Chapter Two

The Emergence of Consensus

The adversarial nature of the judicial process in the United States is both its strength and its weakness. On the one hand, conflict forces participants to pursue a number of different lines of argument and present various types of evidence before allowing a judge (or a jury) to resolve an issue one way or the other. On the other hand, the conflict inherent in the American judicial process forces parties on either side of a question to stretch, distort, and convolute the evidence and arguments available in order to score points for their clients and, it is hoped, to ultimately win the case.

The same could be said for polemical treatments of controversial issues in both the popular and academic presses. Authors do what they can to advance their particular points of view, and the reader is often left to wonder whom and what to believe. Are the winners of the court battles—or the press battles—right? Or are they only the most clever? Surely, there is some way to sort through the morass of competing claims and counterclaims about what is appropriate with regard to making end-of-life decisions for those unable to make such decisions on their own.

One way to move beyond the adversarial judicial process and the personal opinions and biases of authors is to reference the positions of consensus groups. The term *consensus group* is used here to refer, loosely, to a diverse collection of individuals called together to find some sensible common principles that can provide practical and ethical guidance to others.

Although any single author (whether an ethicist, a physician, a lawyer, or a judge) may draw on the writings and thinking of others, the synthesis that results is still slanted, consciously or not, by the writer’s own prejudices. Alternately, there is something more balanced about the conclusions of multidisciplinary consensus groups. These collective bodies tend to draw on a
wide variety of professionals who bring a range of educational, training, clinical, and personal experiences to the table. These groups typically struggle mightily with tough questions in the process of finding some middle ground that all members of the group can accept. As such, their pronouncements represent a plurality of views that reach beyond individual opinion to achieve a more generalized and enduring statement of principles.

Often, consensus group reports are ratified, either formally by vote of an organization's members or informally through citation by others. When this happens, the reports in question take on even greater weight, importance, and legitimacy. The consensus group reports referred to in this chapter have been chosen precisely because they have been legitimated in at least one of two ways: by being adopted by a professional organization or by being widely cited in the writings of scholars, in the opinions of judges, and in the editorials of commentators.

This chapter focuses on the considered opinions of eleven consensus groups, including five health care associations (three physicians' groups, one association of nurses, and one religiously oriented hospital association), two independent nonprofit legal institutes, two task forces (one state and one federal), one not-for-profit bioethics institute, and one interdisciplinary triad of authors who wrote a best-selling book on clinical ethics for medical school students.

The position statements cited here range from elaborate and extensively researched analyses of 500 pages or more (e.g., the President's Commission report) to brief, relatively straightforward statements of general principle (e.g., the compendium of statements issued by the American Nurses Association [ANA]). In each case, however, the statements that emerged from the deliberations of interdisciplinary teams reflect not only the opinions of the group members but also the general sense of the community the particular group was constituted to represent. Of course, not every member of every organization will endorse organizational position statements without dissent, but these statements can be taken as generally representative. It is in that spirit that they are abstracted in this chapter.

Most of these writings are referred to, paraphrased, and quoted in a variety of places. But never has a comprehensive collection of such statements on the key issues associated with end-of-life decision making been collected for comparison, review, and consideration. For that reason and to the degree possible, the positions reported here have been abstracted verbatim. It is hoped that this will allow the reader to capture a fuller, richer sense of what was written and intended by the authors, with as little distortion as possible. For overall ease of reading, citations have been provided only to the statements themselves; citations that were embedded within these statements have been omitted. The full texts of all the statements are readily available (see Tables 2.1, 2.2, and 2.3).
TABLE 2.1 Medical Consensus Groups

<table>
<thead>
<tr>
<th>Medical Consensus Group</th>
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<tr>
<td>The American Medical Association (AMA)</td>
<td>The AMA is among the oldest (founded in 1847), certainly the best known, and arguably the most influential medical organization in the United States today. Well over half of the approximately 460,000 physicians licensed to practice medicine in the United States currently belong to the AMA. The AMA—an organization that is often described (and criticized) as more conservative than the members it purportedly represents (Cummings and Wise 1989: 252)—periodically issues position statements authored by a standing multidisciplinary committee of physicians known as the Council on Ethical and Judicial Affairs.</td>
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<tr>
<td>515 North State Street, Chicago, Ill. 60610</td>
<td>(312) 464-5000</td>
</tr>
<tr>
<td>American College of Physicians (ACP)</td>
<td>Founded in 1915, the American College of Physicians is a professional society of physicians specializing in internal medicine and closely related specialties. The ACP has 80,000 members and published the <em>Annals of Internal Medicine</em>. The ACP's Ethics Committee, composed of practicing internists, medical ethicists, educators, and lawyers, published the Physicians Ethics Manual in the <em>Annals of Internal Medicine</em> in 1989. The ACP updated the manual in 1992.</td>
</tr>
<tr>
<td>Independence Mall, West 6th Street at Race, Philadelphia, Pa. 19106</td>
<td>(215) 351-2400</td>
</tr>
<tr>
<td>American Thoracic Society (ATS)</td>
<td>The ATS was founded in 1905 and currently serves as the medical section of the American Lung Association. The ATS's 11,000 members include specialists in pulmonary diseases, thoracic surgeons, and researchers and public health workers concerned with diseases of the chest and lungs. The ATS publishes <em>The American Review of Respiratory Diseases</em>. The board of directors of the ATS approved formation of the ad hoc Bioethics Task Force, which, in 1991, issued an official statement that defines for ATS members acceptable standards of medical practice regarding the withholding and withdrawing of life-sustaining therapy. The consensus group that authored the statement consisted of thirteen doctors, one nurse, and five consulting specialists in law and ethics.</td>
</tr>
<tr>
<td>1740 Broadway, New York, N.Y. 10019-4374</td>
<td>(212) 315-8700</td>
</tr>
<tr>
<td>American Nurses Association (ANA)</td>
<td>Founded in 1896, the American Nurses Association currently represents 2.3 million registered nurses nationwide and publishes the periodical <em>American Nurse</em>. The ANA's Task Force on the Nurse's Role in End-of-Life Decisions issued the <em>Compendium of Position Statements on the Nurse’s Role in End-of-Life Decisions</em> in 1992 and added two new position statements, one on assisted suicide and one on active euthanasia, in 1994.</td>
</tr>
<tr>
<td>600 Maryland Ave. SW, Suite 100 W, Washington, D.C. 20024-2571</td>
<td>(202) 554-4444</td>
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### TABLE 2.2 Legal Consensus Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>Address</th>
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<tbody>
<tr>
<td>National Center for State Courts (NCSC)</td>
<td>300 Newport Avenue Williamsburg, Va. 23184</td>
<td>(804) 253-2000</td>
</tr>
<tr>
<td>Uniform Law Commissioners (ULC)</td>
<td>676 North St. Clair Street Suite 1700 Chicago, Ill. 60611</td>
<td>(312) 915-0915</td>
</tr>
<tr>
<td>New York State Task Force on Life and the Law (NYSTFLL)</td>
<td>5 Penn Plaza New York, N.Y. 10001-1803</td>
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The NCSC was founded in 1971 to provide assistance to state and local trial and appellate courts by compiling national statistics, conducting studies, and acting as a clearinghouse for the exchange of court-related information. In 1992, the NCSC issued what became a well-respected and widely cited treatise on the role of the state courts in end-of-life decision making, entitled *Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases*. More recently, the NCSC completed a three-year process of writing a follow-up report for caregivers with the publication of *Resolving Disputes over Life-Sustaining Treatment: A Health Care Providers Guide* (Hafemeister and Hannaford 1996). Those involved in formulating this document consisted of four judges, five lawyers, two ethicists, three physicians, and a registered nurse, all of whom had professional experience in end-of-life decision making. Additional input was solicited from other health care professionals, clinical social workers, administrators, legal counselors, and those involved with pastoral care. Input from patients and family members was also solicited.

The ULC, officially known as the National Conference of Commissioners on Uniform State Laws, is an organization of judges, law school deans, professors, and practicing attorneys appointed by the state governors to promote unity in state laws on subjects in which uniformity is deemed desirable and practical. In past years, the ULC has created model statutes that have updated state administrative procedures acts and standardized the commercial and civil codes of the states. In 1985, the ULC adopted the Rights of the Terminally Ill Act, and it amended this model law with its Uniform Rights of the Terminally Ill Act in 1989. More recently, the ULC has issued the Uniform Health-Care Decisions Act, which updates and expands on the first two model statutes.

The NYSTFLL was created in 1985 to devise policies on a host of ethically challenging issues arising from advances in medical technology. Currently, it claims to be "the only standing government commission in the United States with a mandate to recommend public policy on a range of medical/ethical issues" 

*continues*
(NYSTFLL 1992: 1). The interdisciplinary group responsible for publishing *When Others Must Choose: Deciding for Patients Without Capacity* consisted of nine physicians (including the commissioner of health for New York State), a hospital president, a medical school dean and provost, two medical school professors, seven clerics (including a Roman Catholic monsignor, an Episcopal bishop, and two rabbis), four lawyers, and three registered nurses.

Alan Meisel is the only independent author cited here. Meisel’s *The Right to Die* is the most comprehensive and extensively researched source of information on the legal issues on death and dying currently available. The basic text, together with its *Cumulative Supplement*, covers nearly 1,000 pages and includes several thousand citations to the 160 or so important cases that have been argued in the state courts to date. Although Meisel’s writings do not reflect the deliberations of any particular organization, his work is widely cited by a variety of authors and consensus groups as the authoritative source of legal information on such issues.

In addition to publishing *The Right to Die* and a number of related articles, Meisel served as coauthor of an amicus brief accepted by the Pennsylvania State Supreme Court in the Fiori case, discussed in Chapter 1. That brief was filed jointly under the auspices of two respected consensus groups: the University of Pittsburgh Center for Medical Ethics and the Ethics Committee of the University of Pennsylvania Medical Center. Meisel’s writings can be considered to carry greater weight than the works of other independent authors whose thinking has not been so extensively legitimated by external groups. Most of Meisel’s analysis presented here is drawn from a 1991 article published (by the American College of Physicians) in the *Archives of Internal Medicine*, entitled “Legal Myths About Terminating Life Support.”
TABLE 2.3 Ethics Consensus Groups

<table>
<thead>
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<th>Table Entry</th>
<th>Text Entry</th>
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<tr>
<td><strong>Deciding to Forego Life-Sustaining Treatment</strong></td>
<td>The President's Commission report entitled <em>Deciding to Forego Life-Sustaining Treatment</em> (1983) has stood the test of time as probably the most important and authoritative source of ethics-oriented information on end-of-life decision making published to date. This report has served as an important point of reference to which lawyers, judges, health care providers, and ethicists have returned time and again for their bearings. The group of approximately two dozen physicians, ethicists, and lawyers who contributed to the research and writing of this 550-page report charted, in very clear and prescient fashion, the outlines and many of the details of the consensus positions that were to emerge over the ensuing years. Not only is this report widely cited, it is widely—maybe even universally—accepted as the definitive word on the ethics of end-of-life decision making.</td>
</tr>
<tr>
<td>President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research</td>
<td>The Hastings Center is one of the oldest and most respected bioethical organizations in the country. Its 11,500 members are individuals concerned with medical and professional ethics, including physicians, nurses, lawyers, administrators, academics, and other professionals in health-related fields. The Hastings Center conducts research and provides consultant services on a wide variety of issues related to ethics. Founded in 1969, the Hastings Center is one of the oldest and most respected bioethical organizations in the country. Its 11,500 members are individuals concerned with medical and professional ethics, including physicians, nurses, lawyers, administrators, academics, and other professionals in health-related fields. The Hastings Center conducts research and provides consultant services on a wide variety of issues related to ethics. The center's <em>Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying</em> is among the most widely cited documents in the medical and ethical literature. It is also well represented in the texts of legal briefs and court decisions. The document was constructed by a multidisciplinary group consisting of specialists in medicine, law, philosophy, nursing, and health care administration. The report draws on state law (statutory law, constitutional law, and common law), government commission reports, statements of principles issued by professional, religious, and patient advocacy organizations, and medical, legal, and ethical literature on the subject to provide a comprehensive summation of the current state of ethical affairs relevant to the care of the dying.</td>
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<tr>
<td>Library of Congress #83-600503</td>
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TABLE 2.3  (continued)

| Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine (1992, 3rd ed.) | Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine is the product of a collaboration among a professor of medical ethics, a professor of internal medicine, and a professor of philosophy. The writings of these three authors do not reflect the official position of any particular policy-making group or professional organization. The book is included here because it is one of the top-selling medical school books on clinical ethics in the United States today. As such, it has the tacit endorsement of a wide variety of medical schools. In addition, it reflects well the state of the medical, legal, and ethical dimensions of the right-to-die debate in generally straightforward terms. |
| ISBN 0-07-105392-1 | Mark Siegler, M.D., professor of internal medicine, University of Chicago's School of Medicine, Chicago, Ill. |
| | William J. Winslade, Ph.D., J.D., professor of philosophy, University of Texas Medical Branch, Galveston, Tex. |
| Catholic Health Association (CHA) | The CHA, founded in 1915, serves as the professional association for Catholic hospitals, extended care facilities, and health care systems in the United States. With 1,200 member organizations, the CHA is the largest association of not-for-profit health care facilities in the country. After several task forces of theologians, clergy, health caregivers, and ethicists deliberated over how suffering, pain management, and the dying process should be viewed in light of the Catholic tradition, the CHA issued a definitive statement on the subject, entitled Care of the Dying: A Catholic Perspective. |
| 4455 Woodson Road St. Louis, Mo. 63134-0889 (314) 427-2500 | Building Blocks of Consensus |

Position statements from a variety of mainstream medical, legal, and ethical organizations and authors are provided in this chapter as evidence that the modern consensus on the critical questions of end-of-life decision making is both broad and deep. From the medical realm, the positions of the American Medical Association (AMA) Council on Ethical and Judicial Affairs are
The Emergence of Consensus

provided together with the statements of the American College of Physicians (ACP), the American Thoracic Society (ATS), and the American Nurses Association.

From the legal world, position statements from the National Center for State Courts, the Uniform Law Commissioners, and the New York State Task Force on Life and the Law (NYSTFLL) are abstracted along with the legal analysis of Alan Meisel, the country’s preeminent and probably its most widely cited expert in this area of jurisprudence.¹ A medical-ethical position of a religious orientation is provided by the statement on end-of-life decision making published by the Catholic Health Association (CHA), and secular versions of ethical considerations are supplied by the President’s Commission for the Study of Ethical Problems, the Hastings Center, and the writings found in a leading text on the subject, entitled Clinical Ethics: A Practical Approach to Ethical Decisions.

The statements of each of the groups and individuals listed in Tables 2.1 (medical consensus), 2.2 (legal consensus), and 2.3 (ethical consensus) have been parsed and sorted according to five critical issues, each of which was raised in the case of Joey Fiori. First and most sweeping is the general category of decision making: Who should be allowed to make decisions for incompetent patients, and how should these decisions rightfully be rendered? Second is the question of forgoing treatment versus suicide: Does complicity in the forgoing of treatment or the provision of pain medication sufficient to hasten death involve the patient or clinician in suicide or active euthanasia?

Third is the distinction between withholding and withdrawing treatment: Is the distinction important or irrelevant? Can one withhold treatment but not withdraw it, or are the two actions morally equivalent? Fourth is the issue of terminal illness: Must a patient be terminally ill before end-of-life decisions can be made directly or through a surrogate? Fifth and finally comes perhaps the most troubling aspect of this debate for many Americans, artificial nutrition and hydration and the ordinary-extraordinary distinction: Is there anything special about artificially provided food and water that would lead decisionmakers to believe that ANH must always be provided, or should ANH be treated as just another medical procedure?

Decision Making

The consensus position is that competent adults can make any decisions they want regarding their own medical treatment. Surrogates, preferably close family members, may be deferred to, without the involvement of the courts, in making any decision that an incompetent patient could have made if he or she were competent. Surrogates should rely on the incompetent patient’s wishes, expressed and implied, when making decisions—a process referred to as “substituted judgment.” If there is insufficient information to make a substituted judgment, surrogates should weigh the bene-
fits and burdens of various scenarios in an effort to decide which course of action would serve the patient's best interests. The courts need only be involved as a last resort to deal with irreconcilable conflicts within a family or between the family and the patient's caregivers.

American Medical Association

The principle of patient autonomy requires that competent patients have the opportunity to choose among medically indicated treatments and to refuse any unwanted treatment (Council 1992: 2230). The obligation to respect a competent patient's right to self-determination includes the obligation to follow the instructions of an advance directive (Council 1991: 67). When a patient does not have an advance directive . . . the surrogate should base treatment decisions on what the patient would likely decide if he or she were capable of making the decision. This standard, or guiding principle, is called substituted judgment . . . If there is no reasonable basis upon which to interpret what a previously competent patient would have decided, or if the patient never possessed decision-making capacity, the surrogate decision maker should base treatment decisions on which outcome would most likely promote the patient's well-being. This guiding principle is referred to as the "best interests" standard (Council 1991: 68) . . .

Factors that should be considered when weighing harms and benefits of treatment include the expected duration of life with and without treatment, pain and suffering associated with the treatment, and the amount of incapacitation and ability to interact with others if life is sustained. When using the best interests standard, the subjective perspective of the surrogate decision maker will unavoidably enter into judgments about the quality of life that would exist for the patient with life-sustaining treatment. "Quality of life" here is defined as the worth to the individual whose life is in question, and not as a measure of social worth . . . One way to help ensure that a decision is not inappropriately influenced by the surrogate's own values is to determine whether the decision is one that most reasonable persons would choose for themselves in similar circumstances (Council 1991: 68).

The family should be relied upon to make treatment decisions [for incompetent patients] because family members are generally best suited to determine what the patient who lacks decisionmaking capacity would have chosen. Family members are most likely to have had conversations with the patient specifically about the withdrawal of life-prolonging treatment [and] family members have the most intimate understanding of the patient's perspective . . . Moreover, family members are generally the most concerned with the patient welfare. . . . Those who are outside the family, such as the state or health care institutions, should be wary to intrude upon family decisions particularly when the decisions are within a reasonable range of choices (Council 1991: 70–71).

While certain aspects of judicial decisionmaking are attractive . . . the slow and cumbersome nature of the judicial process makes routine judicial review for decisions regarding life support impossible. In addition, the public, adversarial and tremendously time-consuming and costly nature of the judicial process would create significant hardship for the patients and families involved. Furthermore, routine judicial review would remove the decisionmak-
ing process from families, thereby devaluing the family’s role in decision-making (Council 1991: 72).

**American College of Physicians**

The basic principles of informed consent, shared decision making, and the use of surrogate decision makers when necessary . . . apply to end-of-life decisions as well. Principles are manifest as follows: Patients who have decision-making capacity and should have been adequately informed of their clinical situation and options usually have the right to accept or refuse any recommended medical treatment, including life-sustaining treatment. . . . This right of the patient is based on the philosophical concept of autonomy, the common-law right of self-determination, and the more recently enunciated constitutional right of privacy. The crux of the issue is that the competent patient’s (rather than the physician’s) assessment of the benefits and burdens of treatment should determine what treatment is administered or withheld. . . . Surrogate or proxy decision-makers . . . should know the patient’s values well and be free of obvious fiscal or emotional conflicts with the patient. The physician should take reasonable care to ensure that the surrogate’s decisions are motivated by respect for the patient’s interests and values. . . . Whenever possible, these decisions should be reached in the clinical setting by responsible physicians, family, and other caregivers (ACP 1989: 330–331).

**American Thoracic Society**

An adult person who no longer has decision-making capacity should continue to have the right to refuse all forms of medical therapy. However, this right must be exercised on the patient's behalf by an appropriate surrogate decision maker. . . . If no such person exists, the physician should help to identify one or more close family members or close friends of the patient to be the surrogate decision maker, primarily on the basis of their knowledge of the patient’s preferences, values, and goals and their commitment to supporting the patient’s rights and best interests. Whenever possible, out of respect of the patient’s autonomy, the surrogate decision maker should make the same decisions about the patient’s care as the patient would have made if capable of doing so. . . . If circumstances arise in which the surrogate decision maker cannot make a decision based on knowledge either of the patient’s prior statements or of the patient’s values and goals, he or she should collaborate with the patient’s physician and other health care providers to make decisions for the patient based on what is determined to be in the patient’s best interests (ATS 1991: 479–480).

**American Nurses Association**

In the case of the incompetent or never competent patient, any existing advance directives or the decisions of surrogate decision makers acting in the patient’s best interest should be determinative (ANA 1992: 13). In cases where a patient is unable to make his wishes known . . . the decision of a surrogate
The Emergence of Consensus

should be relied upon. A surrogate decision maker, preferably designated by the patient, is one who makes decisions in the best interest of the patient and without self interest (ANA 1992: 9).³

National Center for State Courts

It is increasingly certain ... that family members usually may serve as the patient's surrogate, even without statutory authorization or court appointment. ... First, as a general rule, family members are in the best position to know the patient and have reliable information about the patient's wishes. Second, the interests of the family members are likely to coincide with those of the patient. ... Finally, most individuals want a family member to serve as their surrogate. ... If the patient has not expressed his or her wishes, the surrogate should use ... the “substituted judgment” standard. ... This process involves the surrogate's good faith inquiry into the patient's values, beliefs, and lifestyle ... to determine what the patient would have wanted if he or she had sufficient decision-making capacity to express treatment preferences. ... Unfortunately, a patient's wishes and values may not always be clear. ... Under these circumstances, the usual practice is to permit surrogates to use ... the “best interests” standard. ... Determining a patient's best interests generally includes evaluating objective medical criteria such as the patient's diagnosis and prognosis, the amount of enjoyment and suffering the patient is likely to experience, and the likelihood that the use of life-sustaining medical treatment will restore the patient to his or her previous quality of life. This determination is not a purely clinical one, however. Often it is an almost intuitive determination that requires evaluation of what a reasonable person in the patient's situation would want (Hafemeister and Hannaford 1996: 16–19).⁴

Uniform Law Commissioners

The [Uniform Health-Care Decisions] Act acknowledges the right of a competent individual to decide all aspects of his or her own health care in all circumstances, including the right to decline health care or to direct that health care be discontinued, even if death ensues. ... Unless limited by the principle, an agent has the authority to make all health-care decisions which the individual could have made. ... The Act requires an agent or surrogate ... to make those decisions in accordance with the instructions and other wishes of the individual to the extent known. Otherwise, the agent or surrogate must make those decisions in accordance with best interests of the individual but in light of the individual's personal values. ... (ULC 1993: 1). A health-care decision made by an agent for a principal is effective without judicial approval (ULC 1993: 5).

New York State Task Force on Life and the Law

After consulting with health care professionals, surrogates should decide about treatment based on the patient's wishes or, if the patient's wishes are not reasonably known and cannot be reasonably ascertained, based on the patient's
The Emergence of Consensus

best interests. Assessments of a patient's best interests should be patient-centered and should include consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life; preservation, improvement, or restoration of the patient's health or functioning; relief of the patient's suffering and other such concerns and values as a reasonable person in the patient's circumstances would wish to consider. By and large, decisions made in accordance with the proposed law will be private bedside decisions by those closest to the patient. The courts should not be the avenue of first resort, either as the sole alternative to address conflict or as the primary decision maker for all patients who are neither terminally ill nor permanently unconscious (NYSTFLL 1992: XI).

Over the past decade, two standards for surrogate decision making, "substituted judgment" and "best interests," have been embraced by commentators, policy makers, and the courts. The Task Force proposes that these standards should guide surrogate decisions for health care generally (NYSTFLL 1992: 103).

The study's findings do not support the notion that individuals outside the patient's circle of family or close friends should be designated to act as surrogate. Although family members do not always approximate the patient's wishes, they are more likely than others to do so. Studies have shown that family members are more familiar with the patient's health care wishes than physicians or other health care professionals. They also know far more about the patient than state-appointed representatives, judges, or others who will otherwise be called upon to make surrogate decisions. Family members are also generally those most concerned about and dedicated to the patient's well-being. Connected to the patient by bonds of kinship and caring, family members often play a crucial role as advocate for the patient (NYSTFLL 1992: 94).

Alan Meisel

Every day, and with limited legal guidance, families and doctors are making decisions for patients unable to do so themselves (Meisel 1991: 1498). As everyone associated with a hospital, nursing home, or hospice knows, efforts at prolonging the lives of dying patients are frequently tapered off or halted at the request of patients still possessing decision making capacity or families of patients who have lost the capacity to make decisions (Meisel 1991: 1500). The acceptance of virtually all courts considering the principle that incompetent patients must be accorded the same substantive rights as competent patients has been at the root of the widespread judicial acceptance of the substituted judgment standard. [The best interests standard] has been relegated by most courts to a secondary status, to be applied when the evidence necessary for applying the substituted judgment standard is lacking. When it is applied, the surrogate decision maker assesses what medical treatment would be in the patient's best interests as determined by such objective criteria as relief from suffering, preservation or restoration of functioning, and quality and extent of sustained life (Meisel 1989: 265–266).
President's Commission Report

When a patient lacks the capacity to make a decision, a surrogate decision maker should be designated. Ordinarily this will be the patient's next of kin, although it may be a close friend or another relative if the responsible health care professional judges that this other person is in fact the best advocate for the patient's interests (President's Commission 1983: 126-127).

The decisions of the surrogates should, when possible, attempt to replicate the ones that the patient would make if capable of doing so. When lack of evidence about the patient's wishes precludes this, decisions by surrogates should seek to protect the patient's best interests (President's Commission 1983: 5-6).

The two values that guide decision making for competent patients—promoting patient welfare and respecting patient self-determination—should also guide decision making for incompetent patients. These values are reflected, roughly speaking, in the two standards that have traditionally guided decision-making for the incapacitated: "substituted judgment" and "best interests." The substituted judgment standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose (President's Commission 1983: 132). In assessing whether a procedure or course of treatment would be in a patient's best interests, the surrogate must take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of the life sustained. The impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates (President's Commission 1983: 134-135).

Hastings Center's Guidelines

If the patient receiving life-sustaining treatment is incompetent, a surrogate decision maker should be identified. Without an advance directive that designates a proxy, the patient's family should become the surrogate decision maker. Decisions regarding withholding or withdrawing life sustaining treatment should be based on substituted judgment (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgment, decision makers may consider the patient's advance directive (if any); the patient's values about life and the way it should be lived; and the patient's attitudes towards sickness, suffering, medical procedures, and death. If there is not adequate evidence of the incompetent patient's preferences and values [e.g., in the case of lifelong incompetents or if no suitable surrogates exist], the decision would be based on the best interests of the patient (what outcome would most likely promote the patient's well-being). When there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decisionmaking is recommended before resorting to the courts (Hastings Center 1987: 28).
Clinical Ethics

Traditionally, next of kin have been considered the natural surrogates and medical providers have turned to family members for consent. This practice appears to have been tacitly accepted in Anglo-American law, but until recently, was rarely expressed in statutes. In recent years, many states have enacted legislation that gives specific authority to family members and ranks them in priority. When someone other than the patient is granted authority to decide on behalf of the patient, their decision must promote the patient's welfare. This is determined in two ways:

(a) If the patient has been able to express preferences in the past and has done so, the surrogate must use knowledge of these preferences, or at least of the known values of the individual, in making the decision. This is called "substituted judgment" and has been favored by many legal decisions.

(b) If the patient's own preferences are unknown or are unclear, the proxy must consider the "best interests" of the patient. This requires that the surrogate's decision promote the welfare of the individual. Welfare is defined as those choices about relief of suffering, preservation or restoration of function, extent and quality of life sustained that reasonable persons in similar circumstances would be likely to choose (Jonsen, Siegler, and Winslade 1992: 69-70).

Catholic Health Association

The degree to which the court should be active in resolving decisions about treatment is an issue of great importance. Put simply, the issue is whether the court should be making decisions that should rightfully be made by the patient (or by his or her surrogate). Patient self-determination, then, is properly exercised when the patient (or surrogate), in consultation with the physician, decides what is best. Programs provided by health care ethics committees or pastoral care staffs can also help support the primary decision maker and, if necessary, mediate conflicts (CHA 1993: 24).

Forgoing Treatment Versus Suicide

The consensus position holds that forgoing life-sustaining medical treatment or providing palliative care with the intent of relieving suffering are both entirely ethical acts. Neither act should be confused with mercy killing, active euthanasia, or assisted suicide.

American Medical Association

Assisted suicide and euthanasia should not be confused with the provision of palliative treatment that may hasten the patient's death ("double effect"). The intent of the palliative treatment is to relieve pain and suffering, not to end the patient's life, but the patient's death is a possible side effect of the treatment. It is ethically acceptable for a physician to gradually increase the appropriate
medication for a patient, realizing that the medication may depress respiration and cause death (Council 1994a: 92).

Assisted suicide also must be distinguished from withholding or withdrawing life-sustaining treatment, in which the patient's death occurs because the patient or the patient's proxy, in consultation with the treating physician, decides that the disadvantages of treatment outweigh its advantages and therefore the treatment is refused (Council 1994a: 92). Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. . . . Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis (Council 1994b: 36–37).

American College of Physicians

Physicians should distinguish among withdrawing life-sustaining treatment, allowing the natural process of death to occur, and taking deliberate actions to shorten a patient's life. Objections to assisted suicide and active euthanasia should not deter physicians from withholding or withdrawing medical interventions in appropriate situations (ACP 1992: 955).

American Thoracic Society

Physicians and other health providers have a responsibility to respect patient autonomy by withholding or withdrawing any life-sustaining therapy as requested by an informed and capable patient (ATS 1991: 478). . . . An adult patient who no longer has decision making capacity should continue to have the right to refuse all forms of medical therapy; however this right must be exercised on the patient's behalf by an appropriate surrogate decision maker (ATS 1991: 479). . . . Helping a patient forego life support under these circumstances is regarded as distinct from participating in assisted suicide or active euthanasia, neither of which is supported by this statement (ATS 1991: 478).

American Nurses Association

Honoring the refusal of treatments that a patient does not desire, that are disproportionately burdensome to the patient, or that will not benefit the patient is ethically and legally permissible (ANA 1994a: 1). The profession's opposition to nurse participation in active euthanasia does not negate the obligation of the nurse to provide proper and ethically justified end-of-life care which includes the promotion of comfort and the alleviation of suffering, adequate pain control, and at times, foregoing life-sustaining treatments (ANA 1994a: 2). . . .

While it is well known that pain medications often have a sedative or respiratory depressant side effect, this should not be an overriding consideration in their use for dying patients as long as such use is consistent with the patient's wishes. . . . Nurses should not hesitate to use full and effective doses of pain

Withholding or withdrawing life-sustaining medical therapies or risking the hastening of death through treatments aimed at alleviating suffering and/or controlling symptoms are ethically acceptable and do not constitute active euthanasia (ANA 1994a: 1).

**National Center for State Courts**

In general, increasing the dosage level of medication to achieve adequate symptom control—even when the secondary effect may be to hasten death—is ethically justified when this practice is in accord with the patient’s wishes (Hafemeister and Hannaford 1996: 64–65). . . . There are significant moral and legal distinctions between letting die (including the use of medications to relieve suffering during the dying process) and killing (assisted suicide/euthanasia). In letting die, the cause of the death is seen as the underlying disease process or trauma. In assisted suicide/euthanasia, the cause of death is seen as the inherently lethal action itself (NCSC 1991: 145).

**Uniform Law Commissioners**

The [Uniform Health-Care Decisions] Act acknowledges the right of a competent individual [or designated surrogate] . . . to decline health care or to direct that health care be discontinued, even if death occurs (ULC 1993: 1). The withholding or withdrawing of health care in accordance with the [Act] does not for any purposes constitute a suicide or homicide (ULC 1993: 22).

**New York State Task Force on Life and the Law**

The Task Force . . . distinguishes active measures such as lethal injection from legitimate, reasoned decisions to withdraw or withhold treatment made in accord with appropriate standards. The Task Force’s proposal addresses the need for policies to provide sound, responsible decisions for patients who cannot decide for themselves. It is not intended either as a step on the road to assisted suicide or as a vehicle to extend the authority of the family beyond the traditional boundaries of consent to provide treatment or not to treat (NYSTFLL 1992: 222).

**Alan Meisel**

Courts have recognized an important distinction between killing and letting die and have unanimously concluded that termination of life support is neither murder, suicide, nor assisted suicide. Judicial opinions provide three reasons why this is so. (1) A patient’s death due to the termination of life support is not criminal because the patient’s medical condition—rather than the termination of life support—is the cause of death. The removal of life support merely allows death to take its course. (2) When life support is terminated . . . the intent
is to relieve suffering. . . . (3) Such conduct involves the exercise of a patient’s legal right to refuse treatment (Meisel 1991: 1498).

President’s Commission Report

Although not all decisions to omit treatment and allow death to occur are acceptable, such a choice, when made by a patient or surrogate, is usually morally acceptable and in compliance with the law on homicide (President’s Commission 1983: 61). . . . When some patients are dying of a disease process that cannot be arrested, physicians may, for example, write orders not to provide resuscitation if the heart should stop, forego antibiotic treatment of pneumonia and other infections, cease use of respirators, or withhold aggressive therapy from overwhelmingly burdened patients. Although declining to start or continue life-sustaining treatment is often acceptable, health care providers may properly refuse to honor a patient’s request to be directly killed (President’s Commission 1983: 63).

Hastings Center’s Guidelines

Under the rubric of “termination of treatment” we do not include active euthanasia (“mercy killing”) or assisted suicide. These guidelines have been formulated in the belief that a reasonable, if not unambiguous, line can be drawn between foregoing life-sustaining treatment on the one hand, and active euthanasia or assisted suicide on the other.

Our society forbids assisting suicide or active euthanasia, even if the motive is compassionate. . . . Respecting the individual’s liberty to direct his or her own life requires, however, that patients generally be allowed to refuse medical interventions, even if others feel that this is contrary to the patient’s best interests. Likewise, when a person is suffering greatly, medication and other medical interventions may be used to give relief. This relief may foreseeably lead to an earlier death. Yet it may still be morally and legally acceptable, if the intention is not to kill but to relieve the suffering, if the intervention proposed serves the patient’s needs better than would an alternative, and if the patient or surrogate consents (Hastings Center 1987: 6).

Clinical Ethics

[In cases of euthanasia,] the physician employs a means that will rapidly and definitely interrupt an organic process that is necessary to continued life. This fact distinguishes these cases from the cases [of forgoing treatment], where the physician stopped, or did not provide, some intervention for the support of failing vital processes. . . . The ethical distinction lies in the fact that in the cases [of forgoing treatment] described . . . the duty to continue treatment has been extinguished by the patient’s request or by the inability to achieve any of the goals of medicine. In the cases [of euthanasia], the physician acts directly to kill the patient: this does not correspond to any recognized duty of physicians (Jonsen, Siegler, and Winslade 1992: 107).
Catholic Health Association

It is necessary to examine the distinction between killing and allowing to die. “Killing” is an intentional action or omission bringing about the death of another; the cause of death is the human intervention or omission. . . . “Allowing to die” refers to stopping treatment which is burdensome or offers no reasonable hope of benefit so that the underlying pathology, which called for the use of the treatment in the first place, will run its course and eventually cause the patient’s death. . . . Catholic teaching asserts that allowing a person to die by omitting useless and/or burdensome treatment is permissible and morally different from killing (CHA 1993: 48). . . . The effective use of narcotics to alleviate or suppress pain is the prudent thing to do, even though they may eventually cause loss of consciousness or a quicker death. In all cases, the use of pain relief should be as much as possible under the control of the patient, who must decide what level of pain is tolerable and how much medication is beneficial (CHA 1993: 50).

**Withholding Versus Withdrawing Treatment**

The consensus position here is that although it may be easier psychologically for surrogates and caregivers to withhold a treatment than to stop a treatment, there is no ethically or morally important difference between withholding and withdrawing life-sustaining medical treatment.

American Medical Association

There is no ethical distinction between withdrawing and withholding life-sustaining treatment. Withdrawing life support may be emotionally more difficult than withholding life support. . . . However, as most bioethicists now recognize, such a distinction lacks ethical significance (Council 1992: 2231).

American College of Physicians

The same reasons that justify not starting treatment also justify stopping treatment. Indeed, the reasons for withdrawing a treatment may be more compelling, because it may have proved unsuccessful or because the patient’s prognosis and wishes may have been clarified. . . . Court rulings and most ethicists have found no legal or ethical difference between withdrawing and withholding treatment (ACP 1992: 953).

American Thoracic Society

Physicians and other health care providers have a responsibility to respect patient autonomy by withholding or withdrawing any life-sustaining therapy as requested by an informed and capable patient [or appropriate surrogate decisionmaker]. In this regard, there is no ethical difference between withholding and withdrawing (ATS 1991: 478).
American Nurses Association
There is no ethical or legal distinction between withholding or withdrawing treatments, though the latter may create more emotional distress for the nurse and others involved (ANA 1994a: 1).

National Center for State Courts
No significant legal or ethical distinctions can be made between decisions to withdraw (stop) and to withhold (not start) life-sustaining medical treatment (Hafemeister and Hannaford 1996: 13).

Uniform Law Commissioners
The [Uniform Health-Care Decisions Act] lets you give specific instructions about any aspect of your health care. Choices are provided for you to express your wishes regarding the provision, withholding or withdrawal of treatment to keep you alive (ULC 1993: 8).

New York State Task Force on Life and the Law
The Task Force believes that withholding and withdrawing treatment are morally equivalent and should not be distinguished. The Task Force urges health care facilities to review their policies and practices about life-sustaining treatment and to abandon distinctions based on the difference of whether or not a treatment has already been started (NYSTFLL 1992: 222). Decisions to forego treatment are an integral part of medical practice; the use of many treatments would be inconceivable without the ability to withhold or stop the treatments in appropriate cases (NYSTFLL 1992: 10).

Alan Meisel
Although it may be psychologically more difficult for health care professionals to stop the treatment of a critically ill patient than not to start it, it is a myth that there is a legal requirement to continue treatment if it is properly refused (Meisel 1991: 1499).

President's Commission Report
The distinction between failing to initiate and stopping therapy—that is, withholding versus withdrawing treatment—is not itself of moral importance. A justification that is adequate for not commencing treatment is also sufficient for ceasing it. Moreover, erecting a higher requirement for cessation might unjustifiably discourage vigorous initial attempts to treat seriously ill patients that sometimes succeed (President's Commission 1983: 61-62). . . . Little if any legal significance attaches to the distinction between withholding and withdrawing. Nothing in law—certainly not in the context of the doctor-
patient relationship—makes stopping treatment a more serious legal issue than not starting treatment (President’s Commission 1983: 77).

**Hastings Center’s Guidelines**

Many health care professionals and others seem to believe that withholding life-sustaining treatment may be morally permissible, but that withdrawing treatment is wrong. This categorical distinction between withholding and withdrawing treatment seems to us mistaken. There certainly are psychological differences between withholding and withdrawing treatment. But these differences are only the starting point of ethical reflection; they do not determine its conclusions (Hastings Center 1987: 5–6).

**Clinical Ethics**

Some believe that there is an ethical difference between starting and stopping, the former being more permissible than the latter. There may be psychological or emotional differences: Some physicians find it more troubling to stop an ongoing intervention than not to initiate a new one. . . . In withdrawing treatment, the physician may feel responsible (in a causal sense) for the events that follow, even though he may bear no responsibility (in the sense of ethical or legal accountability) either for the disease process or for the patient succumbing to the disease. . . . It is the common position of medical ethicists, supported by many judicial decisions, that the distinction between stopping and starting is neither ethically nor legally relevant. It is our position that there is no significant ethical difference between stopping and starting, if the essential considerations regarding medical indications, patient preference, and quality of life are the same (Jonsen, Siegler, and Winslade 1992: 97–98).

**Catholic Health Association**

[There is] no moral distinction between withholding or withdrawing treatment (whether it be a mechanical respirator, a cardiac pacemaker, a renal dialysis machine, antibiotics, or medically dispensed nutrition and hydration) when its use is futile or would produce burdens disproportionate to the benefits the patient could appreciate (CHA 1993: 49).

**Terminal Illness**

The consensus position regarding when life-sustaining treatment decisions can be made deals directly with the false assumption that such decisions can only be made for those who are terminally ill. The consensus position holds that a patient need not be terminally ill for that patient (or a surrogate) to make decisions involving the forgoing of life-sustaining medical treatment.
American Medical Association

Even if death is not imminent but a patient is beyond doubt permanently unconscious, and there are adequate safeguards to confirm the accuracy of the diagnosis, it is not unethical to discontinue all means of life-prolonging treatment (Council 1990: 429).

American College of Physicians

The question of discontinuing support for persons who are permanently unconscious but are not terminally ill or brain dead (such as persons in a persistent vegetative state) remains a perplexing one. . . . The best clinical recommendation in these difficult cases is for the physician to elicit the opinions of the patient's family, friends, clergy, primary-care physician, and other caregivers in an effort to determine what the patient would wish in these circumstances (ACP 1989: 332).

American Thoracic Society

The U.S. Supreme Court's 1990 decision in the Nancy Cruzan case in effect recognized a constitutional right of capable adults, even those not terminally ill or facing imminent death, to refuse any medical therapy including life-sustaining therapy and artificially provided hydration and nutrition (ATS 1991: 478).

American Nurses Association

ANA position statements do not directly address this issue.

National Center for State Courts

The use of terms such as "terminal illness," "terminal condition," and "imminently dying" often create more confusion than clarity in life-sustaining medical treatment decisions. Regardless of the patient's condition, the overriding concerns for the health-care provider in the foregoing of life-sustaining medical treatment are: (a) respecting patient autonomy (self-determination), and (b) improving patient well-being (the weighing of benefits and burdens of one plan of care in comparison with alternatives). Health care professionals have a duty to promote the welfare of their patients. However, this does not necessarily include the duty to preserve life at all costs. Where life-sustaining medical treatment fails to promote a patient's welfare, there is no longer an ethical obligation to provide it, and treatments no longer beneficial to the patient may be stopped (NCSC 1991: 143–144).

Uniform Law Commissioners

The "individual instruction" [concerning a health care decision] may but need not be limited to take effect in specified circumstances, such as if the individual
The authority of an agent ... may extend to any health-care decision the principal could have made while having capacity (ULC 1993: 5–6).

New York State Task Force on Life and the Law

Family members or others close to the patient should be authorized to consent to withhold or withdraw life-sustaining treatment, if the treatment would be an excessive burden to the patient and one of the following conditions is satisfied: (I) the patient is terminally ill; (II) the patient is permanently unconscious; (III) the patient’s attending physician confirms that the decision satisfies the substituted judgment/best interests, and an interdisciplinary review committee approves (NYSTFLL 1992: 109). ... Permanently unconscious patients include those in a persistent vegetative state, patients who are completely unresponsive after brain injury or hypoxia and fail to stabilize in a vegetative state, [and] patients who are in the end stage of degenerative neurological conditions such as Alzheimer's disease (NYSTFLL 1992: 109–110, note 7). ... Although the Task Force members hold differing views about whether permanently unconscious individuals can benefit from continued treatment, they agree that society should grant family members and others close to the patient the authority to decide to forego treatment for patients who are either terminally ill or permanently unconscious, in accord with the standards proposed (NYSTFLL 1992: 110).

Alan Meisel

After the Supreme Court’s Cruzan decision, it is virtually indisputable that competent patients have a right to refuse treatment whether terminally ill or not ... as long as the patient is incurably and critically ill, such as patients in a persistent vegetative state (Meisel 1991: 1499).

President’s Commission Report

The decisions of patients’ families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the exception of basic nursing care that is needed to ensure dignified and respectful treatment of the patient (President’s Commission 1983: 6).

Hastings Center’s Guidelines

Patients who are permanently unconscious are unaware of benefits or burdens. The only possible benefit to them of life-sustaining treatment is the possibility that the diagnosis of irreversible unconsciousness is wrong and they will regain consciousness. Accordingly, the major considerations are whether a reasonable person, in the patient’s circumstance, would find that this benefit, as well as the benefits to the patient’s family and concerned friends (such as satisfaction
Clinical Ethics

Since persons in a persistent vegetative state retain some reflex activities, they may have some eye movement, swallowing, grimacing, and pupillary adjustment to light. This is naturally quite disturbing to observers, leading them to hold out much more hope for recovery than is actually warranted by the clinical facts. Medical interventions promise no benefit beyond sustaining organic life. ... [Consequently,] if no preferences of the patient are known ... in our judgment, it is ethically permissible to discontinue respiratory support and all other forms of life-sustaining treatment. In the state of irreversible loss of cognitive and communicative function, the individual no longer has any “interests,” that is, nothing that happens to the patient can in any way advance his or her welfare [and] no goals of medicine other than support of organic life are being, or will be, accomplished (Jonsen, Siegler, and Winslade 1992: 96–97).

Catholic Health Association

The proper respect for the sanctity of life lies between two extremes. One extreme is “physical vitalism,” which advocates the absolute value of maintaining biological life regardless of other values, such as loss of independence, loss of dignity, preventing pain, or saving resources. Physical vitalism can lead to the abuse of overtreatment, that is, doing everything possible to prolong physical life while believing that no cost is too great and no chance too remote to save life. The other extreme is “utilitarian pessimism” which values life for its social usefulness and advocates ending life when it becomes frustrating, useless, or burdensome. ... Between these two extremes, the Catholic principle of sanctity of life affirms that life is a basic good, but not an absolute one to be preserved at all costs. ... Just as one must not sacrifice life as long as there is reasonable hope for its well-being, one also must not sacrifice hope when life has reached its reasonable limits. When the dying patient can no longer appreciate treatment as a benefit, and creative living becomes impossible, then hope should focus on the eternal life after death (CHA 1993: 46–47).

ANH and the Ordinary-Extraordinary Distinction

The consensus position regarding artificially provided nutrition and hydration holds that classifying such a treatment as either “ordinary” or “extraordinary” is not particularly helpful and may even generate confusion. Rather, ANH should be classified as a medical intervention that can be waived, like any other, in accordance with a patient’s preferences, expressed either directly (through informed consent or an advanced directive) or indirectly (through a substituted judgment determination or a best interests analysis).
The distinction between “ordinary” and “extraordinary” treatments has been used to differentiate ethically obligatory vs. ethically optional treatments. In other words, ordinary treatments must be provided while extraordinary treatments may be withheld or withdrawn. Varying criteria have been proposed to distinguish ordinary from extraordinary treatment. Such criteria include customariness, naturalness, complexity, expense, invasiveness, and balance of likely benefits and burdens of the particular treatment. The ethical significance of all these criteria essentially are subsumed by the last criterion—the balance of likely benefits vs. burdens of the treatment (Council 1992: 2230). …

For example, artificial nutrition and hydration has frequently been cited as an objectively ordinary treatment which, therefore, must never be foregone. However, artificial nutrition and hydration can be very burdensome to patients. Artificial nutrition and hydration immobilizes the patient to a large degree, can be extremely uncomfortable (restraints are sometimes used to prevent patients from removing nasogastric tubes), and entails serious risks. … It is far from evident that providing nutrition through a nasogastric tube to a patient for whom it is unwanted is comparable to the typical human ways of feeding those who are hungry (Council 1992: 2230–2231).

In some cases, terminally ill patients voluntarily refuse food or oral fluids. In such cases, patient autonomy must be respected, and forced feeding or aggressive parenteral rehydration should not be employed. Emphasis should be placed on renewed efforts at pain control, sedation, and other comfort care for the associated discomfort (Council 1994a: 96).

American College of Physicians

It is not unethical to discontinue or withhold fluids and nutritional support under certain circumstances. An emerging clinical and judicial position is that enteral and parenteral nutrition and hydration should be likened to other medical interventions and may be withheld or withdrawn according to general principles for decision making outlined above (ACP 1989: 333).

American Thoracic Society

The right to refuse treatment applies equally to withholding therapy that might be offered, such as cardiopulmonary resuscitation (CPR), and to withdrawing therapy that is already under way, such as mechanical ventilation or artificially provided hydration and nutrition. This right is based on the ethical principle of autonomy and self-determination (ATS 1991: 478).

American Nurses Association

Artificial nutrition and hydration should be distinguished from the provision of food and water. … The provision of nourishment and hydration by artificial means (i.e., though tubes inserted into the stomach, intestines, or blood
The Emergence of Consensus

vessels) is qualitatively different from merely assisting with feeding. Like all other interventions, artificially provided hydration and nutrition may or may not be justified. ... As in all other interventions, the anticipated benefits must outweigh the anticipated burdens for the intervention to be justified. ... In cases where a patient is unable to make his wishes known, or is unable to evaluate the benefits and harms of refusing artificial nutrition and hydration, the decision of a surrogate should be relied upon (ANA 1992: 9).

National Center for State Courts

Artificial nutrition and hydration are forms of medical treatment that should be governed by the same practices and policies that apply to other forms of medical treatment (Hafemeister and Hannaford 1996: 13). ... Although issues involving artificial nutrition and hydration are often presented more emotionally, from a moral and legal standpoint, they raise the same questions as do other forms of medical treatment (NCSC 1991: 145)....

Life-sustaining medical treatment can take many forms, from something as simple as a penicillin pill to something as complex as a respirator, depending upon the patient's circumstances. It is these circumstances that are important in making life-sustaining medical treatment decisions and the potential benefit to the patient, and not labels such as "extraordinary," "ordinary," and "heroic," which are of little value in actually making the life-sustaining treatment decision. Indeed, they tend to confuse the decision making (NCSC 1991: 144).

Uniform Law Commissioners

An agent shall make a "health-care decision" in accordance with the principal individual's instructions, if any, and other wishes to the extent known to the agent (ULC 1993: 5)... "Health-care decision" means a decision made by an individual or an individual's agent, guardian, or surrogate, regarding the individual's health care, including ... directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of care (ULC 1993: 3).

New York State Task Force on Life and the Law

Ideally, adults will sign a health care proxy or provide guidance about their wishes. Our laws must also recognize decisions to withhold or withdraw artificial nutrition and hydration for those patients whose wishes cannot be identified or who never were able to formulate their own values or preferences (NYSTFLL 1992: 221).

Alan Meisel

It is a myth that only extraordinary treatment may be foregone but that a patient is obliged to accept ordinary treatment. Physicians may no more compel a patient to accept ordinary treatment than extraordinary treatment, assuming that the difference between them is even meaningful. ...
Some contend that artificial nutrition and hydration is not a medical treatment at all, and that its termination results in a patient starving to death and constitutes active euthanasia. However, it is largely a myth that stopping tube feeding is legally different from stopping other treatments (Meisel 1991: 1499).

**President’s Commission Report**

Whether care is “ordinary” or “extraordinary” should not determine whether a patient must accept or may decline it. The terms have come to be used in conflicting and confusing ways. . . . [To avoid misunderstanding, public discussion should focus on the underlying reasons for or against a therapy rather than on a simple categorization as “ordinary” or “extraordinary.”] . . . This line of reasoning suggests that extraordinary treatment is that which, in the patient’s view, entails significantly greater burdens than benefits and is therefore undesirable and not obligatory, while ordinary treatment is that which, in the patient’s view, produces greater benefits than burdens and is therefore reasonably desirable and undertaken. The claim, then, that the treatment is extraordinary is more of an expression of the conclusion than a justification of it (President’s Commission 1983: 88). . . . The Commission has . . . found no particular treatments—including such “ordinary” hospital interventions as parenteral nutrition or hydration, antibiotics, and transfusions—to be universally warranted and thus obligatory for patients to accept (President’s Commission 1983: 90).

**Hastings Center’s Guidelines**

Among the most effective and widely used methods of sustaining life are medical procedures for supplying nutrition and hydration by tubes, catheters, or needles inserted into the patient’s body. . . . We have concluded that it is wisest and most plausible to understand these methods as medical interventions that may be foregone in some cases. Therefore, the standards to be used for decisions concerning termination of these procedures are essentially those that apply to the termination of other forms of medical treatment. . . . In reaching these conclusions, we have recognized that food and water undeniably have symbolic and psychological importance. They symbolize our caring for and nurturing of one another, and can be a means for the patient to obtain comfort and satisfaction. In certain circumstances, however, the patient experiences more comfort, caring, and satisfaction from foregoing medical procedures for supplying nutrition and hydration, and instead receiving supportive care to keep him or her comfortable (Hastings Center 1987: 59).

**Clinical Ethics**

The traditional discussions of the ethics of foregoing life-sustaining treatment have turned on certain distinctions, such as . . . ordinary/extraordinary care. . . . Recent study has shown these distinctions to be confused and confusing.
They are little more than summary statements of elaborate, and sometimes faulty arguments, rather than justifications. Unfortunately, these terms are often substituted for careful attention to details and to analytic thinking. We recommend that decisions to forego intervention not be based on invocation of these classic distinctions. In place of these distinctions, the "principle of proportionality" has recently been endorsed by many ethicists. This principle states that a medical treatment is ethically mandatory to the extent that it is likely to confer greater benefits than burdens upon the patient. . . The principle of proportionality states that no . . . absolute duty exists: Preservation of life is an obligation that binds only when life can be judged more a benefit than a burden by and for the patient (Jonsen, Siegler, and Winslade 1992: 31-33). . .

In certain cases, it is ethically correct to discontinue artificial nutrients and hydration. The circumstances that justify this decision are: no significant medical goals other than maintenance of organic life is possible, the patient is so mentally incapacitated that no preferences can be expressed now or in the future, and no prior preferences for continued sustenance in such a situation have been expressed (Jonsen, Siegler, and Winslade 1992: 101).

Catholic Health Association

The familiar terms "ordinary" and "extraordinary" can be very misleading when explaining the substance of this teaching. . . The Vatican Declaration on Euthanasia has recognized the ambiguity of these terms and suggests that we might more effectively refer to "proportionate" and "disproportionate" treatment. . . The moral focus [of the revised distinction] is not on the category of disease, the state of medical science, the type of treatment itself, or whether the treatment is simple, customary, non-invasive, or inexpensive. Rather, the true ethical considerations focus on the proportion between the benefit the patient would be able to appreciate from the treatment and the burden the patient would endure. For this reason, the principle is sometimes referred to as the burden/benefit principle. To make proper use of this moral principle, we need to measure the proportionate benefits and burdens for each particular patient, and from the patient's perspective . . in order to determine whether [the proposed treatment] provides a benefit proportionate to the burden the patient will have to bear. If the reasonably foreseen benefits to that patient (such as cure, reduced pain, restored consciousness and bodily functions) outweigh the burdens to the patient or to others, then the treatment is morally obligatory. But the treatment is not obligatory if it would be disproportionately burdensome or futile. . . A treatment is futile when it offers no probable hope of success to restore the patient to a state of reasonable well-being (CHA 1993: 48-49). . .

The burden/benefit principle makes no moral distinction between withholding or withdrawing life-sustaining treatment (whether it be a mechanical respirator, a cardiac pace-maker, a renal dialysis machine, antibiotics, or medically dispensed nutrition and hydration) when its use is futile or would produce burdens disproportionate to the benefits the patient could appreciate (CHA 1993: 49).
Summary

In sum, there can be little doubt about what is ethically, legally, and medically acceptable regarding the key issues of end-of-life decision making if the writings reviewed here can be taken as generally representative of professional sentiment (and there is every indication that they are). Clearly, the Fiori opinions rendered by Judge Leonard Sokolove (in the Bucks County trial court), Judge Phyllis Beck (in the Pennsylvania Superior Court), and Judge Ralph Cappy (in the Pennsylvania Supreme Court) all fall squarely in the mainstream described here. This extraordinarily broad-based consensus—summarized in Table 2.4 and referred to from this point forward as the “consensus position”—appears to provide a firm foundation upon which future public policies can be constructed and private decisions can be made.

At the same time, one might criticize the consensus position for failing to more fully incorporate religious concerns (the CHA being the only religiously oriented group cited). One might also criticize the consensus position as elitist, for the statements reviewed here are largely the product of interdisciplinary teams of highly trained medical, legal, and ethical professionals who, generally speaking, took little explicit accounting of public opinion in formulating their conclusions. As important as the consensus position is, we should not proceed further before addressing its inadequacies in this regard. With that end in mind, Chapter 3 will offer a discussion of the two missing links in the consensus position: religious teachings and public opinion.

TABLE 2.4 The “New Consensus”

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<td>No</td>
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<td>Allan Meisel, University of Pittsburgh Center for Medical Ethics, The Right to Die (1989, 1992)</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<td>President’s Commission for the Study of Medicine and Biomedical and Behavioral Research (1983)</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
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<td>The Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying (1987)</td>
<td>Yes</td>
<td>No</td>
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<td>Clinical Ethics: A Practical Approach, 3d ed. (Jonsen, Seigler, and Winslade 1992)</td>
<td>Yes</td>
<td>No</td>
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<td>Catholic Health Association (CHA): Care of the Dying (1993)</td>
<td>Yes</td>
<td>No</td>
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*a: Issue 1: Can members of the family make end-of-life decisions for an incompetent patient based on what the family perceives to be the patient’s best interests?*  
*b: Issue 2: Do caregivers participate in “assisted suicide” when they are involved in (1) the forgoing of life-sustaining treatment, or (2) the provision of pain medication that hastens death as an unintended side effect?*  
*c: Issue 3: Is there any ethically important distinction between withholding and withdrawing life-sustaining medical treatment?*  
*d: Issue 4: Must patients be terminally ill before end-of-life treatment decisions can be made?*  
*e: Issue 5: Must artificially administered food and water always be provided?*