BE IT RESOLVED, That the American Bar Association supports the principle that individuals who are capable of making health care decisions generally have the right to consent to and to refuse suggested health care interventions, even if the result would be to shorten life's span.

BE IT FURTHER RESOLVED, That the American Bar Association supports the principle that an appropriate surrogate may exercise this right on behalf of an individual who is incapable of making such decisions. This resolution does not commit the American Bar Association to any particular position as to who are "appropriate surrogates," how they are chosen or what standards govern their actions.
Health care decision-making is an issue that affects everyone at one time or another. It always has. But, these decisions have become far more pervasive and worrisome today, because modern medical technology has blurred the once sharp lines between life and death, health and sickness. Recent advances in medical science — such as respirators, dialysis, cardiopulmonary resuscitation, artificial nutrition and hydration, antibiotics, and chemotherapy — have saved lives in many cases. But, at other times, the results are to add suffering and progressive disability to the end of life, sometimes against the wishes and deeply-held values of the patient.

Health care decision-making poses a considerable challenge for our social, economic and legal system. The law is not especially intricate. However, the underlying task is complicated, involving communication and shared deliberation among the individuals directly involved — the patient, physician, family members, and significant others. The process is also a very personal one involving the weighing of fundamental beliefs and feelings, understanding the medical options, and respecting the dignity, rights, and well-being of the patient.

The resolution proposes two appropriate general principles for addressing these health care decisions. The first principle simply reflects the common law right of a competent individual to consent to or to refuse medical treatment — a right which has been held to have a constitutional basis as well. The second principle deals with the more difficult issue of health care decision-making for the incompetent individual, a matter that is presently before the United States Supreme Court in the Cruzan case. Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1988), cert. granted as Cruzan v. Director, Missouri Department of Health, 109 S.Ct. 324 (July 3, 1989) (No. 88-1503). Both principles are consistent with the position of the United States as amicus curiae in the Cruzan case and, as discussed later, are appropriate regardless of the outcome of Cruzan.

I. The Right of a Competent Individual to Refuse or Discontinue Medical Treatment

A. The common law

The common law right to refuse or discontinue medical treatment has been established for many years. Several grounds are asserted for this right. The first is the right of self-determination. In the oft-quoted 1914 case of Schloendoff v. N.Y. Hospital, Justice Cardozo said it as simply as it could be put:

"Every human being of adult years and sound mind has the right to determine what shall be done with his own body." 211 N.Y. 125, 129-30, 105 N.E. 92, 93 (1914).
The other grounds are the right of "informed consent" and the corollary right to refuse treatment. These rights are based on the common law offense of battery which made any offensive, unconsented touching an actionable wrong. Thus, as the Solicitor General states in the *Cruzan* case, "It was well settled at common law that a competent individual could decline medical treatment." Brief for the United States as Amicus Curiae Supporting Respondents, p. 14 (Hereinafter cited as U.S. A/C Br.).

B. Constitutional bases for the right to control personal medical decisions


In the *Cruzan* case the Solicitor General questions whether generalized notions of privacy should be extended to cover decisions about medical treatment, but he agrees that the "liberty" protected by the Due Process Clause would likely be construed to include the interest of a competent adult in refusing unwanted medical treatments. U.S. A/C Br. at 11-13. Some lower courts have also relied on a due process liberty interest in bodily integrity to uphold treatment refusals, *e.g.*, *Gray v. Romeo*, 697 F. Supp. 580 (D. R.I. 1988).

C. Statutory rights

Finally, the right to refuse or stop unwanted medical treatment can be based on state statutes recognizing "Living Wills" and Durable Powers of Attorney for Health Care. Some 40 states and the District of Columbia, have Living Will statutes which, while not creating new substantive rights, at least provide a statutory recognition and means for exercising the right to refuse or stop medical treatment. All 50 states and the District of Columbia have general durable power of attorney
statutes. In addition, 19 states and the District of Columbia have statutes specifically providing for durable powers of attorney for delegating health care decision-making authority.

D. Limits of the right

Strong as it may be, a competent individual's right to refuse medical treatment is not absolute. Four societal interests have been identified by the courts as at least potentially worthy of causing the court to override a competent patient's right to refuse treatment:

1. the preservation of human life;
2. the protection of third parties;
3. the prevention of suicide;
4. the protection of the ethical integrity of the medical profession.

Considering these interests, courts have almost always upheld the decisions of competent patients, except in a few cases where the protection of dependent third parties has been at stake and the treatment would have a curative, life-restoring effect. With respect to third parties, courts have only occasionally viewed their interests as compelling enough to override the patient's decision, most typically when the third party was a minor child or unborn child, dependent upon the patient. Obviously, very few elderly persons will be in such a situation.

II. The Problem of Deciding for Incompetent Patients

Competence is a prerequisite for informed consent and, indeed, for any health care decision. In this context, the question is whether the patient is competent to make a specific health care decision. In other words, does the patient have "decisional capacity"? If the individual has lost decisional capacity and is unlikely to regain it, what happens to the right to consent to or refuse medical treatment? There are two sets of answers to that question. One set of answers articulates the avenues available when the individual plans ahead and gives some form of advance directive, either formal or informal. The other set articulates the options when no advance planning has occurred.

The written tools for advance planning that are sanctioned by specific statute were noted above: the Living Will and the Durable Power of Attorney for Health Care. The ABA already has policies encouraging the use of these two legal tools. The Living Will is part of the "Uniform Rights of the Terminally Ill Act," drafted by the National Conference of Commissioners on Uniform State Laws and endorsed by the ABA in 1985. In August 1989, the ABA adopted a resolution encouraging "the use and recognition of durable powers of attorney for delegating health care decision making authority...." Oral instructions to family and physicians may also function as advance directives, although less formally so.
If a decisionally incapacitated individual has no advance directive, or the advance directive fails to address the patient's medical situation (as is often the case with Living Wills), other decision-making approaches are needed. This group of patients represents by far the larger group since, in everyday medical practice, few patients who are decisionally incapable have a surrogate whom they (or a court) has explicitly appointed. Historically, the most common approach has been to have a natural surrogate, usually a family member, make the decision in consultation with the physician. The interesting paradox here is that most states have no clear legal authority authorizing family members -- not even a spouse -- to step in as surrogate decision-makers. Nor has the ABA previously addressed this situation.

A number of other legal, ethical, and medical authorities have articulated decision-making principles in this context. See e.g., U.S. Congress, Office of Technology Assessment, Life-Sustaining Technologies and the Elderly 141-166 (1987); The Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying 18-34 (1987); President's Commission for the Study of Ethical Issues in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions 15-39 (1982); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 43-90 (1983); Council on Ethical and Judicial Affairs of the American Medical Association, Withholding or Withdrawing Life-Prolonging Medical Treatment (March 1986); American Academy of Neurology, Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient (April 21, 1988); American Geriatrics Society, AGS Position Statement: Medical Treatment Decisions Concerning Elderly Persons (May 1987).

These authorities consistently express the importance of taking into account the well-being of the patient as understood according to the patient's own values and life goals, to the extent they can be known. The health care professional's obligation is to ascertain the potential treatment options for a patient, and, together with the patient or the patient's representative, determine which course of action best promotes the patient's interests.

States that have confronted this issue have either enacted some form of "Family Consent" legislation or, through case law, have sought to identify appropriate surrogates, standards for decision-making, and procedures. Approximately fifteen states have family consent laws that empower relatives of decisionally incapable patients to make at least some decisions on behalf of those patients without a formal guardianship proceeding. In some of these states, family members may make such decisions only after a physician has certified that the patient is terminally ill. Case law in at least five states supports the
right of family members to make health care decisions for patients who are terminally ill or irreversibly comatose. U.S. Congress, Office of Technology Assessment, supra, at 117. The National Conference of Commissioners on Uniform State Laws adopted a "Model Health Care Consent Act" in 1982 that similarly prescribes a family consent approach for decisionally incapacitated patients who have no advance directive.

Running through the case law is the premise that persons who become unable to make current medical decisions have the same rights as persons who are decisionally capable. In other words, they are to be given the treatment plan that offers the best possible future, consistent with their needs, values and preferences. Being incompetent does not mean that a patient is to be treated in a formulaic way.

One of the first cases to articulate this principle was the 1977 case Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417:

"The substantive rights of the competent and the incompetent person are the same in regard to the right to decline potentially life-prolonging treatment....The recognition of that right must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both."

In implementing this right, courts have invariably inquired into the personal values and preferences of the patient in order to determine what the patient would have wanted under the circumstances. Where the patient's wishes can be clearly ascertained, the patient's wishes are generally dispositive, regardless of whether the surrogate or other people would make the same decision. This subjective standard is known as "substituted judgment." As the Saikewicz court stated, this standard requires the surrogate to "don the mental mantle of the incompetent."

Realistically, in most cases patients will not have expressed a clear choice or preference specifically applicable to the treatment choice at hand. Instead, family members or other surrogates will know only the patient's general attitudes and values from which they may try to draw inferences. In other cases, patients without close family or friends may have little or no known past history from which to draw inferences about their preferences. And in still other circumstances, an adult patient may never have been capable of articulating treatment preferences. In these cases, courts have attempted to frame either an objective "best interests" standard or some blend of a "best interest" and 'substituted judgment' test. See e.g., In re Drabick, 200 Cal. App. 3d 185, 245 Cal. Rptr. 840, cert. denied, 109 S.Ct. 399 (1988); In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985); In re Torres, 357 N.W.2d 332 (Minn. 1984).

Courts have also differed on the extent to which the judiciary should be involved in this process of surrogate
decision-making, although most have expressed a clear preference for non-judicial approaches. Nevertheless, while the nature and implementation of these criteria require further refinement in the case law, the starting premise is fairly clear—a decisionally incapable person should be permitted to exercise his or her right to self-determination, although he or she is unable to do so directly. See also, The Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, (1987).

This policy recommendation does not presume to dictate specific procedures for identifying surrogates, or specific criteria for decision-making. Rather, the recommendation focuses on the need to affirm and protect the legal principle that the right to consent to or refuse any medical intervention survives the decisional incapacity of the patient and is exercisable by an appropriate surrogate, usually a family member, without the intervention of the state, except for abuse, or for cases of unresolvable conflict among surrogates and caregivers, or cases where no appropriate surrogate is available. Moreover, just as a fully aware patient may exercise this right even if the outcome may shorten his or her life span, so may a proper surrogate acting on the patient's behalf.

Turning to close family in these circumstances rests on a strong tradition, grounded in a recognition that the family is ordinarily the most concerned about the patient's best interests, usually the most knowledgeable about the patient's values and preferences, and most directly affected by and involved with the patient's suffering and joy. The Solicitor General recognizes this principle in the Cruzan case where he states:

"For example, we believe it entirely permissible for a State (or the federal government) to establish a procedure that does not entail judicial participation in the process of ascertaining the wishes of an incompetent person.... We believe that such an approach -- one that assumes the active involvement of the patient's family and physician is adequate to guard against abuse or mistakes in ascertaining the patient's wishes -- is reasonable and fully consistent with the Constitution." U.S. A/C Br. at 28-29.

Admittedly, in some cases the family is not the most appropriate surrogate, either because someone else is better equipped or because this particular family is not able to act in good faith in furtherance of the patient's interest due to internal family dysfunction or a severe conflict of interest. Procedures need to be sensitive enough to identify and handle these at-risk cases in appropriate ways, including the use of guardianship.
III. The Need for ABA Policy

The matter of health care decision-making -- particularly the right of the competent or incompetent patient to refuse life-sustaining treatment that simply prolongs the natural process of dying where there is no hope of recovery -- is of great importance. And it grows increasingly important because of three factors: continuing advances of medical technology, our skyrocketing health care costs, and the dramatic aging of our population. Currently, about 11 percent of our gross national product goes for health care and about one-third of that care is for the elderly. The fastest growing segment of our population is the group over 85; that group alone, which is now one percent of the population, is projected to be five percent in the year 2050. Since 1900 the percentage of the population over 65 has tripled. In 1987 about 12 percent of our population was over 65. It is projected that persons over 65 will be 20 percent of the population by the year 2030 and that by the year 2050 there will be as many persons over 80 as there are now over 65.

The combination of these three factors makes it imperative to give the widest recognition to personal decisions regarding medical treatment, particularly where the treatment has no curative or beneficial effect. Our proposed principles are designed to give that recognition and respect in accordance with the case and statutory law in the majority of the states and the considered views of the American Medical Association, the American Academy of Neurology, and the experts in the study commission reports cited at p. 4, supra.

The need for ABA policy in this area has been heightened by the Cruzan case, now pending before the Supreme Court of the United States (No. 88-1503). That case departs substantially from the tradition of respecting the decisions of family surrogates to stop treatment of an incompetent; instead it interposes significant state authority -- both legislative and judicial -- to compel treatment even though it offers no hope of recovery. It is the first case in which a state court has relied on an interest in the preservation of human life to override an incompetent patient's right, exercised through family surrogates, to make medical treatment decisions.

The facts of the case are graphic. Nancy Beth Cruzan in 1983, at age 25, suffered a serious car accident which left her in a persistent vegetative state. She is permanently unconscious and completely dependent on others for her care. She is unable to swallow and exists solely by means of an artificial food and hydration tube. It is estimated she could live for some thirty years in this limbo. Her care costs $130,000 a year which the State of Missouri pays because she was a state employee. There is no hope of recovery. Her parents (as co-guardians) asked the Missouri Rehabilitation Center to terminate the nutrition and hydration which was being provided by means of a surgically implanted gastrostomy tube. The request was refused and the Cruzan's filed a declaratory
A judgment action seeking judicial sanction of their request. The trial court approved their request, but the case was appealed by the State and by a guardian ad litem appointed for Nancy Cruzan.

The Missouri Supreme Court by a 4-3 division reversed the trial court's decision and denied the request of Nancy's co-guardians. It reasoned that the State interest in preserving life (demonstrated by the language of Missouri's Living Will Act which prohibits the withdrawal of nutrition and hydration) is an absolute, unqualified interest which requires the preservation of life, especially where, as in Nancy Cruzan's case, she could live for a long time. The case departed dramatically from the decisions unanimously reached by other courts on similar facts. It is the first case in which an appellate court has declined to approve withdrawing artificial feeding from a permanently unconscious patient. It is also the first in which a court has stated that tube feeding is not medical treatment about which choices could be made.

The issue before the Supreme Court of the United States in its review of the Cruzan decision is, of course, a constitutional one -- do Nancy Cruzan's parents (as her surrogates) have a 14th Amendment right to have her artificial feeding and hydration stopped even though that means her death? The principles proposed in the report do not take a position on that constitutional issue. If the Supreme Court of the United States does decide that constitutional issue in favor of the parents, the second principle we propose would become the law of the land. If, however, the Supreme Court of the United States should hold that the parents do not have such a constitutional right, our second principle takes on added importance. For then, the matter of health care decision-making for incompetents is left for determination by each state. The Association should adopt this second principle so that we can urge states to follow the majority view, rather than the Missouri rule narrowly adopted in the Cruzan case.

The major danger of the Cruzan majority's approach is that by recognizing only an unqualified interest in the preservation of life, it has effectively predetermined the outcome of any balancing of interests, and eviscerated the legal and ethical interest of patients in their self-determination, bodily integrity, and privacy. The majority's approach also interferes with the accepted ethical responsibility of physicians to act in the best interests of their patients, as determined by weighing the benefits and burdens of any treatment (including nutrition and hydration) in light of the prior expressed wishes of the patient and attitudes of the family or those who have responsibility for the custody of the patient. See American Medical Association, Statement of the Council on Ethical and Judicial Affairs (March 15, 1986).

The proper approach for the courts should be generally to defer to the decisions of competent individuals and of the families (or other representatives) of incompetent patients to
initiate, continue, or terminate medical treatment. As previously noted (supra, p. 6), the Solicitor General in Cruzan states that this is an "entirely permissible" course for a state to follow. By granting deference to the decisions of patients' families, as informed by the medical profession, the courts will properly protect patients' personal liberty and bodily integrity and avoid embarking on a course of medical rulemaking. The proper role of the courts, while limited, is nevertheless crucial: to ensure a procedural environment in which a decision can properly be made in good faith. See L. Tribe, American Constitutional Law, §16-31, at 1596-1601 (2d ed. 1988).

To conclude:

1. The first proposed principle simply reflects the common law (and probably constitutional) right of a competent individual to refuse medical treatment, even though that may shorten the individual's life.

2. The second proposed principle follows the majority view reflected in state case and statutory law and in the medical community. It emphasizes the importance of private, family-oriented decision-making for decisionally incapable patients with minimal judicial intrusion. Simply worded, its avoidance of certain qualifiers is intentional. Thus, the principle is not limited to cases of terminal illness; nor to patients in a particular age group; nor is it subject to an exclusion for nutrition and hydration. Nor does it attempt to define or offer guidelines for determinations of decisional capacity. Instead, it aims to reinforce the legal recognition that individuals may control decisions about their care, either directly or through appropriate surrogates, without preemptive interference by the State.

Finally, nothing in this report sanctions euthanasia. Decisions to forego medical treatment are sometimes described as active or passive euthanasia. That is inaccurate. If death occurs, it is the result of the disease or trauma, not the decision to refuse treatment which may only prolong the natural process of dying. Previous generations were not put to the choice, because such means were not available. The fact that life-prolonging techniques may now be available should not be any reason for denying the choice our ancestors had made for them automatically.

Respectfully submitted,

John H. Pickering
Commission on Legal Problems of the Elderly
February 1990
GENERAL INFORMATION FORM

To Be Appended to Reports with Recommendations

No. (Leave Blank)

Submitting Entity: Commission on Legal Problems of the Elderly

Submitted By: John H. Pickering

1. Summary of Recommendation(s).

Supports the principle that individuals who are capable of making health care decisions have the right to consent to and to refuse suggested health care interventions, and that appropriate surrogates may exercise this right on behalf of individuals who are incapable of making such decisions.

2. Approval by Submitting Entity.

October 4, 1989, approved by Commission.

3. Previous Submission to the House or Relevant Association Position.

No previous submission on this topic. Related (and consistent) ABA policies are (1) endorsement of the ABA's endorsement of the Uniform Rights of the Terminally Ill Act (1985) and (2) a policy encouraging the use and recognition of durable powers of attorney for health care (August 1989).

4. Need for Action at this Meeting.

The ABA is seen as a major participant in the development of law and public policy in this area, and for the first time, the United States Supreme Court is considering the constitutional underpinnings of health care decision-making for incompetent persons in the case Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1988), cert. granted as Cruzan v. Director, Missouri Department of Health, 109 S.Ct. 324 (July 3, 1989) (No. 88-1503), argued December 6, 1989.

5. Status of Legislation. (If applicable.)

There is presently no pending federal or state legislation directly related to this recommendation.

6. Cost to the Association. (Both direct and indirect costs.)

None.
7. Disclosure of Interest. (If applicable.)

None.

8. Referrals.

Commission on the Mentally Disabled
Forum Committee on Health Law
Judicial Administration Division
Section of Family Law
Section of General Practice
Section of Individual Rights and Responsibilities
Section of Real Property, Probate & Trust Law
Section of Science and Technology
Section of Tort and Insurance Practice
Senior Lawyers Division
Young Lawyers Division

9. Contact Person. (Prior to meeting.)

Nancy Coleman or Charles Sabatino, ABA, 1800 M Street, N.W.,

10. Contact Person. (Who will present the report to the House.)

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