

**Guidelines for Physicians: Forgoing Life-Sustaining
Treatment for Adult Patients**

**Joint Committee on Biomedical Ethics
of the
Los Angeles County Medical Association
and
Los Angeles County Bar Association**

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**GUIDELINES FOR PHYSICIANS: FORGOING LIFE-SUSTAINING
TREATMENT FOR ADULT PATIENTS**

Preamble:

Patients with decision-making capacity have the right to make decisions about their health care in light of their own values and desires. To the greatest extent possible, decisions made for patients who have lost that capacity ought to be the decisions that the patients themselves would have made in similar circumstances. These Guidelines are designed to help physicians work with patients or their surrogate decision-makers who face issues about life-sustaining treatment.

A. Relevant Legal And Ethical Principles

1. Patients With Capacity Have The Right To Make Their Own Health Care Decisions.

As long as patients have capacity,¹ they are entitled to make health care decisions.² Patients are presumed to have the capacity to make health care decisions unless their primary physicians determine otherwise. Patients with capacity may delegate their decision-

¹ “Capacity” is a person’s ability to understand the nature and consequences of a health care decision and to make and communicate such a decision. This includes the ability to understand the significant benefits, risks, and alternatives of any proposed treatments. Probate Code Section 4609. (Find this and other code sections at <http://www.leginfo.ca.gov>.) Minors who (1) have received a declaration of emancipation from the court, (2) are living apart from their parents and are self-supporting, (3) are in the Armed Forces, or (4) are married or were previously married, have the right to consent to or refuse medical treatment, and the principles relevant to medical decision making for adults (including those discussed in these Guidelines) apply to them. For other minors, *see* Los Angeles County Medical Association and Los Angeles County Bar Association Joint Committee on Biomedical Ethics, “*Guidelines: Forgoing Life-Sustaining Treatment for Minors*” (1996), available upon request through LACMA or LACBA.

² A “health care decision” is a decision regarding a patient’s health care, which includes “directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation.” Probate Code Section 4617.

making powers to others, and they must inform their physicians if they wish others to make health care decisions for them. A physician should not conclude that a patient lacks capacity solely because the patient makes what the physician thinks is a wrong decision. Unless challenged, a physician's determination that a patient lacks decision-making capacity need not be confirmed by a court. However, physicians should be aware that a court may have made a previous determination as to a patient's capacity.

2. Forgoing Life-Sustaining Treatment Is A Health Care Decision Under California Law.

Health care decisions include decisions to forgo life-sustaining treatment; that is, to have life-sustaining treatment withheld or withdrawn. Life-sustaining treatment includes, but is not limited to, artificial nutrition and hydration and cardiopulmonary resuscitation ("CPR"). Patients with decision-making capacity have the right to forgo life-sustaining treatment, whether or not they are terminally ill. Health care providers are not required to continue life-sustaining treatment solely because it has been initiated.

3. Patients Who Lack Capacity Are Entitled To Have Decisions Made On Their Behalf.

When a patient lacks capacity to make health care decisions, the physician must ascertain both whether the patient has provided specific health care instructions, either written or oral, and whether the patient has designated a surrogate decision-maker. It is important to note that a written document, while highly desirable, is not necessary. If no such information is available, the physician should identify the appropriate surrogate decision-maker. The physician should provide the surrogate decision-maker with the same information that he/she would provide to a patient with capacity. The physician must comply with the decision of the surrogate

decision-maker, except as provided in Section A.5. California law generally requires health care providers to comply with a health care decision for the patient made by an appropriate surrogate decision-maker as if the decision had been made by the patient when the patient had capacity.³

4. When Patients Lack Capacity, Health Care Providers Are Required To Identify The Appropriate Surrogate Decision-Maker.

a. Agent. An agent is an individual who has been so designated by the patient in a valid power of attorney for health care (“PAHC”) or other advance directive to make health care decisions for the patient. An agent is required to make health care decisions in accordance with the patient’s individual health care instructions or wishes, if any, to the extent that such instructions or wishes are known to the agent. Otherwise, the agent must make decisions in accordance with the agent’s determination of the patient’s best interests. The agent should consider the best interests of the patient by analyzing the comparative benefits and burdens of treatment, as well as the patient’s attitudes and beliefs, and such other factors as relief of suffering, the preservation or restoration of function, the quality and extent of life sustained, and any other relevant issue. The agent has priority over any other person, except the patient, in making health care decisions for the patient.

b. Conservator or Guardian. For the purposes of these Guidelines, a conservator or guardian is an individual appointed by a court to make health care decisions for a patient who lacks capacity. California law states that the standards the conservator or guardian must use to make health care decisions are identical to those the PAHC agent must use except in

³ See Paragraph 5 below for exceptions.

rare circumstances.⁴ If a patient has both a PAHC agent and a conservator or guardian, the PAHC agent has priority over the conservator in making health care decisions.

c. Closest Available Relative or Close Friend. While the issue is not expressly addressed by statute, California courts have long permitted reliance on relatives, domestic partners and close friends to make health care decisions on behalf of patients without capacity. Health care providers turn to such individuals when the patient has not appointed an agent and when the court has not appointed a conservator. When a relative, friend, or domestic partner makes health care decisions on behalf of a patient, the surrogate decision-maker should follow the patient's wishes, if known, or act in the patient's best interests.

In seeking to identify the appropriate surrogate decision-maker of the patient with whom to consult, the health care provider should consider immediate family members who: (1) are "in the best position to know (the patient's) feelings and desires (regarding treatment);" (2) "would be most affected by the (treatment) decision;" (3) "are concerned for the patient's comfort and welfare;" and (4) have expressed an interest in the patient by visits or inquiries to the patient's physician or hospital staff.⁵ In addition to family members, it may be appropriate to rely on non-relatives who satisfy these criteria.

d. No Surrogate Decision-Maker of Any Kind Available. Health care providers regularly care for patients who lack capacity to make their own decisions and have no advance directives or relatives, close friends, or other qualified surrogate decision-makers for health care decisions. California law offers some options to address such situations. However,

⁴ Where the conservatee is conscious but lacks capacity, the conservator may withhold or withdraw artificial nutrition and hydration only if there is clear and convincing evidence of the patient's wish for withdrawal. In re *Conservatorship of Wendland*, 16 Cal. 4th 519 (2001).

⁵ *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1021, fn. 2 (1983).

these options do not adequately address issues of forgoing life-sustaining treatment when such treatment is medically inappropriate or not in the best interests of the patient.

If a patient without decision-making capacity has no surrogate decision-maker, a physician may petition the court to appoint a conservator. In cases where a court has found that a patient lacks capacity, the conservator may make certain health care decisions. One practical problem with conservatorships is that the court must find someone to appoint. If an individual who knew the patient prior to the onset of the patient's incapacity is available, the need for a conservatorship generally would not arise. If no such individual is available, the court may look to an independent conservator or to the Public Guardian's office. Unfortunately, neither of these may agree to serve when the patient lacks financial resources. Further, some are reticent to consent to the forgoing of life-sustaining treatment.

Providers also may avail themselves of the Probate Code Section 3200 petition process. In that process, a provider petitions the court to issue an order that authorizes a designated individual to make a particular health care decision, including a decision about forgoing life-sustaining treatment. That process can be cumbersome and expensive and is unsuited to ongoing decision-making.

California law does **not** require a provider to obtain a conservatorship or file a Probate Code 3200 petition for such a patient.

The patient who lacks capacity, who has no advance directive, and for whom no surrogate decision-maker can be found requires special protection when health care decisions are to be made on the patient's behalf. Physicians find especially challenging those situations in which the initiation or continuation of life-sustaining treatment may provide no medical benefit, violate patient dignity, or cause unnecessary pain and suffering. Health care facilities should

develop a process similar to that described in Section D.2. below to make sure that decisions to forgo life-sustaining treatment on behalf of patients who lack surrogate decision-makers are within the range of ethically acceptable alternatives.

5. Health Care Providers Have An Ethical And Legal Obligation To Comply With The Decisions Of Patients Or Surrogate Decision-Makers Except In Very Limited Circumstances.

a. California law⁶ requires health care providers to comply with individual health care instructions and health care decisions of patients or, when appropriate, their surrogate decision-makers except:

(1) When the decision of a patient or surrogate decision-maker would require medically ineffective health care; or

(2) When the decision of a patient or surrogate decision-maker would require health care contrary to generally accepted health care standards; or

(3) For reasons of conscience.⁷

b. Section D.1., below, describes the procedure that should be followed when a physician and a patient or a surrogate decision-maker disagree about the appropriateness of life-sustaining treatment for the patient.

c. Forgoing life-sustaining treatment does not constitute encouraging or participating in suicide or homicide.⁸

⁶ Probate Code Sections 4734 and 4735.

⁷ An ethical or religious objection by any member of the health care team generally should be accommodated to the extent possible.

⁸ Probate Code Section 4656.

d. A physician who implements a decision to forgo life-sustaining treatment consistent with California law is not subject to civil or criminal liability or discipline against his/her medical license for unprofessional conduct.⁹ The same is true for a physician who declines to do so based on a belief that the person requesting it lacks authority.

B. General Treatment Principles

1. Life-sustaining treatment often is started on an emergency basis when the patient's treatment preferences are unknown. At any time, the patient or the surrogate decision-maker may decide to discontinue the treatment.

2. When life-sustaining treatments are discontinued, health care providers should make every effort to promote the dignity, hygiene and comfort of patients.

3. Health care providers should order and give adequate levels of medication for pain or discomfort even if the medication may increase the risk of or hasten death. They may not provide medication with the intent to cause or hasten death.

4. Health care providers should evaluate medically administered nutrition and hydration, such as nasogastric tubes, gastrostomies, intravenously administered fluids, and hyperalimentation in the same way as any other medical treatment. However, nutrition and hydration have a powerful symbolic significance to many people, including health care providers. Therefore, it is particularly important that people who take care of the patient fully understand the rationale for any order to forgo medically administered nutrition and hydration. A health care provider who disagrees with an order to forgo hydration and nutrition is permitted

⁹ Probate Code Section 4740.

to withdraw from caring for the patient once an equally qualified health care provider assumes care of the patient.

C. Working With Patients and Surrogate Decision-Makers

1. Before a patient with decision-making capacity forgoes life-sustaining treatment, the physician should assess the patient carefully to identify any factors, such as pain or depression, that may affect the patient's judgment. The physician should discuss any such factors with the patient and treat them, if possible. Ultimately, the patient has a right to forgo treatment, even though the physician may disagree.

2. The physician must provide sufficient information to the patient or, when appropriate, the surrogate decision-maker, to enable him/her to understand the patient's medical condition and the treatment options and their possible consequences, including the option to forgo treatment. With time, the patient or surrogate decision-maker may better understand his/her options. Therefore, the physician should treat decision-making as a process, rather than as an isolated event. In order for a patient or surrogate decision-maker to have adequate time to reach a decision, the physician should provide information about treatment options at the earliest possible opportunity.

3. A physician should question a surrogate decision-maker's health care decision if the decision appears to be inconsistent with the patient's previously expressed wishes, as known to the physician, or with the patient's best interests if the patient's wishes are not known. If the physician disagrees with the surrogate decision-maker's health care decision, the physician should thoroughly discuss the issue with the surrogate decision-maker and explain the reasons for disagreeing with the decision. If this discussion does not resolve the issue, the surrogate decision-maker or the physician should initiate the process described in Section D.1 below.

D. Facility Processes To Assist In Decision-Making

1. A Facility Process Approved By The Medical Staff Should Be Available To Resolve Disputes About Life-Sustaining Treatment Between Physicians And Patients Or Surrogate Decision-Makers.

a. Before a physician decides not to comply with an individual health care instruction or health care decision, the physician should make serious efforts to reconcile his/her views with those of the patient or the surrogate decision-maker.

b. If these efforts fail, the physician should convene members of the health care team, including consultants, nurses, social workers, clergy and others involved in the patient's physical and spiritual care to meet with the patient/surrogate decision-maker and whomever the patient/surrogate invites in an effort to reach agreement. The facility's bioethics committee or a similar body can be helpful in such situations by facilitating discussion and clarifying the issues.

c. If these efforts fail, the physician must:

(1) promptly inform the patient and/or the surrogate decision-maker;

(2) make all reasonable efforts to assist in transferring the patient to another physician who is willing to comply or to another facility; and

(3) provide continuing care until transfer can be arranged or until it appears that a transfer cannot be accomplished.

d. There is much disagreement among physicians and other health care professionals, lawyers and ethicists about the circumstances in which it is justifiable to forgo or continue life-sustaining treatment over the objections of a patient or surrogate decision-maker. The law does not define "medically ineffective health care" or "care contrary to generally

accepted health care standards” nor does it clearly specify a course of action when the efforts to transfer the patient have failed. Therefore, facility policies and procedures, approved by both the hospital and the medical staff, should require all of the following elements:

(1) that where the physician is unwilling to follow the patient’s or surrogate decision-maker’s wishes for reasons of conscience, it is the physician’s duty to transfer the patient to another physician who is willing to follow the patient’s or surrogate decision-maker’s wishes.

(2) that when the physician’s decision not to comply with a patient’s or surrogate decision-maker’s decision concerning life-sustaining treatment is based on either “medically ineffective health care” or “care contrary to generally accepted health care standards,” the case is reviewed to ensure that the proposed actions are within the range of medically and ethically appropriate alternatives.

(3) that the procedure by which the decision is implemented is clearly defined.

(4) that legal advice is sought as appropriate.

e. In all cases, physicians must continue to order comfort measures, including pain relief and other palliative care.

f. If the matter remains unresolved, the physician should consult legal counsel.

2. Facility Policies and Procedures Approved By The Medical Staff Should Be Available For Patients Who Lack Capacity, Have Left No Instructions And Have No Surrogate Decision-Makers.

Facility policies and procedures should require that any decision to forgo life-sustaining treatment for such a patient be subject to review before implementation to ensure that the proposed action is within the range of ethically appropriate alternatives. However, prior to initiating any such procedure, the facility must confirm (a) that a physician has determined that the patient lacks capacity and must verify that determination; (b) that the patient has no advance directive; and (c) that a diligent search for a surrogate decisionmaker has, in fact, been conducted and that no surrogate was found. The medical team should carefully document the finding of lack of capacity. The facility should explain in detail the steps it took to search for both a surrogate decision-maker and an advance directive. The goal should be to assure that the decision made is consistent with the patient's best interests.

a. When there is unanimity about the decision among the team caring for the patient, the review may be carried out by one or more persons¹⁰ designated by the facility to conduct such reviews. When there is disagreement among the health care team, there should be a formal process to resolve the issue.

b. The process should:

(1) Ensure that the diligent search has already been made for a surrogate decision-maker and that a reasonable attempt has been made to obtain historical

¹⁰ At least one such person must not be a member of the health care team caring for the patient.

information about the patient that might afford an understanding of how that patient might view the burdens and benefits of continued treatment;

(2) Involve a formally constituted interdisciplinary advisory committee, which may be the facility's bioethics committee. The committee should include at least one person who is not a health care professional and at least one person from the community. These may be the same person;

(3) Require that any person with a conflict of interest, real or apparent, with regard to the treatment of the patient in question, disclose such conflict; and

(4) Provide an opportunity for the views of the nursing staff and other health care providers to be presented.

c. The advisory committee should:

(1) Review all relevant medical information regarding the patient's medical history, current condition, and prognosis;

(2) Determine whether the treating physicians generally agree on the patient's prognosis;

(3) Hear the views of all interested parties;

(4) View the burdens and benefits of continued treatment from the point of view of the patient;

(5) Exclude from consideration any economic impact on providers (physicians or facilities);

(6) Exclude from consideration any judgment about the "social value" of the patient;

(7) Not devalue or underestimate the benefit of continued life to any patient, including a patient with disabilities; and

(8) Indicate whether or not the proposed decision is an ethically acceptable option.

d. The advisory committee's recommendation should be entered in the patient's medical record. The patient's attending physician is ultimately responsible for the patient's treatment.

e. If the advisory committee does not concur in a proposed decision to forgo life-sustaining treatment, treatment should continue while legal advice is sought.

E. Bioethics Committees

1. Bioethics committees may be helpful in discussing and exploring alternative approaches to life-sustaining treatment dilemmas, clarifying legal or ethical issues, facilitating communication, resolving any disputes or questions among members of the health care team, or identifying perspectives on the issues not previously considered. Such committees are advisory. They should not make treatment decisions. Such decisions are to be made by patients or surrogate decision-makers and treating physicians.

2. Individuals entitled to bring a case to the attention of the bioethics committee include those caring for the patient, the patient, the patient's surrogate decision-maker, other family members, friends, and any facility employee or volunteer.

F. Documentation

1. In cases in which life-sustaining treatment is forgone, the medical record should include:

a. A clear statement in the physician's progress notes of all relevant information concerning the treatment decision, including the treatment plan, the diagnosis and prognosis, and how they have been established, along with documentation of any consulting opinions that have been obtained;

b. A statement in the physician's progress notes that documents discussions with a patient with decision-making capacity or with an appropriate surrogate decision-maker or a valid advance directive. In the case of a patient without capacity and without a surrogate decision-maker and who has not left instructions, the review described in Section D.2 above is documented.

c. A written order, if an order is required to effectuate the decision.

2. Decisions to forgo life-sustaining treatment should be made in accordance with any applicable facility policies and procedures.

G. Role of the Courts

1. Most cases involving the forgoing of life-sustaining treatment can be, should be, and are, resolved without the involvement of the courts.

2. However, when necessary, the courts may be approached to resolve legal disputes, such as when a physician believes that the surrogate decision-maker is not acting in the patient's best interests or if the physician cannot choose among available surrogate decision-makers with similarly close relationships to the patient.

APPENDIX I

Neurological Determination of Death

(Brain Death)

The Uniform Determination of Death Act provides for the determination of death by either circulatory-respiratory or neurological criteria: “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.” (California Health & Safety Code Section 7180.) Separate Code sections also require that a death diagnosed on neurological grounds must be independently confirmed by a second physician, and that neither physician making such a determination shall participate in the procedures for removing or transplanting a body part from the deceased.

Because “accepted medical standards” change in accordance with medical and technological progress, facilities should maintain current policies and procedures for determination of death by neurological criteria.

1. The attending physician should inform the surrogate decision-maker of the determination of death and the need to remove all medical interventions. The surrogate decision-maker should have an opportunity, if desired, to request confirmation of the neurological determination by a physician of the surrogate decision-maker’s choosing before ventilatory support or other such interventions are removed. The determination of death remains a medical decision, however.

2. Prior to removal of medical interventions, a physician or nurse involved in the case should, in appropriate circumstances, consult the hospital's organ donation policy to determine whether further action is required regarding the donation of organs or other body parts.¹¹

3. Individuals who meet the neurological criteria for the determination of death and who are maintained on a respirator retain some of the indicia ordinarily associated with life: bodily warmth, a moving chest, heartbeat, and normal skin color. Physicians should be sensitive to how this might be perceived by survivors and explain that notwithstanding the patient's appearance, the patient meets the medical and legal criteria for death. Once death has been pronounced, all medical interventions should be withdrawn. Medical interventions may be continued to preserve the viability of organs for transplant or, in unusual circumstances, for a limited time at the request of the family.

¹¹ California Health & Safety Code Section 7184.

APPENDIX II

Advance Communication of Patient Wishes and Treatment Decisions

In California, health care decision-making is largely governed by the Health Care Decisions Law, which became effective in July, 2000. This law¹² defines the types of health care decisions that can be made by an individual or his/her surrogate decision-maker. The law expressly covers decisions related to forgoing life-sustaining treatment, including artificial nutrition and hydration and cardiopulmonary resuscitation. It describes the various ways in which individuals can communicate their wishes or health care decisions to physicians and ways to designate a surrogate decision-maker.¹³ The law grants immunity to health care providers who comply in good faith with a health care decision. Further, the law establishes the circumstances under which health care providers may decline to comply with such decisions.

This brief description of the Health Care Decisions Law is not intended to be complete. Physicians who have questions about the law should consult legal counsel.

A. Selecting a Surrogate Decision-Maker

1. Power of Attorney for Health Care (PAHC).

The law contains a “model form” Power of Attorney for Health Care (PAHC), which permits an individual to designate an agent. No one is required to use this form. In the absence of knowledge to the contrary, a PAHC executed in another state or jurisdiction is presumed valid.

¹² The relevant provisions of the law can be found at Probate Code Sections 4600-4780.

¹³ The Health Care Decisions Law specifically repealed the so-called Natural Death Act and removed the concept of the Natural Death Act Directive or Declaration from California law. However, directives or declarations prepared under the repealed law are still valid.

2. Oral Designation of a Surrogate Decision-maker.

A patient can also designate a surrogate decision-maker by personally informing his/her physician. The oral designation of a surrogate decision-maker is effective only during the course of treatment or illness, during a stay in a healthcare institution when the designation is made or sixty days, whichever period is shorter. Such a designation overrides a written document during the effective period of the oral designation.

B. Giving Instructions

1. The PAHC.

In addition to naming an agent, a patient may also choose to give instructions about his/her healthcare in a PAHC.

2. Telling the Physician.

A patient can always give an oral individual health care instruction by personally informing his/her physician. Such an instruction overrides a written document. There is no statutory time limit on an oral health care instruction.

The physician must document oral instructions about a patient's preferences in the patient's medical record. Not only does such documentation serve as a permanent record, but it also facilitates communication among the members of the health care team.

3. Other Advance Directives.

A patient may present one or more of a variety of other documents that could serve as an advance directive, such as a "living will." In general, a living will is any written statement in which a patient states what treatment is desired or

rejected at some future time. Such written “forms” and documents may also appoint a surrogate decision-maker. Forms have been developed by various organizations and have been given a variety of names. Provided they are signed, dated, and either witnessed or notarized, such documents are legally valid advance directives.¹⁴

C. Documents That Are Not Advance Directives

Because it is the intent of California law that a patient’s wishes be followed whenever possible, a document that actually expresses a patient’s wishes may generally be respected, even if it does not fulfill all the criteria for legal validity as an advance directive. Courts will generally treat any document as evidence of a patient’s desires. Providers may generally use any document as evidence about the care that a patient desires to accept or to forgo.

1. Pre-Hospital Do Not Resuscitate (DNR) Form.

A physician may be presented with an “Emergency Medical Services Pre-Hospital Do Not Resuscitate Form” (DNR Form), which is an official state document developed by the California EMS Authority and the California Medical Association. When completed correctly, the DNR Form allows a patient to forgo specific resuscitative measures that may keep him/her alive. The DNR Form is not an advance directive, in that it may be signed by the patient or his/her surrogate decision-maker and must be signed by the patient’s physician. The patient may also have a Medic Alert bracelet that indicates his/her DNR status.

¹⁴ Probate Code Section 4673.

Although an advance directive may address resuscitative measures, the DNR Form may be a very good way for a patient who is located outside of a health care facility to document his/her wishes regarding resuscitation. The law provides that if the patient has such a form, it should also be followed in a facility. However, the DNR Form does not take the place of a facility's own system for documenting and then following the DNR wishes of an individual.

2. Preferred Intensity of Care or Preferred Intensity of Treatment Forms.

Physicians should also be aware that some documents presented to them may have been completed without the participation of either the patient or the patient's surrogate decision-maker. For example, physicians may encounter so-called "Preferred Intensity of Care" or "Preferred Intensity of Treatment" documents which are often prepared by skilled nursing facilities. Before a physician acts on any such document, the physician should evaluate whether the document does, in fact, express the **patient's or surrogate decision-maker's** wishes.

The physician should also review inflexible directions in the document (*e.g.*, "no antibiotics" or "no hospitalization.") If a physician has any questions about the validity of any such document or the directions it contains, he/she should discuss it with the patient or surrogate decision-maker.

D. State Department of Health Services Brochure

Physicians should be familiar with the brochure, prepared by the California Department of Health Services, the language of which must be used by California hospitals, skilled nursing facilities, home health agencies, and hospices, and prepaid managed care plans to meet certain requirements of the federal Patient Self-Determination Act (PSDA). Under

the PSDA, such entities are required to provide written information on admission or first contact concerning the patient's right under state law to make decisions regarding medical care. This includes the right to accept or refuse treatment and the right to formulate advance directives. The brochure summarizes those aspects of the law relating to advance directives and designation of an agent or other representative to make decisions on behalf of a patient.

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