

November 6, 2001

Dear (Chief of Staff, Chair of Ethics Committee, Interested Parties),

The Santa Clara County Medical Association has recently approved for consideration, by the hospitals of this county, a model policy addressing the problem of healthcare decision-making in patients lacking the capacity to make decisions and/or lacking relatives, friends, or other appropriate surrogates. We felt that the policy was necessary since the legal system, conservatorship, and courts are often cumbersome venues for making medical decisions.

A task force made up of physicians, lawyers, administrators, nurses, social workers, and ethicists was assembled to develop this policy. The policy itself went through six drafts before being approved by the SCCMA Council.

We encourage you to read the policy and consider its adoption or a version of your own. If you have any questions, please address them to Joetta Cox at SCCMA. She will forward them to Sameer Awsare, MD or John Longwell, MD, co-chairs of the Bioethics Committee.

Sincerely,

Lynn B. Rosenstock, MD

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SCCMA President

A Preface to the
Santa Clara County Medical Association Ethics Committee
Model Policy on
Health Care Decisions for Patients Without Surrogates
Developed by the Task Force on Decision-Making for
Unbefriended and Conserved Patients

The Santa Clara County Medical Association recently approved a model Policy on Health Care Decisions for Patients Without Surrogates. The Policy was adopted because the recently enacted California Health Care Decisions Law,¹ which provides legal guidance for the medical management of patients who lack medical decision-making ability, contained no provisions concerning medical decisions for patients who also lack a surrogate decision-maker. The failure of the new law to address this aspect of medical care is regrettable given the vulnerability of these patients to inconsistent and *ad hoc* practices of medical treatment decision-making. This issue is especially important when the medical decision involves withholding or withdrawing life-sustaining treatments. Despite their incapacity, these patients are entitled to have appropriate medical decisions made on their behalf and to have these decisions made in their best interest, respecting their wishes and values as much as these can be known. However, there exists in the County no set standard of practice for accomplishing these goals. The Ethics Committee determined, therefore, that there is a need for standard setting and this Policy is intended to create processes to manage medical decision-making for incapacitous unrepresented patients.

To create this Policy, a 27- member Task Force of the Ethics Committee was formed, comprised of physicians, medical and elder law attorneys, members of the Offices of the Court Investigator, County Counsel, and Public Guardian, Long Term Care Ombudsman and a private conservator. All of these individuals were either members of local medical ethics committees or they dealt with unrepresented patients as part of their professional duties. The Policy was developed after a process of literature review, canvassing the hospitals in the County concerning local practice, and receiving input from various local hospital ethics committees. Also, two existing documents served as resources for the Task Force—the Veteran’s Health Administration Directive on informed consent and the Addendum to the Guidelines on Foregoing Life-sustaining Treatment for Adults published by the Joint Committee on Biomedical Ethics of the Los Angeles County Medical and Bar Associations.^{2,3} In addition to developing this Policy, the Task Force reviewed current procedures within the Office of the Public Guardian regarding medical decision-making for conserved adults and San Andreas Regional Center protocol for decision-making regarding their clients.

¹ California Probate Code § 4600-4805, 1999 Cal. Stat. ch.685, AB 891.

² Veterans Health Administration, Department of Veterans Affairs, Informed Consent, VHA Directive 1004, February 21, 1996, pages 5-7.

³ Kirschner, M. and Michel, V., Guideline Addendum, The April 2, 1990, LACMA Physician Guidelines for Foregoing Life-Sustaining Treatment for Adult Patients. Supplement: Patient’s Without Decision-making Capacity who lack surrogates, *LACMA Physician*, July 12, 1993.

This Policy was approved by a majority of the members of the Ethics Committee after extensive discussion of the pros and cons of its implementation. It was then approved by the Santa Clara County Medical Association for potential adoption by hospitals and nursing facilities.

Among the perceived benefits of the Policy was that it provides for a process of objective review of medical decisions made on behalf of unrepresented patients. This review process was believed to promote the interests of patients and also to relieve treating physicians from what can be the conflictual role of sole medical decision-maker. Secondly, if the Policy is generally adopted, it could create both a medical and legal standard of practice and eliminate inconsistency in medical decision-making for these patients. Problems associated with adoption of the policy were related to variance in local ethics consultation practices. For instance, some health care institutions, such as nursing homes and federal hospitals, need to adhere to regulations that may be inconsistent with this Policy. Also, some ethics committees may not have sufficient staff to manage the work required to review the medical care of all unrepresented patients. Ethics committees may also have their own internal decision-making processes that conflict with the process specified in this Policy. However, despite such variances in ethics committee practice, it is hoped that the medical facilities in the County could adopt the fundamentals of the Policy as much as possible without altering effective internal practice.

Another aspect of the Policy deserves special attention. It was recognized that this Policy creates an alternative role for most medical ethics committee members who normally serve as advisors only and not as participants in medical decision-making. Under this Policy, for decisions to withhold or withdraw life-sustaining treatment for unrepresented patients, a small group of ethics committee members would serve as surrogate decision-makers. This new role is an attempt to provide a meaningful and practical solution to the difficult problem of selecting the most appropriate and reasonably available persons to serve as surrogates for these patients. Treating physicians and employees of the health care institution can be perceived as having a conflict of interest in the matter since the physicians and the institution receive compensation (or sometimes they do not) for providing medical care for the patient. This is one reason why the California Health Care Decisions Law provides that, in most circumstances, neither the supervising health care provider nor an employee of the health care institution where the patient is receiving care can act as surrogate decision-maker for the patient. To compound the problem, independent public or private conservators or guardians are not often reasonably available to serve these patients. And judicial intervention is openly disfavored under the Health Care Decisions Law. For these reasons, it was believed that a small multi-disciplinary group of experienced ethics consultants available to the medical institution offered the best alternative. Using members of several disciplines, including a non-medical member, was intended to prevent bias based on the perspective of any particular discipline. A committee would also ensure that no one interested person would control the medical fate of the patient. It is also common for medical ethics committees to

include members who are not employees of the facility and these members, if qualified, would be excellent candidates for the sub-committee surrogate work.

Finally, both the Veterans Administration and the Los Angeles County Medical and Bar Associations endorsed the use of institutional ethics committees to review physician decisions to withhold or withdraw life-sustaining medical treatment for unrepresented incapacitous patients. One reason, however, that the VA Directive and Los Angeles County Guidelines were not adopted *in toto* was that they contained no provision for a patient surrogate. Consequently, these documents provided that medical decisions to withhold or withdraw life-sustaining treatment were ultimately made by either the Chief of Staff or the attending physician. Inclusion of a surrogate in this process preserves the accepted role of the physician to recommend and provide medical treatment after having obtained the consent of the patient or surrogate and, as much as is practicable, preserves the right of the incapacitous patient to have a surrogate weigh the risks and benefits of foregoing life-sustaining treatment and make the decision based on the patient's desires, if known, or based on the patient's best interests.

It is hoped that this Policy provides a reasonable and workable standard for the ethical treatment of incapacitous patients who lack surrogates so that the Policy will be adopted as accepted practice by the medical facilities in Santa Clara County. It is also hoped this Policy will be considered outside of this county.

The Task Force was chaired by Serl Zimmerman, MD, JD and Doris E. Hawks, Esq., Elder Law Attorney.

Primary drafter of the Model Policy was Margaret Eaton of the Ethics Committee at Stanford Hospital. Members of the Sub-Committee on Health Care Decisions for Patients without Surrogates were: Susan Branch, Esq., Allan Hikoyeda, Esq., Stan Ulrich, Esq. and Serl Zimmerman, MD.

The Sub-committee on Decision-making by the Public Guardian and for developmentally disabled adult individuals included: Les Lindop, Sharon O'Neill, Ron Willsey, and Ann Hubrich, LCSW.

Other members of the Task Force included: Beverly Chan, Esq., Sidney Chapman, Thomas Dailey, MD, Donna Di Minico, Allen Fleishman, Esq., Stephen Henry, MD, Steve Jackson, MD, Tamara Lopez, Esq., Sandra Mangiapia, MD, Elizabeth Menkin, MD, Marilyn Regan, MFT, Elisabeth Ryzen, MD, Edna Smyth, MSW, Gary Steinke, MD, LouAnn Trent, ACSW, Cheryl Walsh, Esq., and Sheldon Zitman, MD.

Recommendation for Establishing Policy on
Health Care Decisions for Incapacitated Patients Without Surrogates

Santa Clara County Medical Association
San Jose, California
February 2001

I. Purpose Statement

To provide procedural mechanisms whereby health care decisions can be made for patients who lack health care decision-making capacity and for whom no surrogate exists.

II. Background

A. This policy represents a consensus among the medical and legal professionals of the Ethics Committee of the Santa Clara County Medical Association about the most appropriate manner in which to make medical decisions on behalf of incapacitated patients who lack surrogate decision-makers. Despite their incapacity, such patients are entitled to have appropriate medical decisions made on their behalf and to have these decisions made in their best interest, respecting their wishes and values as much as they can be known. The procedures set forth here are intended to meet these goals. This policy is considered necessary since no clear-cut legal guidelines exist that cover these circumstances. As a consequence, unrepresented patients tend to be managed inconsistently and on an *ad hoc* basis, which often confounds and delays medical decisions. Finally, this policy and its procedural protections were considered especially important for the irreversible decisions to forgo life-sustaining treatment for unrepresented patients.

B. This policy is procedural in nature and applies to all medical decisions for which informed consent is usually required.

C. This policy is meant to support the institution's underlying consent policy.

D. Goals to be achieved

To make and effect health care decisions in accordance with a patient's best interest, taking into consideration the patient's personal values and wishes to the extent that these are known.

To establish uniform procedures to implement appropriate health care decisions for unrepresented patients. Appropriate healthcare decisions include both the provision of needed and wanted medical treatment and the avoidance of nonbeneficial or excessively burdensome treatment. Appropriate health care decisions are also those that are based on sound medical advice and made without the influence of material conflicts of interest.

E. Circumstances where policy is not applicable or is applied only with additional considerations

This policy does not apply in emergency medical situations.

This policy does not apply in situations where, using sound medical judgment, a physician makes a bedside decision to cease attempts at cardio-pulmonary resuscitation of a patient.

If the Public Guardian is appointed, the Public Guardian must be involved in medical decision-making under this policy. Medical circumstances will dictate when medical providers can delay decision-making in order to include the Public Guardian.

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

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

F. Application: The patient's age, sex, religion, ethnic or social status, the ability to pay for healthcare services, or avoidance of burden to family or to society shall not be used to bias considerations about the appropriateness of any health care decision under this policy.

III. Who Is An Incapacitated Patient Who Lacks A Surrogate?

A. 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.

B. No agent, conservator, or guardian has been designated to act on behalf of the patient.

C. No dispositive individual health care instruction is in the patient's medical record.

D. No surrogate decision-maker can be selected or the surrogate is not reasonably available. For the purpose of this policy, a surrogate can be an adult family member. Also, an individual with a close personal relationship to the patient can serve as a surrogate. Any surrogate needs to have shown care and concern for the patient's welfare and must have some familiarity with the patient's activities, health, religious beliefs, and values. There must be medical record documentation (such as by a social service worker) that this surrogate has been interviewed and satisfies the above criteria to serve as a surrogate decision-maker.

Efforts to establish whether or not a surrogate is reasonably available should be diligent and can 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.

IV. Referral To Ethics Committee

If no surrogate can be located, medical decisions on behalf of incapacitated patients will be made using the following procedures.

A. Medical decisions for which informed consent is required

An ethics consultant (one or more people) will provide advice about the process of medical decision-making. This consultant will come from the facility's Ethics Committee or, if there is none, the consultant will possess appropriate skill and experience in ethical medical decision-making. The consultant will ensure that treatment decisions are made consistent with this policy. In this process, the consultant will make all reasonable efforts to learn about the patient's medical treatment preferences. The consultant should contact others for expanded advice should the circumstances warrant.

B. Medical decisions about withholding or withdrawing life-sustaining treatment

a. The medical team will obtain a second opinion about the decision from an independent physician with relevant medical qualifications.

b. The Chair of the Ethics Committee will appoint a sub-committee to act as surrogate decision-maker and review the proposed decision to ensure that the decision was based on sound medical advice and made in conformity with this policy.

c. Composition of Sub-Committee: The sub-committee will consist of multidisciplinary medical personnel capable of independently appreciating the medical consequences of the healthcare decision. At least one non-medical member of the Ethics Committee will be named to the sub-committee. If the patient is in a long-term care facility, the sub-committee will include an ombudsman as a member. All members will be asked whether they have any material conflict of interest, real or apparent, in the matter and, if so, will be excused from the sub-committee.

d. Conduct and Standards of Review by Sub-Committee: The sub-committee will advocate on behalf of the patient. The sub-committee will interview the relevant medical treatment providers and anyone else closely involved with the patient. The sub-committee will inquire about the process to determine the decision-making capacity of the patient, the attempts made to learn about the patient's medical preferences and to locate a surrogate decision-maker, the medical basis for the conclusion that medical treatment should be withheld or withdrawn, and about the other available medical options and their likely outcomes. The sub-committee will consider the patient's cultural, ethnic or religious perspectives, if known. If possible, someone of the patient's cultural, ethnic or religious background should be consulted

to determine if it is likely that these factors would influence what treatment the patient would prefer. The sub-committee will also inquire about the likelihood of restoring the patient to an acceptable quality of life. The patient's quality of life will be considered from the perspective of the patient and not from that imposed by any sub-committee member. The sub-committee will weigh and balance all of the above considerations, keeping in mind that the best interest of the patient do not require that life support be continued in all circumstances, such as when the patient is terminally ill and suffering, where there is no hope of recovery of cognitive functions, or where treatment is otherwise nonbeneficial.

e. Decision-making by Sub-Committee: The sub-committee will assure itself that there were adequate safeguards to confirm the accuracy of the diagnosis and that the medical decision was made in good faith, was based on sound medical advice, and is in the patient's best interest according to this policy. The sub-committee can ask for further medical opinions to verify the primary conclusions. The sub-committee can also ask that further investigations be made about the availability of surrogates, the patient's treatment preferences, or other relevant matters. After this investigation is completed, the sub-committee will then make an independent finding about the proposed decision.

f. Subsequent Action: If the sub-committee is in general agreement about the proposed decision, the decision can be implemented by the primary treating physician. If the sub-committee cannot reach a general agreement or if it disapproves of the medical decision, the Chief of Staff or his/her designee will be included in the decision-making process to assist in resolving any disagreements. In any case where a medical decision to withhold or withdraw life-sustaining treatment will be implemented under this policy, the Chief of Staff must approve of the decision. Irresolvable conflicts can be referred to court for legal resolution with the understanding that a legal remedy should only be sought in extreme circumstances. Any implementation of a decision to withhold or withdraw life-sustaining medical treatment will be the responsibility of the primary treating physician.

V. Record Keeping

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

- a. The findings used to conclude that the patient lacks medical decision-making capacity,
- b. The finding that there is no durable power of attorney for healthcare, no conservator or guardian, and no medical instructions,
- c. The attempts made to locate surrogate decision-makers and the results of those attempts,
- d. Any interviews of individuals with a close personal relationship to the patient willing to serve as surrogate and facts to substantiate their qualifications under this policy,
- e. The medical bases for the decision to withhold or withdraw life-sustaining treatment and the likely outcome if the decision is implemented, and
- f. Any findings and conclusions by the ethics consultant, the appointed ethics sub-committee, or the Chief of Staff.

VI. References

- (1) Veterans Health Administration, Department of Veterans Affairs, Informed Consent, VHA Directive 1004, February 21, 1996, pages5-7.
- (2) Kirschner, M. and Michel, V., Guideline Addendum, The April 2, 1990 LACMA Physician guidelines for Foregoing Life-Sustaining Treatment for Adult Patients. Supplement: Patient's without decision-making capacity who lack surrogates, *LACMA Physician*, July 12, 1993.
- (3) 22 CCR 70707
- (4) JCAHO Patient Rights and Organizational Ethics, RI.1
- (5) California Probate Code § 3200 *et seq*
- (6) Health Care Decisions Law (California Probate Code § 4600), specifically, Part 2, Uniform Health Care Decisions Act (California Probate Code §§ 4670, 4735)

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