

2.1.2 Decisions for Adult Patients Who Lack Capacity

Respect for patient autonomy is central to professional ethics and physicians should involve patients in health care decisions commensurate with the patient's decision-making capacity. Even when a medical condition or disorder impairs a patient's decision-making capacity, the patient may still be able to participate in some aspects of decision making. Physicians should engage patients whose capacity is impaired in decisions involving their own care to the greatest extent possible, including when the patient has previously designated a surrogate to make decisions on his or her behalf.

When a patient lacks decision-making capacity, the physician has an ethical responsibility to:

- (a) Identify an appropriate surrogate to make decisions on the patient's behalf:
 - (i) the person the patient designated as surrogate through a durable power of attorney for health care or other mechanism;
 - (ii) a family member or other intimate associate, in keeping with applicable law and policy if the patient has not previously designated a surrogate.
- (b) Recognize that the patient's surrogate is entitled to the same respect as the patient.
- (c) Provide advice, guidance, and support to the surrogate.
- (d) Assist the surrogate to make decisions in keeping with the standard of substituted judgment, basing decisions on:
 - (i) the patient's preferences (if any) as expressed in an advance directive or as documented in the medical record;
 - (ii) the patient's views about life and how it should be lived;
 - (iii) how the patient constructed his or her life story;
 - (iv) the patient's attitudes toward sickness, suffering, and certain medical procedures.
- (e) Assist the surrogate to make decisions in keeping with the best interest standard when the patient's preferences and values are not known and cannot reasonably be inferred, such as when the patient has not previously expressed preferences or has never had decision-making capacity. Best interest decisions should be based on:
 - (i) the pain and suffering associated with the intervention;
 - (ii) the degree of and potential for benefit;
 - (iii) impairments that may result from the intervention;
 - (iv) quality of life as experienced by the patient.
- (f) Consult an ethics committee or other institutional resource when:

- (i) no surrogate is available or there is ongoing disagreement about who is the appropriate surrogate;
- (ii) ongoing disagreement about a treatment decision cannot be resolved; or
- (iii) the physician judges that the surrogate's decision:
 - a. is clearly not what the patient would have decided when the patient's preferences are known or can be inferred;
 - b. could not reasonably be judged to be in the patient's best interest;
 - c. primarily serves the interests of the surrogate or other third party rather than the patient.

AMA Principles of Medical Ethics: I,III,VIII

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 4-A-01 Decisions for adult patients who lack capacity

2.1.2 Decisions for Adult Patients Who Lack Capacity

Respect for patient autonomy is central to professional ethics and physicians should involve patients in health care decisions commensurate with the patient's decision-making capacity. Even when a medical condition or disorder impairs a patient's decision-making capacity, the patient may still be able to participate in some aspects of decision making. Physicians should engage patients whose capacity is impaired in decisions involving their own care to the greatest extent possible, including when the patient has previously designated a surrogate to make decisions on his or her behalf. [new content sets out key ethical values and concerns explicitly]

When a patient lacks decision-making capacity, the physician has an ethical responsibility to:

- (a) Identify an appropriate surrogate to make decisions on the patient's behalf:
 - (i) the person the patient designated as surrogate through a durable power of attorney for health care or other mechanism;
 - (ii) a family member or other intimate associate, in keeping with applicable law and policy if the patient has not previously designated a surrogate.
- (b) Recognize that the patient's surrogate is entitled to the same respect as the patient.
- (c) Provide advice, guidance, and support to the surrogate.
- (d) Assist the surrogate to make decisions in keeping with the standard of substituted judgment, basing decisions on:
 - (i) the patient's preferences (if any) as expressed in an advance directive or as documented in the medical record;
 - (ii) the patient's views about life and how it should be lived;
 - (iii) how the patient constructed his or her life story;
 - (iv) the patient's attitudes toward sickness, suffering, and certain medical procedures.
- (e) Assist the surrogate to make decisions in keeping with the best interest standard when the patient's preferences and values are not known and cannot reasonably be inferred, such as when the patient has not previously expressed preferences or has never had decision-making capacity. Best interest decisions should be based on:
 - (i) the pain and suffering associated with the intervention;
 - (ii) the degree of and potential for benefit;
 - (iii) impairments that may result from the intervention;
 - (iv) quality of life as experienced by the patient.

- (f) Consult an ethics committee or other institutional resource when:
- (i) no surrogate is available or there is ongoing disagreement about who is the appropriate surrogate;
 - (ii) ongoing disagreement about a treatment decision cannot be resolved; or
 - (iii) the physician judges that the surrogate's decision:
 - a. is clearly not what the patient would have decided when the patient's preferences are known or can be inferred;
 - b. could not reasonably be judged to be in the patient's best interest;
 - c. primarily serves the interests of the surrogate or other third party rather than the patient.

AMA Principles of Medical Ethics: I,III,VIII

EXECUTIVE SUMMARY

At the 1991 Annual Meeting, the American Medical Association adopted the report of the Council on Ethical and Judicial Affairs, "Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients." The recommendations of this report were the basis for amendments to Opinion 2.20, "Withholding or Withdrawing Life-Sustaining Medical Treatment." Since the incorporation of these guidelines into the AMA's *Code of Medical Ethics*, the Council has deferred to Opinion 2.20 to address inquiries involving surrogate decision making, even though the guidelines presented in this Opinion refer only to decisions made near the end of life.

With continued discussion concerning health care preferences for all patients, including those who are incompetent, and greater options available to secure health care directives, the involvement of a third parties in a patient's health is becoming increasingly important. In addition, the Council recognizes that there is a spectrum of decision-making capacity ranging from immaturity, to mental illness, to serious brain damage, and that health care decisions often must be made for individuals with diminished decisional faculties over extended periods of time. This analysis expands on CEJA's previous guidelines to accommodate for decisions that may not be made near the end of life, to include patients with diminished decision-making capacity, and identifies features related to a meaningful and effective physician-proxy relationship.

The report recommends that physicians should make a reasonable effort to identify a documented advance directive when an incompetent patient is to receive medical treatment. In the absence of such a directive, a surrogate decision maker should be identified. When there is evidence of what the patient would have decided if competent, the decision maker should adhere to a substituted judgment standard. Otherwise decision makers should employ a best interest standard when making decisions for a patient. The recommendations also provide guidelines for mediating disagreements and fostering an effective physician-proxy relationship. Finally, the recommendations encourage physicians to discuss various options related to advance directives with their patients.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS[□]

CEJA Report 4-A-01

Subject: Surrogate Decision Making

Presented by: Herbert Rakatansky, MD, Chair

Referred to: Reference Committee on Constitution and Bylaws
(William J. Mangold, Jr., MD, Chair)

1 INTRODUCTION

2

3 At the 1991 Annual Meeting, the American Medical Association adopted the report of the Council
4 on Ethical and Judicial Affairs, “Decisions to Forgo Life-Sustaining Treatment for Incompetent
5 Patients.” The recommendations of the report were the basis for amendments to Opinion 2.20,
6 “Withholding or Withdrawing Life-Sustaining Medical Treatment.” The report itself provides
7 guidelines for physicians who may have to identify a surrogate decision maker, assist a surrogate
8 or proxy in making decisions for incompetent patients, and resolve conflicts that may arise
9 between decision makers, or between the decision maker’s choice and medically appropriate
10 options. Since the incorporation of these guidelines into the AMA’s *Code of Medical Ethics*, the
11 Council has deferred to Opinion 2.20 to address inquiries involving surrogate decision making,
12 even though the guidelines presented in this Opinion refer only to decisions made near the end of
13 life.

14

15 With continued discussion concerning health care preferences for all patients, including those who
16 are incompetent, and greater options available to secure health care directives, the involvement of
17 third parties in a patient’s health becomes more likely in decisions that may occur in instances
18 other than the end of life.

19

20 In addition, the Council recognizes that there is a spectrum of decision-making capacity ranging
21 from immaturity, to mental illness, to serious brain damage, and that health care decisions often
22 must be made for individuals with diminished decisional faculties over extended periods of time.
23 The Council offers the following report to expand on its previous guidelines and to identify
24 features related to a meaningful and effective physician-proxy relationship.

25

26 The report begins by defining a number of terms related to health care directives before presenting
27 theoretical frameworks used in making decisions for incompetent patients. It then provides a
28 protocol for identifying a surrogate decision maker as well as guidance for physicians who may
29 run into conflict either assisting the surrogate in coming to a decision or with the decision itself.
30 Finally, the Report offers guidelines for nurturing an effective physician-proxy relationship.

31

32 *Defining Key Terms*

33

34 An advance directive is a document that enables competent persons to exercise their rights to
35 direct medical treatments in the event that they lose their decision-making capacity. Previously,

[□] Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 the Council on Ethical and Judicial Affairs considered two general categories of advance
 2 directives: 1) a living will, which indicates the types of treatment an individual wishes to receive
 3 or forgo under specified circumstances, and 2) a durable power of attorney for health care (or a
 4 health care proxy appointment), which designates another person to make health care decisions on
 5 behalf of the patient.^{1,2}

6
 7 Confusion and debate over advance directives grouped in the second category arises primarily
 8 from inconsistencies in identifying different types of decision makers, and determining the scope
 9 of their authority.^{**} This may result from the fact that although all fifty states have established
 10 laws that govern advance directives, either statutorily or through case law, each differs in its
 11 standards and terminology.² There are also a number of different advance directives currently
 12 available, offering varying degrees of empowerment to the decision maker. Some advance
 13 directive forms combine a proxy designation with specific instructions for the proxy so that the
 14 distinctions between a living will and a durable power of attorney for health care are beginning to
 15 blur. For the purposes of this report, the term “proxy” will be used to refer to a person who has
 16 been chosen by the patient, through a documented advance directive, to be the substitute health
 17 care decision maker, while the term “surrogate” will refer to a person whose authority to make
 18 health care decisions for a patient is based on state statute, case law, or a decision made by the
 19 medical team such as a physician or ethics committee.

20 21 MAKING DECISIONS FOR INCOMPETENT PATIENTS

22
 23 There are two basic principles that should guide any treatment decisions: respecting and promoting
 24 patient autonomy, and fostering the well-being of the patient.¹ The same right of self-
 25 determination that underpins the doctrine of informed consent provides legitimacy for the use of
 26 advance directives; that is, the patient’s right to choose a course of action remains after he or she
 27 loses decision-making capacity. Likewise, provisions should be made to respect the patient’s
 28 wishes even after competence is lost.³

29
 30 To protect the well-being and autonomy of the incompetent patient, three standards have been
 31 established in ethics and law to such guide decisions. These standards are referred to as: 1) the
 32 documented advance directive, 2) substituted judgment, and 3) the best interest standard.

33 34 *Documented Advance Directives*

35
 36 The designation of a proxy through a durable power of attorney for health care and the
 37 implementation of a living will are often effective ways to ensure the appropriate implementation
 38 of the patient’s preferences with regard to health care decisions.¹ While a detailed living will may
 39 ensure that decisions will accurately reflect the patient’s wishes in anticipated situations, a pre-
 40 designated proxy may be more suitable to interpret the patient’s wishes in unforeseen
 41 circumstances. To have the benefits of both a living will and a durable power of attorney, patients
 42 may document a proxy designation and, while competent, discuss with their proxy the preferences,
 43 values, or specific instructions that should be considered when making treatment decisions.
 44 Traditionally, advance directives have been associated with end-of-life decisions. However, health
 45 care directives that can be used in any circumstance in which a patient is incompetent or
 46 incapacitated are more effective and desirable.

47 48 *Substituted Judgment*

49
 50 When a patient does not have documented treatment preferences or goals, decisions concerning the
 51 incompetent patient’s health care should proceed by substituted judgment. Substituted judgment

1 asks that someone who knows the patient attempt to make a decision in the manner that the patient
2 would (if he or she were capable of making the decision).^{1,3} The decision maker should look to the
3 patient's previously expressed preferences and values to determine what the patient would have
4 decided. Substituted judgment is a valuable guiding principle because it gives weight to the
5 subjective nature of medical decisions.

6
7 However, much empirical research indicates a low correlation between proxies' decisions and
8 what patients would have decided in hypothetical situations.^{4,5} Because there is no direct deductive
9 relationship between values and a particular choice, or between previous decisions and current
10 positions, the surrogate is often left to make an approximation of what the patient would have
11 wanted.⁴ At best, substitute decision making requires great imaginative effort to process a
12 patient's web of values, preferences, and medical judgments.^{2,4}

13
14 With the recent criticisms of the substituted judgment standard, some authors have offered an
15 alternative that is similar and in some ways more amenable to thinking about a medical decision.
16 Rather than attempt to predict what the patient would say about treatment preferences, the
17 patient's life story is considered, and a particular option is evaluated in terms of its "fit" with the
18 elements of the patient's life story.³ This narrative model rests on the idea that individuals create
19 an identity for themselves through their life story and it is through this narrative that persons
20 conceptualize themselves. Thus, the physician and the surrogate have a *prima facie* moral
21 obligation to continue the story in a manner that is meaningful and consistent with the patient's
22 self-conception. It is possible that more than one choice is compatible with the patient's self-
23 conception. Thus, the narrative approach seems to avoid the problems that arise from trying to
24 predict which single course of action the patient would have decided when competent, as well as
25 problems that arise when making decisions for patients who may have never been completely
26 competent.⁶

27 *Best Interest Standard*

28
29
30 Traditionally, when there has been no reasonable basis for interpreting how the patient would have
31 decided, surrogate decision makers have based treatment decisions on predicted outcomes that
32 would most likely promote the patient's well-being.¹ This guiding principle is referred to as the
33 "best interest" standard and is most often invoked for patients who have never possessed decision-
34 making capacity or for those whom an appropriate surrogate cannot be identified. Making a
35 decision based on another's best interests is less an act of respecting the patient's autonomy than it
36 is an expression of beneficence. Employing this standard requires a more objective analysis of the
37 harms and benefits of various options. Factors that should be considered when weighing the
38 harms and benefits of various options include the pain and suffering associated with treatment, the
39 degree and potential for benefit, and any impairments that may result from treatment.^{1,7}

40
41 While some courts and scholars have used the term "objective standard" to characterize best
42 interest reasoning, the subjective perspective of the surrogate decision maker will unavoidably
43 enter into judgments concerning the patient's quality of life. In the more difficult cases, the best
44 interest standard for decision making is essentially a judgment about quality of life.⁷ For the
45 surrogate to make an impartial decision using the best interest standard, he or she should measure
46 quality of life as the worth to the individual whose course of treatment is in question, and not as
47 the social worth of that life.⁸ One way to test whether a decision is inappropriately influenced by
48 the surrogate's own values is to ask if the decision is one that most reasonable persons would
49 choose for themselves in similar circumstances.¹

50

1 WHO SHOULD DECIDE

2
3 When a medical decision needs to be made for an incompetent patient, physicians should first
4 inquire whether the patient had directly expressed wishes in a written document, such as a living
5 will or a durable power of attorney for health care. If the patient has not left such a document, a
6 surrogate should be appointed. Many states have codified protocols for identifying surrogates in
7 the absence of any prior designation. In general, these statutes indicate that the family of the
8 patient should be responsible for medical decisions. “Family” is generally understood to be the
9 person’s closest biological or legally recognized relations.¹ Many states have established a
10 hierarchy for identifying a surrogate decision maker in the absence of a documented advance
11 directive. The order of priority for appointing a surrogate is often listed as legal guardian of the
12 patient first, then a spouse, adult children of the patient, a parent of the patient, an adult sibling,
13 and finally a close friend of the patient.

14
15 In this report, family includes whoever is closely associated with the patient. For instance,
16 unmarried living partners and close friends should be considered as appropriate decision makers in
17 addition to spouses, children, parents, or siblings. Recognizing this extended concept of “family”
18 is increasingly important as alternatives to marriage and the nuclear family unit become more
19 common.¹ In the case where there is no person who is closely associated with the patient, but there
20 are persons who both care about and have some relevant knowledge of the patient, these persons
21 should participate in the decision-making process, and in some situations, may be appropriate
22 surrogates.

23
24 The family’s default authority to make medical decisions for an incompetent patient rests on a
25 number of bases. It is often claimed that families have an intimate knowledge of the patient’s
26 values and can best make the same medical care decisions that the patient would have made. In
27 addition, because an individual’s values are developed primarily in the family, family members are
28 most familiar with the patient’s entire life context. Moreover, family members are generally the
29 most concerned with the patient’s welfare for it is the family who has traditionally provided for the
30 patient’s comfort, care, and best interests. Finally, participation “in an intimate association is one
31 important way in which individuals find or construct meaning in their lives.”¹

32
33 While it is common to assume that family members are best suited to determine what the patient
34 would have decided, there is significant evidence indicating a lack of concordance between
35 patients’ treatment preferences and family members’ prediction of those preferences.⁹ Such
36 information has caused many to question the moral authority of the family to make decisions.
37 However, most of these studies offer no alternative “default surrogate” that fares any better at
38 predicting patient choices.¹⁰ Furthermore, the moral importance of the family as a social unit in
39 which values and preferences are fostered and realized is consistently promoted and, in this case,
40 codified into most regulations that designate a procedure for designating surrogacy.

41 42 *Resolving Conflicts*

43
44 Decisions which profoundly affect a loved one who is incompetent to make medical decisions can
45 be difficult for a family due to the emotional distress resulting from the situation. It is essential for
46 physicians and other health care providers to be sensitive to the range of emotional and
47 psychological responses of the family. Emotionality should not be interpreted as irrationality and
48 used to justify overriding the family’s decision-making authority. Rather, if a physician feels that
49 the decision-making capacity of the family as a surrogate is significantly diminished by emotional
50 distress, efforts should be made to help the family in its decisions. Offering counseling services or
51 the assistance of an ethics committee or chaplain are examples of such efforts.

1
2 Not only is effective communication between the physician and the surrogate essential for
3 appropriate decision making, but it also goes far in preventing major disputes among family
4 members and health care providers. Physicians should offer relevant medical information and
5 explanations as well as medical opinions based on professional expertise. In the absence of a
6 documented advance directive, physicians should explain to the surrogate that decisions should be
7 based on substituted judgment when possible, and otherwise on the best interest principle.¹

8 9 Disputes Among Family Members

10
11 Surrogates often make decisions as members of a family unit whose relationship will continue
12 after a particular decision is made. These relationships deserve the respect of the health care team,
13 and physicians should seek to maintain family harmony. Accordingly, physicians should not
14 intentionally pit the interests of a particular family member against those of other family members
15 to advocate for what the physician believes to be the most appropriate course of treatment.

16
17 In some instances, it may be appropriate to have recourse to an ethics committee. However,
18 physicians and ethics committees should generally refrain from making treatment decisions.¹
19 Rather they should attempt to mediate disputes. Family members may disagree when they do not
20 understand the medical circumstances, each other's view points, or that decisions should be made
21 using a substituted judgment standard whenever possible. Physicians and ethics committees
22 should try to facilitate an understanding of these factors.

23
24 Sometimes, a single designated surrogate can resolve a case in which several family members
25 disagree.¹¹ However, differences may arise when the patient has not designated a proxy and the
26 family cannot agree on which member should act as the surrogate. Physicians or ethics
27 committees should explain that the people who have the best understanding of the patient's values
28 will likely make a decision that reflects what the patient would have decided. Specifically, this
29 refers to people who have had fairly involved and recent discussions with the patient about life,
30 death, illness, religion, and/or specific treatments. Therefore, factors that may guide the search for
31 an appropriate surrogate include the amount of personal contact with the patient, amount of recent
32 personal contact, and the amount of dedication to the patient.¹

33 34 Disputes Between Physicians and Surrogates

35
36 Physicians should generally respect decisions based on well-reasoned substituted judgment or the
37 best interest standard, even if the decision results in a different course of treatment than the
38 physician recommended. Religious and culturally based decisions that reflect beliefs or values
39 held by the patient also should be respected. However, no choice, no matter how well intentioned,
40 should make physicians agents of harm. Such conflicts pit the professional integrity of the
41 physician and well-being of the patient against the ethical obligations to respect the patient's
42 delegated autonomy.¹¹

43
44 When a physician challenges the decision of a surrogate, an ethics committee should first verify
45 that the challenge is based on a belief that the decision is clearly not what the patient would have
46 decided or, cannot reasonably be judged to promote the patient's well-being.¹ In most cases, a
47 negotiated understanding of the patient's values or best interests offers the best protection for the
48 relationship between physicians and surrogates.¹¹

49
50 In the event that a conflict is intractable, even after consulting an ethics committee, the dispute
51 should be referred to the courts.¹ A tremendous disservice is done to the family and the patient

1 when the decision-making process is unnecessarily brought into a forum that is burdensome and
2 adversarial. Traditionally, ethics committees are more informal than the courts, and can maintain
3 the privacy of the family decision-making process better than judicial review, putting less strain on
4 the family and its relationship with the physician or hospital. It is strongly encouraged that when
5 judicial review becomes necessary, the courts appoint an appropriate surrogate to make decisions
6 rather than making treatment decisions.¹

7 8 THE PROXY-PHYSICIAN RELATIONSHIP

9
10 With the rise in the use and discussion of advance directives and surrogate decision makers, the
11 doctor-proxy relationship has fallen under increased scrutiny. Research has shown that proxies
12 and surrogates frequently feel marginalized in the decision-making process.² This may be a result
13 of misunderstandings regarding the role and authority of health care proxies and surrogates, or that
14 physicians tend to predetermine the “correct” medical decision and promote that option before the
15 decision maker.² While some physicians feel that a medical decision should be discussed only
16 among the family members or decision makers, proxies and surrogates are usually eager to receive
17 information about the patient’s condition and appreciate guidance helping them to make decisions
18 that reflect the patient’s wishes or best interests.²

19
20 Recognizing the proxy or surrogate as an extension of the patient, entitled to the same respect and
21 professional obligations as the decisionally capable patient, and eliciting his or her active
22 participation in discussions and decisions can only enhance the quality of care provided to the
23 patient. These obligations include, but are not limited to, providing the decision maker with timely
24 and accurate information about the patient’s diagnosis, prognosis, and treatment options;
25 confidentiality of the discussion between physician and proxy or surrogate; and an
26 acknowledgement that he or she is entitled to receive advice, guidance and support.² Surrogates
27 are frequently asked about further treatment at the same time they are given the news about their
28 loved one becoming incompetent. If possible, surrogates should be given time to absorb this new
29 information before being asked about further treatment.¹¹

30
31 When disputes or conflicts arise, physicians should use this time to address the barriers to
32 agreement. For instance, a physician could hold a family meeting to elicit and respond to the
33 concerns of the entire family. Mediation and negotiation techniques are important to resolving any
34 sort of dispute. If a physician simply facilitates discussion to help parties clarify issues and come
35 to a mutually satisfactory solution, he or she becomes less of an arbiter and may avoid appearing
36 confrontational. This allows physicians to support a family’s final decision and to share the
37 burden of more difficult decisions with the decision maker or surrogate. The uncertainty that
38 accompanies many medical decisions is compounded by knowing that the consequences of the
39 decision will affect a vulnerable and dependent loved one. Thus, support for decision makers
40 should be offered so that they do not feel alone in their decisions. Such support may include
41 counseling services, access to an ethics committee, social services, or spiritual support.

42
43 Although patients cannot always anticipate their future medical conditions or health care needs,
44 they can begin the process of advance care planning. Physicians should urge each of their patients
45 to appoint a health care proxy and to discuss with that person health care wishes and goals.^{12,13}
46 Physicians should also present other options such as a living will.¹⁴ During these discussions it is
47 important for physicians to remain sensitive to and respect religious and cultural issues that may
48 be central to the patient’s identity. If physicians take the time to encourage advance care planning
49 with competent patients, they may avoid the difficulties associated with seeking out and
50 appointing an appropriate surrogate.

51

1 CONCLUSION

2
3 To ensure that the autonomy of an individual patient is maintained in the case of injury or illness
4 that results in incompetence, physicians should respect any advance directive that a patient holds.
5 To further secure the autonomy of an incompetent patient in the absence of an advance directive, a
6 surrogate decision maker should be identified. In this case, the decision maker should adhere to a
7 substituted judgment standard when there is evidence of what the patient would have decided or,
8 in the absence of such evidence, select the course of treatment that most likely promotes the
9 patient’s well-being. Physicians should discuss with patients various options related to advance
10 directives and the benefits of having directives in place before the need for such decisions arise.
11

12
13 RECOMMENDATIONS

14
15 The Council recommends that the following be adopted and the remainder of the report be filed:
16

17 Competent adults may formulate, in advance, preferences regarding a course of treatment
18 in the event that injury or illness causes severe impairment or loss of decision-making
19 capacity. These preferences should be followed by the health care team out of respect for
20 patient autonomy. Patients may establish an advance directive by documenting their
21 treatment preferences and goals or by designating a proxy to make health care decisions
22 on their behalf.
23

24 If an incompetent patient is to receive medical treatment, a reasonable effort should be
25 made to identify the presence of an advance directive. When such a patient lacks a
26 documented advance directive, or when reasonable efforts have failed to uncover such
27 documentation, physicians should defer to state law to identify a surrogate decision
28 maker. In the absence of state law, the patient’s family, or persons with whom the patient
29 is closely associated such as close friends or domestic partners, should become the
30 surrogate decision maker. In the case when there is no family, but there are persons who
31 have some relevant knowledge of the patient, such persons should participate in the
32 decision-making process. In all other instances, a physician may wish to utilize an ethics
33 committee to aid in identifying a surrogate decision maker or to facilitate sound decision
34 making.
35

36 When there is evidence of the patient’s preferences and values, decisions concerning the
37 patient’s care should be made by substituted judgment. This entails considering the
38 patient’s advance directive (if any), the patient’s values about life and how it should be
39 lived, how the patient constructed his or her identity or life story, and the patient’s
40 attitudes towards sickness, suffering, and certain medical procedures.
41

42 In some instances, a patient with diminished or impaired decision-making capacity can
43 participate in various aspects of health care decision making. The attending physician
44 should promote the autonomy of such individuals by involving them to a degree
45 commensurate with their capabilities.
46

47 If there is no reasonable basis on which to interpret how a patient would have decided,
48 the decision should be based on the best interests of the patient, or the outcome that
49 would best promote the patient’s well-being. Factors that should be considered when
50 weighing the harms and benefits of various treatment options include the pain and
51 suffering associated with treatment, the degree of and potential for benefit, and any

1 impairments that may result from treatment. Any quality of life considerations should be
2 measured as the worth to the individual whose course of treatment is in question, and not
3 as a measure of social worth. One way to ensure that a decision using the best interest
4 standard is not inappropriately influenced by the surrogate’s own values is to determine
5 the course of treatment that most reasonable persons would choose for themselves in
6 similar circumstances.

7
8 Physicians should recognize the proxy or surrogate as an extension of the patient, entitled
9 to the same respect as the competent patient. Physicians should provide advice,
10 guidance, and support; explain that decisions should be based on substituted judgment
11 when possible and otherwise on the best interest principle; and offer relevant medical
12 information as well as medical opinions in a timely manner. In addition to the physician,
13 other hospital staff or ethics committees are often helpful to providing support for the
14 decision makers.

15
16 In general, physicians should respect decisions made by the appropriately designated
17 surrogate on the basis of sound substituted judgment reasoning or the best interest
18 standard. In cases where there is a dispute among family members, physicians should
19 work to resolve the conflict through mediation. Physicians or an ethics committee should
20 try to uncover the reasons that underlie the disagreement and present information that
21 will facilitate decision making. When a physician believes that a decision is clearly not
22 what the patient would have decided or could not be reasonably judged to be within the
23 patient’s best interests, the dispute should be referred to an ethics committee before
24 resorting to the courts.

25
26 Physicians should encourage their patients to document their treatment preferences or to
27 appoint a health care proxy with whom they can discuss their values regarding health care
28 and treatment. Because documented advance directives are often not available in
29 emergency situations, physicians should emphasize to patients the importance of
30 discussing treatment preferences with individuals who are likely to act as their surrogates.

REFERENCES

- ¹ Report of the Council on Ethical and Judicial Affairs, American Medical Association. "Decisions to Forego Life-Sustaining Treatment for Incompetent Patients." *JAMA*. 1992; 267(16): 2229-2233.
- ² Post LF, Blustein J, Dubler NN. "The Doctor-Proxy Relationship: An Untapped Resource." *Jrnl. of Law Medicine & Ethics*. Spring 1999; 27(1): 5-12.
- ** In the interest of clarity and accuracy, the terms *proxy* and *surrogate* are distinguished in the following manner: a *legally appointed proxy* refers to a person who has been chosen and legally appointed by a patient to be the substitute health care decision maker; a *surrogate by state law* refers to a person whose authority to make health care decisions for someone else is based on state statute or case law; and an *informal surrogate* refers to a person who is asked by the medical team to help make treatment decisions because no one has been appointed by the patient or is legally authorized.
- ³ Kuczewski, MG. "Narrative Views of Personal Identity and Substituted Judgement in Surrogate Decision Making." *Jrnl. of Law Medicine & Ethics*. Spring 1999; 27(1): 32-36.
- ⁴ Emanuel EJ and Emanuel LL. "Proxy Decision Making for Incompetent Patients." *JAMA* 1992; 267(15): 2067-2071.
- ⁵ Suhl J, Simons P, Reedy T, Garrick T. "Myth of Substituted Judgement: Surrogate Decision Making Regarding Life Support is Unreliable." *Arch Intern Med* January 1994; 154: 90-96.
- ⁶ The narrative approach shifts the focus of the decision from what the patient would have decided, which is an aspect of substituted decision making that has been the focus of several studies, to deciding on an option that best fits with the patient's life-story or self-identity. This is also helpful in cases where patients have never been competent. Traditionally, a guardian of a patient that has never been competent would invoke the best interest standard to make a medical decision because it is not possible to infer what this patient would have decided. However, some would argue that it is possible to develop a relationship with an incompetent or incapacitated individual where the individual's goals and values can be clearly understood even though they have never been clearly articulated or expressed. Thus, the narrative approach to substituted decision making is more amenable to making decisions for patients that have never been competent to make a medical decision
- ⁷ Drane JF and Coulehan JL. "The Best Interest Standard: Surrogate Decision Making and Quality of Life." *Journal of Clinical Ethics* Spring 1995: 20-29.
- ⁸ Council on Ethical and Judicial Affairs, American Medical Association. Opinion 2.07: Quality of Life. *Code of Medical Ethics* 2000; Chicago, IL.
- ⁹ Pearlman RA, Uhlmann RF, Jecker NS. "Spousal Understanding of Patient Quality of Life: Implications for Surrogate Decisions." *Journal of Clinical Ethics* Summer 1992; 3(2): 114-120.
- ¹⁰ Brock DW. "What is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients?" *Journal of Clinical Ethics* Summer 1992; 3(2): 121-123.
- ¹¹ Ann Alpers and Bernard Lo. "Avoiding Family Feuds: Responding to Surrogate Demands for Life-Sustaining Interventions." *Journal of Law, Medicine & Ethics* Spring 1999; 27(1): 74-80.
- ¹² Marquis DK. *Advance care Planning: A Practical Guide for Physicians*. American Medical Association; Chicago, IL: 2001.
- ¹³ Emanuel L, Danis M, Pearlman RA, and Singer PA. *Advance Care Planning as a Process: Structuring the Discussion in Practice*. *J Am Geriatr Soc*. 1995 April; 43(4): 440-446.
- ¹⁴ Emanuel L. *The Health Care Directive: Learning How to Draft Advance Care Documents*. *J Am Geriatr Soc*. 1991 Dec; 39(12): 1221-1228.