he or she should seek transfer of care to another physician at CHLA who is willing to comply with the family's wishes. If no physician at CHLA can be found who is willing to assume care, then the parents or legal guardians should be informed and their permission sought to pursue transfer to another physician at another institution willing to assume responsibility and to comply with their wishes. This should be arranged by the responsible physician with assistance, if necessary, from the hospital administration. The physician may not withdraw until another physician has been found at CHLA who will assume responsibility or the patient is transferred to the care of another physician at another hospital willing to assume responsibility.

A house officer or non-physician member of the health care team who finds that the plan of care conflicts with her or his personal values or spiritual beliefs should report this concern to her or his supervisor for the purpose of being replaced. (Please refer to policy MHR 47.0, "Staff Rights").

The ERC Supports the physician's position: In this case, the Committee takes the position that foregoing life-sustaining treatment under the circumstances is not acceptable. The Committee thereby affirms that the parents' or legal guardians' wishes may be overridden in this case because considerations such as beneficence or non-maleficence should take precedence, and that the benefits of therapies in question outweigh the burdens. In other words, it is the determination of the Committee that the parents or legal guardians are not making decisions as the patient would have or in the patient's best interests. For this reason, it is strongly recommended that the hospital administration, risk management and legal counsel be involved in further decision-making, especially if representatives were not present for the consultation meeting. Available options include:

1) The ERC could request that the responsible physician pursue further attempts at consensus with the patient or surrogate.

If the consultation process uncovered potential avenues of mediation that might result in consensus between the responsible physician and the patient's family, then the Committee might have legitimate grounds for wanting the physicians to pursue these possibilities. If this option is chosen, the consultation report must indicate explicitly the nature and time frame of the proposed mediation, and to commit to alternative options if the mediation fails.

2) **The ERC could recommend a judicial resolution to the conflict.**

If the consultation process concluded that the patient's parents or legal guardians were not acting in the patient's best interest, then judicial resolution may be sought. *In a non-emergency situation a court order is required to initiate treatments without the family's consent.* This also would create the opportunity for re-evaluation of the patient's care plan and re-consideration of the advisability of discontinuing life-sustaining treatments. In this case, the family should be made aware of their right to seek legal representation.

c) **Family wants to initiate or continue treatment that is not recommended by physicians, ERC supports the family's position**

If the Committee does not support the responsible physician's assessment that further treatment is inappropriate or harmful, the physician may:

1) Continue to provide treatment:

Based upon the deliberations of the Committee, the responsible physician and other clinicians may come to see the situation differently. One of the explicit purposes of the process of deliberation is to elicit values and understandings that may not have been articulated in the initial discussions with the clinicians. If this occurs, the responsible physician may agree that continuation of treatment is an acceptable option; or

Seek transfer of care to another physician or another institution:

If the responsible physician continues to believe that further treatment violates his or her own professional integrity, he or she should seek transfer of care to another physician at CHLA who is willing to comply with the family's wishes. If no physician at CHLA can be found who is willing to assume care, then the family should be informed and their permission sought to pursue transfer to another physician at another institution willing to assume responsibility and to comply with the patient's or surrogate's wishes. This should be arranged by the responsible physician with assistance, if necessary, from the hospital administration.

A house officer or non-physician member of the health care team who finds that the plan of care conflicts with her or his personal values or spiritual beliefs should report this concern to her or his supervisor for the purpose of being replaced.

d) If the Committee Supports the Physicians' position

The Committee may support the health care providers' assessment that further treatment is inappropriate or harmful. The Committee thereby affirms that the parents' or legal guardians' wishes may be overridden in this case because considerations such as beneficence or non-maleficence should take precedence and the burdens of the therapies in question outweigh any possible benefits. In this case a decision has been made by the Committee that the parents or legal guardians are not acting in the best interests of the patient. For this reason, it is strongly recommended that the hospital administration, risk management and legal counsel be involved in further decision-making, especially if representatives were not present for the consultation meeting. Available options might include:

The ERC may recommend that the responsible physicians pursue further attempts at consensus with the patient and family.

If the consultation process uncovered potential avenues of mediation that might result in consensus between the responsible physician and the patient, patient's parents or legal guardians, then the Committee might have legitimate grounds for wanting the physician to pursue these possibilities. If this option is chosen, the consultation report needs to explicitly indicate the nature and time frame of the proposed mediation, and to commit to alternative options if the mediation fails.

The ERC may recommend that physicians pursue transfer of care.

This option should be used only if the treatment in question is considered inappropriate but not harmful. The process of seeking to transfer the patient to another facility may serve as a "check" on the judgment that continued therapy is inappropriate, since successful transfer might imply a lack of consensus about that judgment within the broader medical community. If the treatment is considered harmful, however, transfer should not be considered as this would abrogate the physicians' and the institution's responsibility to the patient.

The ERC may recommend for physicians to pursue a judicial resolution to the conflict.

If the consultation process concluded that the patient's parents or legal guardians were not acting in the patient's best interest, then judicial resolution may be sought. This would create the opportunity for re-evaluation of the patient's care plan and re-consideration of the advisability of continuing with life-sustaining treatments.

The ERC could recommend, and have the hospital administration and legal counsel sanction, the unilateral foregoing or removal of life-sustaining treatments.

Such action should occur only after informing the patient and family of the plan and only after giving the family sufficient opportunity to seek legal advice and possibly judicial involvement, if desired. It is recommended that assistance be provided to the family in order to obtain knowledgeable legal representation, and a waiting period of at least 48 hours be provided prior to withholding treatment in order to allow the family time to initiate court proceedings, if desired.

References:

With gratitude, this addendum was based on two documents of the same name, *Resolving Conflicts over Possibly Inappropriate or Harmful Life-Sustaining Therapies*, from Boston Children's Hospital, provided by Dr. Robert Truog, and from Massachusetts General Hospital, provided by Dr. Erik Krakauer.

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Addendum authors: ERC Subcommittee on Medical Futility: Karen McVeigh MD, Robert Stanton MD, Rebecca Hanson MD, Brigham Willis MD, Marisha Madrigal MSW, Rev. Dan Hudson, with revisions made on the recommendations of Thomas Keens, MD, Cheryl Lew MD, Sherry Nolan RN and Randall Wetzel MBBS.

APPENDIX M: LEGAL Considerations in the Issue of Futility

Overview

The issue of medical futility has been much discussed and debated in the medical, legal, and ethical literature. Attempts to “define” medical futility have not generated broad consensus. Most of the recent attempts to deal with this issue are process-based, recognizing that the facts and circumstances of medical futility issues will vary broadly and are best treated on a case-by-case basis. Perhaps the best known of the process-based recommendations is the Report of the Council on Ethical and Judicial Affairs of the American Medical Association. Its report, “Medical Futility in End-of-Life Cases,” was published in Volume 281, No. 10 of *JAMA* (March 10, 1999). In that report, the recommended “fair process” included the involvement of an institutional committee, such as an ethics committee, in disagreements between a physician and a patient’s representative, and attempts to transfer the patient to another physician and facility that would agree to provide the desired care.

Case Law

California case law does not provide a clear answer to whether the physician or the patient (at a children’s hospital usually the patient’s parent or legal representative) has the right to control the continuation of care in circumstances where the physician regards such care as futile. In the 1983 case of *Barber v. Superior Court*, a California Court of Appeals dismissed criminal charges against two physicians who wrote orders discontinuing artificial nutrition and hydration for an elderly, comatose patient at the request of the patient’s family. The opinion contains language that a physician has no duty to continue treatment if “it has proved to be ineffective [or] its use has become futile in the opinion of qualified medical personnel [or] further treatment would be or no reasonable benefit to the patient.” However, this case did not involve a disagreement between the patient’s legal representative and the physician, and it would be a mistake to stretch the language of the *Barber* opinion to resolve the legal issues surrounding such a disagreement.

Cases involving a disagreement between the patient’s representative and the physician have come before the courts in other states, with mixed results. In *In re Wanglie*, a Minnesota court supported the desire of the patient’s guardian for continued ventilation, despite the disagreement of the physicians. Under somewhat unique factual circumstances, a federal court in Virginia ruled in *In the Matter of Baby K* that EMTALA required continued ventilation of an anencephalic infant at the mother’s insistence. By contrast, several recent state court decisions in Massachusetts, such as *Gilgunn v. Massachusetts General Hospital*, have exonerated physicians’ decisions to remove a ventilator or enter a DNR order, despite family objections.

In short, the California courts have not addressed this issue, and the results of court decisions in other states are mixed.

III. I. Statutes

In a few states, including New York, Virginia, and Georgia, statutes provide that a DNR order may not be entered without the consent of the patient’s representative, except under extreme circumstances. Texas has enacted a statute that provides a legal “safe harbor” for a physician’s decision to withhold futile care. The Texas Advance Directives Act requires that the medical caregivers follow a specified procedure, including ethics consultation, an attempt to transfer care to another provider physician and institution, and the right of the patient’s representative to seek an extension of time from a state court. If

this procedure is followed, the treatment team may unilaterally withdraw futile treatment with immunity from civil or criminal prosecution. There is no similar statute in California.

The most relevant California statutes are those addressing the legal effects of advanced directives. Sections 4735 and 4736 of the California Probate Code provide as follows:

4735. A health care provider or health care institution may decline to comply with an individual health care instruction or health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards applicable to the health care provider or institution.

4736. A health care provider or health care institution that declines to comply with an individual health care instruction or health care decision shall do all of the following: (a) Promptly so inform the patient, if possible, and any person then authorized to make health care decisions for the patient. (b) Unless the patient or person then authorized to make health care decisions for the patient refuses assistance, immediately make all reasonable efforts to assist in the transfer of the patient to another health care provider or institution that is willing to comply with the instruction or decision. (c) Provide continuing care to the patient until a transfer can be accomplished or until it appears that a transfer cannot be accomplished. In all cases, appropriate pain relief and other palliative care shall be continued.

Sections 4735 and 4736 are part of California's new Health Care Decisions Law, which became effective July 1, 2000. They are based on Sections 7(f) and 7(g) of the Uniform Health-Care Decision Act of 1993. The Report of the California Law Revision Commission states that "medically ineffective health care," as used in [Section 4735] means treatment that would not offer the patient any significant benefit."

Most significantly, Section 4740 of the California Probate Code provides (with underlining added):

4740. A health care provider or health care institution acting in good faith and in accordance with generally accepted health care standards applicable to the health care provider or institution is not subject to civil or criminal liability or to discipline for unprofessional conduct for any actions in compliance with this division, including, but not limited to, any of the following conduct: (a) Complying with a health care decision of a person that the health care provider or health care institution believes in good faith has the authority to make a health care decision for a patient, including a decision to withhold or withdraw health care. (b) Declining to comply with a health care decision of a person based on a belief that the person then lacked authority. (c) Complying with an advance health care directive and assuming that the directive was valid when made and has not been revoked or terminated. (d) Declining to comply with an individual health care instruction or health care decision, in accordance with Sections 4734 to 4736, inclusive.

This section is also part of the new Health Care Decisions Law, and is based on a similar provision contained in the Uniform Health-Care Decision Act of 1993.

Unfortunately, the provisions of California's Health Care Decisions Law do not expressly apply to children. The term "patient," as used in this statute, is defined in Section 4625 as "an adult whose health care is under consideration." Likewise, "health care decision" is defined in Section 4617 to mean "a decision made by a patient or the patient's agent, conservator, or surrogate." The statutory definitions of "agent," "conservator," and "surrogate" do not encompass the parents of a minor. In short, Sections 4735 and 4736 of California's Health Care Decisions Law apply only to adults, not to minors.

If a physician or hospital is challenged for withholding or withdrawing life sustaining care against the wishes of a parent on the basis of "futility," the legal argument would have to be based on the general language of the Barber case, although such language is dictum and not legally binding, and a "policy argument" that, although minors are not covered by the literal text of the Health Care Decisions Law, there is no meaningful distinction that can be drawn between the legal representative of an adult and the legal representative of a child with respect to "futile care." Another legal argument would be that the decision to deny "futile care" to a minor conforms to "generally accepted health care standards." However, a parent might argue that the issue is not the negligence or malpractice of the physician, but the parent's lack of consent, and that the two are legally different.

In sum, there are some credible legal arguments that can be used to defend a physician's decision to deny care to a minor based on medical futility. But these arguments have not been adopted or approved by California courts or the California legislature. In light of this, there is uncertainty and risk involved in relying on these arguments. The fact of the matter is that decisions regarding futile care of minors represent uncharted waters under California law.

Hospital Policies

An article in the Fall 2000 issue of the *Cambridge Quarterly of Health Care Ethics* urges the implementation of futility policies, stating: "Hospitals are likely to find the legal systems willing (and even eager) to defer to well-defined and procedurally scrupulous process for internal resolution of futility disputes." The authors surveyed 26 California hospitals, including UCSF, Kaiser Permanente, Stanford, UCLA, and Cedars-Sinai, that had policies or protocols in place dealing with futile treatment, and reported that 24 of the 26 permit doctors to unilaterally deny wanted life-supporting care over the objections of the patient's representative.

IV. II. Non-Legal Factors

Before a decision is made to override the desires of the patient's representatives (in CHLA's case, usually the child's parents), the potential consequences of adverse publicity and possible legal action should be considered. Most of the recent literature on this subject advises a process that emphasizes the exhaustion of all reasonable efforts to communicate with, and provide information to, the parents in an effort to bring about their acceptance of the decision to terminate or withhold care. Whatever the ultimate outcome, the process should be one that any outsider (court, press, etc.) would regard as unquestionably reasonable, caring, and fair. The process should demonstrate respect for the opinions and feelings of the parents, and should provide a reasonable amount of time for the parents to understand the medical information provided and to come to terms with their emotions.

APPENDIX N - GLOSSARY

ADULT: Person who has reached the age of 18 or a minor who has entered into a valid marriage (whether or not the marriage was terminated by dissolution), who is on active duty with the armed forces of the United States of America, or has been declared emancipated pursuant to California Civil Code Section §64.

ADVANCED LIFE SUPPORT MEASURES: Any medical procedures or use of interventions which utilize mechanical or artificial means to sustain, restore or supplant a vital function and which would only prolong the process of dying. (See Procedure, P.1) {where the patient cannot expect to be returned by any means to a reasonable quality of life (as defined by the individual patient), a life without intolerable suffering.}

ASSENT: This concept rests on the ethical principle of respect for persons with a basic right to know or to be informed and to exercise the right of autonomy or self-determination. "Assent" recognizes the involvement of the child in the decision-making process while also acknowledging that the child's level of participation may be less than fully competent. Assessment of competence in children involves four basic elements: understanding, choosing, reasoning and appreciating (the nature of the resulting decision). Data indicates the average 14 year old can employ such competent reasoning. Where research is concerned, the child's "no" should be carefully considered (See "Assent Policy" ETH-20.0)

BASIC ETHICAL PRINCIPLES:

Justice: Generally is used to mean distributive justice: just distribution in society structured by various moral, legal and cultural rules and principles that form the terms of cooperation for that society. It is an attempt to connect the properties or characteristics of persons and the morally correct distribution of benefits and burdens in society.

Beneficence: Production of benefit. The principle of beneficence asserts an obligation to help others further their important and legitimate interests. One should confer benefits and act to prevent and remove harms, as well as balance the potential goods against the possible harms of an action.

Non malfeasance: (Non infliction of harm) The most stringent moral principle, associated with the maxim *Primum non nocere* (Above all, do no harm). Simply, one ought not to inflict evil or harm.

Respect for Autonomy: Respect for the right of individual self-governance: personal rule of the self while remaining free from both controlling influences of others and personal limitations such as inadequate understanding, that prevent meaningful choice. The Autonomous person acts in accordance with a freely chosen and informed plan. This principle gives rise to the concept of informed consent as well as many other forms of decision making.

BENEFITS VS. BURDENS (Proportionality of treatment): Determining whether treatment is proportionate or disproportionate Ethical construct where the benefits of treatment are articulated and measured against the potential burdens of that treatment. As explained in Appendix A, "where the burdens exceed the benefits, there is no ethical obligation to provide or continue treatment."

CARE GIVER: In the context of patient care, it is useful to distinguish between two principle groups or types of care givers. The broad interests and goals of the two groups may differ; certainly the roles and responsibilities towards the patient differ. Family care giver: includes all persons intimately involved with the patient. This term should not be limited to biological family, but should also extend to those persons who have special attachment (e.g. foster parents and siblings; close friends). These persons provide caring and physical care within the greater social context. These relationships are lifelong and

transcend concerns beyond health care. The specific goals of these persons re the patient are driven by greater social and spiritual concerns and values which may or may not coincide with those of the professional care giver.

Professional care giver: includes all persons in the health care team proper (e.g. physicians, nurses, consultants in a variety of disciplines). While these persons often experience significant emotional attachment towards the patient which approaches the degree expected in family care givers, there are specific obligations incumbent in the role of professional care giver. These obligations define the fiduciary nature of the health professional's relationship to the patient. The principal overriding goal of the professional care giver is to alleviate the physical and spiritual suffering of the patient and family resulting from illness and disease. Thus, the responsibilities usually include obligations to carry out appropriate diagnostic evaluations and to propose appropriate management plans which optimize the balance between benefits and burdens of treatment while respecting the familial values context. The role of professional care giver may appear, at times, to overlap that of family care giver. The risk for conflict of interest, under such circumstances, is great. The professional may engage in behavior which essentially disempowers the patient and family by substituting his or her own values for those of the patient and family. It is part of the fiduciary responsibility of the professional caregiver to remain vigilant against inadvertent abuses of power with respect to the patient and family.

COMPETENCY: For the purposes of consenting to medical treatment, competency is defined as the ability to understand the nature and consequences of that to which one is asked to consent.

EMANCIPATED MINOR: A minor 14 years of age or older whom the court has heard and granted a petition for emancipation. In such cases the Department of Motor Vehicles will issue an identification card which states that the minor is emancipated. (See also SELF-SUFFICIENT MINOR)

FIDELITY: Refers to the keeping of promises, whether explicit as in a specific contract or implicit as in fidelity-generating role relationships such as that between a health-care giver and patient.

GUARDIAN: Court-appointed surrogate (See also SURROGATE DECISION-MAKER)

HOSPICE: Refers to a philosophy of care (rather than a particular place), an interdisciplinary approach which emphasizes palliative and supportive services for the child and family. Hospice care exists within a continuum of services provided to the child with progressive life-threatening illness and his family through the transition from life to death. Cornerstones of hospice care are pain and symptom management and response to needs of the patient in a holistic way: physical, developmental, emotional, psychological and spiritual.

INCOMPETENT PATIENT: Persons who are defined by law as not having the ability to consent, have been declared legally incompetent, or persons who, in the opinion of the attending physician, are either permanently (for example, mentally deficient or senile) or temporarily (for example, head injury or drug abuse) and, therefore, incapable of giving consent.

LIVING WILL: Any written statement in which the patient states what treatment is desired or rejected at some future time. Living wills are not recognized by statute in California although the courts have treated them as significant evidence of the patient's desires. (Refer to Appendix D - Medical Legal Concerns for discussion.)

MINOR: A minor is a person under the age of 18.

PATERNALISM: The type of doctor-patient relationship in which the physician makes decisions for the patient instead of with the patient.

PERSISTENT VEGETATIVE STATE (PVS): In general, child neurologists define PVS in infants and children in terms of the persistent loss of higher cortical functions rather than the persistence of vegetative functions. Please review appendix J.

PRIMARY ATTENDING: The responsible attending physician of record as noted in the medical record and as recognized by the patient.

SELF-SUFFICIENT MINOR: A minor 15 years of age or older who is living separate from his or her parent(s) or legal guardian, and managing his or her own financial affairs, regardless of the income. In the absence to the contrary, the hospital may reasonably believe that the affirmations made by the minor are correct without independent verification. (See also EMANCIPATED MINOR)

SURROGATE DECISION-MAKER: Person(s) who makes a medical decision on behalf of another. Whether a particular surrogate has or should have legal authority to make such decisions is an issue which must be determined (See also GUARDIAN)

TERMINAL CONDITION: The prelude to death and as such may have a variable time span. Specifically, per the Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying (The Hastings Center, 1998): an incurable or irreversible condition which has a high probability of resulting in death with a relatively short time regardless of treatment. The time span in the Guidelines is defined as one year.

VASOACTIVE DRUGS: (Pressors, inotropic agents) Pharmacologic agents used therapeutically to increase cardiac output.

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