

Health Care Decisions for Unrepresented Patients

Model Policy for General Acute Care Hospitals

The purpose of this policy is to provide a process for making ethically and medically appropriate treatment decisions on behalf of persons who lack health care decision-making capacity and for whom there is no substitute decision maker. Hospitals that elect to adopt this or a similar policy must read “V. Adults Lacking Capacity and Not Under a Conservatorship” on page 3.19 in chapter 3 of CHA’s Consent Manual and consult legal counsel prior to implementation.

Preamble

This policy guides health care professionals through a process to make medical treatment decisions on behalf of an incapacitated patient who lacks a substitute decision maker and when there is no known family member or friend who is willing and able to make medical treatment decisions on behalf of the patient. Despite their incapacity, such “unrepresented” patients are entitled to have ethically and medically appropriate medical decisions made on their behalf and to have these decisions made in their best interest. The process set forth in this policy is intended to meet these goals. This policy is considered necessary since no clear-cut legal guidelines exist that cover these circumstances. This policy is designed to provide uniformity and consistency within the institutional setting of California’s general acute care hospitals¹ on the process to make medical treatment decisions for unrepresented patients.

Decisions made without clear knowledge of an unrepresented patient’s specific treatment preferences must be made in the patient’s best interest, taking into consideration the patient’s personal history, values and beliefs to the extent that these are known. Decisions about treatment should be based on sound medical advice and should be made without the influence of material conflicts of interest. These decisions must be made with a focus on the patient’s interests, and not the interests of providers, the institutions, or other affected parties. In this regard, appropriate health care decisions include both the provision of needed medical treatment and the avoidance of nonbeneficial or excessively burdensome treatment, or treatment that is medically ineffective or contrary to generally-accepted health care standards.²

This policy is procedural in nature and applies to most medical decisions for which informed consent is usually required. This policy is meant to support the institution’s underlying consent policy.

Adoption of this policy does not preclude any party from seeking judicial intervention. Appropriate judicial remedies may include a timely court order authorizing the provision, withdrawing, or withholding of treatment or appointment of a conservator or other decision maker; however, courts are not necessarily the proper forum in which to make health care decisions.³

When Use of This Policy is Appropriate

This policy may be used when all of the following conditions are met:

1. The patient has been determined by the primary physician (with assistance from appropriate consulting physicians if necessary) to lack capacity to make health care decisions. Capacity

means a patient's ability to understand the nature and consequences of proposed health care, including its significant benefits, risks, and alternatives, and to make and communicate a health care decision. Conditions for which psychiatric or psychological treatment may be required do not, in and of themselves, constitute a lack of capacity to make health care decisions.

2. No agent under a durable power of attorney for health care, conservator, orally-designated surrogate pursuant to Probate Code Section 4711 or guardian has been designated to act on behalf of the patient.
3. There is no individual health care directive or instruction in the patient's medical record or other available sources that would eliminate the need for a substitute decision maker.
4. No decision maker, family member, or friend can be located who is reasonably available⁴ and who is willing and able to serve. Efforts to locate a decision maker should be diligent and may include contacting the facility from which the patient was referred, and contacting public health or social service agencies known to have provided treatment for the patient.

This policy does not address the criteria for determining and appointing an appropriate decision maker when one or more are available and willing to serve. And finally, this policy is not meant to be applied in emergency medical situations.

Policy

When use of this policy is appropriate (as outlined above), medical decisions will be made by a multi-disciplinary team whose members shall include, but not be limited to, individuals directly involved with the care of the patient. It is recommended that the multi-disciplinary team include an attending physician, nurse familiar with the patient, social worker familiar with the patient, chair or vice-chair of the ethics committee, non-medical (community) member of the ethics committee or other appropriate committee and, if available and appropriate, consulting clinicians and pastoral care staff.⁵ It is very important to include on the multi-disciplinary team a person who will represent the patient's interests. Some patients may have a family member or friend who is unable or unwilling to take full responsibility for making health care decisions on behalf of the patient, but who is willing to serve as part of this team. If no such person exists, the hospital may consider including an ombudsman, patient advocate, bioethicist, community member, or other person whose role is to protect the patients' interests. If it is not possible to include such a person on the multi-disciplinary team in a particular case, document the reasons therefore.

In order to determine the appropriate medical treatment for the patient, the multi-disciplinary team should:

1. Review the diagnosis and prognosis of the patient and assure itself of the accuracy thereof.
2. Determine appropriate goals of care by weighing the following considerations:
 - a. Patient's previously-expressed wishes, if any and to the extent known
 - b. Relief of suffering and pain
 - c. Preservation or improvement of function
 - d. Recovery of cognitive functions

- e. Quality and extent of life sustained
 - f. Degree of intrusiveness, risk or discomfort of treatment
 - g. Cultural or religious beliefs, to the extent known
3. Establish a care plan based upon the patient's diagnosis and prognosis and the determination of appropriate goals of care. The care plan should determine the appropriate level of care, including categories or types of procedures and treatments.
 4. Notify the patient, both orally and in writing, that:
 - a. He or she has been determined to lack the capacity to make a health care decision;
 - b. It has been determined that he or she lacks a substitute decision maker;
 - c. Medical intervention has been prescribed by the attending physician (the prescribed treatment must be described);
 - d. A multi-disciplinary team will make a decision about the prescribed treatment, and the patient has the right to have a representative participate on this multi-disciplinary team; and
 - e. He or she has the right to seek judicial review of the above determinations.
 5. A sample notification form is attached. Health care providers should modify it to fit their circumstances.
 6. Except in emergency circumstances, the prescribed medical treatment should not be implemented until after notice has been given to the patient and the patient has been given a reasonable opportunity to seek judicial review.

Except to the extent that such a factor is medically relevant, any medical treatment decision made pursuant to this policy shall not be biased based on the patient's age, sex (including gender identity and gender expression), race, color, religion, ancestry, national origin, disability, medical condition, genetic information, marital status, sexual orientation, citizenship, primary language, immigration status, the ability to pay for health care services, or avoidance of burden to family/others or to society.

Under the terms of this policy, the multi-disciplinary team may make the same treatment decisions, and will have the same limitations, as an agent appointed pursuant to a power of attorney for health care specified under current law.^{6,7} However, this policy shall not apply to decisions pertaining to disposition of remains, autopsies, or anatomical gifts; specific laws apply to these procedures.⁸

The multi-disciplinary team must assure itself that the medical decision is made based on sound medical advice, is in the patient's best interest and takes into account the patient's values, to the extent known. In determining the best interest of the patient, it is not required that life support be continued in all circumstances, such as where treatment is otherwise nonbeneficial, medically ineffective or contrary to generally-accepted health care standards; when the patient is terminally ill and suffering; or where there is no reasonable expectation of the recovery of cognitive functions.

Agreement on Treatment

1. If all members of the multi-disciplinary team agree to the appropriateness of providing treatment, it shall be provided.
2. If all members of the multi-disciplinary team agree to the appropriateness of withholding or withdrawing treatment, it shall be withdrawn or withheld. Any implementation of a decision to withhold or withdraw life-sustaining medical treatment will be the responsibility of the primary treating physician.⁹

Disagreement on Treatment

If the members of the multi-disciplinary team disagree about the care plan, the ethics committee, ethics resource expert(s) or other resource experts will meet with the team to explore their disagreement and facilitate resolution.

1. If agreement is reached either to provide or to forgo treatment, the decision of the multi-disciplinary team then becomes final.
2. If agreement still is not reached, current treatments will be continued and any other medically necessary treatments provided, until the issue is resolved through court intervention or the disagreement is otherwise resolved.¹⁰ Court-imposed legal remedies should be sought only in extreme circumstances and as a last resort.³

In all cases, appropriate pain relief and other palliative care shall be continued.

Exceptional Circumstances

Legal counsel should be consulted if a decision to withdraw or withhold treatment is likely to result in the death of the patient and the situation arises in any of the following circumstances:

1. The patient's condition is the result of an injury that appears to have been inflicted by a criminal act.
2. The patient's condition was created or aggravated by a medical incident.
3. The patient is pregnant.
4. The patient is a parent with sole custody or responsibility for support of a minor child.

Documentation

Signed, dated and timed medical record progress notes will be written for the following:

1. The findings used to conclude that the patient lacks medical decision-making capacity.
2. The finding that there is no advance health care directive; no conservator, guardian, orally-designated surrogate or other available decision maker; and no relevant health care instructions in the patient's medical record or other available sources.
3. The attempts made to locate substitute decision makers, family members, and friends and the results of those attempts.
4. Notification was provided to the patient, both orally and in writing, that includes the information listed in paragraph 4 on page 3. A copy should be given to the person representing the patient's interests.

5. The bases for the decision to treat the patient and/or the decision to withhold or withdraw treatment.
6. Any information from the ethics committee or other consult, should it be convened.

End Notes

- 1 This policy is intended for use in general acute care hospitals. It is based on California Health and Safety Code Section 1418.8, which sets forth a statutory decision-making process for patients in a skilled nursing facility or intermediate care facility.
- 2 California Probate Code Section 4735 states that: “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.”
- 3 California Probate Code Section 4650(c) states that: “In the absence of controversy, a court is normally not the proper forum in which to make health care decisions, including decisions regarding life-sustaining treatment.” In addition, in *Barber v. Superior Court*, 147 CalApp.3d 1006 (1983), the court stated, or quoted with approval: “we agree with those which have held that requiring judicial intervention in all cases is unnecessary and may be unwise ... we consider that a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession’s field of competence, but because it would be impossibly cumbersome ... the absence of legislative guidance, we find no legal requirement that prior judicial approval is necessary before any decision to withdraw treatment can be made.”
- 4 California Probate Code Section 4717 states that:
 - (a) Notwithstanding any other provision of law, within 24 hours of the arrival in the emergency department of a general acute care hospital of a patient who is unconscious or otherwise incapable of communication, the hospital shall make reasonable efforts to contact the patient’s agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient. A hospital shall be deemed to have made reasonable efforts, and to have discharged its duty under this section, if it does all of the following:
 - (1) Examines the personal effects, if any, accompanying the patient and any medical records regarding the patient in its possession, and reviews any verbal or written report made by emergency medical technicians or the police, to identify the name of any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient.
 - (2) Contacts or attempts to contact any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient, as identified in paragraph (1).
 - (3) Contacts the Secretary of State directly or indirectly, including by voice mail or facsimile, to inquire whether the patient has registered an advance health care directive with the Advance Health Care Directive Registry, if the hospital finds evidence of the patient’s Advance Health Care Directive Registry identification card either from the patient or from the patient’s family or authorized agent.
 - (b) The hospital shall document in the patient’s medical record all efforts made to contact any agent, surrogate, or a family member or other person the hospital reasonably believes has the authority to make health care decisions on behalf of the patient.
 - (c) Application of this section shall be suspended during any period in which the hospital implements its disaster and mass casualty program, or its fire and internal disaster program.
- 5 California Probate Code Section 4736 states that:

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.

Institutions should designate by policy the particular types and numbers of providers who may constitute the multi-disciplinary team, and should ensure that non-medical/community representatives are properly prepared to serve on the multi-disciplinary team.

6 California Probate Code Section 4617 states that:

“Health care decision” means a decision made by a patient or the patient’s agent, conservator, or surrogate, regarding the patient’s health care, including the following: (a) Selection and discharge of health care providers and institutions. (b) Approval or disapproval of diagnostic tests, surgical procedures, and programs of medication. (c) Directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation.

California Probate Code Section 4683 states that: “Subject to any limitations in the power of attorney for health care: (a) An agent designated in the power of attorney may make health care decisions for the principal to the same extent the principal could make health care decisions if the principal had the capacity to do so.”

7 California Probate Code Section 4652 states that: “This division does not authorize consent to any of the following on behalf of a patient: (a) Commitment to or placement in a mental health treatment facility. (b) Convulsive treatment (as defined in Section 5325 of the Welfare and Institutions Code). (c) Psychosurgery (as defined in Section 5325 of the Welfare and Institutions Code). (d) Sterilization. (e) Abortion.”

8 Health and Safety Code Sections 7100 (disposition of remains), 7113 (autopsy), and 7150 *et seq.* (anatomical gift).

9 California Probate Code Section 4734 states that:

(a) A health care provider may decline to comply with an individual health care instruction or health care decision for reasons of conscience.

(b) A health care institution may decline to comply with an individual health care instruction or health care decision if the instruction or decision is contrary to a policy of the institution that is expressly based on reasons of conscience and if the policy was timely communicated to the patient or to a person then authorized to make health care decisions for the patient.

10 California Probate Code Section 4736 states that:

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.

Sample Notification Form for Unrepresented Patients

(Must be given to the patient both orally and in writing)

Patient Name: _____

Your doctor, Dr. _____, has carefully evaluated your physical, medical and cognitive condition and concluded that you don't have the ability to make decisions about your medical treatment.

The hospital has tried to find a family member or friend of yours to make health care decisions for you. The hospital hasn't been able to find anyone to do that. If you have a family member or friend who you want to make health care decisions for you, please tell us.

Your doctor has recommended the following treatment, believing that this is the best treatment for you under the circumstances:

A multi-disciplinary team of health care professionals, including your doctor and nurses and others, agrees that this is the best treatment for you. You have the right to have someone represent you on this team. Please tell us if there is someone you want to participate on this team.

Unless your doctor receives direction otherwise, your doctor intends to proceed with this treatment. You have the right to ask a judge to stop this treatment. You can also ask a judge to let you make your own health care decisions. You can contact a judge at:

[Hospital to insert contact information for local Superior Court]

Here are some people who might be able to help you contact a judge:

[Hospital to list any local resources, such as an ombudsman, law school legal assistance clinic, Adult Protective Services, any assistance the local Superior Court offers, etc.]

Hospital Employee to Complete:

I gave a copy of this form to the above-named patient and explained to him/her the contents of it on _____ [date] at

_____ [time] a.m./p.m.

Signature: _____

Print name: _____

ORIGINAL: TO PATIENT

COPY: IN MEDICAL RECORD

TO PERSON REPRESENTING THE PATIENT ON THE MULTI-DISCIPLINARY TEAM

