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BAY AREA NETWORK OF ETHICS COMMITTEES

TERMINATION OF LIFE SUPPORT: GUIDELINES FOR THE DEVELOPMENT OF INSTITUTIONAL POLICY

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INTRODUCTION

The Bay Area Network of Ethics Committees (BANEC) was founded in 1987 through a joint effort of the Hastings Centers and the San Francisco Medical Society to assist the work of local Ethics Committees. Two of our specific goals are to "provide a clearinghouse for guidelines and policies developed by member institutions for sharing with member committees to assist in the development of their policies" and to "work to develop uniform policies on ethical issues with area-wide significance." To this end we decided our first focus of policy collection and development would be in the area of termination of life support.

We gathered from our members in the San Francisco Bay Area (six counties represented) the termination of life support policies of twelve hospitals, including health maintenance organizations, and private and county hospitals - large and small. On reviewing these various policies, and a number of guidelines issued by other organizations, it became apparent that each had its useful sections and each had its omissions, and that, if combined, a unique and comprehensive termination of life support policy might emerge. A small subcommittee, composed of two physicians and registered nurse, who is also a health care education consultant, then proceeded to write a composite policy using parts of the various hospitals' policies, reworking, reorganizing,

and rewriting many sections. We had the very detailed and helpful input of numerous people, including a person involved with publishing, lawyers, ethicists, and health care providers. We are pleased with the result and decided to make this document available to a wider audience.

This document is far from being the final word, but may instead be used as a reference point or starting point for institutions involved in writing similar policies. Nor is it intended to represent the standard of care for this community, but we do hope that it will help to promote the development of such a standard on the issue of termination of life support.

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BAY AREA NETWORK OF ETHICS COMMITTEES COMPOSITE POLICY: TERMINATION OF LIFE SUPPORT

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PRINCIPLES AND GUIDELINES IN DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT

A. Principles

1. Patient Autonomy

a. Decisions to forego life-sustaining treatment are based primarily in the legal and moral right to self-determination, i.e., a person's right to form, revise over time, and pursue his or her own plan of life.

Respect for self-determination in health care means that decisions about treatment will be made by the patient in collaboration with health providers and family members, consistent with the institution's philosophy, and will be based on the particular patient's values, goals, religious convictions, and life philosophy.

b. The preferences and desires of adolescent children must be elicited and granted great weight in the decision-making process concerning terminating life support.

2. Proportionality

a. Decisions to forego life-sustaining measures can be guided by a consideration of the benefits and burdens of treatment to patients considered holistically (that is, taking into account their medical condition as well as personal values, religious convictions, psychological resources, etc.).

Treatment becomes ethically unnecessary either when it is of no benefit to the patient or when the burdens resulting from treatment are disproportionate to the benefits hoped for or obtained. Such judgments are obviously value judgments and are not always easily made (see Guidelines).

b. Medical interventions may be disproportionate when the patient has an underlying incurable medical condition,

does not have any reasonably conceivable possibility of recovery or long-term survival, or there is no medical purpose which would be achieved by the application of the intervention should the natural course of a patient's medical condition cause vital functions to fail. A medical intervention may also be found disproportionate by a competent and informed patient, but in such cases the decisions should be reserved to the patient rather than surrogate decision makers.

3. Informed Consent

a. Patient choice is honored whenever possible.

b. Although the informed content doctrine has substantial foundations in common law and the constitutional right to privacy, it is essentially an ethical imperative grounded in the moral right to self-determination and autonomy.

c. The voluntary choice of a competent and informed adult patient should determine whether life-sustaining therapy will be undertaken or continued, just as such choices provide the basis for other decisions about medical treatment. Patients have primary responsibility for their health care.

d. Patients should have access to necessary information, which would include diagnosis and prognosis, treatment options, risks and benefits, and recommendations. Health care providers may not withhold unpleasant information simply because it is unpleasant for them or for the patient.

e. Ethically valid consent is a process of shared decision-making based on mutual respect and participation. Health care professionals have an obligation to enhance the patient's ability to make decisions on their own behalf and to promote understanding of available treatment options.

f. It is the responsibility of the attending physician or his or her designee to document in the patient's medical record that informed consent to withhold or withdraw life-sustaining treatment has been obtained and from

whom.

4. Presumption of Decision-Making Capacity

a. Patients are presumed to possess the capacity to make health care decisions. Lack of such capacity must be demonstrated (see Guidelines point 9: Determination of Decision-Making Capacity).

B. GUIDELINES

1. *Preservation of Patient Dignity*: Withholding or withdrawing useless or burdensome treatments does not mean abandoning the patient. In all cases the patient's dignity, comfort, hygiene, and social, psychological, and spiritual support must be preserved.

2. *Futile Therapies*: Therapies expected to be futile need not be provided. When intervention would simply prolong the dying process and there is no compelling social or psychological reason to intervene, the natural process of death should be allowed to occur. Nevertheless, basic, humane and dignified care to ensure the patient's comfort should be provided at all times.

3. *Life-Support is Reversible*: Under appropriate circumstances any intervention may be withdrawn. Continued use is not required solely because such support was initiated at an earlier time.

4. *Physician May Decline Participation*: It is the right of any physician to decline to participate in continuing or foregoing life-sustaining treatment. In exercising that right, however, the physician must take appropriate steps to transfer the care of the patient to another qualified physician.

5. *Mediation/Role of Ethics Committees*: When there is controversy about the appropriateness of diminishing care or substituting a lower-technology type of medical care, the physician should obtain another opinion to confirm diagnosis, prognosis and care decision. Ethics committees, where they exist, would be helpful in situations of persistent disagreement among the care team or with surrogate decisionmakers regarding treatment.

6. *Religious and Cultural Values*: Religious and cultural perspectives on death and dying should be taken into account in decisions regarding withdrawal of life-support systems when the patient or

patient's surrogate believes these to be important.

7. *Treatments That May Be Forgone*: The treatment that may be withheld or withdrawn includes all medical procedures, including artificial feeding and hydration, the administration of antibiotics or pressor agents, dialysis, and mechanical ventilation.

8. *Proportionality*: Whether a treatment is proportionate or disproportionate depends on an assessment of the treatment's expected benefits versus the burdens to the patient it may cause. An intervention which is deemed to be disproportionate should be withheld or withdrawn.

   The unique facts of each must be considered. The relevant considerations include:

   a) What is the degree of certainty regarding prognosis and the possible effect of treatment?

   b) How long the treatment is likely to extend life and can it improve the patient's prognosis for recovery?

   c) What may the quality of the patient's additional life be, and specifically what are the possibilities of a return to cognitive, sapient life and of a remission of symptoms enabling a return towards a normal, functioning, integrated existence?

   d) What is the degree of intrusiveness, risk, and discomfort associated with the treatment?

9. *Determination of Decision-Making Capacity*

   a) Inquiry into the patient's capacity should be made in such conditions as: delirium, dementia, depression, mental retardation, psychosis, intoxication, stupor, or coma. Decision-making incapacity can be a transient condition and can be specific to a particular decision. Therefore, patients who suffer from any of the above should be reassessed periodically by more than one evaluator.

   b) A former assessment of capacity is a process that could include consultation with the family and other health

care providers and is documented by the attending physician. A psychiatric/psychological consultation may be desirable if psychiatric factors are thought to be compromising capacity.

c) Refusal of specific treatment to which most patients would agree does not mean that the patient lacks decision-making capacity, but may initiate further inquiry into the matter of capacity.

d) A legal determination of incompetence and incapacity to make a specific medical decision are not the same, and one does not necessarily imply the other.

e) Questions to ask to determine capacity:

1) What is your present physical condition (diagnosis)?

2) What is the treatment that is being recommended?

3) What do you and your doctor think will/might happen to you if you decide to accept the treatment?

4) What do you and your doctor think will/might happen to you if you decide not to accept the treatment?

10. *Rights of Patients Lacking Decision-Making Capacity*

a) Patients who lack decision-making capacity have the same substantive ethical and legal rights as those who do possess such capacity. The only distinction is that in the case of patients lacking decision-making capacity, health care decisions must be done on their behalf by a surrogate decisionmaker.

b) Decisions made on the behalf of patients lacking decision-making capacity should, when the patient's wishes are known, replicate the decision they would have made for themselves had they had the capacity to do so.

c) If the patient has executed a "living will" or any other form of advance directive to a health care provider, this document should serve as strong evidence of the patient's wishes. However, health care professionals are not

obligated to provide services that are against good standards of ethical practice or the law. In this light, advance directives given to a physician or Durable Power of Attorney for Health Care (DPAHC) should be given proper consideration.

d) Where the patient, prior to losing decision-making capacity, has designated a surrogate either in writing such as a Durable Power of Attorney for Health Care (DPAHC) or verbally, the patient's choice of surrogate must be documented and must be respected under some circumstances. The attending physician may be so designated by the patient although this is not a desirable situation.

11. *Surrogate Decision Makers*

a) The appropriate decision-makers for a patient incapable of giving consent are: the parents or guardian of a minor, the attorney-in-fact designated under a Durable Power of Attorney of Health Care (DPAHC), and a conservator with court-ordered authority to consent to an adult conservatee's medical treatment. In the absence of any of these relationships, conventionally recognized surrogate decisionmakers include the patient's closest available relative(s) or significant others. Attention should be paid to identifying the person who can best represent the patient's interests and is most familiar with his/her wishes and values.

b) However, family or guardians could be disqualified from serving as the patient's surrogate for decisionmaking because of decision-making incapacity, an irresolvable disagreement among them, or their choice of an action which is, in the opinion of the caregivers, clearly against the patient's best interests.

c) If no surrogate decisionmaker can be identified, a no-code order may be issued when the patient's physician determines it is medically appropriate. In such cases, it is advisable, but not required, that the physician seek a consultation before issuing the order and/or notifying the administration. Orders to withhold or withdraw other forms of life-sustaining treatment when there are no

surrogate decisionmakers who can act on behalf of the patient may not be issued unless the patient's physician has consulted with appropriate parties and notified the administration of the proposed order and secured confirmation of the propriety of the proposed order (California Hospital Association Guidelines).

d) Although complete consensus is not required, ideally the family or significant others should concur with the medical decision, if the patient is unable to make a decision and there is no legally designated decisionmaker.

e) Surrogates and health care personnel should work together to make decisions for seriously ill patients lacking decision-making capacity. Recourse to the courts should be reserved for occasions when adjudication is clearly required by state law, or as a last resort when concerned parties have disagreements that they cannot resolve on matters of substantial import.

II. PROCEDURES

A - PATIENTS WITH DECISION-MAKING CAPACITY

1. When the question of terminating or withholding life-support measures arises with respect to patients having decision-making capacity, inquiry should be made into whether this patient has, in any way, made his or her wishes known. The conscious, competent patient's wishes prevail over those of family members and health care providers for medically-indicated procedures.

2. If patient has not done so, he or she should be asked to complete a "Directive to Physicians."

3. Patient should be given the option of designating an attorney-in-fact by executing a Durable Power of Attorney for Health Care (DPAHC).

4. Patient should be involved in any decisions to withhold life-sustaining interventions.

B - PATIENTS LACKING DECISION-MAKING CAPACITY

1. When the question of terminating or withholding life-support

measures arises with respect to patients lacking decision-making capacity, initial inquiry should be made into whether this patient has, in any way, made his or her wishes known. Inquiry will be made to determine if a "Directive to Physicians" or Durable Power of Attorney for Health Care (DPAHC) has been signed or if the patient has made specific statements making clear such a desire.

2. When termination of or withholding life support in a patient deemed terminally ill has become a focus of disagreement, the desire of family members to remove life-support systems, when fully documented in the medical record, is legally sufficient for removal. If there is disagreement among family members, consultation with the hospital ethics committee, where one exists, should be considered.

3. The diagnosis and prognosis should be explained by the patient's physician to the patient's immediate family and/or surrogate. The attending physician may then suggest what treatment is futile and might therefore properly be withdrawn or withheld. A "futile" or "useless" treatment is one which cannot and does not improve the prognosis for recovery, nor does it ameliorate the patient's condition nor maintain comfort.

C - DETERMINATION OF DEATH

1. *Medical Standards for the Determination of Death:*

   a) the Determination of Death Act states that: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."

2. *Medical Criteria for Determination of Cardiorespiratory Death*

   a) Cessation of circulatory and respiratory functions determined by clinical examination for responsiveness, heartbeat, and respiratory effort. Medical circumstances may require the use of confirmatory tests, such as an electrocardiogram.

b) Irreversibility of the above cessation of function is recognized by persistent cessation of functions during an appropriate period of observation and/or trial of therapy.

c) Children and young adults require special consideration since recuperative powers are great and standard tests of brain function may be misleading. Consultation with those skilled in pediatric neurology is necessary in these instances.

3. *Medical Criteria For Determination of Brain Death*

a) Cessation of all functions of the brain

1) Absence of cerebral cortical activity

a) This is defined as the presence of deep coma, with no seizure decerebrate or decorticate posturing and no evidence of cerebral responsiveness or receptivity. EEG is not mandatory, but if some question exists, an EEG should be obtained, repeated in 24 hours, and interpreted by someone skilled in reading EEGs. Should question still exist, cerebral blood blow studies such as angiography or nuclear medicine scans may be necessary. Absence of blood flow is diagnostic of brain death.

2) Absence of Brain Stem Functions

a) Cranial nerve reflexes: A physician experienced in detailed neurological examination should test the pupillary light, corneal, oculocephalic, oculovestibular, oropharyngeal, and respiratory reflexes. If the attending physician lacks particular skills in this area, consultation should be obtained.

b) Apnea testing (respiratory reflex):

(1) Ventilate with 100% 0_2 concentration for 10 minutes.

(2) Withdraw ventilator and continue passive

flow of oxygen.

(3) Adults: Absence of spontaneous breathing after 10 minutes confirms brain stem death. If doubt exists, obtain arterial blood sample to document $PaCO_2$ of greater than 60mm Hg.

(4) Children: Below the age of five [5] years/newborns: Absence of spontaneous breathing after two-to-five minutes confirms brain death if $TcPCO_2$ monitoring reflects $PaCO_2$ of greater than 60 mm Hg.

b. Irreversibility of Loss of Brain Function

1) The cause of coma must be established and be sufficient to account for the loss of brain functions. The possibility of the recovery of any brain function must be excluded.

2) Excluded Conditions, which must be corrected, if possible, before the determination of brain death can be made, include but are not limited to:

a) Metabolic derangement (e.g., hepatic encephalopathy, hyperosmoles coma, and preterminal uremia.
b) Drug intoxication
c) Hypothermic condition (core temperature less than 32.2°C)
d) Neurogenic shock
e) Cardiogenic shock
f) Hypovolemic shock
g) Neuromuscular blockade
h) Brain stem encephalitis

3) If sufficient cause for irreversible coma is not established, evaluation and observation for the above conditions is recommended. If intoxication is found, death may not be declared until the intoxicant is metabolized or intracranial circulation is tested and found to have ceased.

c) Without confirmatory tests: Clinical observation for 12 hours in absence of confirmatory tests is sufficient for a determination of brain death in adults except:

1) In patients having suffered anoxic insufficiency: A 24 hour period of clinical observation is recommended when confirmatory tests have not been performed.

2) A 72 hour period of clinical observation is recommended when confirmatory tests have not been performed in children under five [5] years/newborns. Auditory evoked stimuli can be helpful in children, particularly if drugs are being used and EEG is silent.

d) With confirmatory tests: Observe cessation of functions over an appropriate period of time (six hours is recommended by the President's Commission) and/or therapeutic trail. If confirmatory tests have been performed (angiography, isotope flow studies etc) absent cerebral flow associated with clinical determination of loss of all brain functions is diagnostic of death.

e) Brain death must be independently confirmed by a second physician.

4. *Procedure After Death is Declared:* If cardiorespiratory or brain death has been documented, then the attending physician will:

a) Notify family members or significant others that legally and medically the patient is dead, and that life-support systems will therefore be removed.

b) If the family or significant others object, attempt to convince them that the objection is not reasonable. Even if objections continue, after reasonable efforts by the physician and/or others to convince the family otherwise, life-support systems should be removed. The chief of service or ethics committee may be of help in these situations.

c) All of the above will be documented in the medical record.

d) Written consent by family members or significant others is not necessary for removal of life-support systems.

e) If the patient is pregnant, appropriate consultation should be sought from the hospital administration, ethics committee where present, and medical-legal services.

f) The physicians who determine that the patient is dead will not participate in any procedures for removing or transplanting any organ of the decedent.

D - TERMINATING LIFE SUPPORT IN PERMANENT VEGETATIVE STATE

This is a specific case of patients who lack decision-making capacity and is highlighted due to specific clinical problems often presented (see "Procedures, Section B").

There are patients who are permanently comatose or who are in a permanent vegetative state from whom any and all life-sustaining treatments may be withheld or withdrawn.

1. The diagnosis of coma or vegetative state with a very high probability of permanence should be made by a physician and confirmed by another physician experienced with such diagnoses. (In the Barber-Nejdl/Herbert case, the California Court of Appeal referred to patients like Mr. Herbert as those who have been "reliably diagnosed as in a comatose state from which any meaningful recovery of cognitive brain function is exceedingly unlikely.") If the diagnosis or the likelihood of permanence is in doubt, all treatment should be continued until the issue is resolved.

2. The diagnosis and prognosis should be explained by the patient's physician to the patient's family and/or legal surrogate. The attending physician may then suggest what treatment is futile and that such treatment may properly be withdrawn or withheld.

3. If the patient's preferences regarding treatment are clearly known (whether these were written in a "living will" or expressed verbally while the patient was competent), these should be honored.

4. If the patient's preferences are not reliably known, the physician, in consultation with the patient's family/surrogate should attempt to act in the patient's "best interests." Issues which may arise in

considering a patient's "best interests" include:

* Relief of suffering;
* Preservation or restoration of functioning;
* Quality as well as extent of life (by "quality of life" is meant the value of the patient's life to him or herself); and
* Burdens versus the benefits of any proposed or ongoing treatment.

If several treatment options are acceptable to all concerned, then the course chosen by the immediate family should generally be followed. If the attending physician and the patient's immediate family or surrogate disagree about what treatment is or is not in the patient's best interests, the hospital's ethics committee, where one exists, may be consulted. In the case of persistent disagreement, court referral may be required.

E - ORDERS TO WITHHOLD SPECIFIC INTERVENTIONS

1. *Classification of Orders to Limit Resuscitative Services*

   a. "DO NOT RESUSCITATE (DNR)": When there is consensus among patient, physician(s), staff and family members that, should the patient suffer cardiopulmonary arrest, the burden of resuscitative efforts would outweigh their benefits, cardiopulmonary resuscitation (CPS) should be withheld. A "Do Not Resuscitate" order is written in the patient's chart to prevent the initiation of such resuscitative efforts. In the absence of such an order, full CPR will be provided to patients in the event of arrest. (Continuation of resuscitation efforts after initiation shall be the decision of the physicians who respond to the patient at the time of cardiopulmonary arrest, based on their best knowledge of the patient's status and the intentions of the Attending of Record.)

   In addition to "Do Not Resuscitate" orders, the scope of which is to withhold any resuscitation effort, specific efforts to limit resuscitative efforts may be written. Some examples follow:

   b. "NO ENDOTRACHEAL INTUBATION": The airway will be maintained only with bag and mask, oral airway,

oxygen and other noninvasive measures. Mechanical ventilation will not be used. Otherwise resuscitation will proceed according to American Heart Association Advanced Life Support (AHA/ALS) criteria.

c. "NO CHEST COMPRESSION": External chest compression, either manual or mechanical, will not be utilized. Resuscitation efforts will otherwise parallel AHA/ALS guidelines.

d. "CHEMICAL AND/OR ARRHYTHMIA THERAPY ONLY": Although medical therapy may be provided, efforts will not include endotracheal intubation, external chest compression or defibrillation/cardioversion.

e. Other specific orders might be: Do not transfer to Intensive Care Unit; Do not dialyze; Do not begin pressor agents; Do not transfuse, and Do not start antibiotics.

2. *Procedure*

a. No Potential Medical Benefit: When the Attending of Record has determined that CPR or other resuscitative interventions are not of potential medical benefit, he/she may write an order to that effect.

1) If the patient is lucid, he/she should be informed of the decision. A note must be written in the progress notes section of the medical record documenting the rationale for the decision and that the patient has been informed and helped to understand. If possible, the family should also be aware of the order and its rationale.

2) If the Attending of Record has determined that the patient is not lucid and is unable to participate in a discussion, or is a minor, the family or guardian should be informed, if possible, of the clinical situation and the rationale for the order. A note should be written in the progress notes section of the medical record documenting that the family or guardian has been informed. While consent of the family is not strictly required, in cases of family discomfort with the order, vigorous efforts to achieve

consensus are appropriate. If it is not possible to contact family members, the efforts to locate family should be documented in the progress notes.

3) If the consensus is not achieved and the patient or family continues to request resuscitation despite the conviction of the Attending Physician that it is not of benefit, consultation with the chief of service or referral to the Ethics Committee for discussion may be helpful in achieving resolution.

b) Of Uncertain Medical Benefit: When the Attending of Record determines that life-sustaining interventions could be successful, but may not be appropriate, the preference of the patient or his/her proxy is determining. Life-sustaining interventions may not be appropriate, because of either poor quality of life before intervention or poor quality of life expected after life-sustaining interventions. Quality of life is determined according to the patient's own values, to the extent they are known.

1) If the patient is lucid, he/she should be offered the option of life-sustaining interventions. The discussion and he decision of the patient should be documented in the progress notes and any order limiting resuscitative efforts desired by the patient written on the order sheet.

2) If the patient is not lucid, a proxy able to relay the patient's characteristic preferences should be sought. The DNR order, if felt by the proxy to be consistent with the patient's characteristic preference, should be documented.

3) The revocation of one form of intervention does not automatically imply the revocation of other forms. Supportive care to maintain comfort and dignity is always required.

c. Orders to limit life-sustaining treatments should be periodically reviewed as clinically appropriate to ensure that the order remains appropriate.

F - ADVANCE DIRECTIVES

1. *Durable Power of Attorney for Health Care*

Sections 2430 and following of the California Civil Code provide that treatment decisions, including those to withhold or withdraw life-sustaining treatment, may be made on behalf of a patient incapable of making such a decision by his or her attorney-in-fact, appointed pursuant to a properly executed Durable Power of Attorney for Health Care (DPAHC).

A health care provider may rely upon the treatment decision of such an attorney-in-fact without being subject to civil or criminal liability or professional disciplinary action (except to the same extent that the provider would be liable if the patient had made the decision himself or herself) if:

a. The patient has become incompetent, and

b. the provider believes in good faith that the attorney-in-fact is properly authorized under the Durable Power of Attorney for Health Care (DPAHC) to make the decision; and

c. the provider believes in good faith that the decision is not inconsistent with the desires of the patient; and

d. the provider has made a good-faith effort to determine the desires of the patient, to the extent that he or she is able to convey those desires, and the results of the provider's efforts are entered in the patient's medical records.

A health care provider may refuse to comply with the decision of a properly appointed attorney-in-fact to withdraw life-sustaining treatment without being subject to civil or criminal liability or professional disciplinary action. That provider is then responsible for finding the patient another physician who will comply with the patient's wishes.

2. *Natural Death Act Directive*

The patient may also, while competent, execute a Natural Death Act Directive instructing his physician to withdraw or withhold

treatment in a terminal condition. There are two types of such directives. The mandatory directive occurs when the patient has been told that he/she has a terminal condition, has waited for a 14-day period, and then signed the directive. In such a situation, the doctor must comply with the patient's wishes or transfer him to a doctor who will do so. Failure to do this shall be considered unprofessional conduct.

The permissive directive occurs when the patient has properly signed and executed a directive under any other circumstances in the last five years. With a permissive directive, the physician, at his or her discretion, may discontinue life support.

There are three prerequisites to reliance on a directive of either type: (i) the patient must be in a terminal condition, (ii) death must be imminent whether or not life-sustaining procedures are used, and (iii) the formal requirements of Health and Safety Code 7188 must be met. These requirements include two unrelated witnesses and execution within the last five years in an approved form. It is recommended that physicians, relying upon directive, consult with the medical-legal department to assure that formal requirements have been met.

G - DOCUMENTATION OF DECISIONS AND ENTRY OF ORDERS

When it has been determined that a particular life-sustaining procedure is to be foregone, the resulting order must be written into the patient's medical record by the attending physician or a designate as directed by the attending physician. Proximate to the entry of the order, the attending physician must ensure that the order and its meaning are discussed with appropriate members of the hospital staff (including nursing staff and house staff) so that all involved professionals understand the order and its implications.

Progress Notes: At the time an order to limit life sustaining treatment is written, a companion entry should be made in the progress notes, which includes at a minimum the following information:

1. medical condition, diagnosis and prognosis;

2. the patient's wishes (when known) or surrogate's wishes (if patient lacks decision-making capacity) and/or family members' wishes (where known);

3. the recommendations of the treating team and consultants with documentation of their names;

4. a description of the patient's decision-making ability at the time the decision was made and the efforts made to ascertain the patient's capacity;

5. if the patient is deemed incapacitated to make medical decision on his/her behalf, a statement indicating the basis on which a particular person or persons have been identified as appropriate surrogate decision-maker(s) for the patient; and

6. a statement indicating that the physician has informed the patient or surrogate decision-maker of the nature and advisability of the risks and complications inherent in, and the probable consequences (which would include death) of withholding or withdrawing the treatment in question.

H - FOREGOING LIFE-SUSTAINING TREATMENT FOR INFANTS AND OTHER CHILDREN

These guidelines are directed at clinical situations involving adults only (persons 18 years or older and emancipated minors). Although in general parents and court-appointed guardians have legal authority to make treatment decisions for minor children, recent developments in Federal and California law relating to "medical neglect" and the publication of relevant regulations by the United States Department of Health and Human Services make such decisionmaking far more complex and sensitive. For current information, physicians should consult administrators, legal counsel or ethics committees at their hospitals. Additional information is available in the "California Association of Hospitals and Health Systems Consent Manual" Chapter 5 (14th Edition, 1987) which discusses developments in this area and the reporting requirements that may be applicable.

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APPENDIX

UNIFORM DETERMINATION OF DEATH ACT (FEDERAL)

"An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."

CONNECTICUT DETERMINATION OF DEATH STATUTES

SEC. 19a-279h(b)

"Without limiting any other method of determining death, a donor may be pronounced dead if two physicians determine, in accordance with the usual and customary standards of medical practice, that the donar has suffered a total and irreversible cessation of all brain function. A total and irreversible cessation of all brain function shall mean that the heart and lungs of the donor cannot function, and are not functioning, without artificial supportive measures."

SEC. 19a-504a(b)

"For purposes of making a determination concerning the continuation or removal of any life support system in a general hospital licensed under section 19a-491, an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. Determination of death shall be made in accordance with accepted medical standards."

For the purposes of this policy, a physician qualified to determine brain death as required by the Medical Staff of Hartford Hospital shall be defined as any Neurologist, Intensivist or Neurosurgeon on the Hartford Hospital Medical Staff or housestaff, licensed in Connecticut, and designated as qualified by the Department of Neurosurgery, Neurology, or Division of Pediatric Neurology.

Determination of brain death requires a written documentation of the findings of two separate examinations by at least two qualified physicians (one of whom must be an attending physician who has been certified [vide supra] in the determination of brain death) as well as documentation of the appropriate supporting medical data in the patient's chart. The first examination need be performed by one qualified physician. The second examination *must* be performed by two qualified physicians; both of whom certify the event and time of death in the record. The *same* qualified physicians need not be present at both exams.

THE DETERMINATION OF DEATH BY BRAIN DEATH CRITERIA

A. AN INDIVICUAL WITH IRREVERSIBLE CESSATION OF ALL FUNCTIONS OF THE ENTIRE BRAIN, INCLUDING THE BRAINSTEM, IS DEAD.

The "function of the entire brain" that are relevant to the diagnosis are those that are clinically ascertainable. Where indicated, the clinical diagnosis is subject to confirmation by laboratory tests as described below.

1. CESSATION IS RECOGNIZED WHEN EVALUATION DISCLOSES FINDINGS OF a AND b:

a. CEREBRAL FUNCTIONS ARE ABSENT, AND...

There must be deep coma, that is, cerebral unreceptivity and unresponsivity as evidenced by total unresponsiveness to environmental stimuli. There will be no spontaneous movement, no posturing to noxious stimuli, nor will there be any vegetative response to painful stimulus. Purely spinal reflexes such as the deep tendon reflexes and the triple flexion response may be maintained. Decorticate or decerebrate posturing, indicative of diencephalic and or brain stem function shall immediately exclude the patient from a declaration of brain death.

b. BRAINSTEM FUNCTIONS ARE ABSENT.

Pupillary light, corneal, oculocephalic, oculovestibular, oropharyngeal, and respiratory (apnea) reflexes should be tested. When these reflexes cannot be adequately assessed, confirmatory tests are recommended. Adequate testing for apnea is very important.

Pupils

The presence of mydriatic agents should be excluded. The pupils will be fixed in diameter and will not respond to sharp changes of light intensity.

Corneal Reflex

The corneal reflexes will be absent. The eyes will be checked for both direct and consensual blink responses. An effort will be made to ascertain the patient's status as either a contact wearer or the recipient of previous eye surgery which might blunt the response to the corneal reflex test.

Oropharyngeal

No cough, gag or response to endotracheal suctioning will be present.

Oculocephalic Reflex

The response to the oculocephalic (doll's eyes) maneuver is absent. This test will be done only after suitable X-ray examination of the cervical spine in the injured patient.

Oculovestibular Reflex

Oculovestibular (caloric) responses will not be present. The procedure will be the instillation of at least 100 cc.'s of ice water in the ear after otoscopic inspection has insured that the external audiotory canal is patent and that the stimulus can reach the tympanum. The test will be performed on both sides with the lapse of at least five minutes between the delivery of stimuli. In children there will be instillation of at least 100 cc.s of ice water. This test need be done by one of the two certifying physicians and witnessed by the other.

Apnea

Spontaneous respirations will be absent. The procedure for documenting apnea in the patient will be as follows:

Preoxygenation with 100% oxygen for at least ten minutes. An intial ABG (Arterial Blood Gas) will be drawn to document the starting PaO_2 and $PaCO_2$. At this time the patient will be disconnected from the ventilator and an O_2 cannula used to direct the flow of oxygen down the endotracheal tube at 6-8 liters per minute. The patient will then be observed and auscultated for any ventilatory efforts for at least 10 minutes. The test will be terminated for evidence of cardiovascular instability. At the conclusion of the 10 minutes or at the time of instability another arterial blood gas will be drawn for a documentation of pCO_2 level. The pCO_2 at the conclusion of the apnea test should be greater than or equal to 55 mm Hg. If the terminating pCO_2 test is lower, the appropriate ventilator adjustments will be made to insure that the starting pCO_2 is in the range of 30-35 mm Hg which should result in the terminating pCO_2 to be in the range of 55 or greater.

An alternative technique:

Preoxygenation with 100% oxygen for at least ten minutes. An intial ABG will be drawn to document the starting PaO_2 and $PaCO_2$. At the beginning of the test the ventilator should be set to establish Continuous Positive Airwave Pressure (CPAP) and the patient should continue to receive O_2 via the endotracheal tube. The patient should be observed and auscultated for respiratory effort. In a patient who is normocapneic at the onset of the test, the duration should be 5 minutes. If the patient is hypocapneic, the duration should be 10 minutes. An ABG should be otained prior to resuming mechanical ventilation. If the pCO_2 is less than 55 mm Hg, the apnea test should be repeated for a longer duration. In the event of cyanosis or a 10% change in blood pressure or pulse over baseline values, the test should be terminated after MBGs are drawn.

The apnea documentation is done only once, at the *second* examination of the two required, by one of the two certifying physicians and witnessed by the other.

2. IRREVERSIBILITY IS RECOGNIZED WHEN EVALUATION DISCLOSES FINDINGS OF a AND b AND c:

   a. THE CAUSE OF COMA IS ESTABLISHED AND IS SUFFICIENT TO ACCOUNT FOR THE LOSS OF BRAIN FUNCTIONS, AND...

      Most difficulties with the determination of death on the basis of neurologic criteria have resulted from inadequate attention to this basic diagnostic prerequisite. In addition to a careful clinical examination and investigation of history, relevant knowledge of causation may be acquired by computed tomographic scan, measurement of core temperature, drug screening, EEG, angiography, or other procedures.

   b. THE POSSIBILITY OF RECOVERY OF ANY BRAIN FUNCTIONS IS EXCLUDED, AND...

      The most important resersible conditions are sedation, hypothermia, neuromuscular blockade, and shock. In the unusual circumstance where a sufficient cause cannot be established, irreversibility can be reliably inferred only after extensive evaluation for drug intoxication, extended observation, and other testing. A determination that blood flow to the brain is absent can be used to demonstrate a sufficient and irreversible condition.

   c. THE CESSATION OF ALL BRAIN FUNCTIONS PERSISTS FOR AN APPROPRIATE PERIOD OF OBSERVATION AND/OR TRAIL OF THERAPY.

      Even when coma is known to have started at an earlier time, the absence of all brain functions must be established at the initiation of the observation period.

      Except for patients with drug intoxication, hypothermia, young age, or shock, medical centers with substantial experience in diagnosing death neurologically report no cases of brain functions returning following a six hour cessation, documented by clinical examination and confirmatory EEG. *In the absence of confirmatory tests, there shall be a period of observation of at least*

twelve hours, when an irreversible condition is well established. For anoxic brain damage where the extent of damage is more difficult to ascertain, there shall be observation for twenty-four hours. In anoxic injury, the observation period may be reduced if a test shows cessation of cerebral blood flow or if an EEG shows electrocerebral silence in an adult patient without drug intoxication, hypothermia, or shock.

Confirmation of clinical findings by EEG is desirable when objective documentation is needed to substantiate the clinical findings. Electrocerebral silence verifies irreversible loss of cortical functions, except in patients with drug intoxication or hypothermia. (Important techncal details are provided in: American Electroencephalographic Society, *Guidelines in EEG 1980,* Section 4: "Minimum Technical Standards for EEG Recording in Suspected Cerebral Death," pp. 19-24, Atlanta, 1980.) When jointed with the clinical findings of absent brainstem functions, electrocerebral silence confirms the diagnosis.

Complete cessation of circulation to the normothermic adult brain for more than ten minutes is incompatible with survival of brain tissue. Documentation of this circulatory failure is therefore evidence of death of the entire brain. Four-vessel intracranial angiography is definitive for diagnosing cessation of circulation to the entire brain (both cerebrum and posterior fossa) but entails substantial practical difficulties and risks. Test are available that assess circulation only in the cerebral hemispheres, namely radioisotope bolus cerebral angiography and gamma camera imaging with radioisotope cerebral angiography. Without complicating conditions, absent cerebral blood flow as measured by these tests, in conjunction with the clinical determination of cessation of all brain functions for at least six hours, is diagnostic of death.

Complicating Conditions

A. Drug and Metabolic Intoxication

Drug intoxication is the most serious problem in the determination of death, especially when multiple drugs are used.

Cessation of brain functions caused by the sedative and anesthetic drugs, such as barbiturates, benzodiazepines, meprobamate, methaqualone, and trichloroethylene, may be completely reversible even though they produce clinical cessation of brain functions and electrocerebral silence. In cases where there is any likelihood of sedative presence, toxicology screening for all likely drugs is required. If exogenous intoxication is found, death may not be declared until the intoxicant is metabolized or intracranial circulation is tested and found to have ceased.

Total paralysis may cause unresponsiveness, areflexia, and apnea that closely simulates death. Exposure to drugs such as neuromuscular blocking agents or aminoglycoside antibiotics, and diseases like myasthenia gravis are usually apparent by careful review of the history. Prolonged paralysis after use of succinylcholine chloride and related drugs, requires evaluation for pseudo-cholinesterase deficiency. If there is any question, low-dose atropine stimulation, electromyogram, peripheral nerve stimulation, EEG, tests of intracranial circulation, or extended observation, as indicated, will make the diagnosis clear.

In drug-induced coma, EEG activity may return or persist while the patient remains unresponsive, and therefore the EEG may be an important evaluation along with extended observation.

In the presence of barbiturates used to control intracranial pressure the following guidelines shall be followed.

a. In the event that the barbiturate level can be documented to be less than 10 mg.%, the above guidelines may be used to establish brain death on a clinical basis.

b. If the barbiturate level is greater than 10 mg.%, the procedure to establish the diagnosis of brain death shall begin with a redionuclide blood flow study which must show absent intracranial flow. This study may be interpreted *only* by individuals certified as qualified by the Chairman of the Department of Nuclear Medicine or his/her appointed deputy. If the radionuclide study shows no flow, a cerebral angiogram will be required to document the lack of intracranial blood flow.

   The absence of evoked potentials is not a criteria of brain death at this time. At any time, the examiner may elect to use short latency evoked potentials to ascertain that brain activity is *present.*

Some severe illnesses (e.g., hepatic encephalopathy, hyperosmolar coma, and preterminal uremia) can cause deep coma. Before irreversible cessation of brain function can be determined, metabolic abnormalities should be considered and, if possible, corrected. Confirmatory tests of circulation or EEG may be necessary.

B. Hypothermia

Criteria for reliable recognition of death are not available in the presence of hypothermia (below 32.2°C core temperature). The variables of cerebral circulation in hypothermic patients are not sufficiently well studied to know whether tests of absent or diminished circulation are confirmatory. Hypothermia can mimic brain death by ordinary clinical criteria and can protect against neurologic damage due to hypoxia. Further complications arise since hypothermia also usually precedes and follows death. If these complicating factors make it unclear whether an individual is alive, the only available measure to resolve the issue is to restore normothermia. Hypothermia is not a common cause of difficulty in the determination of death.

C. Children

The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods than do adults. Physicians should be particularly cautious in applying neurologic criteria to determine death in children younger than two years. Additional guidelines for the declaration of neonates and children under two years of age:

a. absence of brainstem function as documented for adults;

b. the examination results should remain consistent with brain death throughout the observation and testing period; and

c. the observation period will depend on the age of the patient and the use of confirmatory testing.

7 days - 2 months

Two examinations and EEGs separated by at least 48 hours.

2 months - 1 year

Two examinations and EEGs separated by at least 24 hours. Repeat examination and EEG are not necessary if a concomitant cerebral radionuclide angiographic study demonstrates no visualization of cerebral arteries.

1 year

If clinical criteria are met, the observation period should be 12 hours and confirmatory laboratory test are not required.

In the case of hypoxic ischemic encephalopathy the first examination should not take place sooner than 6 hours after the insult, and observation should last 24 hours. With an EEG consistent with electrocerebral silence or a cerebral radionuclide angiographic study which does not visualize cerebral arteries, the observation period may be shortened to 12 hours.

D. Shock

Physicians should also be particularly cautious in applying neurologic criteria to determine death in patients in shock because the reduction in cerebral circulation can render clinical examination and laboratory test unreliable. The mean arterial blood pressure shall be 70 mm Hg or greater. This may be accomplished with use of volume expanders or with pressor agents such as dopamine. In children or infants the mean arterial pressure shall be 50 mm Hg or greater.