When Others Must Choose

Deciding for Patients Without Capacity

The New York State
Task Force on Life
and the Law

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In March 1985, Governor Cuomo convened the New York State Task Force on Life and the Law. He charged the 25-member Task Force to develop recommendations for public policy in New York State on a host of issues arising from recent medical advances including: the determination of death, the withdrawal and withholding of life-sustaining treatment, organ transplantation, the treatment of disabled newborns and new technologies and practices to assist reproduction.

The Task Force membership includes prominent physicians, nurses, lawyers, academics and representatives of numerous religious communities. Through its deliberations, the Task Force seeks to balance the views of different disciplines and traditions to forge a consensus and identify responsible public policies.

For each issue the Task Force addresses, it recommends policy for New York State in the form of proposed legislation, regulation, public education or other measures. The Task Force reports are designed to explain the bases for its recommendations, and to facilitate public discussion and understanding of the ethical, social, and legal questions posed by medical advances.

New York State Task Force on Life and the Law
5 Penn Plaza
New York, NY 10001-1803
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Task Force Members

Karl Adler, M.D.
Dean, New York Medical College

Rev. Msgr. John A. Alesandro
Chancellor, Roman Catholic Diocese of Rockville Centre

John Arras, Ph.D.
Clinical Associate Professor of Bioethics
Albert Einstein College of Medicine/Montefiore Medical Center

Mario L. Baeza, Esq.
Debevoise & Plimpton

The Right Rev. David Ball
Bishop, Episcopal Diocese of Albany

Rabbi J. David Bleich
Professor of Talmud, Yeshiva University
Professor of Jewish Law and Ethics, Benjamin Cardozo School of Law

Evan Calkins, M.D.
Professor of Medicine, Emeritus
SUNY-Buffalo

Richard J. Concannon, Esq.
Kelley, Drye & Warren

Myron W. Conovitz, M.D.
Attending Physician, North Shore University Hospital
Clinical Associate Professor of Medicine
Cornell University Medical College

Saul J. Farber, M.D.
Dean and Provost
Chairman, Department of Medicine
New York University School of Medicine

Alan R. Fleischman, M.D.
Director, Division of Neonatology
Albert Einstein College of Medicine/Montefiore Medical Center

Samuel Gorovitz, Ph.D.
Dean, College of Arts and Sciences
Professor or Philosophy, Syracuse University

Jane Greenlaw, J.D., R.N.
Director, Division of the Medical Humanities
University of Rochester School of Medicine and Dentistry

Beatrix A. Hamburg, M.D.
Chairman, Division of Child and Adolescent Psychiatry
Mount Sinai School of Medicine

Denise Hanlon, R.N., M.S.
Clinical Specialist, Rehabilitation and Gerontology

Rev. Donald W. McKinney
First Unitarian Church of Brooklyn
Chairman Emeritus, Choice in Dying

Maria I. New, M.D.
Chief, Department of Pediatrics
New York Hospital-Cornell Medical Center

John J. Regan, J.S.D.
Professor of Law, Hofstra University School of Law

Rabbi A. James Rudin
National Director of Interreligious Affairs
The American Jewish Committee

Rev. Betty Bone Schiess
Episcopal Diocese of Central New York

Barbara Shack
The New York Civil Liberties Union

Rev. Robert S. Smith
Director, Institute for Medicine in Contemporary Society
SUNY Health Science Center at Stony Brook

Elizabeth W. Stack
Commissioner, New York State Commission on
Quality of Care for the Mentally Disabled

Task Force Staff

Tracy Miller, J.D.
Executive Director

Anna Maria Cugliari, M.S.
Health Policy Analyst

Aaron L. Mackler, M.A.
Staff Ethicist

Ellen H. Moskowitz, J.D.
Associate Counsel

Elizabeth Peppe
Administrative Assistant

Jean Pohoryles
Administrative Secretary

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Preface

In 1985 Governor Mario Cuomo convened the Task Force on Life and the Law to recommend policy on a host of issues raised by medical advances, including the determination of death, decisions about life-sustaining treatment, organ transplantation, the new reproductive technologies, and the treatment of severely disabled newborns. Governor Cuomo charged the Task Force to enhance public understanding of each issue and, when appropriate, to recommend legislation or regulation.

Decisions about medical treatment to save or prolong life are a central part of the Task Force's mandate. In 1986 the Task Force prepared a report and proposed legislation covering orders not to provide cardiopulmonary resuscitation. That proposal became law in July 1987 and, based on recommendations by the Task Force, was amended in 1991. Addressing the critical need to empower adults to plan in advance for treatment decisions, the Task Force issued a report in 1987 discussing the social and ethical questions presented when adults decide to forgo life-sustaining treatment for themselves. The report also recommended policies and legislation granting adults the right to appoint someone they trust to decide about treatment on their behalf. Enacted in July 1990, the health care proxy law covers all treatment decisions, but only for adults who sign a proxy form.

This report examines decisions for patients who lack the capacity to decide for themselves and have not signed a health care proxy. The recommendations build on the policies established in New York's laws on do-not-resuscitate (DNR) orders and the health care proxy. Even as the Task Force proposed the proxy law, it recognized that many individuals would not sign a health care proxy or would not have the capacity to do so. Likewise, the law on DNR orders was an important first step in responding to the needs of patients who lack capacity, but covered only one of the medical technologies now available to save or extend life.

The DNR and health care proxy laws have yielded tremendous insight. They have provided health care professionals, policymakers, and the public at large with the experience gained from implementing these policies in diverse health care settings and in the lives of thousands of patients. Significantly, they have also demonstrated that New York State can respond to the dilemmas posed by medical advances with policies that are sound and sensitive to the pluralism that characterizes our state.

The proposal described in this report encompasses all treatment decisions for many patients, not just decisions about life-sustaining measures. The Task Force concluded that existing law may present a hurdle for some patients in gaining access to needed treatment. Individuals without family available to consent to treatment are especially vulnerable in this regard. Like the health care proxy law, this proposal seeks to fill a gap in New York law on treatment decisions generally.

The Task Force's previous reports and proposals have informed and focused public debate. On matters of shared concern, they have provided a model for other states. Ultimately, too, they have served as a catalyst for broad public consensus within New York State. The Task Force hopes this report will achieve the same goals.

The Task Force consulted many individuals and organizations in preparing this report. They graciously extended their insight, their expertise, and their ideas. We are grateful to them. The comments and studies we received on the DNR and health care proxy laws also informed the judgments we faced in developing this proposal.

We have deliberated about the policies presented in this report for close to four years. During much of that time, we had the benefit of Dr. David Axelrod's extraordinary leadership. As chairman of the Task Force, Dr. Axelrod brought to this process, among other strengths, his tremendous intellect, a keen interest in the issues, and a commitment to informed, reasoned debate. He was devoted to protecting the personal beliefs of each individual and to the possibility of achieving consensus, among diverse religious, moral, and professional views, even on these most difficult questions. His vision of how the Task Force, and government, could serve to forge that consensus has animated all our efforts, and guides us still.

Executive Summary

Many individuals – children, adolescents, and adults who have lost capacity for a short or long time period – cannot decide about treatment for themselves. With passage of the do-not-resuscitate and health care proxy laws, New York State took major strides to address the hard choices posed by decisions for these patients. It should now enact policies to encompass the broad spectrum of treatments available to save or prolong life for patients who have not signed a health care proxy or left clear guidance about their treatment wishes.

These treatment decisions are now made in a legal vacuum. In New York State, only legislation can empower family members and others to decide for incapacitated patients. Legal authority and policies for treatment decisions on behalf of patients who have no family member available to decide for them are also needed. The lack of a readily accessible vehicle to provide consent for these patients impairs their access to treatment.

This report discusses the ethical and social choices presented by surrogate decisions. It also proposes policies and legislation. The legislative proposal seeks first and foremost to promote the wishes and interests of incapacitated patients. It sets forth a process for determining incapacity, a priority list of those who may act as surrogate, and standards for surrogate decisions. In essence, the proposal identifies who may decide about treatment for incapacitated patients and by what criteria.

The Task Force believes that society must acknowledge both under and overtreatment as critical problems in the delivery of modern medical care. In crafting policies for surrogate decisions, the Task Force sought to balance these two important problems. Its recommendations and legislative proposal are summarized below. The proposed legislation appears as Appendix A. All the Task Force members support the legislative proposal, except for Rabbi J. David Bleich. His minority report appears on page 239.

Planning in Advance

- The Task Force urges adults to consider in advance their wishes about treatment and to appoint a health care agent. Appointment of an agent under the health care proxy law is the best vehicle to foster a person's rights and an informed decision-making process following the loss of decision-making capacity.

- Reliance on surrogates for patients without capacity, while a crucial option for many patients, is a default decision-making process, not a preferred approach. Whenever possible, physicians and other health care professionals should discuss advance directives with adult patients, encouraging them to designate an agent or to leave treatment instructions.

- A health care agent should have priority over any other potential surrogate, and decisions by an agent should be governed by the health care proxy law, not by the policies recommended for surrogates in this report. If a patient's prior statements about treatment provide a decision that meets the clear and convincing evidence standard, health care professionals should rely on the patient's decision rather than seek consent from a surrogate.

Deciding for Patients with Surrogates

- Family members, other individuals close to the patient, and court-appointed representatives should be authorized to decide about treatment for incapacitated patients. With appropriate safeguards, this authority should encompass all treatment decisions, including decisions about life-sustaining treatment.

- All adults should be presumed capable of deciding about treatment. A surrogate's authority to decide about treatment should begin only after the patient has been determined incapable of deciding for himself or herself. A judgment that the patient lacks capacity should be made by the patient's attending physician and one other health care professional.

- If a physician determines that a patient lacks decision-making capacity because of a mental illness or developmental disability, the physician should consult a health care professional with specialized training or experience in diagnosing and treating mental illness or disabilities of the same or similar nature.

- If the patient objects to the determination of incapacity or to a surrogate's decision about treatment, the patient's objection should prevail unless the physician or surrogate obtain a court order.

- 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 best interests. Assessment 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 such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.

- 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 circumstances is present: the patient is terminally ill; the patient is permanently unconscious; the decision is approved by a multidisciplinary committee (bioethics review committee) within the health care facility; or a court issues an order approving the decision.

- A parent or legal guardian of a minor child should have the authority to refuse life-sustaining treatment for the child, subject to the same standards for decisions to withdraw or withhold treatment for adults. If a minor has decision-making capacity, the minor's consent should be required to forgo life-sustaining treatment.

- A minor patient who is emancipated (16 years of age or older and living independently, or under 18 and the parent of a child) should be authorized to decide about life-sustaining treatment, with appropriate review of any decision to forgo treatment. If the health care facility can readily ascertain the identity of the minor's parents or legal guardian, it should notify them prior to discontinuing treatment.

- The courts should be authorized to appoint a "health care guardian" to decide about life-sustaining treatment for children without available parents or legal guardians, such as children in foster care. A physician or hospital, certain authorized public agencies, or an adult who has assumed responsibility for care of the child should be permitted to seek appointment as health care guardian for dying and severely ill children. This will provide a mechanism, when needed, for timely, compassionate decisions for these extremely vulnerable children.

- By and large, decisions made in accord with the proposed law will be private bedside decisions by those closest to the patient. However, further consultation should be available if conflict arises or for treatment decisions that are especially sensitive. The Task Force proposes that multidisciplinary, institutionally-based committees, known as "bioethics review committees," should fulfill this function.

- Each hospital and nursing home should establish a bioethics review committee or participate in a review committee that serves more than one facility. Review committees should be consulted in the event of conflict between and among health care professionals, family members, and others close to the patient. The committees should operate in accord with standards and procedures that assure full consideration of each case, access to the process by patients and surrogates, and respect for patient confidentiality.

- The bioethics review committees should review decisions to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious, and issue a recommendation. If the committee does not approve the decision, family members or others should not have the authority to consent to discontinue treatment but should be able to seek a court order authorizing the decision.

- The courts should be available as an alternative for those who do not want to participate in a decision-making process at a hospital or nursing home and as a last resort for disputes or cases that cannot be resolved in the health care facility. However, 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.

Deciding for Patients Without Surrogates

- Society has a clear obligation to ensure that individuals who have no family or others to consent to treatment receive timely, appropriate medical care. To achieve this goal, a facility-based process for making decisions for these vulnerable individuals should be established.

- Decisions for patients who lack capacity and have no surrogate available should meet the standards proposed for patients with surrogates, including the standards for withholding or withdrawing life-sustaining treatment.

- The attending physician should be authorized to decide about routine medical treatment for patients without a surrogate. For decisions about major medical treatment, the attending physician should consult with other health care professionals directly involved with the patient's care and must obtain the concurrence of a second physician. In addition, recommendations to forgo life-sustaining treatment should be subject to review and approval by the bioethics review committee.

Ethical Issues and Dilemmas

- Surrogates should have the authority to consent equally to the withholding or withdrawal of treatment, under the same standards. The Task Force believes that withholding and withdrawing treatment are morally equivalent and should not be distinguished. It urges health care facilities to review their procedures and practices about life-sustaining treatment and to abandon distinctions based solely on the difference of whether or not treatment has already been started.

- The authority extended to surrogates to decide about treatment should not encompass the right to insist on treatment that offers the patient no benefit in terms of cure, care, or the prolongation of biological function. In this regard, a request for treatment by a surrogate should not create any greater duty to provide treatment than a request by a competent patient. In all cases, however, a physician should talk with the patient or surrogate before treatment is withheld or withdrawn on grounds of futility. This conversation promotes good decision making, enhances trust, and allows the patient or surrogate an opportunity to seek a second opinion or inquire about the physician's assessment of futility.

- Health care professionals have a duty to offer effective pain relief to patients when necessary, in accord with sound medical judgment and the most advanced approaches available. The provision of pain medication is ethically acceptable, even when such treatment may hasten the patient's death, if the medication is intended to alleviate pain, not to cause death, and is provided in such a way that the benefits of the treatment outweigh the risks. The Task Force urges health care professionals and facilities to accord pain control a higher priority in medical practice and education than they have to date.

- Decisions about artificial nutrition and hydration are highly sensitive, requiring caution and careful attention to the personal and medical circumstances of each particular patient. Special efforts should be made to identify patients' wishes about artificial nutrition and hydration, but separate legislative policies for these measures are not necessary. The Task Force believes that the safeguards proposed for decisions about other life-sustaining treatments are appropriate and sufficient for decisions about artificial nutrition and hydration.

- The Task Force does not recommend any change in current New York State law prohibiting active measures to cause a patient's death. The Task Force's proposal addresses the need for policies to provide sound, responsible treatment decisions for patients unable to decide for themselves. It is not intended to permit or promote suicide, assisted suicide, or euthanasia.

Health Care Providers — Responsibilities and Protections

- Physicians have a duty to provide surrogates with the information necessary to make an informed decision on the patient's behalf. Health care professionals should respect the surrogate's authority and should assist the surrogate to exercise that authority in accord with the patient's wishes and best interests.

- The proposed legislation does not require health care professionals to honor a health care decision that is contrary to their sincerely held religious beliefs or moral convictions. In these cases, health care professionals should inform the person who made the decision and the health care facility of their objection and cooperate in transferring care of the patient.

- The proposed legislation does not require private health care facilities to honor a health care decision if the decision is contrary to a formally adopted policy of the facility expressly based on sincerely held religious beliefs or sincerely held moral convictions central to the facility's operating principles. The facility should be allowed to exercise an objection on religious or moral grounds only if it informed the patient or family of the policy prior to or upon admission, if reasonably possible, and cooperates in promptly transferring the patient to another facility willing to honor the decision. If the patient is not transferred, the facility should seek judicial relief or honor the decision.

- Health care professionals and facilities that act in good faith and honor decisions made by surrogates and others in accord with the proposed policies should be protected from criminal sanctions, civil liability, and professional penalties.

- Any physician or health care facility that refuses to honor a decision to forgo treatment made by a surrogate in accord with the proposed legislation should not be entitled to recover the costs of treatment or services provided in violation of the legislation. Existing remedies under case law and statutes for wrongfully providing treatment without consent should also remain available.

Scope of the Policies Proposed

- The proposed legislation covers all treatment decisions for incapacitated adults, but only decisions about life-sustaining treatment by the parents or legal guardian of a minor child or by emancipated minors. Treatment decisions by parents and guardians for minor children are authorized and governed by existing New York statutes and case law.

- The proposed legislation incorporates many of the policies of the DNR law, which served as the basis for the proposal. The Task Force recommends that the DNR law be integrated with legislation covering all surrogate decisions about medical treatment, with separate policies retained for decisions about CPR where appropriate.

- The proposed legislation does not cover decisions for residents of mental hygiene facilities, except for provisions granting courts the authority to approve decisions to forgo life-sustaining treatment for these patients, under standards proposed in the legislation.

Part I

Social, Legal, and Ethical Issues

Introduction

When patients are incapable of deciding for themselves, the array of treatment decisions required by modern medical advances must be made by others. Such decisions, often referred to as "surrogate decisions,"[1] present one of the most pervasive and important ethical questions posed by contemporary medical practice.

Who decides when the patient cannot, and according to what criteria? These basic questions touch the lives of all members of society. Some individuals unable to decide for themselves are elderly and have lost decision-making capacity due to dementia or other chronic illness. Many are infants and children, unable to decide because they have not yet developed the ability to do so. Others are adolescents, on the cusp of attaining the capacity to decide, or adults in the middle years of life who have lost capacity for a short or long duration due to an accident or illness. Finally, some adults who are developmentally disabled or mentally ill have never been, and will never be, able to decide about treatment for themselves.

Over the past decade, society has increasingly recognized the individual's own wishes, values, and beliefs as the benchmark for decisions about treatment, including treatment that can prolong or sustain life. For surrogate decisions, by definition, that benchmark is totally or partially absent. Some adults leave clear statements about their wishes that apply to decisions that arise or appoint someone to decide on their behalf. Many do not. And some individuals – infants, children, and the mentally ill or developmentally disabled – never had the capacity to develop personal views about health care.

Surrogates may be called upon to make decisions on matters ranging from the routine administration of antibiotics to more complex matters

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[1] This report uses the term "surrogate" to mean the person identified as the decision maker *after* the patient loses decisional capacity. Drawing on the language used in New York's health care proxy law, the report refers to a person appointed by the patient while competent as a "health care agent" or "agent."

such as heart surgery, chemotherapy, or experimental treatment for AIDS. Surrogates may also face choices about life-sustaining treatment, such as the artificial respirator, dialysis, or cardiopulmonary resuscitation (CPR).

Some dimensions of surrogate decision making are uncontroversial and have evolved as part of medical practice. By long-standing custom, family members consent to medical treatment on behalf of their loved ones. Parents are vested with broad legal authority to decide for their children. In an emergency, consent to treatment is presumed for all those unable to provide consent.

In recent years, New York State has taken major strides to address surrogate decisions for health care. In 1986 a program was established to authorize committees to consent to treatment for individuals who are mentally ill or developmentally disabled and have no family or others to consent on their behalf. In 1987 New York passed legislation providing a legal basis and policies for decisions about CPR for all patients unable to decide for themselves. Another breakthrough occurred in 1990 with passage of the health care proxy law. The proxy law gives competent adults the right to appoint someone they trust to decide about treatment, including life-sustaining measures, if they lose the capacity to decide directly.

Despite these developments, many aspects of surrogate decisions remain unresolved in New York. This report examines those issues and sets forth the Task Force's recommendations for public policy.

The report is divided into two sections. Part I explores the social, ethical, and legal context for surrogate decisions. Chapter One discusses the different medical and social settings for surrogate decisions and presents information about facilities and practices in New York State. Chapter Two describes existing law for surrogate decisions for the diverse patient populations and types of decisions that fall under the umbrella of surrogate decision making. The third chapter focuses on the ethical foundations for surrogate decisions, examining the judgments that must be made by those called upon to act as surrogates and by society at large.

The second half of the report presents the Task Force's recommendations and discusses the legal and ethical bases for the policies proposed. Based on an analysis of New York law, the Task Force concluded that legislation on surrogate decisions is essential. Its legislative proposal appears as Appendix A of this report.

1

The Clinical and Social Context for Surrogate Decisions

Questions about who should decide for patients unable to decide for themselves and the bases for the decisions arise in all spheres of our health care system: hospitals, nursing homes, hospices, and home care programs. The questions are an inescapable and integral part of delivering health care.

Surrogate decisions must be made about the full spectrum of treatments available, from routine treatment such as medication for high blood pressure to major surgery such as coronary bypass or amputation. An adult child may be asked to consent to cataract surgery for his father suffering from dementia and impaired vision. A husband may request additional pain relief for his wife recovering from surgery. Surrogate consent may also be necessary for certain diagnostic procedures, such as a brain biopsy to determine the course of treatment for a patient with a cerebral lesion, or an angiogram to assess the condition of a patient's heart.

Decisions about withholding or withdrawing life-sustaining treatment must also be made for patients who lack capacity. For example, parents of a ten-year-old child dying from cancer may need to decide whether to initiate experimental chemotherapy. A close friend of an unconscious patient with AIDS may consider whether antibiotics should be administered, or withheld allowing the disease to take its natural course.

A comprehensive list of treatments that might be considered life-sustaining in the broad sense is not possible. The treatments most commonly associated with the term "life-sustaining" are CPR, artificial respiration, dialysis, antibiotics, and artificial nutrition and hydration.[1] For some patients, other treatments, such as heart medication or chemotherapy, may also be life-saving. In effect, decisions to refuse a wide range of treatments may entail a judgment about whether or not to save or extend life.

Relationships That Inform Surrogate Decisions

Health care professionals often turn to family members or others close to the patient to decide about treatment for incapacitated patients. Over the past decade of discussion about surrogate decisions, the notion of a partnership between physician and family has emerged as a model for such decisions. In that partnership, the physician provides the medical information essential for health care decisions – information about the patient's diagnosis, the expected prognosis following proposed treatments, and treatment alternatives. Other health care professionals may also offer insight about the course of care and the day-to-day realities of implementing treatment decisions. In addition, physicians routinely recommend a course of treatment. Family members or others close to the patient must then make a judgment on the patient's behalf. [2]

Surrogates may be called upon to weigh the benefits and burdens of modern medical advances. Health care decisions may involve weighing acceptance of death against a continued life of severe pain or disability. An individual's capacity to tolerate pain, disfigurement, or dependency must be considered along with the patient's overall attitudes about health care and sickness. Religious and moral beliefs are also central to health care decisions, which touch upon basic understandings about human life, personal identity, and obligations to self and to others.

When patients cannot decide for themselves, family members can often provide information about the patient's wishes and values – about what the patient would choose if he or she were able.[3] Studies have shown that most people trust their family members to decide

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[1] For an excellent description of the medical uses, risks, benefits, and outcomes of these life-sustaining treatments see U.S. Congress, Office of Technology Assessment, *Life Sustaining Technologies and the Elderly* (Washington: U.S. Government Printing Office, 1987), 205-345.

[2] A poll conducted for Time Magazine/CNN found that 85% of those surveyed believe end-of-life treatment decisions for terminally ill patients who cannot decide for themselves should be left to family members and doctors. The survey was conducted by Yankelovich, Clancy and Shulman, Westport, Conn., October, 1989.

[3] See discussion in chapter 3, 50-53, on choosing a surrogate.

about treatment.[4] At the same time, studies have also highlighted the importance of discussions about treatment choices among patients, their family members, and physicians whenever possible.

For example, one study asked patients about their wishes concerning five treatments (artificial respiration, CPR, chemotherapy, amputation, and tube feeding) and compared their responses to those of family members or others chosen by physicians to decide on the patient's behalf.[5] The choices made by surrogates frequently diverged from the patient's own choice: 24 percent of the time for decisions about tube feeding, 44 percent for CPR, and as often as 50 percent for chemotherapy. For artificial respiration, tube feeding, and amputation, the divergence between patient and surrogate choices arose most often because the patient would have refused the treatment, and the surrogate would have accepted it. In contrast, for decisions about CPR, 70 percent of the patients and surrogates who made different judgments did so because the patient wanted CPR and the surrogate would have refused the treatment.[6]

Another study compared the wishes of elderly outpatients for CPR with predictions by the patient's physician and spouse about the patient's wishes. The study found that spouses consistently overestimated the patient's desire for CPR while physicians consistently underestimated patients' desire to be resuscitated. In three of six scenarios presented, spouses' predictions of the patient's wishes were significantly better than chance alone. In contrast, physicians' predictions were better than chance alone in only one of six circumstances.[7]

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[4] D. M. High and H. B. Turner, "Surrogate Decision-Making: The Elderly's Familiar Expectations," *Theoretical Medicine* 8 (1987): 303-20; B. Lo and G. A. MacLeod, "Patient Attitudes to Discussing Life-Sustaining Treatment," *Archives of Internal Medicine* 146 (1986): 1613-15.

[5] N. R. Zweibel and C. K. Cassel, "Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies," *Gerontologist* 29 (1989): 615-21.

[6] It is significant that the study also found a high concordance (e.g., 93% for CPR and 95% for amputation) between what surrogates would choose for themselves and what they chose for the patient.

[7] R. Uhlmann, R. Pearlman, and K. L. Cain, "Physicians' and Spouses Predictions of Elderly Patients' Resuscitation Preferences," *Journal of Gerontology* 43 (1988) M115-M121. Nonetheless, 78% of physicians, compared to 76% of spouses, believed that their predictions were accurate. A recent study of CPR preferences conducted at Mt. Sinai Hospital in New York City also found that physicians were not significantly better than chance at predicting their patient's wishes for CPR in the two scenarios provided – current health and moderate dementia. Family members again achieved

Although physicians are often confident that they can anticipate their patients' wishes, these studies suggest that in an age of advanced medicine and specialization this confidence is frequently misplaced.[8] Many physicians do not have the kind of ongoing or long-standing relationship with their patients that would yield this insight. Moreover, treatment decisions, especially in the face of advanced technologies to sustain life with risk of higher degrees of disability and impairment, are more varied. Even spouses and other close family members, while they fared better than physicians in estimating their loved ones' wishes, fell far short of direct guidance from the patient.

Taken together, the studies comparing patient choices with physician and surrogate estimates of those choices underscore the importance of a discussion among patients, their potential surrogates, and physicians about the treatment decisions that may lie ahead. The studies also demonstrate the inevitability of making decisions in the face of uncertainty about the patient's wishes, when the opportunity for a dialogue with the patient never existed or has been lost.

Often patients are not consulted even when they are able to decide because physicians are reluctant to talk with patients, especially patients who are severely ill and for whom the discussion is most relevant.[9] This reluctance persists, despite a growing consensus favoring

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a higher concordance with patients. See A. B. Seckler et al., "Substituted Judgment: How Accurate are Proxy Predictions?" *Annals of Internal Medicine* 15 (1991): 92-98. Comparing residents' choices about four treatments with predictions by the patients' family members, physicians, and nurses, one study found that relatives were most likely to know what the patient would choose, and physicians were least likely to know. In particular, physicians often failed to anticipate elderly patients' wishes for more aggressive treatment. See J. Ouslander, A. Tymchuk, and B. Rahbar, "Health Care Decisions Among Elderly Long-Term Care Residents and Their Potential Proxies," *Archives of Internal Medicine* 149 (1989): 1367-72. Other studies also suggest that a relatively high proportion of elderly people desire intensive intervention to prolong their lives. See M. Danis et al., "Patients' and Families' Preferences for Medical Intensive Care," *Journal of the American Medical Association* 260 (1988): 797-802.

[8] Ulhmann, Pearlman, and Cain; Ouslander, Tymchak, and Rahbar; and Seckler et al.

[9] S. Bedell and T. Delbanco, "Choices About Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk With Patients?" *New England Journal of Medicine* 310 (1984): 1089-93; S. Miles and M. Ryder, "Limited Treatment Policies in Long-Term Care Facilities," *Journal of the American Geriatric Society* 33 (1985): 707-11. In New York State, some physicians have objected strenuously to the obligation to talk with patients about a decision to withhold CPR, especially for patients who are severely ill for whom the discussion is most relevant. Although these physicians have argued principally that the discussion harms patients, others have

the right of patients to decide about treatment. In effect, patient autonomy has been widely embraced in principle but only partially realized in practice.

In recent years, legal and other developments have fostered change and a greater openness about some of the hard choices at life's end. Studies of legislation in New York about decisions not to initiate CPR in the event a patient arrests show that physicians believe they are now far more likely to discuss CPR with patients or their families before entering an order not to resuscitate the patient.[10] Although debate continues within the medical community about the obligation of physicians to talk to patients about CPR, studies of patient attitudes have consistently shown that people want information about their medical condition and the opportunity to decide for themselves about the often qualified blessings of modern technologies.[11]

This desire to control medical treatment is also reflected in the growing reliance on advance directives, either a living will specifying health care wishes or a health care proxy appointing someone to decide on the patient's behalf. Both the United States Supreme Court case

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objected to the obligation to talk with patients on grounds that CPR is futile for some patients. See discussion of medical futility in chapter 14.

[10] In a survey of physician perceptions of the DNR law, 68% of the respondents agreed with the statement: "The DNR law has made it more likely that I will raise the issue of DNR status with my patients." N. Spritz, "Views of Our Membership Concerning the DNR Issue and the New York State DNR Law: New York Chapter of American College of Physicians." in *Legislating Medical Ethics: A Study of New York's DNR Law,* ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Adademic Publishers, forthcoming). See also R. Baker et al., "Legal and Professional Enforcement of Bioethical Reform: A Comparative Study of the 1988 New York and JCAHO DNR Reforms," in *Legislating Medical Ethics.* However, studies of actual practice found that patient participation in decisions about CPR did not increase with families deciding about CPR on behalf of patients in most instances. See studies by R. S. Kamer et al., "Effect of New York State's Do-Not-Resuscitate Legislation on In-Hospital Cardiopulmonary Resuscitation Practice," *American Journal of Medicine* 88 (1990): 108-11; and T. E. Quill and N. M. Bennett, "The Effects of a Hospital Policy and State Legislation on Resuscitation Orders for Geriatric Patients," in *Legislating Medical Ethics.*

[11] In one study, 87% of the elderly outpatients surveyed thought discussions about CPR should take place routinely; 70% felt such discussions should take place during periods of health, and 84% felt their views should be part of the medical record. R. Shmerling et al., "Discussing Cardiopulmonary Resuscitation: A Study of Elderly Outpatients," *Journal of General Medicine* 3 (1988): 317-21; see also T. Finucane et al., "Planning with Elderly Outpatients for Contingencies of Severe Illness," *Journal of General Internal Medicine* 3 (1988): 322-35.

concerning Nancy Cruzan and her family, as well as passage of the New York State health care proxy law in July 1990, sparked intense interest in advance directives in New York State.[12] Advance directives give adults an opportunity to plan in advance for their treatment, inviting a discussion among patients, those close to them, and health care professionals about how the patient's values and overall life goals should inform health care choices.

Deciding in Health Care Facilities

In each clinical setting, diverse factors influence treatment decisions by patients. These same factors often shape surrogate decisions by family members and others. Health care facilities – hospitals, nursing homes, hospices – provide different resources and pose different obstacles for the decision-making process. The patient-physician or family-physician relationship offers the context for informed consent. This relationship, the treatments provided, and legal and financial pressures vary in each health care setting. Distinct policies also exist within similar types of facilities; the location (urban versus rural), size (number of beds), patient population, affiliation (religious or secular), and public or private character of a hospital or nursing home shape facility policies and practices.

Legal and regulatory requirements also affect the decision-making process. As discussed in Chapter Two, legal constraints are especially profound in New York State when others must decide about life-sustaining treatment on the patient's behalf. Just as significant as the law itself is the environment within which the law is interpreted, conveyed, and implemented; the goals and values of health care facilities and individual professionals determine the law's impact in the transition from legal principle to practice. Legal counsel for facilities, administrators, and a growing cadre of specialists known as "risk managers" have become increasingly involved in bedside decisions. These professionals usually interpret existing law, and design facility policies, to minimize liability. A single-minded focus on liability often diminishes the autonomy of health care professionals and the rights of patients by narrowing the options available to both.

Health care professionals, in the day-to-day course of providing care, also give content to legal standards; in their relationship with

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[12] See discussion of advance directives and the *Cruzan* decision in chapter 2.

patients, family members, and others close to the patient, the rights of individuals and obligations of professionals are defined.[13] Health care professionals' understanding of the law, and the parameters it imposes, is therefore crucial. Studies and experience have shown that health care professionals are often ill-informed about the law on treatment decisions as it applies to them and their patients.[14]

Treatment decisions are also influenced by financial incentives and disincentives, including policy initiatives designed to curb rising costs and reallocate resources. For example, one initiative, the federal Medicare prospective payment system, sets a ceiling on reimbursement rates for admissions to hospitals based on diagnosis-related groups. The system creates incentives to decrease hospital length of stay and substitute lower-cost services. In the long-term care setting, nursing homes generally recover a higher reimbursement rate for patients who are tube fed than for patients who are fed by hand. At a time of government cutbacks and financial losses for facilities in both the for-profit and not-for-profit sectors, fiscal constraints are likely to exert growing pressure on decisions about patient care.

Not only funds for health care, but personnel, equipment, and beds may also be in short supply, forcing physicians and administrators to allocate resources among patients. Physicians have long made such triage decisions in admitting patients to the intensive care unit. In the wake of overcrowding in emergency rooms throughout New York City, physicians have also been forced to set priorities for delivering emergency care in that setting as well.[15]

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[13] As stated at a public hearing on the DNR law: "The uncertainties created by the fear of criminal prosecution and civil litigation have interfered with both the fundamental right of patients to make decisions about their care, and the basic notion that such decisions are best made in medical and family settings rather than in courtrooms." J. Karkenny and K. Meyer, Testimony on behalf of the Greater New York Hospital Association, New York State, Senate and Assembly Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resuscitate Orders*, February 12, 1987, 83.

[14] For example, the Baker et al. study assessed clinicians' comprehension of New York's DNR law and found that physicians often misunderstood or over-interpreted the law, often in ways that added to the procedures in the law. The study results may reflect, in part, the tendency of health care facilities to adopt policies that impose additional requirements on patients, surrogates, and health care professionals.

[15] L. Belkin, "Why Emergency Rooms Are on the Critical List," *New York Times*, October 6, 1991, sec. 4, p. 6.

The Hospital Setting

New York State has 274 hospitals, ranging in size from 20 beds to 1,291 beds.[16] Twenty-one percent of hospitals in the state are small (under 100 beds), 65 percent are mid-size (100-500 beds) and 13 percent are large tertiary care hospitals with over 500 beds. Most of the hospitals are voluntary, not-for-profit institutions. Thirty-four hospitals are public, including the 13 hospitals that comprise the Health and Hospitals Corporation System in New York City.

Acute care hospitals, with the full panoply of advanced technologies, are committed to using these technologies to save and extend life. While this mission serves the needs of many patients, if unchecked by a commitment to honoring patients' wishes and the Hippocratic directive to "do no harm," it may also create a technological imperative – a drive to use technologies that offer little benefit to the patient.

In deciding for incapacitated patients, surrogates often confront this technological imperative, as well as fiscal, legal, and administrative pressures. But surrogates may be assisted in fulfilling their responsibilities to the patient by diverse resources in the acute care setting. Social workers and chaplains can offer counseling to family members unable to reconcile themselves to a loved one's illness or in conflict about difficult choices that must be made. In many facilities, patient representatives are available to assist patients and families. In a growing number of hospitals, chaplains or ethicists on staff consult with patients and families as well as health care professionals to address ethical questions.

Hospitals have also responded to ethical dilemmas by developing institutional policies. Many of these policies encompass decisions to forgo life-sustaining or life-saving treatment, offering guidance to health care professionals about hard cases. Hospital policies can also ensure that like cases are treated alike – that the rights of patients and the obligations of professionals do not vary depending upon which physician happens to treat the patient.

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[16] New York State Department of Health, Bureau of Hospital Services, 1990. There are a total of 71,658 certified beds with almost half of the beds located in the New York City region (34,664). Some hospitals in New York State, such as the Hospital for Special Surgery or Memorial Sloan-Kettering Cancer Center, are highly specialized and serve a particular patient population. For an insightful discussion of ethical issues as they arise and are discussed in the hospital setting, see S. Gorovitz, *Drawing the Line: Life, Death, and Ethical Choices in an American Hospital* (New York: Oxford University Press, 1991).

A 1989 study of hospitals in New York State by the Task Force on Life and the Law found that 50 out of 140 or 36 percent of hospitals responding to the survey had established policies about decisions to withdraw or withhold life-sustaining treatment.[17] The policies covered treatments ranging from dialysis to antibiotics and artificial nutrition and hydration. Under New York's law on do-not-resuscitate (DNR) orders, all facilities must have a policy about decisions to forgo CPR.[18] Over the last 15 years, many hospitals have also created committees, known as "ethics committees," to address conflicts and dilemmas that arise in the decision-making process.[19]

The Long-Term Care Environment

Approximately 100,000 persons in New York State, and five percent of persons over age 65 nationally, reside in long-term care facilities, generally referred to as nursing homes.[20] The average age of nursing home residents in New York is 83 years old. While patients typically suffer from several medical conditions, most enter a nursing home because they have lost functional abilities and are no longer able to care for themselves. The average length of stay for nursing home residents is 2.9 years; most residents die during their stay in the nursing home.[21]

Surrogate decisions are pervasive in nursing homes. The majority of long-term care residents cannot make some or all health care decisions for themselves and must have family members or others decide on their

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[17] See appendix E for survey data.

[18] N.Y. Pub. Health Law § 2972 (McKinney Supp. 1992).

[19] See discussion of ethics committees on page 16.

[20] General data in this section have been provided by Long Term Care Services, Office of Health Systems Management, New York State Department of Health, and by L. S. Libow and P. Starer, "Care of the Nursing Home Patient," *New England Journal of Medicine* 321 (1989): 93-96. For a discussion of the ethical considerations in the long-term care setting see B. Collopy, P. Boyle, and B. Jennings, "New Directions in Nursing Home Ethics," *Hastings Center Report* 21, no. 2, suppl., 1-16.

[21] New York State has 329 skilled nursing facilities that care for persons with chronic disabilities and the greatest medical needs, and an additional 225 facilities that operate partly as a skilled facility and partly as a health-related facility for patients with less serious health care needs. Half of these facilities are proprietary for profit, while 40 percent are private and nonprofit. Only 10% are public. Nursing homes range in size from just 30 or 40 beds to over 200, with one third in the over-200-bed category. Federal regulations include both skilled nursing facilities and health-related facilities as nursing facilities. See Libow and Starer.

behalf.[22] For many residents, decisional capacity has already diminished when they enter the facility. For others, the circumstances of institutional living contribute to their intellectual decline.[23] Admission to any health care facility inevitably entails a substantial loss of privacy and autonomy. Patients in hospitals, for example, no longer make such routine decisions as when to rise, when to eat, or what to wear. These losses are compounded in long-term care facilities, where the constraints of group living impose even greater limits on personal independence. Equally important, the loss of privacy and control is permanent and often results, over time, in increasing passivity and an actual decline in decision-making ability.

The decision-making ability of residents may also be compromised by physical and chemical restraints. Chemical restraints, such as psychotropic and other medications, may severely impair intellectual functioning. Studies have found that chemical and physical restraints are used at an alarming rate in nursing homes: 53-60 percent of elderly nursing home residents receive psychotropic medication, and 25-85 percent are physically restrained.[24]

The vulnerability of nursing home residents is also heightened by isolation and near total dependence on the facility. Although most persons enter long-term care facilities with the assistance of relatives or friends who care for them, this support may decrease as significant others withdraw or as residents outlive those close to them. As a result,

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[22] New York State Health Facilities Association, "Survey Response on Health Care Decision Making," unpublished memorandum, November 26, 1986. Task Force study data have been previously reported in New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (New York: New York State Task Force on Life and the Law, 1987), 126.

[23] The syndrome of "learned helplessness" is characterized by passivity, hopelessness, and intellectual slowness, resulting from ongoing situations over which the individual has no control. See I. Robertson, "Learned Helplessness," *Nursing Time* 17 (1986): 28-30; J. Avorn and E. Langer, "Induced Disability in Nursing Home Patients: A Controlled Trial," *Journal of the American Geriatric Society* 30 (1982): 397-400.

[24] See L. K. Evans and N. E. Strumpf, "Tying Down the Elderly: A Review of the Literature on Physical Restraint," *Journal of the American Geriatric Society* 37 (1989): 65-74; S. M. Johnson, "The Fear of Liability and the Use of Restraints in Nursing Homes," *Law, Medicine and Health Care* 18 (1990): 263-73; M. E. Tinetti et al., "Mechanical Restraint Use Among Residents of Skilled Nursing Facilities," *Journal of the American Medical Association* 265 (1991) 468-71; M. Beers et al., "Psychoactive Medication Use in Intermediate-Cares Facility Residents," *Journal of the American Medical Association* 260 (1988): 3016-54; and J. Buck, "Psychotropic Drug Practice in Nursing Homes," *Journal of the American Geriatric Society* 36 (1988): 409-18.

some residents have no family member or close friend available and willing to act as surrogate and make decisions on their behalf.[25]

When residents are able to participate in treatment decisions, long-term care affords the opportunity for ongoing discussion among residents, their family members, and health care professionals. In contrast to acute care, where such a dialogue may be foreclosed by the emergency nature of the care delivered or the one-time nature of treatment provided, the long-term care setting allows for more extensive discussion. If residents cannot decide about treatment for themselves, family members or others can plan, with health care professionals, for the resident's treatment, identifying immediate and long-term objectives.

All long-term care facilities in the state also have a residents' council, designed to give residents a voice in the facility.[26] In general, however, nursing homes have fewer resources and less experience than hospitals in responding to the dilemmas posed by medical advances.[27] Scrutiny of ethical questions initially focused on acute care hospitals where treatments such as the artificial respirator and advanced CPR were introduced and disseminated. Over time, ethical debate shifted to other treatments generally administered in nursing homes, including antibiotics and artificial nutrition and hydration. In addition, as treatments such as CPR became more prevalent in acute care, nursing

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[25] In one study of decisions about CPR in a nursing home, health care professionals were able to identify a family member or friend for virtually all (180 of 185) patients who lacked capacity. However, almost half of those contacted failed to respond to repeated attempts to obtain a decision about entry of a DNR order, suggesting an unwillingness or reluctance to assume responsibility for critical health care decisions. A. M. Faber et al., "Implementing a 'Do-Not-Resuscitate' (DNR) Policy in a Nursing Home," *Journal of the American Geriatric Society* 37 (1989): 544-48.
Even when nursing home residents are fully capable of deciding about treatment, they are often not consulted about treatment decisions. For example, in one study of 198 competent nursing home residents, 61% said that they would want to participate in deciding about whether they should receive CPR, including 35% who wanted to be very involved in the decision. Only 7% had been asked about their preferences for CPR. T. Wetle et al., "Nursing Home Resident Participation in Medical Decisions: Perceptions and Preferences," *Gerontologist* 28, suppl. (1988): 32-38.

[26] See N.Y. Comp. Codes R. & Regs. tit. 10, § 415.26(b)(8) (1991).

[27] This is not true for some nursing homes that have devoted their energies to addressing ethical questions and educating staff members.

homes confronted the question of whether to transfer residents to the hospital to receive such treatment.[28]

Many nursing homes have little experience addressing ethical questions through committee deliberation or in facility policies. Administrative decisions are often more centralized, and the avenues for discussion and criticism of medical policies are more limited. In contrast to hospitals where different departments and staff members participate in setting policies, in nursing homes, one individual may exercise this authority.

Long-term care facilities are also less likely than hospitals to have explicit policies to guide decisions about life-sustaining treatment. In New York State, policies for decisions about life-sustaining treatment increased in nursing homes between 1986 and 1988 but were less common in long-term than in acute care. In 1986, 38 (19 percent) of the 196 nursing homes that responded to the survey had policies on withdrawing or withholding treatment, 110 (56 percent) stated that the facility had no such policy, and 47 (24 percent) said that a policy was "in progress."[29] In 1988, 56 of the 212 nursing homes that responded (26 percent) had developed policies on treatments other than CPR, 131 (62 percent) said that the facility did not have a policy, and 19 (9 percent) said that the policy was in progress. Long-term care facilities were also less likely than acute care hospitals to have the benefit of ethics expertise from sources such as an ethics committee or ethicist.

Ethics Committees

Beginning in the 1970s, ethics committees emerged in hospitals as a resource for responding to dilemmas and conflicts posed by decisions to forgo life-sustaining treatment. Since then, the number of committees has risen steadily. A wealth of literature describing how the

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[28] As advanced technologies have proliferated in hospitals, the transfer decision has become more significant in long-term care. Transfer to a hospital may offer residents their only opportunity to receive life-extending or life-enhancing treatment such as an operation to widen a blocked blood vessel or treatment for a urinary track infection. But transfers also impose risks for long-term care residents who may not adapt to a new environment or to care givers unfamiliar with their needs.

[29] See appendix E for survey data. See also T. Miller and A. M. Cugliari, "Withdrawing and Withholding Treatment: Policies in Long-Term Care Facilities," *Gerontologist* 30 (1990): 462-68.

committees ought to work is available, with relatively little information available about how the committees actually function.[30]

In 1986 and again in 1988, the Task Force undertook studies to identify the prevalence and basic characteristics of ethics committees in New York State hospitals and nursing homes. The 1988 survey of hospitals found that 51 percent of responding hospitals had "a committee that considers ethical issues, resolves conflicts, or offers guidance to decision-making parties about the withholding or withdrawal of life-sustaining treatment." An additional 6 percent were in the process of developing such committees. These figures reflect an increase from 1986, when 33 percent of hospitals reported having ethics committees. A 1985 national survey found that 59 percent of hospitals responding had ethics committees, representing a two-fold increase from 1983.[31]

Most of the early development of ethics committees took place in acute care facilities. Fewer ethics committees exist in long-term care, although they are becoming more common in these facilities as well.[32] However, the data also suggest that many committees in long-term care are not as active or well established as committees in the acute care setting. The 1988 Task Force survey found that a fifth of the ethics committees in long-term care facilities had not met in the previous six

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[30] General sources presenting guidelines for ethics committees include J. W. Ross, *Handbook for Hospital Ethics Committees* (Chicago: American Hospital Publishing, 1986); R. E. Cranford and A. E. Doudera, eds., *Institutional Ethics Committees and Health Care Decision Making* (Ann Arbor: Health Administration Press, 1984); B. Hosford, *Bioethics Committees: The Health Provider's Guide* (Rockville, Md.: Aspen Systems, 1986); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington: U.S. Government Printing Office, 1983), 160-70; C. Bayley and R. E. Cranford, "Ethics Committees: What We Have Learned," in *Making Choices: Ethics Issues for Health Professionals* (Chicago: American Hospital Publishing, 1986), 193-99. Cautions and sympathetic criticisms may be found in B. Lo, "Behind Closed Doors: Promises and Pitfalls of Ethics Committees," *New England Journal of Medicine* 317 (1987): 46-50; and R. McCormick, "Ethics Committees: Promise or Peril?" *Law, Medicine and Health Care* 12 (1984): 150-55.

[31] See appendix E for survey data. Results of the national survey, conducted by the American Hospital Association's National Society for Patient Representatives, are found in "Ethics Committees Double Since '83: Survey," *Hospitals* 59, no. 21 (November 1, 1985): 60. Response rates were about 20% in the national survey and 58% in the New York survey.

[32] In 1986, 13% of the long-term care facilities in New York State reported that they had an ethics committee. By 1988, that percentage had increased to 27%. Data for long term care facilities have been presented in Miller and Cugliari.

months, and only 16 of 57 committees had met more than twice during that time.[33]

Composition

Ethics committees are multidisciplinary, drawing upon the expertise and perspectives of diverse individuals in the health care setting. Suggested guidelines for membership often include physicians, nurses, social workers, clergy, ethicists (those with expertise in medical ethics), attorneys, administrators, patient representatives, community representatives or others unaffiliated with the institution, and (especially for long-term care facilities) patients or residents.[34] Diversity of membership provides a broad range of experience and promotes the fairness of the decision-making process. Such representation also tends to strengthen the credibility of the committee and its decisions. It provides a safeguard against conflicts of interest and helps to avoid the dominance of any individual or group, or the uncritical acceptance of a single point of view.[35]

The 1988 Task Force study showed that virtually all ethics committees in New York State facilities included physicians and nurses. Most hospital ethics committees included social workers, lawyers, and clergy. Administrators, ethicists, and members of the outside community participated in about 40 percent of the committees. Virtually all the committees in long-term care facilities included social workers, with clergy and administrators participating in almost half of the committees. Lawyers and community members were less likely to participate on committees in long-term care facilities than in hospitals, while only 12 percent of ethics committees in long-term care facilities included an ethicist.[36]

Functions

Ethics committees can perform several functions. One pivotal role is education. An ethics committee can inform health care professionals about ethical issues through programs such as rounds and conferences. It can also serve as a focal point for interdisciplinary discussion about ethical problems. Less commonly, ethics committees may educate

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[33] See appendix E for survey data.

[34] E.g., American Hospital Association, "Guidelines: Hospital Committees on Biomedical Ethics," in Ross, 111.

[35] See, e.g., President's Commission, 166.

[36] See appendix E for survey data.

patients and families about issues related to ethics and health care decisions.[37]

Ethics committees often contribute to the development of policies and guidelines in health care facilities. They may discuss cases and general issues, formulate or review policy proposals, and offer recommendations to the facility. In formulating policies, committees generally devote the greatest attention to those areas in which dilemmas are most acutely felt; these include orders not to attempt CPR, advance directives, decisions to forgo life-sustaining treatment, and the treatment of seriously disabled newborns.[38]

Ethics committees may also consider less dramatic but nevertheless important issues related to patient autonomy and daily life. In long-term care facilities, such concerns might include privacy, the behavior of residents that offends the sensibilities of others in public areas or in shared rooms, and the scope of choice for residents in scheduling their activities.[39] In recent years, greater attention has been given to the role of committees in addressing questions posed by AIDS, patient confidentiality, and the need to allocate scarce medical resources.[40]

In addition to their intrinsic importance, activities to educate health care professionals and develop policy contribute to other ethics committee functions, such as case consultation and review. The

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[37] R. E. Cranford and A. E. Doudera, "The Emergence of Institutional Ethics Committees," in Cranford and Doudera, 12; President's Commission, 163.

[38] Ross, 52-56. The development of institutional review committees for decisions about newborns has been encouraged by the American Academy of Pediatrics, "Guidelines for Infant Bioethics Committees," *Pediatrics* 74 (1984): 306-10; and the U.S. Department of Health and Human Services, "Services and Treatment for Disabled Infants, Model Guidelines for Health Care Providers to Establish Infant Care Review Committees," 50 Fed. Reg. 14893-14901 (1985). New York State Department of Health regulations require level III perinatal care programs to establish an infant Bioethics Review Committee, N.Y. Comp. Codes R. & Regs. tit. 10, § 405.21(h)(3)(ii) (1989). See also A. R. Fleischman, "Bioethical Review Committees in Perinatology," *Clinics in Perinatology* 14 (1987): 379-93.

[39] See R. A. Kane and A. L. Caplan, eds., *Everyday Ethics: Resolving Dilemmas in Nursing Home Life* (New York: Springer, 1990); "Nursing Home Ethics Panels Face Dilemmas in Daily Living," *Medical Ethics Advisor* 7 (1991): 129-31.

[40] See, e.g., C. B. Cohen, "Ethics Committees as Corporate and Public Policy Advocates," *Hastings Center Report* 20, no. 5 (1990): 36-37; M. A. Farley, "Institutional Ethics Committees as Social Justice Advocates," Health Progress 65, no. 9 (1984): 32-3, 36; D. W. Brock, "Ethics Committees and Cost Containment," *Hastings Center Report* 20, no. 3 (1990): 29-31; and "Ethics Committee Members Likely Candidates for HIV Panels," *Medical Ethics Advisor* 7 (1991): 109-11.

enhances the knowledge of committee members, strengthens the committee as a group, and establishes the committee's credibility in the institution at large.[41]

Many ethics committees also consider particular cases. Committees may mediate disputes between the patient or family and health care professionals, provide advice in response to a request for consultation, or review and evaluate a proposed course of treatment. In some instances, ethics committees mediate disputes at the request of individuals involved in a conflict. Under New York's law on decisions about CPR, all facilities must provide a process to mediate disputes; the process may, but need not, involve an ethics committee.[42]

Committees may seek to resolve problems by explaining alternative courses of action; supplying information on medical, ethical, and legal standards relevant to the case; or offering advice to patients, family, and health care professionals. Typically, committees consult on cases referred by an attending physician. Most commentators agree that it is appropriate, and even crucial, for committees to review cases brought by other health care professionals or by a patient or family member.[43]

Even in the absence of conflict, committees may routinely review certain types of cases, such as decisions to forgo life-sustaining treatment for disabled newborns, or other cases in which important decisions arise for vulnerable patients. In the words of the President's Commission, committee review can "seek to ensure that the interests of all parties, especially those of the incapacitated patient, have been

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[41] Some commentators, though, emphasize the differences between various committee roles and suggest the possible need for different committees to fulfill different functions; e.g., R. M. Veatch, "The Ethics of Institutional Ethics Committees," in Cranford and Doudera, 35-50, and G. J. Annas, "Legal Aspects of Ethics Committees," in Cranford and Doudera, 51-59.

[42] N.Y. Pub. Health Law § 2972 (McKinney Supp. 1991); New York State Task Force on Life and the Law, *Do Not Resuscitate Orders*, 2d ed. (New York: New York State Task Force on Life and the Law, 1988), 49-51.

[43] Most commentators suggest that an ethics committee inform the patient or surrogate when it considers a case, and provide an opportunity for their participation. See R. Macklin, "Consultative Roles and Responsibilities, in Cranford and Doudera, 157-68; J. A. Robertson, "Committees as Decision Makers: Alternative Structures and Responsibilities," in Cranford and Doudera, 87-91; and Ross, 56-62. Robert M. Veatch argues that patient or surrogate consent should be a prerequisite for committee consideration in "Advice and Consent," *Hastings Center Report* 19, no. 1 (1989): 20-22.

adequately represented, and that the decision reached lies within the range of permissible alternatives."[44]

Many commentators have suggested that ethics committees should not make decisions, but rather should assist and review decisions by patients, surrogates, and health care professionals. A committee could issue nonbinding advisory opinions and might be granted the power to delay implementation of a controversial treatment decision until administrative or judicial action could be taken. Ethics committees could also be given powers to approve or disapprove a proposed course of action.[45]

In surveys of New York State health care institutions, approximately two thirds of hospital ethics committees and just under one half of committees in long-term care facilities reported education and policy development as committee roles. Dispute resolution was the most common function for ethics committees in long-term care facilities (79 percent). Many hospital committees (66 percent) reported that they perform this function as well. Two thirds of committees in both types of institutions engage in case consultation, with prospective case review listed for 20 percent of hospitals and 32 percent of long-term care facilities.[46]

Assessing Ethics Committees

The growth of ethics committees has been accompanied by expressions of caution and criticism. Perhaps the strongest objection has been that the committees intrude on the physician-patient relationship. Some commentators believe that committee deliberation diminishes the physician's sense of responsibility for treatment choices. Others argue that ethics committees can be too deferential to the decisions of physicians or may be dedicated to protecting the institution and affiliated health care professionals rather than the patient. Some express greatest concern about case review, intended to protect patients, asserting that this function must be performed by courts, unless ethics

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[44] President's Commission, 164.

[45] Capron, "Decision," 179-84; Robertson, 91-94.

[46] See appendix E for survey data. It seems likely that respondents understood the terms "consultation" and "case review" in a variety of ways, not necessarily corresponding to those discussed above.

committees are formulated as public bodies with formal due process protections.[47]

No studies are available about the actual functioning and effectiveness of ethics committees. While committee effectiveness is difficult to gauge, it is likely to vary depending on such factors as membership, institutional support, the openness and independence of committee deliberations, and the effort, integrity, and ethical sensitivity of all involved.

Many commentators acknowledge potential problems with ethics committees, suggesting that committees should be developed and operated with caution and careful attention. At the same time, they note that alternative policies entail significant shortcomings as well. Committee review for surrogate decisions can serve to protect the interests of vulnerable patients. Court proceedings are too cumbersome, expensive, and adversarial to fulfill this function routinely. Many believe that, at least for some types of cases, ethics committees could provide better and more timely decisions than the courts.[48]

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[47] M. Siegler, "Ethics Committees: Decisions by Bureaucracy," *Hastings Center Report* 16, no. 3 (1986): 22-24; G. J. Annas, "Ethics Committees: From Ethical Comfort to Ethical Cover," *Hastings Center Report* 21, no. 3 (1991): 18-21; Veatch, "Ethics,"; and McCormick. Lo warns that the group dynamics of committees ("group think") may engender superficial and uncritical consideration of issues.

[48] President's Commission, 164-65; Capron, "Decision," 179-84.

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Deciding About Treatment: Rights and Responsibilities Under Existing Law

New York law on treatment decisions is exceptional in two respects: the breadth of authority granted to adults while competent, and the stringency of standards that govern decisions for adults who are unable to decide for themselves and have not signed a health care proxy. The standards that apply to adults, as well as the law governing decisions by parents for their minor children, provide the context for considering changes in public policy and law to address the needs of New York State citizens.[1]

The Right to Decide: Adults with Capacity

Adults with decisional capacity have a firmly established right to accept or reject medical treatment. This right is based, first and foremost, on the common law principle that "every individual of sound mind and adult years has a right to determine what should be done with his own body."[2] A capable adult may not be treated without his or her consent, except in limited circumstances.[3]

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[1] Laws on treatment decisions, like other laws, originate from different sources. Statutes are enacted by the New York State Legislature. State agencies, such as the New York State Department of Health, promulgate regulations that help implement statutes. Judges are responsible for interpreting statutes and regulations and also for originating and developing the common law, a body of principles that may be changed by statute. The common law, statutes, and regulations must all conform to the requirements of the New York State and United States Constitutions.

[2] *Schloendorff v. Soc'y of N.Y. Hosp.*, 211 N.Y. 125, 129-30, 105 N.E. 92 (1914) (Cardozo, J.).

[3] Four widely recognized exceptions to the informed consent requirement are (i) an emergency, (ii) the therapeutic exception intended to prevent harm to the patient from a discussion about treatment, (iii) the patient's incapacity to consent, and (iv) waiver by the patient. See generally A. Meisel, "The 'Exceptions' to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical

The right to decide about treatment includes the right to refuse life-sustaining measures. The New York Court of Appeals, the state's highest court, first enunciated this principle in a 1981 decision, *In re Eichner*.[4] *Eichner* concerned Joseph Fox, an 83-year-old member of a religious order who became permanently unconscious during surgery. Another member of his order, Philip Eichner, sought court authorization to discontinue the artificial respiration that sustained Joseph Fox's life. Although Joseph Fox died before the Court of Appeals could decide his case, the court found that he would not have wanted life-sustaining treatment in the event of a permanent loss of consciousness. Ruling that competent adults have the right to forgo treatment, even when treatment is beneficial or necessary to preserve life, the court authorized the withdrawal of Joseph Fox's respirator. In subsequent decisions, the Court of Appeals affirmed this principle, and found that the right to refuse treatment is protected by the New York State Constitution.[5]

The right to forgo treatment is also protected by the United States Constitution. In a 1990 decision, *Cruzan v. Director, Missouri Department of Health*,[6] the United States Supreme Court recognized that competent individuals have a liberty interest in refusing unwanted medical treatment, including life-sustaining measures.[7]

Decisionmaking," *Wisconsin Law Review* 1979 (1979): 413-88. See also N.Y. Pub. Health Law 2805-d (McKinney Supp. 1992), governing medical malpractice actions for lack of informed consent.

[4] Decided with *In re Storar*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981).

[5] *Rivers v. Katz*, 67 N.Y.2d 485, 504 N.Y.S.2d 74 (1986). See also *In re Westchester County Medical Center (O'Connor)*, 72 N.Y.2d 517, 534 N.Y.S.2d 886 (1988); *Fosmire v. Nicoleau*, 75 N.Y.2d 218, 551 N.Y.S.2d 876 (1990).

[6] 110 S. Ct. 2841 (1990).

[7] In *Cruzan*, the Court declined to decide that the Constitution requires states to honor decisions by competent adults to forgo life-sustaining treatment in all circumstances. 110 S. Ct. at 2851-52. Instead, the Court noted that the consequence of forgoing life-sustaining treatment is great, and therefore an important factor in determining whether state policies or actions infringe on this liberty interest. 110 S. Ct. at 2852. Significantly, the Court identified the right to refuse treatment as a liberty interest, not as an extension of the right to privacy. Many lower court decisions had treated the right to refuse treatment as an extension or a part of the privacy right. For example, in the landmark case, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976), the New Jersey Supreme Court authorized the discontinuance of artificial respiration based on Karen Ann Quinlan's constitutional right of privacy.

In evaluating the right to refuse treatment, courts have identified countervailing state interests that alone, or in combination, might outweigh the right. Most often, the cases consider or assess the state's interest in preserving life, preventing suicide, protecting third persons, and maintaining the ethical integrity of the medical profession.[8] In cases decided to date, the competent patient's right to refuse life-sustaining treatment has generally prevailed over these interests.[9]

In some states, the courts have concluded that the state's interest in preserving life depends on the patient's prognosis and the invasiveness of the proposed treatment.[10] Under this formula, as the invasiveness of treatment increases and the patient's prognosis worsens, the patient's right to refuse is strengthened.

The New York Court of Appeals has expressly declined to limit the right to refuse treatment to instances when patients are terminally or hopelessly ill.[11] Under New York law, the right to decide is also not dependent on the nature of the medical procedures or treatment sustaining the patient's life; competent adults can refuse life-sustaining treatments even if they are minimally invasive or impose slight risks.

Competent adults also have the right to refuse artificial nutrition and hydration under judicial principles that do not recognize a difference between these measures and other life-sustaining treatments.[12]

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[8] See, e.g., *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987), where the New Jersey Supreme Court found that these four interests did not outweigh the right of a competent woman, Kathleen Farrell, paralyzed by amyotrophic lateral sclerosis (Lou Gehrig's disease), to be disconnected from the respirator that sustained her breathing.

[9] But see, for example, *Cruzan v. Harmon*, 760 S.W.2d 408, 420-22 (Mo. 1988), where the Missouri Supreme Court suggests that the state's "unqualified interest in life" could outweigh the right of a competent patient to refuse life-sustaining treatment.

[10] For example, according to the widely quoted formula from *In re Quinlan*, "the State's interest [in preserving life] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims." 355 A.2d at 664. The New Jersey Supreme Court later rejected this approach in *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985), a decision authorizing the withdrawal of nasogastric feeding from a terminally ill, incompetent, nursing home patient. It ruled that life-sustaining treatments cannot be legally distinguished from other treatments based upon their level of intrusiveness.

[11] *Fosmire v. Nicoleau*, 551 N.Y.S.2d at 881-82 (1990), upholding right of adult to refuse blood transfusions when full recovery could be expected following treatment. See notes 15-16 and accompanying text.

[12] See *O'Connor*, which rejects a request to authorize the withholding of nasogastric

Nor does New York law distinguish decisions to withhold treatment from decisions to stop treatment once it has been started. Both types of decisions are protected as an extension of the common law and constitutional right to decide about treatment.

In New York, as elsewhere, the courts have recognized that the state has a legitimate interest in preventing suicide. However, as defined under New York law, suicide relates solely to intentional, self-inflicted injury and does not encompass a patient's decision to refuse treatment unless the underlying injury is self-inflicted.[13]

The courts have been asked to evaluate the state interest in protecting third parties primarily in cases when the parent of a minor child refuses life-sustaining treatment, potentially leaving the child parentless or with only one parent.[14] The New York Court of Appeals confronted this question in a 1990 case, *Fosmire v. Nicoleau.*[15] In *Fosmire*, Denise Nicoleau, a Jehovah's Witness, lost massive amounts of blood following a caesarean delivery. When she refused blood transfusions, the hospital obtained a court order to administer transfusions against her wishes. On appeal, the hospital argued that the transfusions were proper because the patient was in good health except for blood loss and because her life should be preserved for the sake of her child. The Court of Appeals ruled that the transfusions should not have been ordered, resting its decision on a judgment that the state's legitimate interests in maintaining family unity and protecting the

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feeding from a severely demented, elderly nursing home resident. The case does not distinguish artificial nutrition and hydration from any other life-sustaining measure. See notes 25-29 and accompanying text. See also *Delio v. Westchester County Medical Center*, 129 A.D.2d 1, 516 N.Y.S.2d 677, 691 (2d Dep't 1987), which authorized the withdrawal of artificial nutrition and hydration from Daniel Delio, who had been rendered permanently unconscious at the age of 33 after suffering cardiac arrest during routine surgery. The court ruled that "the withdrawal or withholding of feeding by artificial means should be evaluated in the same manner as any other medical treatment." In *Cruzan*, the United States Supreme Court also drew no distinction between artificial nutrition and hydration and other life-sustaining measures. 110 S. Ct. at 2851-2856. New York's health care proxy law does distinguish artificial nutrition and hydration from other treatments for decisions made by a health care agent on behalf of an incapacitated patient. See discussion, chapter 15.

[13] *Fosmire v. Nicoleau*, 551 N.Y.S.2d at 881-82; *In re Eichner*, 52 N.Y.2d at 377 n. 6. See also *In re Farrell*, 529 A.2d at 411 (citing cases).

[14] See Annotation, *Patient's Right to Refuse Treatment Allegedly Necessary to Sustain Life*, 93 A.L.R.3d 67 (1979).

[15] 75 N.Y.2d 218, 551 N.Y.S.2d 876 (1990).

welfare of young children do not outweigh a competent adult's right to determine the course of his or her own medical treatment.[16]

In cases decided to date, the state interest in maintaining the ethical integrity of the medical profession has never outweighed the right to refuse treatment. In *Eichner*, the New York Court of Appeals ruled that the patient's rights are paramount to what might otherwise be a physician's obligation to provide care and that a physician who honors a competent patient's wish to forgo treatment "cannot be held to have violated his legal or professional responsibilities."[17] The court found that existing law "consistently support[s] the right of a competent adult to make his own decisions by imposing civil liability on those who perform medical treatment without consent, although the treatment may be beneficial or even necessary to preserve the patient's life."[18]

Deciding for Incapable Adults

Determining Incapacity

The determination of patient "incapacity" – i.e., the patient's inability to make an informed decision about health care – has critical

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[16] 551 N.Y.S.2d at 882-83. Compare, for example, *In re President and Directors of Georgetown College, Inc.*, 331 F.2d 1000, *reh'g denied*, 331 F.2d 1010 (D.C. Cir.), *cert. denied sub nom. Jones v. President and Directors of Georgetown College, Inc.*, 377 U.S. 978 (1964), ordering the administration of life-sustaining blood transfusions over the patient's religious objection. The court based its ruling, in part, on the state's interest in protecting the patient's seven-month-old child.

[17] 52 N.Y.2d at 377.

[18] Ibid. For example, in *Leach v. Shapiro*, 13 Ohio App. 3d 393, 469 N.E.2d 1047 (Ct. App. 1984), an intermediate appellate court in Ohio ruled that physicians and hospitals may be liable for damages, including pain and suffering, for providing life-sustaining treatment in a case where the patient clearly refused the treatment. *Elbaum v. Grace Plaza of Great Neck, Inc.*, N.Y.L.J., Jan. 19, 1990, at 26 (Sup. Ct., Nassau Co.), a trial court decision that is currently on appeal, suggests that health care providers may be unable to recover the cost of treatment administered over the objections of patients or those speaking on their behalf. After a brain hemorrhage rendered Jean Elbaum permanently unconscious, her family asked the nursing home to discontinue tube feeding based on evidence of her wishes. The facility refused, and the family ceased to pay for her care. The New York Appellate Division ordered the nursing home to honor Jean Elbaum's clearly expressed choice to forgo tube feeding in her current condition. 148 A.D.2d 244, 544 N.Y.S.2d 840 (2d Dep't 1989). Thereafter, the trial court dismissed an action by the nursing home to recover payment for services, holding, "When medical services are provided to a patient over the objections of the patient, the provider of such services is not entitled to reimbursement."

but [illegible]

implications. Patients with capacity have the right to control the course of their medical treatment. Patients who lack capacity cannot exercise this authority. Their decision-making rights exist only to the extent that others are obligated to honor their previously expressed wishes.

A determination of whether an adult patient has lost capacity usually takes place at the bedside, not in a court room. The attending physician, generally with input from the patient's family and sometimes in consultation with a psychiatrist or other medical specialist, makes the determination. If the physician concludes that the patient lacks capacity, he or she will turn to the patient's family for decisions about treatment. As long as the patient agrees to or expresses no opinion about the determination of incapacity or the course of medical treatment, more formal procedures are not employed. This "bedside" resolution of the capacity issue has long-standing support in custom and practice. However, only a judicial finding of incapacity can curtail or remove the patient's right to decide about treatment.[19]

In a judicial proceeding to establish incapacity, an adult patient is presumed capable unless proven otherwise by clear and convincing evidence.[20] A patient's decision to refuse treatment, even life-sustaining treatment, cannot by itself support a finding of incapacity.[21] Instead, the court must make an independent determination that the patient is unable to decide about treatment.

Recent New York legislative initiatives authorize nonjudicial determinations about capacity for health care decisions under certain circumstances. For example, New York's health care proxy law permits a competent adult to choose an agent to make treatment decisions if he or she loses the capacity to decide. The agent's authority begins when the attending physician determines that the patient has lost decision-making capacity. No court is involved in determining incapacity unless the patient or others object to the physician's determination.[22]

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[19] See *Rivers v. Katz*, 67 N.Y.2d 485, 504 N.Y.S.2d 74 (1986), ruling that a public psychiatric facility violated the constitutional rights of involuntarily committed patients by administering antipsychotic medications over their objections. The court found that an extra-judicial appeal procedure, which included the right to appeal the attending physician's treatment decision to the head of service, the facility director, and to a regional director, failed to protect adequately the patients' rights.

[20] See *Rivers v. Katz*, 504 N.Y.S.2d at 81.

[21] See *Fosmire v. Nicoleau*, 551 N.Y.S.2d at 881 (1990).

[22] N.Y. Pub. Health Law Article 29-C (McKinney Supp. 1992) ("Health Care Agents and Proxies"). Another recently enacted medical decision-making statute that relies

Advance Directives

Two kinds of instruments, generally referred to as "advance directives," enable persons to retain some control over health care decisions after they have lost the capacity to participate directly in decision making: (i) written instructions about treatment, usually called a "living will," and (ii) the written appointment of a person, often called an "agent," with authority to make health care decisions on the person's behalf. Patients can also leave advance oral instructions about treatment, although such statements are generally more difficult to rely upon unless documented by health care professionals.

Written and oral instructions. A living will contains treatment instructions to be followed in the event the individual who creates the document becomes incapable of making treatment decisions directly. Living wills usually specify only wishes about life-sustaining treatment. Forty-three states and the District of Columbia have thus far enacted living will statutes that delineate the circumstances under which living wills are valid and set forth the rights and obligations afforded patients and health care providers under the documents.[23]

New York has no statute governing living wills. However, as held by the New York Court of Appeals, living wills and other written or oral evidence of treatment wishes provide the basis for withdrawing or withholding life-sustaining measures if the instructions qualify as clear and convincing evidence of the patient's wishes.[24]

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upon nonjudicial determinations of incapacity is N.Y. Mental Hyg. Law Article 80 (McKinney 1988 & Supp. 1992) ("Surrogate Decision-Making for Medical Care and Treatment"). See also N.Y. Pub. Health Law Article 29-B (McKinney Supp. 1992) ("Orders Not To Resuscitate"), empowering physicians to make a bedside determination of patient incapacity to trigger a surrogate decision about CPR.

[23] See Choice in Dying, *Refusal of Treatment Legislation* (1991 & Supp.). To date, the seven states without living will legislation are Massachusetts, Michigan, New York, Nebraska, Ohio, Pennsylvania and Rhode Island.

[24] See *In re Eichner (In re Storar)*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981); *In re Westchester County Medical Center (O'Connor)*, 72 N.Y.2d 517, 534 N.Y.S.2d 886 (1988). See also N.Y. Comp. Codes R. & Regs. tit. 10, §§ 400.21 and 700.5 (1991), requiring health care facilities to ensure compliance with the laws governing advance directives. The regulation provides that "adults who express their wishes orally or in writing concerning life-sustaining treatment in a clear and convincing manner are entitled, based on decisions of both the United States Supreme Court and the New York Court of Appeals, to have those wishes recognized." See appendix C for statement issued by the Department of Health for distribution to patients, which describes patients' rights to decide about treatment under New York law.

This legal principle was most fully described in the 1988 New York Court of Appeals decision, *In re Westchester County Medical Center (O'Connor).*[25] *O'Connor* concerned Mary O'Connor, a 77-year-old woman who was severely incapacitated, although conscious, following a series of strokes. Her two adult daughters, on her behalf, sought to prevent the provision of artificial nutrition and hydration. Pointing to statements their mother had made in response to the lingering deaths of her husband, two of her brothers, and her stepmother, Mary O'Connor's daughters asserted that she would not wish to live maintained by artificial means in her current condition.[26]

The court ruled that those seeking to forgo life-sustaining treatment on behalf of an incompetent patient must establish by clear and convincing evidence that the patient, while competent, held a firm and settled commitment to terminate treatment under similar circumstances. The previous oral or written statements by the patient must refer to treatments and conditions not "qualitatively different" from those actually confronted.[27] Suggesting that the ideal evidence of an advance decision to refuse life-sustaining treatment is a written statement by the patient, such as a living will, the court also specified that oral evidence can satisfy the standard.[28]

Applying these principles in *O'Connor,* the court denied the request to withdraw artificial nutrition and hydration.[29] It found that the evidence of Mary O'Connor's wish to forgo treatment did not satisfy the clear and convincing standard because her medical condition and treatment differed from those she had confronted and discussed with her daughters over the years.

In 1991 the New York State Department of Health established regulations requiring facilities to assess whether proof of a patient's wishes is sufficiently specific to satisfy New York's standard. The regulations, issued in response to federal mandates, also require

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[25] 72 N.Y.2d 517, 534 N.Y.S.2d 886 (1988).

[26] The daughters described Mary O'Connor as a religious woman who "felt that nature should take its course" and medical interventions should not be used if someone was "not going to get any better." One daughter testified that her mother had informed her on several occasions that if she became ill and unable to care for herself, she would not want her life sustained artificially. 534 N.Y.S.2d at 890.

[27] 534 N.Y.S.2d at 892-93.

[28] Ibid.

[29] 534 N.Y.S.2d at 894.

facilities to document advance oral and written instructions about treatment.[30]

As stated in the regulations and established in court decisions, health care providers need not obtain court approval before honoring living wills or other clear advance expressions of treatment choices.[31] For example, in *In re Heath (Finsterbach)*,[32] a 1990 New York Supreme Court case, a hospital sought court authorization to insert a tube into the stomach of an incapacitated patient, Fred Finsterbach, for purposes of administering artificial nutrition and hydration. The patient was terminally ill with advanced Alzheimer's disease, degenerative senile dementia, and Parkinson's disease. While competent he had executed a living will. He had also worn a bracelet with the words, "No resuscitation, no IV, no INJ, no Intubation," which was on his wrist upon his admission to the hospital. The court held that life-sustaining treatment to prolong Fred Finsterbach's life violated his living will. It also found that "so long as the medical profession complies with [a living will], it will be fulfilling its legal and professional responsibilities. No additional procedures are required and court authorization is unnecessary."[33] Hence, in *Finsterbach* and other cases, New York courts have authorized the discontinuance of life-sustaining treatment based on written or oral evidence of a patient's wishes.[34] However, cases like *O'Connor* have also demonstrated the difficulty of meeting New York's evidentiary standard.[35]

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[30] N.Y. Comp. Codes R. & Regs. tit 10, §§ 400.21 and 700.5 (1991). See note 24.

[31] E.g., *In re Eichner*, 438 N.Y.S.2d at 276. See also N.Y. Comp. Codes R. & Regs tit X, §§ 400.21(d)(3) and 700.5(d)(3) (1991), obligating health care facilities to "assess" living wills and advance oral instructions about treatment but stipulating that the regulation does not "require that a facility must or may not seek a court determination that any individual advance directive has been expressed in a clear and convincing manner."

[32] Unpublished slip opinion of the New York Supreme Court, Oneida County, issued June 14, 1990.

[33] Ibid., 5.

[34] E.g., *Elbaum v. Grace Plaza of Great Neck, Inc.*, 148 A.D.2d 244, 544 N.Y.S.2d 840 (2d Dep't. 1989). See note 18.

[35] For example, in *Hayner v. Child's Nursing Home*, No. 0188-015609, slip op. at 4 (Sup. Ct., Albany Co., Dec. 5, 1988), a court denied a petition to discontinue artificial nutrition and hydration for a 92-year-old woman who was permanently unconscious. Two witnesses testified that the patient, after seeing artificial nutrition provided to another nursing home patient by gastrostomy tube, told them that she "did not want to live on a feeding tube." The court, relying on *O'Connor*, held that the patient's

In *Cruzan v. Director, Missouri Department of Health*, the United States Supreme Court held that states may, consistent with constitutional standards, demand clear and convincing evidence of the wish to forgo life-sustaining treatment.[36] In so doing, the Court did not mandate that every state adopt this evidentiary standard, but more narrowly found that the standard does not violate an individual's constitutional right to decide about treatment. In her concurring opinion, Justice O'Connor characterized the *Cruzan* decision as follows: "Today we decide only that one State's practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the 'laboratory' of the States . . . in the first instance."[37]

Health care proxies. Beginning in the 1980s, the health care durable power of attorney, or "proxy," emerged as a second generation of advance directive designed to overcome the limitations presented by reliance on living wills. Unlike living wills, which specify treatment decisions in advance, the health care proxy establishes a decision-making process. Health care proxy laws permit individuals to delegate to a trusted person the authority to make health care decisions in the event of a future loss of capacity. Currently, the District of Columbia and 37 states, including New York, have statutes that permit appointment of an agent with the authority to refuse life-sustaining treatment.[38] Most health care proxy laws permit the delegation of all health

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statements were "a reaction to the unfortunate situation of another" and did not constitute clear and convincing evidence of the patient's wish to decline medical treatment.

[36] 110 S. Ct. 2841, 2852-54 (1990). The United States Supreme Court affirmed a Missouri Supreme Court decision that Nancy Cruzan's parents could not authorize the withdrawal of artificial nutrition and hydration because they failed to present clear and convincing evidence of their daughter's wish to forgo the measures. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988). On December 4, 1990, after considering new evidence of Nancy Cruzan's wishes, a Missouri trial court ruled that Missouri's clear and convincing evidence standard had been satisfied and ordered the measures withdrawn. Nancy Cruzan died on December 26, 1990. T. Lewin, "Nancy Cruzan Dies, Outlived by a Debate over the Right to Die," *New York Times*, December 27, 1990, sec. A, p. 1.

[37] 110 S. Ct. at 2859.

[38] See Choice in Dying, *Refusal of Treatment Legislation* (1991 & Supp.). The 13 states that presently lack this legislation are Alabama, Alaska, Arizona, Colorado, Connecticut, Hawaii, Maryland, Montana, Nebraska, New Mexico, Oklahoma, Pennsylvania, Washington. Of these, eight states have statutes that expressly permit the appointment of an agent to make treatment decisions, but without clear authority

care decisions, although a few are part of living will statutes and limit the agent's authority to treatment choices that arise at the end of life.[39]

New York's health care proxy law allows adults to delegate authority to decide about all health care treatment, including life-sustaining measures.[40] Individuals can also delegate authority to make some decisions and not others. Treatment instructions from the patient to the agent can be oral, or written on the proxy document or elsewhere. The designated person – the "health care agent" – must make decisions in accord with the patient's wishes, if they are reasonably known, or, if they are not reasonably known, in accord with a judgment about the patient's best interests. The only exception applies to decisions about artificial nutrition and hydration. If the patient's wishes about artificial nutrition and hydration are not reasonably known and cannot with reasonable efforts be determined, the agent cannot decide about these measures. Health care professionals must honor decisions by the health care agent to the same extent as if they had been made by the patient, and they are protected from liability for doing so.

Decisions by Family and Others

If a patient lacks capacity to decide about life-sustaining treatment and did not leave an advance directive covering the decisions, the crucial legal issues are whether a family member or other person can decide on the patient's behalf and how to protect the patient's dual rights: the right to refuse treatment and the right not to have life foreshortened.

National trends: the law on life-sustaining treatment in other states. Currently, 16 states and the District of Columbia have statutes

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to forgo life-sustaining treatment. They are Alaska, Colorado, Connecticut, Hawaii, New Mexico, Pennsylvania and Washington. See R. N. Swidler, "The Health Care Agent: Protecting the Choices and Interests of Patients Who Lack Capacity," *New York Law School Journal of Human Rights* 6 (1988): 1-61.

[39] For example, the California Durable Power of Attorney for Health Care Act, Cal. Civil Code 2430 to 2444, 2500 to 2508 (West Supp. 1991), governs the appointment of an agent authorized to make all health care decisions, including a decision to forgo life-sustaining treatment. The Minnesota Adult Health Care Decisions Act, Minn. Stat. 145B. 01 to .17 (Supp. 1990), a living will law, also permits the appointment of an agent authorized to make health care decisions but only when the patient is in a "terminal condition." The agent lacks authority for routine or major medical decisions, even if the patient is incapable of deciding for himself or herself.

[40] N.Y. Pub. Health Law Article 29-C (McKinney Supp. 1992). A suggested form prepared by New York State Department of Health appears as appendix D. See also T. E. Miller, "Public Policy in the Wake of *Cruzan*: A Case Study of New York's Health Care Proxy Law," *Law, Medicine and Health Care* 18 (1990): 360-67.

that permit surrogate decisions for life-sustaining treatment, subject to a variety of safeguards.[41] In seven other states, the highest state courts have upheld the validity of surrogate decisions for life-sustaining treatment.[42]

Although most courts describe surrogate decision making as a mechanism to preserve the incapable patient's right to refuse treatment, at least one court has characterized the practice as an effort to safeguard the right retained by incompetent patients to have

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[41] In all but one state, the statutes expressly grant this authority. In Indiana, the state's highest court has construed a general substitute consent statute as including this power. **ARKANSAS**, Ark. Code Ann §§ 20-17-201 to -218 (Supp. 1989); **CONNECTICUT**, Conn. Gen. Stat. §§ 19a-570 to -575 (Supp. 1989); **FLORIDA**, Fla. Stat. Ann. §§ 765.01 to .15; **ILLINOIS**, Health Care Surrogate Act (H.B. 2334, enacted September 26, 1991); **INDIANA**, Ind. Code Ann §§ 16-8-12-1 to -12 (Burns Supp. 1990), as construed by the Indiana Supreme Court in *In re Lawrance*, No. 29S04-9106-CV-00460, 1991 Ind. LEXIS 170 (Sept. 16, 1991); **IOWA**, Iowa Code Ann. §§ 144A.1 to .11 (1989); **LOUISIANA**, La. Rev. Stat. Ann. §§ 40:1299.58.1 to .10; **MAINE**, Me. Rev. Stat. Ann. tit. 18-A, §§ 5-701 to -714; **MONTANA**, Mont. Code Ann. §§ 50-9-101 to -106, -111, -201 to -206 (1987 & Supp. 1991); **NEVADA**, Uniform Act on Rights of the Terminally Ill (S.B. 442, 1991); **NEW MEXICO**, N.M. Stat. §§ 24-7-1 to -11 (1986); **NORTH CAROLINA**, N.C. Gen. Stat. Ann. §§ 90-320 to -322 (1989); **OREGON**, Or. Rev. Stat. §§ 127.605 to 650 (1990); **TEXAS**, Tex. Rev. Civ. Stat. Ann. §§ 672.001 to .021 (Vernon Supp. 1990); **UTAH**, Utah Code Ann. §§ 75-2-1101 to -1118 (Supp. 1990); **VIRGINIA**, Va. Code §§ 54.1-2981 to -2992 (Supp. 1991). See Choice in Dying, *Refusal of Treatment Legislation* (1991 & Supp.); See generally J. Areen, "The Legal Status of Consent from Families of Adult Patients to Withdraw or Withhold Treatment," *Journal of the American Medical Association* 258 (1987): 229-35; R. F. Weir and L. Gostin, "Decisions to Abate Life-Sustaining Treatment for Nonautonomous Patients," *Journal of the American Medical Association* 264 (1990): 1846-53.

[42] **ARIZONA**, *Rassmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987); **DELAWARE**, *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334 (Del. 1980); **GEORGIA**, *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); **MASSACHUSETTS**, *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); **MINNESOTA**, *In re Torres*, 357 N.W.2d 332 (Minn. 1984); **NEW JERSEY** *In re Jobes*, 108 N.J. 394, 528 A.2d 434 (1987); and **WASHINGTON**, *In re Grant*, 109 Wash. 2d 545, 747 P.2d 445 (1987), *modified by*, 747 P.2d 534 (1988). *See also* **CALIFORNIA**, *In re Drabick*, 200 Cal. App. 3d 185, 245 Cal. Rptr. 850 (1988) (lower court opinion); **CONNECTICUT**, *Foody v. Manchester Memorial Hosp.*, 40 Conn. Supp. 127, 482 A.2d 713 (Super. Ct. 1984) (lower court opinion, but statute authorizes surrogate decisions); **FLORIDA**, *In re Browning*, No. 784,134, slip op. (Fla. Supreme Ct., Sept. 13, 1990) (highest state court, and statute also authorizes surrogate decisions); **ILLINOIS**, *In re Greenspan*, No. 67903, slip op. (Ill. Supreme Ct., July 9, 1990) (highest state court, and statute also authorizes surrogate decisions); **MICHIGAN**, *In re Rosebush*, No. 88-349180A2, slip op. (Mich. Cir. Ct., July 29, 1988) (lower court opinion); **NORTH DAKOTA**, *In re Bayer*, No. 4131, slip op. (N.D. Co. Ct., Feb. 11, 1987) (lower court opinion).

appropriate decisions made on their behalf.[43] The key issues confronted in the cases are (i) identifying the surrogate, (ii) the role of the court, (iii) the decision-making standard, (iv) medical predicates for surrogate decisions, and (v) procedural protections.

The cases invariably regard members of the patient's family as the most appropriate persons to decide about life-sustaining treatment on behalf of the patient, except in rare circumstances.[44] Although in several decisions a family member has sought court approval or judicial appointment as the patient's guardian, the cases often hold that such appointments are unnecessary for a family member to act as the surrogate. Courts affirmatively discourage routine applications for judicial approval in the absence of disputes about the patient's treatment or the surrogate's authority.[45] In cases where the patient has not had a close relative, courts have appointed a guardian to act as surrogate.[46]

The court decisions generally require the surrogate to strive to make the choice that the patient would have made if able to decide. In instances where the surrogate cannot ascertain the patient's wishes, the decisions turn to the "best interests" standard, described as either an evaluation of the projected benefits and burdens of a proposed treat-

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[43] *In re Drabick*, 200 Cal App. 3d 185, 245 Cal. Rptr. 840 (Ct. App. 1988), authorizing the discontinuance of tube feeding for William Drabick, a man rendered permanently unconscious after an automobile accident.

[44] E.g., *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987), where the court authorized the withdrawal of tube feeding from Nancy Jobes, a 32-year-old permanently unconscious patient based on the "substituted judgment" of her family members. Explaining its decision, the court stated, "Almost invariably, the patient's family has an intimate understanding of the patient's medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient's medical decisions."

[45] For example, the *Jobes* decision states, "Courts are not the proper place to resolve the agonizing personal problems that underlie these cases. Our legal system cannot replace the more intimate struggle that must be borne by the patient, those caring for the patient, and those who care about the patient." 529 A.2d at 541. *In re Grant*, 109 Wash. 2d 545, 747 P.2d 445,456 (1987), discussed at note 49, describes the judicial process as "an unresponsive and cumbersome mechanism for decisions of this nature." The court concludes, "[T]hese decisions are best left, whenever possible, to the incompetent patient's guardian, immediate family and physicians."

[46] See *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977), authorizing a court-appointed guardian to withhold chemotherapy from a profoundly retarded cancer patient who had no family member willing to make a decision about his treatment.

ment, or an effort to picture what a hypothetical "reasonable person" would choose in the patient's circumstances.[47]

In many cases, family members have sought to discontinue treatment for patients who are permanently unconscious. As a result, several decisions recognize the legitimacy of surrogate decisions for patients in this condition.[48] Other opinions authorize the discontinuance of life-sustaining treatment for terminally ill patients who are conscious but incapable of deciding about treatment.[49]

The courts have also imposed procedures to protect the patient from inappropriate termination of treatment. For example, they have required the concurrence of other physicians in the patient's prognosis.[50] Other safeguards have been framed for particular patient populations.[51]

In general, the surrogate decision-making statutes list and rank persons with a close relationship to the patient, such as a court-appointed guardian, the spouse, an adult child, or a parent.[52] The highest ranked person reasonably available, willing, and able to serve as sur-

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[47] For example, in *Rasmussen v. Fleming*, 741 P.2d 647 (Ariz. 1987), the court authorized a public guardian to forgo all but routine care for a permanently unconscious elderly nursing home resident, Mildred Rasmussen, who had no involved family members and had not expressed her treatment instructions while competent. The court held that this treatment decision could be made based on the patient's best interests.

[48] The courts have provided different rationales for this authority. In *Rasmussen*, for example, the court concluded that any treatment "would have provided minimal, if any, benefits and would have only postponed Rasmussen's death, rather than improved her life." 741 P.2d at 689.

[49] E.g., *In re Grant*, 109 Wash. 2d 545, 747 P.2d 445 (1987), permitted the mother and guardian of Barbara Grant, a 22-year-old woman with Batten's disease, an incurable, degenerative neurological disorder, to direct the withholding of treatment on behalf of her daughter. The court specifically held that an incompetent patient need not be permanently unconscious before treatment could be refused on his or her behalf.

[50] *In re Grant*, discussed at note 49, requires that two physicians agree that the patient is in an "advanced stage of a terminal and permanent illness;" *Foody v. Manchester Memorial Hosp.*, 40 Conn. Supp. 127, 482 A.2d 713 (Super Ct. 1984), requires that two physicians confirm that the patient is permanently unconscious.

[51] E.g., *Saikewicz* (institutionalized developmentally disabled patients), discussed at note 46; *In re Conroy* (institutionalized elderly), discussed at note 10.

[52] A few statutes, such as Connecticut's Removal of Life Support Systems Act, do not contain a ranked list, but instead permit the "next of kin" to make treatment decisions. Conn. Gen. Stat. § 19a-571(3) (Supp. 1989).

rogate is granted legal authority to decide on the patient's behalf. Most state laws also obligate the surrogate to decide as the patient would decide, if able to do so. Almost all the laws expressly require that the patient must be seriously ill before a surrogate can decide to forgo life-sustaining treatment on his or her behalf. Some accomplish this by requiring that the patient's death must occur shortly, despite the provision of treatment.[53] Other state laws are less restrictive, allowing the surrogate to decide if the patient's death will occur in a short time period without the provision of treatment.[54] This standard encompasses patients who are permanently unconscious as well as those who are severely and chronically ill, such as patients with advanced Alzheimer's disease. Two states authorize the patient's physician to forgo life-sustaining treatment for patients who have no available surrogate.[55] All of these laws grant protection from liability to health care professionals and facilities that withdraw treatment in accordance with the statute.

New York law. Although New York law does not explicitly recognize the authority of family members to consent to treatment when patients are unable to decide for themselves, health care providers routinely turn to family members for consent. Under legal doctrines enunciated by the Court of Appeals, however, family members or others close to the patient cannot determine that life-sustaining treatment should be withdrawn or withheld.

The New York Court of Appeals first established this approach to decisions about life-sustaining treatment in a 1981 decision, *In re Storar*.[56] John Storar was a 52-year-old profoundly retarded man dying of bladder cancer. His treatment included frequent transfusions to replace blood lost from an inoperable bladder lesion. John Storar's

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[53] For example, Florida's Life-Prolonging Procedure Act requires that the patient have "an injury, disease, or illness from which, to a reasonable degree of medical certainty, there can be no recovery and which makes death imminent." Fla. Stat. Ann. § 765.03(6) (H.B. 2334, enacted September 26, 1991).

[54] The Texas Natural Death Act takes this approach, requiring that the patient must have an "incurable or irreversible condition . . . which, without the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and, where the application of life-sustaining procedures serves only to postpone the moment of death of the patient. Tex. Rev. Civ. Stat. Ann § 672.001 (Vernon Supp. 1990).

[55] North Carolina Right to Natural Death Act, N.C. Gen. Stat. § 90-322(b) (1989); Oregon Rights with Respect to Terminal Illness Act, Or. Rev. Stat. § 127.635(3) (1990). Neither statute requires court authorization or a court-appointed guardian.

[56] 52 N.Y.2d 363, 438 N.Y.S.2d 266 (1981).

mother sought a court order to stop the transfusions because her son found them painful and disturbing and because, at best, they could extend his life for only three to six months. The New York Court of Appeals explained that it was unrealistic to attempt to determine what John Storar would have chosen for himself because he never had the capacity to make treatment decisions. On this basis, the court refused to grant Mrs. Storar's request, ruling that no one, not even a concerned family member, can refuse life-sustaining treatment for another person.[57]

The health care proxy law provides an important exception to this general rule, but only for individuals who have signed a proxy form. Another exception was established by New York's statute governing orders not to resuscitate, which authorizes specified surrogates to consent to a DNR order directing health care professionals not to provide CPR in the event of cardiac or respiratory arrest. Surrogates can consent to a DNR order only if the patient faces one of four medical circumstances[58] and a surrogate decides that the order would comport with the patient's wishes or, if they are not known, with a judgment about the patient's best interests. For patients who have no surrogates, physicians can enter a DNR order if they determine that CPR would be medically futile for the patient.

Several New York statutes and regulations authorize surrogate decisions, but do not encompass decisions about life-sustaining treatment. For example, the Mental Hygiene Law empowers courts to appoint a committee to make personal decisions for an incompetent adult,[59] and the Surrogate's Court Procedure Act authorizes courts to

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[57] 438 N.Y.S.2d at 275. The New York Court of Appeals restated its opposition to surrogate decision-making in *People v. Eulo*, 63 N.Y.2d 341, 482 N.Y.S.2d 436, 446 (1984), a case involving the legal standard to determine death. This stringent approach has evoked substantial criticism. See, for example, G. J. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," *Hastings Center Report* 11, no. 3 (1981): 19-20. Annas contends that the decision "fails to recognize that there may be times when [life-sustaining] treatment only prolongs suffering and is itself cruel; and it fails to suggest any test that parents, families, or lower courts can apply to decide if it is ever legally permissible to withhold life-sustaining treatment from this group of patients."

[58] The four circumstances are (i) the patient has a terminal condition, (ii) the patient is permanently unconscious, (iii) resuscitation would be medically futile, or (iv) resuscitation would impose an extraordinary burden on the patient in light of the patient's condition and the expected outcome of the procedure. N.Y. Pub. Health Law § 2965 (McKinney Supp. 1992).

[59] N.Y. Mental Hyg. Law Article 78 (McKinney 1988 & Supp. 1992).

appoint a guardian to make personal decisions for the mentally retarded or developmentally disabled.[60] These appointees often make health care decisions for their wards.[61] In addition, under Article 80 of the Mental Hygiene Law, special committees comprised of health care professionals, lawyers, and persons familiar with the problems of the mentally disabled are authorized to make specified major medical treatment decisions for incapable residents of mental hygiene facilities.[62] The authority of these committees does not extend to decisions about life-sustaining treatment.

Health Care Decisions and Minors

Deciding for Minors

In general, persons younger than 18 years of age have no right to decide about their own health care.[63] That right and responsibility ordinarily rests with parents. Treatment decisions by parents have traditionally been accorded great deference. Indeed, parents possess a fundamental, constitutionally protected right to rear and raise their children free from state interference, including the right to make decisions for their children about health care.[64]

A 1979 New York Court of Appeals decision, *In re Hofbauer*,[65] underscores the deference accorded parental decisions. In *Hofbauer*,

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[60] N.Y. Surr. Ct. Proc. Act Article 17-A (McKinney 1967 & Supp. 1992).

[61] See *Grinker v. Rose*, N.Y.L.J., May 3, 1991, at 22, col. 5 (N.Y. Ct. of Appeals, April 30, 1991), ruling that conservators appointed pursuant to Article 77 of the Mental Hygiene Law lack the authority to make major health care decisions for their wards. See also D. L. Moore, "The Durable Power of Attorney as an Alternative to the Improper Use of Conservatorship for Health Care Decisionmaking," *St. John's Law Review* 60 (1986): 631-73.

[62] N.Y. Mental Hyg. Law Article 80 (McKinney 1988 & Supp. 1992).

[63] N.Y. Pub. Health Law 2504(1) (McKinney 1985). The rule is derived from common law, under which infancy was a legal disability, and the law sought to protect minors from their own immaturity. A minor, absent evidence to the contrary, was deemed to lack judgment, an adult's knowledge of the probable consequences of his or her actions, and the capacity to make effective use of the knowledge he or she possessed. 66 N.Y. Jur. 2d *Infants* §§ 2 and 3 (1987).

[64] See, e.g., *Santosky v. Kramer*, 455 U.S. 645 (1982), determining that parents' fundamental rights preclude states from terminating parental rights without clear and convincing evidence of parental unfitness; *In re Hofbauer*, 47 N.Y.2d 648, 419 N.Y.S.2d 936 (1979), discussed at notes 65 and 66 and accompanying text.

[65] 47 N.Y.2d 648, 419 N.Y.S.2d 936 (1979).

the court refused to override a decision by parents to obtain metabolic and nutritional therapy for their child suffering from Hodgkin's disease, rather than chemotherapy and radiation, the conventional treatment. The court ruled that parents have broad discretion to choose among alternative treatments so long as parents, "once having sought accredited medical assistance and having been made aware of the seriousness of their child's affliction and the possibility of cure if a certain mode of treatment is undertaken, have provided for their child a treatment which is recommended by their physician and which has not been totally rejected by all responsible medical authority."[66]

Parents' authority to decide about health care for their children is not unfettered. The outer limits of that authority are defined under New York law by statutes[67] and judicial decisions[68] on abuse and neglect, and by judicial decisions that constrain any surrogate, including parents, from refusing life-sustaining treatment for another person.[69]

In other states where courts have addressed parental decisions about life-sustaining treatment for minor children, judicial decisions vary. In some instances, courts have ordered treatment for newborns

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[66] 419 N.Y.S.2d at 941. See also *Weber v. Stony Brook*, 95 A.D.2d 587, 467 N.Y.S.2d 686 (2d Dep't 1983), the so-called "Baby Jane Doe" case, where an intermediate appellate court invoked this principle to permit parents to refuse surgery and opt for minimal measures for their child born with spina bifida. The New York Court of Appeals affirmed the decision, although on procedural grounds. 60 N.Y.2d 208, 469 N.Y.S.2d 63, *cert. denied*, 464 U.S. 1026 (1983).

[67] See, for example, N.Y. Fam. Ct. Act Article 10 (McKinny 1983 &. Supp. 1992), defining child abuse and neglect, and specifying how physicians, hospitals, and other authorized persons can obtain temporary or permanent custody of children in cases of abuse or neglect, including for purposes of providing medical treatment; N.Y. Soc. Serv. Law § 383-b (McKinney Supp. 1992), authorizing local commissioners of social services or health to consent to treatment for abused or neglected children; N.Y. Soc. Serv. Law § 384-b(4) (McKinney 1983 & Supp. 1992), specifying that parental status may be involuntarily terminated by a court upon a finding of parental unfitness based on abandonment, mental disability, permanent neglect, or severe or repeated abuse.

[68] See, for example, *Hofbauer* and *Weber v. Stony Brook*, discussed at notes 65 and 66 and accompanying text. When faced with parental abuse or neglect due to a failure to provide treatment, courts have had little difficulty overriding even religiously based parental decisions, following the clear guidance from the United States Supreme Court that "parents may be free to make martyrs of themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children." *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944).

[69] E.g., *In re Storar* and *People v. Eulo*, discussed at notes 56 and 57 and accompanying text.

with severe disabilities, notwithstanding parental objections.[70] These decisions emphasize the state's obligation to preserve life and decline to accord weight to either quality-of-life considerations or to the risks or burdens of proposed treatments. In other cases, courts have applied the principles developed in cases involving adults without decision-making capacity, permitting parents to refuse life-sustaining treatment if the decision serves the child's best interests, as determined by an assessment of the benefits and burdens posed by the treatment.[71]

The 1982 Indiana case, *Baby Doe*,[72] exemplifies a less common, more problematic approach to decisions for newborns. In *Baby Doe*, parents of an infant born with Down's syndrome refused relatively low-risk and effective surgery to remove a life-threatening esophageal blockage. Indiana state courts, including the Indiana Supreme Court, refused to intervene to override the decision, and the infant died of pneumonia six days after birth.

Largely in response to this case, the federal government issued statutory and regulatory guidelines on medical decisions for severely disabled newborns. In 1984 Congress amended the federal Child Abuse Prevention and Treatment Act to require states, as a condition of receiving federal funds to prevent child abuse, to implement programs to protect severely disabled newborns from "medical neglect." The law defines medical neglect to include "the withholding of medically-indicated treatment from a disabled infant with a life threatening condition."[73] It also identifies circumstances when the withdrawal or withholding of treatment is not medical neglect and requires states to develop policies for reporting, investigating, and intervening in medical neglect cases.[74]

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[70] See, e.g., *In re Elin Daniels*, No. 81-15577FJ01, slip op. (Fla. Cir. Ct., June 23, 1981), ordering treatment for newborn with spina bifida.

[71] See, e.g., *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982), overriding parental decision to treat three-year-old son's leukemia with laetrile, based on medical testimony on the product's ineffectiveness; *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984), authorizing parents to withdraw life-sustaining treatment from their infant daughter who was terminally ill and permanently unconscious.

[72] *In re Infant Doe*, No. GU8204-004A, slip op. (Monroe Co. Cir. Ct., Apr. 12, 1982), *writ of mandamus dismissed sub nom State ex rel Infant Doe v. Baker*, No. 482-140, slip op. (Ind. Sup. Ct. May 27, 1982), *cert. denied sub nom Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

[73] 42 U.S.C.A. §§ 5101-5106g (West Supp. 1991); 45 C.F.R. § 1340 and appendix (1990).

[74] Ibid.

Decisions by Minors

New York law contains important exceptions to the general rule that minors cannot make their own health care decisions. The exceptions recognize that sound public policy is served by allowing adolescents younger than 18 to control their own health care under certain circumstances. For example, statutes authorize minors to consent to treatment if they are either married or a parent.[75] If specified conditions are met, New York law also permits minors to consent to certain treatments, for example, treatment for venereal disease,[76] substance abuse,[77] mental illness,[78] and prenatal care,[79] as well as to blood donation[80] and HIV-related testing.[81] In addition, under New York's DNR law, a DNR order cannot be issued for a minor without the minor's consent, if the minor possesses decisional capacity.[82]

New York courts have also recognized that minors can consent to treatment if they are "emancipated."[83] Minors have been declared emancipated when an intentional rending of the parent-child relationship has occurred: parents must have intentionally relinquished control over the minor, and the minor must have intentionally withdrawn from

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[75] N.Y. Pub. Health Law § 2504(1) (McKinney 1985).

[76] N.Y. Pub. Health Law § 2305(2) (McKinney 1985).

[77] N.Y. Mental Hyg. Law §§ 21.11 and 33.21 (McKinney 1988).

[78] N.Y. Mental Hyg. Law §§ 9.13(a) and 33.21 (McKinney 1988).

[79] N.Y. Pub. Health Law § 2504(3) (McKinney 1985).

[80] N.Y. Pub. Health Law § 3123 (McKinney 1985).

[81] N.Y. Pub. Health Law § 2781 (McKinney Supp. 1992). This provision construes the capacity to consent to HIV-related testing as an individual's ability, determined without regard to age, to understand and appreciate the nature and consequences of a proposed health care service, treatment or procedure and to make an informed decision concerning such service, treatment or procedure.

[82] N.Y. Pub. Health Law §§ 2967(1) and 2967(2)(a) (McKinney Supp. 1992). The law defines decisional capacity as the ability to understand the nature and consequences of a DNR order and reach an informed decision about the order. In addition, the law permits any dispute about CPR arising between a minor and his or her parent or guardian to be submitted to dispute mediation in the facility where the minor is a patient.

[83] A number of states have comprehensive statutes that provide for the early emancipation of minors based upon the circumstances of the parent-child relationship. New York does not. See D. Castle, "Early Emancipation Statutes: Should They Protect Parents as Well as Children?," *Family Law Quarterly* 20 (1986): 358-63.

legitimate parental control and guidance. Emancipation has been found in cases where minors have married,[84] where minors are gainfully employed and self-supporting,[85] where minors enter military service,[86] and where minors voluntarily leave the parental home without consent or good cause to do so.[87]

In New York, the emancipated minor doctrine has been used most often by courts as a common law exception to the legal obligation of parents to provide financial support for their children until the children reach the age of 21.[88] Courts have generally applied the doctrine to recognize minors' consent to health care, in the context of determining financial liability for treatments previously provided to minors.[89]

Courts in other states have developed and relied upon a "mature minor doctrine" to authorize adolescents to decide about their own treatment. These courts have focused on a minor's actual ability to understand the nature and consequences of a given treatment and to reach an informed decision.

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[84] See *Bach v. Long Island Jewish Hosp.* discussed at note 89.

[85] See *Cidis v. White* discussed at note 89.

[86] See *Zuckerman v. Zuckerman*, 154 A.D.2d 666, 546 N.Y.S.2d 666 (2d Dept. 1989), holding that a father's support obligation, pursuant to a divorce agreement, was terminated when his 17-year-old son became emancipated upon entering the United States Military Academy at West Point.

[87] *See Roe v. Doe*, 29 N.Y.2d 188, 324 N.Y.S.2d 71 (1971), holding that where a minor voluntarily abandons the family home and flouts legitimate and appropriate parental mandates, the minor is no longer entitled to support from the parent, and *In re Daniel N.*, N.Y.L.J., June 14, 1990, at 33, col. 6 (Westchester County Fam. Ct. 1990), holding that although a minor had left the family home, her father was still responsible for her support because she had good cause to leave, and because she had not left voluntarily.

[88] See, e.g., Besharov, *Supplementary Practice Commentaries*, N.Y. Fam. Ct. Act § 413 (McKinney Supp. 1992).

[89] See *Bach v. Long Island Jewish Hosp.*, 49 Misc. 2d 207, 267 N.Y.S.2d 289 (Sup. Ct., Nassau County 1966), where the validity of a minor's consent to nonemergency dermatological treatment was challenged. The minor was 19 and married when she consented to treatment. The legal age of consent was 21 and the case arose prior to statutory authorization for married minors to consent to medical treatment. The court held that the consent was valid because the minor was emancipated by marriage. See also *Cidis v. White*, 71 Misc. 2d 481, 336 N.Y.S.2d 362 (Dist. Ct., Nassau Co. 1972), recognizing that a self-supporting minor who lived at home with her parents, but who paid for her room and board, was an emancipated minor who could consent to the provision of services by, and the purchase of contact lenses from, a licensed optometrist.

In one case, a 1990 decision, the Illinois Supreme Court applied the mature minor doctrine to permit minors to refuse life-sustaining treatment. *In re E.G*[90] concerned a 17-year-old minor with leukemia who needed life-sustaining blood transfusions. The minor and her mother refused to consent on religious grounds. A lower court ruled that the minor was medically neglected and appointed a temporary guardian to consent to blood transfusions on her behalf. On appeal, the Illinois Supreme Court held that the minor could be treated as an adult capable of controlling her own medical treatment if it was shown, by clear and convincing evidence, that she was sufficiently mature to appreciate the consequences of her actions and to exercise the judgment of an adult. The court also found that maturity should be assessed by examining the minor's age and the nature of the proposed medical treatment. The court commented that if parents or guardians oppose a mature minor's refusal of life-sustaining treatment, this opposition should weigh heavily against the minor's right to refuse.

In another 1990 decision, *In re Long Island Jewish Medical Center,*[91] a New York trial court urged New York to adopt the mature minor doctrine. In that case, a 17-year-old minor refused, for religious reasons, blood transfusions necessary to sustain his life. His parents also opposed the transfusions. The court ordered the hospital to administer the transfusions, holding that the parents did not have the right to refuse life-sustaining treatment for their son. Declining to base its decision on the mature minor doctrine, the court concluded that the son had failed to demonstrate he possessed the capacity to make a decision based upon a "mature understanding of his own religious beliefs or of the fatal consequences to himself."[92] The court recommended that the legislature and appellate courts consider adopting the mature minor doctrine as either statutory or decisional law.

The United States Supreme Court has not yet decided whether mature minors possess a federal constitutional right to refuse life-sustaining treatment. Similarly, the New York Court of Appeals has not considered whether the right to refuse life-sustaining treatment, guaranteed by the New York State Constitution, extends to mature minors. However, the fact that both constitutions recognize that competent adults possess this right suggests that decisions by mature

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[90] 133 Ill. 2d 98, 549 N.E.2d 322 (1990).

[91] N.Y.L.J., May 23, 1990, at 26 (Sup. Ct., Queens County 1990).

[92] Ibid.

minors to forgo treatment may be accorded constitutional protection, albeit of a more qualified nature than decisions by competent adults.[93]

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[93] Compare the constitutional protection the Supreme Court has extended to mature minors in the area of reproductive rights. Mature minors have been determined to possess a constitutional right of privacy that is more constrained than an adult's but which nonetheless prohibits states from imposing a blanket prohibition or a blanket parental consent requirement on reproductive choices. See *Bellotti v. Baird*, 443 U.S. 662 (1979) (minors' privacy rights require states to recognize that there may be instances when a minor is sufficiently mature to make an independent decision about abortion, or when abortion without parental consent will be in her best interests even if she lacks the maturity to make her own decision); *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983) (although minors' privacy rights prohibit states from making a blanket decision that all minors are too immature to consent to abortion, or that abortion will never be in a minor's best interests without parental consent, states' interests in protecting immature minors will sustain a requirement of a judicial bypass procedure where a minor must prove she is sufficiently mature to make her own decision, or that abortion without parental consent is in her best interests).

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Ethical Choices, Values, and Dilemmas

This chapter addresses several basic ethical issues that arise when treatment decisions must be made for patients who lack the capacity to decide for themselves. It begins by examining the ethical values and principles underlying surrogate decision making and then focuses on three basic questions posed by surrogate decisions: who should speak for the patient, what standards should guide the decisions, and what should be the boundaries of surrogate authority?[1]

Basic Values Underlying Surrogate Decisions

The personal nature of treatment decisions and the importance of autonomy in the health care arena have been increasingly recognized in recent decades. Autonomy or self-determination encompasses basic rights of liberty and bodily integrity: the freedom to make life choices and to refuse unwanted bodily intrusion. A protected sphere of autonomy allows individuals to live in accord with their own religious, philosophical, and personal values, even when these differ from values held by others. Respect for autonomy also recognizes the moral worth and dignity of each person.[2]

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[1] General references for this chapter include New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (New York: New York State Task Force on Life and the Law, 1987); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington: U.S. Government Printing Office, 1983); T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 3d ed. (New York: Oxford University Press, 1989); A. E. Buchanan and D. W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989); and R. F. Weir, *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life* (New York: Oxford University Press, 1989).

[2] Task Force, 33-36; President's Commission, *Making Health Care Decisions* (Washington: U.S. Government Printing Office, 1982), 41-51; National Commission

Respecting the autonomous choices of patients also has the instrumental value of promoting their interests, as individuals are generally deemed the best judges of how their interests can be realized in health care and other personal dimensions of life. Although autonomy has been widely acknowledged for these reasons as an important value in making health care decisions, debate continues about the relevance of autonomy for surrogate decisions, and the weight autonomy should carry when it clashes with other societal values.[3]

Another fundamental principle or value guiding surrogate decisions is beneficence. One basic aspect of beneficence prohibits harming others.[4] Beneficence also entails an obligation to help others, preventing or removing harms and positively promoting their well-being. Both

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for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington: U.S. Government Printing Office, 1979), 4. For further discussion of autonomy, see G. Dworkin, *The Theory and Practice of Autonomy*, (New York: Cambridge University Press, 1988) and R. R. Faden and T. L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), 235-69.

Diverse religious communities acknowledge the importance of respecting patients' autonomous choices, while urging patients to exercise their autonomy responsibly. For example, the American Jewish Congress writes: "Many Jewish authorities mandate an active role for patients in making difficult medical decisions, including cases when the benefits of treatment are unclear or need to be weighed against risks that the treatment poses." "Substitute Medical Decision-Making for Patients who Lack Capacity," May 1991, 13.

Protestant denominations also stress the significance of individual choices about treatment. For example, a statement by the Presbyterian Church affirmed: "In a pluralistic society where people have different beliefs about life and death, basic Christian respect for persons demands that a person's decisions about death be honored in most instances." General Assembly of the Presbyterian Church, "The Covenant of Life and the Caring Community," July 1983. See also Catholic Health Association of the United States, "The Patient Self-Determination Act of 1990," 1991, 3. Religious views concerning decisions to forgo life-sustaining treatment are discussed further in Task Force, 33-35.

[3] See, e.g., Buchanan and Brock, 98-122; J. J. Glover, "A Philosophical Analysis of Substitute Decision Making: The Case of Ms. Nancy Cruzan," *Midwest Medical Ethics* 5 (1989): 10-11; L. H. Tribe, *American Constitutional Law*, 2d ed. (Mineola, N.Y.: Foundation Press, 1988), 1368-71.

[4] Many commentators stress the special stringency of obligations of nonmaleficence, or negative duties not to harm others. The classical statement of beneficence in medicine is found in the Hippocratic work *Epidemics*: "As to disease, make a habit of two things — to help, or at least to do no harm;" quoted in Beauchamp and Childress, 209.

surrogate decision makers and physicians have special obligations to promote the patient's interests and welfare.[5]

The principle of justice mandates that all individuals are treated fairly and that benefits and burdens are distributed equitably. In the context of surrogate decisions, justice demands that each patient receives a fair share of resources and opportunities and that no one is deprived as a result of his or her vulnerable condition. At the same time, the principle of justice acknowledges that when health care resources are limited, in a particular health care setting or in society at large, decisions about allocating resources among patients may be required.[6]

Other ethical considerations guide, and sometimes constrain, surrogate decisions. The patient's illness and the course of treatment may have a profound impact on family members and others close to the patient. These individuals must be respected, and their interests carry moral weight. Health care professionals also have personal interests. At times, their religious, ethical, or professional convictions may conflict with treatment decisions made by patients or others on their behalf. Institutions may also be committed to values or policies that delimit the options available to patients.

Some ethical concerns are expressed in terms of the interests of the state or society. Paramount among these concerns are preserving

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[5] Beauchamp and Childress, 120-27, 194-212; President's Commission, *Making Decisions*, 42-44; National Commission, 4-5. Religious and secular views of health care affirm the central importance of benefitting the patient. Edmund D. Pellegrino and David C. Thomasma write: "Acting for the good of the patient is the most ancient and universally acknowledged principle in medical ethics. . . . It is the ultimate court of appeal for the morality of medical acts." *For the Patient's Good* (New York: Oxford University Press, 1988), 73. Pellegrino and Thomasma understand beneficence broadly, as reflecting the patient's values, capacity to choose, preferences, and biomedical well-being.

[6] Beauchamp and Childress, 256-306; National Commission, 5. The principle of justice has long been of fundamental importance for religious traditions and moral philosophy, as well as jurisprudence and political thought. Justice has become an increasingly prominent theme in bioethics and health policy as both the potential benefits offered by health care and the accompanying expenses have grown dramatically. While all agree that health care should be provided in a just manner, commentators differ in their interpretations of justice. President's Commission, *Securing Access to Health Care*, vol. 1, *Report*, and vol. 2, *Appendices: Sociocultural and Philosophical Studies* (Washington: U.S. Government Printing Office, 1983), the latter providing an excellent collection of articles presenting diverse views; N. Daniels, *Just Health Care* (Cambridge: Cambridge University Press, 1985); C. Fried, "Equality and Rights in Medical Care," *Hastings Center Report* 6, no. 2 (1976): 29-34.

human life, preventing suicide, maintaining the ethical integrity of the medical profession, and protecting the interests of others affected by the patient's treatment decisions.[7]

Religious traditions and other world views understand human life to have transcendent value apart from the particular interests of individuals. Some express this value in terms of the sanctity of life. They believe life to be given by God, imposing on individuals responsibilities as stewards of their lives, beyond the pursuit of personal interests. Understandings of what is meant by the "sanctity of life," however, and of the nature and extent of related obligations, vary significantly.[8]

While all these ethical considerations are important, concern with the wishes, values, and welfare of the particular patient remains at the heart of surrogate decision making. This is especially important in our pluralistic society, in which public policies must recognize a diversity of religious and moral beliefs.

Choosing a Surrogate

The determination that a patient lacks capacity to make a particular health care decision in itself has important ethical and personal implications.[9] When patients are determined to lack decision-making capacity, the question of who speaks for the patient must be addressed.[10]

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[7] See the discussion of state interests in chapter 2, 25.

[8] A strong formulation is offered by one Orthodox Jewish scholar: "Only the Creator who bestows the gift of life may relieve man of that life even when it has become a burden rather than a blessing." J. D. Bleich, *Judaism and Healing* (Hoboken, N.J.: Ktav, 1981), 140. The Vatican's 1980 "Declaration on Euthanasia" states: "Most people regard life as something sacred and hold that no one may dispose of it at will, but believers see in life something greater, namely a gift of God's love, which they are called upon to preserve and make fruitful." In President's Commission, *Forego*, 302. For differing understandings of the implications of the sanctity of life for health care decision making, see pp. 57-60 in this chapter.

[9] See, e.g., Buchanan and Brock, 17-86; R. Macklin, *Mortal Choices* (New York: Pantheon Books, 1987), 83-97.

[10] For general discussion of choosing a surrogate, see, e.g., U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, OTA-BA-306 (Washington: U.S. Government Printing Office, 1987), 109 ff.; J. F. Childress, "Protecting Handicapped Newborns: Who's in Charge and Who Pays," in *Genetics and the Law III*, ed. A. Milunsky and G. J. Annas (New York: Plenum Press, 1985), 274-75.

The choice of surrogate is clearest when the patient previously designated someone, a "health care agent," to make decisions on his or her behalf. Decisions by an appointed agent are generally accorded greater deference, legally and morally, than decisions by an unappointed surrogate. Respect for the patient's delegation of authority as well as greater confidence in the person's commitment to the patient underlie the special status granted an appointed agent. Under New York's health care proxy law, all competent adults in the state can appoint a health care agent.[11]

Family Members and Close Friends

In clinical practice, if patients have not designated an agent, health care professionals usually look first to family members or close friends to act as surrogate. Family members generally best understand the patient's values and preferences, which inform and guide treatment decisions. In addition, relatives or close friends ordinarily share an intimate history with the patient and are deeply committed to his or her well-being.

The choice of family members to make treatment decisions also reflects the special status of the family in our society. As the locus of many of our most intimate relationships, family life is granted certain protections by law and custom to promote the privacy essential for those relationships to flourish. The special role of the family in our society therefore also supports the presumption in favor of family members as surrogates.[12]

Nonetheless, due in part to changes in values and patterns of family life, someone outside the family may be best suited to act as a surrogate for many individuals. In some cases, family members may be unavailable, unwilling, or incapable of acting as a surrogate. For example, an elderly husband may lack the ability to decide for his wife. Children of an elderly parent may live far away and be uninvolved in their parent's

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[11] N.Y. Pub. Health Law Article 29-C (McKinney Supp. 1992); Task Force.

[12] R. M. Veatch, "Limits of Guardian Treatment Refusal: A Reasonableness Standard," *American Journal of Law and Medicine* 9 (1984): 445-47; N. K. Rhoden, "Litigating Life and Death," *Harvard Law Review* 102 (1988): 437-39. Joanne Lynn and Jacqueline Glover write: "Virtually everyone trusts their families to make the decision, and they also would rather have families risk error than have the decisions be dictated by some other authority. Society runs real risks of damaging the social institution of families by mistrusting them, by ignoring that they will have to live with and make sense of the decisions made, and by abrogating long traditions of family responsibility in favor of state decision making." "*Cruzan* and Caring For Others," *Hastings Center Report* 20, no. 5 (1990): 11.

care. Family members may be estranged from the patient or unwilling to make decisions that promote the patient's wishes and well-being. Finally, even when family members are available, the person closest to the patient may be related to the patient by life experience but not by blood or marriage.

Complications may arise in determining which family member or friend should serve as surrogate. Many commentators suggest choosing the individual who seems closest to the patient, by making a determination on a case-by-case basis.[13] Others object that such a determination is often unclear and that physicians and other health care professionals have no special expertise or authority to select the best surrogate. Routine use of more formal procedures, such as court appointment of a surrogate, would be impractical. For this reason, many laws in New York and other states provide a serial list of surrogates by relationship, with, for example, spouses routinely taking priority over other family members.[14]

Some commentators have suggested that family members are not appropriate surrogates, in part because of the likelihood of conflicts of interest. However, other potential decision makers, such as physicians and the courts, are widely seen as even more problematic, and cannot offer the special advantages of those close to the patient. Concerns about conflict of interest are ordinarily addressed through safeguards that recognize the role played by physicians and the courts as well as others when family members fail to fulfill their responsibilities as surrogates.[15]

Patients without a Ready Surrogate

Despite a vast literature on surrogate decision making, little discussion has been devoted to choosing an appropriate surrogate when no family member or close friend is available. An individual who has no

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[13] President's Commission, *Making Decisions*, 182n; Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (Briarcliff Manor, N.Y.: The Hastings Center, 1987), 24.

[14] E.g., N.Y. Pub. Health Law § 2965 (McKinney Supp. 1992) ("Orders Not to Resuscitate"); D.C. Code Ann. § 21-2210 (1989) ("Health Care Decisions Act"); Fla. Stat. Ann. § 765.07 ("Life Prolonging Procedure Act"); Illinois Health Care Surrogate Act (H.B. 2334, enacted September 26, 1991). Individuals close to the patient other than the primary surrogate often play a significant although less formal role in decision making.

[15] P. Ramsey, *Ethics at the Edges of Life* (New Haven: Yale University Press, 1978), 201-3; Rhoden, 440; Buchanan and Brock, 139-41.

prior relationship with a patient lacks the guidance provided by information about the patient's choices and the shared history which supports the premise that the surrogate will act in accord with the patient's wishes and interests.

Various alternatives to family surrogates have been proposed, none of which is fully satisfactory. Some commentators have recommended that, in the absence of family members or close friends, health care professionals should decide based on the best interests of the patient. This approach creates the potential for serious conflict of interest and the possibility that the personal values of particular health care professionals will guide decisions. A physician ordinarily performs an important role in recommending treatment options, reviewing decisions made by surrogates, and challenging those that seem clearly wrong. This safeguard is lost when one person acts as both surrogate and physician. Some commentators suggest that participation by a second physician and an ethics committee provides sufficient protection for these vulnerable patients.[16]

Other commentators have recommended that state entities or individuals officially designated by the state be empowered to act as surrogates when family members are not available. Others insist that these cases should be decided by courts, either directly or through the formal appointment of guardians. These alternatives involve time-consuming and cumbersome procedures that may not correspond to the realities of medical practice or to the frequency with which treatment decisions must be made. By delaying decisions or discouraging health care professionals from pursuing certain treatment options, such procedures may effectively deny some patients a course of treatment that would best serve their interests. It also may not be feasible to implement some of these approaches for the large population of patients in nursing homes and hospitals who are isolated and have no surrogate.[17]

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[16] Veatch, 442-43, 457-60; Pellegrino and Thomasma, 167-68; A. S. Relman, "The *Saikewicz* Decision: A Medical Viewpoint," *American Journal of Law and Medicine* 4 (1978): 233-42.

[17] President's Commission, *Forego*, 129-32; Hastings Center, 24-26; Veatch, 466-67. In one program in New Mexico, volunteers talk to a patient about his or her values and preferences, find an appropriate surrogate when possible, and serve as likely candidates for formal appointment as guardians when necessary. See "Medical Treatment Guardian Program, Executive Summary to the Retirement Research Foundation," October 12, 1988 (J. M. Gibson, Project Director); P. Lambert, J. M. Gibson, and P. Nathanson, "The Values History: An Innovation in Surrogate Medical Decision-Making," *Law, Medicine and Health Care* 18 (1990): 202-12.

Ethical Guideposts for Surrogate Decisions

A broad consensus has emerged over the past decade supporting two standards for surrogate decision making: formulating a "substituted judgment" as to what the patient would have decided, and choosing in accord with the patient's "best interests." Respect for personal autonomy undergirds the substituted judgment standard, while the obligation to promote the patient's well-being in more objective terms forms the basis of the best interests standard.[18]

The Substituted Judgment Standard

The substituted judgment standard requires the surrogate to make decisions about treatment according to the patient's own values, personal preferences, and goals: in effect, to decide in the same way as the patient would if he or she were capable.[19] Many sources of information help to guide the surrogate's exercise of substituted judgment, ranging from information about the patient's treatment preferences in particular circumstances to more general knowledge about the patient's moral and religious values.[20] The substituted judgment standard has generally been favored by courts as well as commentators for those cases in which it is applicable. The subjective and personalized perspective takes the patient's own values and views of well-being into account, and seeks to promote the patient's self-determination.

Although the substituted judgment standard is widely recognized and relied upon, frequent application of the standard has also served to highlight its limitations. While some commentators have posed the theoretical problem of whether one can truly know what a formerly competent individual, now incompetent, would choose, criticism more often focuses on claims that the standard has been applied inappropriately in some cases and that it simply offers no guidance in others. Even with previously competent patients, application of the substituted judgment standard is often somewhat speculative. Many have criticized courts in several cases for stretching the limits of substituted judgment when the basis for deciding what the patient would have chosen was actually quite limited. This propensity to justify

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[18] See, e.g., President's Commission, *Forego*, 132-36; American Jewish Congress, 18-22; Catholic Health Association, 4.

[19] A surrogate following the substituted judgment standard does not simply provide his or her own judgment as a "substitute" for that of the patient but seeks to assume the patient's perspective and decide as the patient would have.

[20] In some cases, a prior decision by the patient may clearly apply to a treatment choice that must be made, rendering a surrogate decision unnecessary. See chapter 4.

decisions under an expansive notion of substituted judgment has led some commentators to caution that the standard is so elastic that it may lead to poor decisions.[21]

Attempts to apply the substituted judgment standard are even more problematic for individuals who have never been competent, such as Joseph Saikewicz, a 67-year-old profoundly retarded man who was dying of leukemia. In the *Saikewicz* case, the court held that chemotherapy could be withheld, relying on a finding that Mr. Saikewicz would have chosen this course of treatment for himself if he were "competent but taking into account the present and future incompetency of the individual."[22] Most commentators agree that for adults who have never been competent, and for children who have not yet developed the opportunity to arrive at and communicate their decisions or personal values, the substituted judgment standard simply offers no guidance.[23]

The Best Interests Standard

When little or no evidence of the patient's wishes is available, the most widely embraced guidepost for surrogate decisions is the best interests standard. Unlike a substituted judgment, which focuses on the patient's known preferences in seeking to infer what the patient would have wanted, the best interests standard relies to a greater extent upon objective criteria; it serves primarily to protect and promote the well-being of vulnerable patients. The best interests standard is often understood to reflect a societal consensus, or the perspective of a "reasonable person," choosing as most people would choose for themselves.

Many commentators urge that under the best interests standard, the surrogate should weigh the benefits and burdens of treatment as objectively as possible. In assessing the patient's interests, the surrogate should consider the potential goals of treatment in the context of the patient's particular circumstances. Possible benefits that should be weighed include the prolongation of life, the alleviation of pain and suffering, and the preservation or restoration of function. Treatment "burdens" involve the pain, risk, degree of invasiveness of medical interventions, and the possibility of needlessly prolonging the dying

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[21] G. J. Annas, "Quality of Life in the Courts: Earle Spring in Fantasyland," *Hastings Center Report* 10, no. 4 (1980): 9-10; Buchanan and Brock, 113-14. See also Rhoden, 376.

[22] *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

[23] Beauchamp and Childress, 171-73; G. J. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," *Hastings Center Report* 11, no. 3 (1981): 19-20.

process. According to most commentators, the burden or discomfort of the patient's ongoing condition should also be taken into account.[24]

Some commentators urge that the best interests of the patient should be identified by taking the view of a hypothetical average "reasonable person" in the patient's circumstances and deciding about treatment as we believe most people would decide for themselves. Others believe that we must, to the best of our ability, vicariously assume the perspective of the particular individual. For example, these commentators suggest that a life of profound handicap and mental retardation might be worth living from the perspective of one who has known no other condition, even if it might not seem worth living to others.[25]

There is obvious potential for tension and conflict among the values pivotal to determining best interests. It may be difficult to decide what constitutes or contributes to the patient's overall well-being in particular circumstances. In some situations, treatment may preserve or prolong the patient's life, but at the cost of burdening the patient with

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[24] E.g., President's Commission, *Forego*, 135. The President's Commission explicitly includes "the quality as well as the extent of the life sustained" among factors to be considered in assessing the patient's best interests. Other commentators insist that only the intrinsic burdens of a treatment, such as pain and risks directly caused by the treatment, can be counted as burdens of treatment. William E. May et al. state: "Traditionally, a treatment has been judged as excessively burdensome when whatever benefits it offers are not worth pursuing for one or more of several reasons: it is too painful, too damaging to the patient's bodily self and functioning, too psychologically repugnant to the patient, too restrictive of the patient's liberty and preferred activities, too suppressive of the patient's mental life, or too expensive." "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine* 3 (1987): 205, 208. Paul Ramsey, while wary of appealing explicitly to quality of life considerations, argues that burdens and benefits must be assessed from the perspective of the patient's overall condition. "It is this [person], and not the diseases one by one, that is the subject of medical treatment." *The Patient as Person* (New Haven: Yale University Press, 1970), 130.

[25] J. D. Arras, "Toward an Ethic of Ambiguity," *Hastings Center Report* 14, no. 2 (1984): 29-31; President's Commission, *Forego*, 135, 218-19; Rhoden, 394-419. Further complications arise in the case of a previously competent patient who loses decision-making capacity. A profoundly limited life might seem acceptable from the current view of the patient, who is now unaware of the problematic nature of his or her condition, but might seem unacceptable from the viewpoint of the patient's life-long personality, or that of a reasonable person who had enjoyed such a life. See R. S. Dresser and J. A. Robertson, "Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach," *Law, Medicine and Health Care* 17 (1989): 234-44; N. Rhoden, "How Should We View the Incompetent?" *Law, Medicine and Health Care* 17 (1989): 264-68.

pain or suffering. Alternatively, effective doses of pain relief may risk hastening the patient's death. In other cases, the treatment itself may not cause the patient discomfort, but may sustain the patient's life in circumstances that offer no hope for recovery or possibility for human interaction or awareness.

A determination of best interests often rests upon basic understandings about the nature and meaning of human life. What qualities of human life do we cherish? How do we affirm our caring and basic human commitments to one another at life's end? Diverse values, often shaped by religious and moral beliefs, have been embraced as central to the best interests standard. Indeed, in our pluralistic society, we do not share a single vision of the best possible outcome for patients in many circumstances; the broad concepts of benefits and burdens of treatment are identified and weighed differently.

Sanctity of life and quality of life. Some commentators, often identified as emphasizing "sanctity of life," believe that continued life is an intrinsic and personal good and that the limitations or burdens imposed by illness must always be weighed in that light. In one formulation of this position: "No matter how burdened it may be, human life remains inherently a good of the person. Thus, remaining alive is never rightly regarded as a burden."[26]

According to this viewpoint, an assessment of benefits and burdens that fails to value continued biological life as an unambiguous good shifts the ethical focus of treatment decisions to unacceptable judgments about the quality of the life preserved. For these commentators, burdensomeness should be assessed by focusing on the pain or invasiveness caused by the treatment itself, not by evaluating the quality of life that such medical intervention may sustain. Hence, if a treatment such as antibiotics is minimally invasive and has limited or no side effects, it should be provided to sustain a patient's life regardless of the quality of that life.[27] Proponents of sanctity of life also argue that quality-of-life judgments threaten to undercut societal commitments to the preservation of life and the protection of vulnerable persons.[28]

Other commentators view life as a basic and precious good, but one that is valued principally as a precondition for other higher goods, such

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[26] May et al., 205.

[27] Attempts to prolong life when a patient is imminently dying are generally understood to be futile and thus not morally obligatory.

[28] May et al., 205, 209. See also Ramsey, *Ethics*, 155, 172.

as experience, thought, and human interaction. Sustained biological function is not regarded as a goal in and of itself, apart from the patient's overall condition and the benefits or burdens that continued life may offer to the patient. According to this view, discontinuing treatment, even if it leads to the patient's death, is consistent with his or her best interests when the treatment is hopeless and serves only to sustain biological existence that is painful or of no benefit to the patient. As expressed by one commentator, "Medicine has traditionally refused to make prolongation of life its goal, not only because the goal was finally unreachable, but also because it recognized that efforts in that direction often produced more harm than good – in pain and discomfort as well as anguish and anxiety."[29]

These commentators reject the notion that an approach that considers the quality, and not just the duration, of the patient's life devalues human life. They argue instead that it affirms those dimensions of human life that infuse it with meaning – our capacity for consciousness, thought, and human interaction. Indeed, several commentators have explicitly argued that quality-of-life judgments are compatible with respect for the sanctity of life, properly understood. While life has intrinsic value, provision of life-sustaining treatment may entail excessive burdens in some particular cases. As stated by Richard McCormick: "Quality-of-life assessments ought to be made within an over-all reverence for life, as an extension of one's respect for the sanctity of life. However, there are times when preserving the life of one with no capacity for those aspects of life that we regard as human is a violation of the sanctity of life itself."[30]

Most commentators who support quality-of-life considerations are careful to specify how they use the term. Most would reject an interpersonal sense of the term, in which evaluations are made based on social worth or the value of the lives of individuals to others. A few

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[29] L. R. Kass, "Ethical Dilemmas in the Care of the Ill: What Is the Patient's Good?" *Journal of the American Medical Association* 244 (1980): 1947.

[30] R. McCormick, *How Brave a New World?* (Washington: Georgetown University Press, 1981), 407. Robert Weir (334) similarly asserts: "One can surely have a religious perspective on life according to which one affirms that individual human lives are gifts from God, that these lives have meaning and value beyond the assessments of other persons, and that these lives are rightly lived only when individuals understand themselves to be exercising stewardship over something precious, fragile, and transitory. *At the same time* one can have a philosophical perspective on life according to which neither life nor death is absolutized, the tragic occurrence of lives that are no longer worth living is admitted, and the occasional need for decisions having life-and-death implications is recognized."

commentators present quality of life as a threshold concept, where a life completely devoid of certain qualities (e.g., the capacity to think or relate to others) is not worth living, but comparisons are not made between gradations above that threshold.[31] Most commonly, quality of life is understood from the individual's own perspective: the value of the patient's life for the patient, not the value of the patient's life to others.[32]

Many commentators emphasize that the distinction between the substituted judgment and best interests standards is far from absolute, and cannot be reduced to a differentiation between subjective and objective criteria. Legal scholar Nancy Rhoden, for example, has argued that any plausible interpretation of the patient's interests involves subjective elements. Those who focus narrowly on objective or more measurable criteria of pleasure and pain exclude important though more subjective values such as dignity and bodily integrity.[33]

While some commentators advocate merging all considerations, including the patient's wishes and interests, into a single standard, others suggest viewing the substituted judgment and best interests standards as alternatives, to be applied as appropriate to particular

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[31] R. McCormick, "To Save or Let Die: The Dilemma of Modern Medicine," *Journal of the American Medical Association* 229 (1974): 172-76; A. R. Jonsen, M. Siegler, and W. J. Winslade, *Clinical Ethics*, 2d ed. (New York: Macmillan, 1982), 102-5.

[32] President's Commission, *Forego*, 135; Buchanan and Brock, 123-26; J. D. Arras, "Quality of Life in Neonatal Ethics: Beyond Denial and Evasion," in *Ethical Issues at the Outset of Life*, ed. W. Weil and M. Benjamin (Boston: Blackwell Scientific Publications, 1987), 151-86. Some who are sympathetic to patient-centered evaluations about quality of life reject use of that term as misleading and too readily linked to "insidious judgments of social worth." Accordingly, they advocate a standard of the patient's best interests, incorporating judgments generally associated with quality-of-life considerations, but less liable to misunderstanding and abuse. J. F. Childress, *Priorities in Biomedical Ethics* (Philadelphia: Westminster Press, 1981), 45. See also Weir, 355-56; Pellegrino and Thomasma, 92-98, 167-68.

[33] Rhoden argues that consideration of a patient's best interests properly entails inherently subjective judgments, such as dignity, and, as far as possible, the patient's own preferences and values, blurring the distinction between the standards. Rhoden, "Litigating," 396 ff., 406-10. Broadly understood, the reasonable person standard would include the elements such as "dignity" that Rhoden identifies as subjective, if the feelings would be shared by most people. An appraisal of best interests from the patient's perspective would also be likely to incorporate such elements.

cases. Although an absolute distinction between the standards cannot be made, they provide useful guidance for surrogate decisions.[34]

Identifying the interests of permanently unconscious patients. Many commentators have argued that the logic and value of relying on the best interests standard are strained when decisions are made for patients who are permanently unconscious.[35] These patients have lost all higher brain function – the capacity for consciousness, thought, feeling, and pain – even though their basic bodily functions, such as breathing and circulation, may continue for many years. They therefore have no conscious experience of either the benefits or burdens of treatment.

Several commentators have suggested that the best interests standard and an assessment of the benefits and burdens of treatment are simply irrelevant for permanently unconscious patients. This position rests on diverse claims, including a belief that such patients no longer possess attributes that we associate with persons, or that while these patients must be treated as persons, they do not have any significant current interests.[36] According to others, the best interests standard could apply for these patients, but would in most cases support a decision to forgo life-sustaining treatment.[37] Others disagree, arguing

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[34] Weir, 354-65, 158-59; Task Force, *Do Not Resuscitate Orders*, 2d ed. (New York: New York State Task Force on Life and the Law, 1988), 43-44.

[35] 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, patients who are in the end stage of degenerative neurological conditions such as Alzheimer's disease, patients with intracranial mass lesions, and patients with congenital hypoplasmia of the central nervous system. American Medical Association, Council on Scientific Affairs and Council on Ethical and Judicial Affairs, "Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support," *Journal of the American Medical Association* 263 (1990): 426-30; R. E. Cranford, "The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)," *Hastings Center Report* 18, no. 1 (1988): 27-32.

[36] See, e.g., Weir, 404-7. Most radically, some argue that these patients should no longer be considered persons, or should be regarded as dead. See President's Commission, *Defining Death* (Washington: U.S. Government Printing Office, 1981), 38-40; M. B. Green and D. Wikler, "Brain Death and Personal Identity," *Philosophy and Public Affairs* 9 (1980): 105-33; H. T. Engelhardt, Jr., *The Foundations of Bioethics* (New York: Oxford University Press, 1986), 210-16.

[37] See, e.g., J. D. Arras, "Beyond Cruzan: Individual Rights, Family Autonomy and the Persistent Vegetative State," *Journal of the American Geriatrics Society* 39 (1991): 1018-24. Arras argues that the substituted judgment and best interests standards represent appropriate criteria for decision making for purposes of public policy.

that the well-being of these patients is almost always promoted by providing life-sustaining treatment.

The previous interests of formerly autonomous patients might remain relevant even if they are seen to have no current interests. A patient may have expressed a desire that a certain treatment, or all treatment, be provided or withheld should he or she become permanently unconscious. Under a substituted judgment standard, such a wish would generally be decisive. Even if the patient did not explicitly state his or her wishes regarding particular treatments, the surrogate's familiarity with the patient's values and preferences might provide the basis for reasonable knowledge of what the patient would have wanted.[38]

For patients for whom no views or wishes can be discerned, a reasonable person standard would assess what most people would choose for themselves under the same circumstances. Especially in cases in which no previous wishes are known, some commentators argue that it is ethically permissible for the interests of others, such as family members, to determine the course of treatment.[39]

The possibility of mistaken diagnosis or a slim chance of recovery has been identified as a potential benefit of treating unconscious patients. Some regard even a slight chance at the restoration of consciousness as an overriding interest, especially in the absence of pain or other currently felt burdens for the permanently unconscious patient. Others respond that if permanent unconsciousness is carefully diagnosed, the chance of recovery is infinitesimal, and is not a significant interest of the patient.[40]

Some commentators also argue that, even aside from the possibility of recovery, permanently unconscious patients retain an interest in continued biological life as "inherently a good of the person," despite

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[38] The previously expressed wishes of those who are no longer able to communicate, and even of the dead, are often taken to be legally or morally decisive; for example, in the disposition of estates. Joel Feinberg discusses the concept of surviving interests in *Harm to Others* (New York: Oxford University Press, 1984), 83-93.

[39] For example, treatment might be continued if family members derive emotional solace from continuing care for the patient; alternatively, treatment could be withdrawn if family members are anguished by the patient's continued existence in a permanently unconscious state. The interests of others in society in the allocation of health care resources might also be considered; see pp. 64-65. See generally Buchanan and Brock, 126-32.

[40] President's Commission, *Forego*, 181-83; Weir, 408.

the individual's loss of consciousness. Concern is also expressed that withholding at least some types of life-sustaining treatment from the permanently unconscious might lead to the devaluing and neglect of others who are incompetent or are deemed to have low social worth.[41]

Whose Benefits and Burdens?

In arriving at a decision, surrogates must weigh the benefits and burdens of treatment alternatives. The question of whose benefits and burdens the surrogate may consider is ethically crucial. Should the surrogate focus solely on the patient, or is it permissible to weigh the benefits or burdens that continued treatment confers on others? Two related questions arise. The first is to what extent the patient's own wishes and interests encompass consequences or burdens for others. The second focuses on whether and under what circumstances a patient's interests may legitimately give way to conflicting interests of family members and others.

The Patient's Own Interests in Others

For many people, the emotional and financial burden on family or others close to them would be an important factor in decisions about treatment. Following a substituted judgment standard, these considerations would be weighed in determining what the patient would have chosen; the benefits and burdens for others would be assessed from the particular patient's point of view.[42]

Some commentators have suggested that even under a best interests standard, when little or no evidence exists about the patient's own preferences, burdens on family or others may be considered since "most people do have an important interest in the well-being of their families or close associates."[43] In essence, this position is an extension of the reasonable person standard, incorporating burdens on family because most people would wish to do so. This imputed altruism has been severely criticized. Some commentators have argued that strong evidence that the particular patient would consider burdens to others

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[41] May et al., 205 ff.; Bleich, 135; D. M. Feldman and F. Rosner, *Compendium on Medical Ethics*, 6th ed. (New York: Federation of Jewish Philanthropies of New York, 1984), 101-2.

[42] President's Commission, *Forego*, 132-34; Rhoden, "Litigating," 392-94.

[43] President's Commission, *Forego*, 135-36, 183. The Commission (136) counsels caution and the imposition of "especially stringent standards of evidence" in including the interests of others when assessing a patient's best interests.

is essential, and that a surrogate's assessment of best interests should remain strongly patient centered.[44]

Conflicting Interests of Others

The substituted judgment or best interests of a patient may conflict with the interests of other individuals, including family members, health care professionals, and others in society. A strong consensus recognizes the patient's interests and wishes as the paramount and generally decisive consideration for health care decisions. Some commentators have argued that the interests of others should also be considered, especially when the patient's interests are marginal and the interests of others are strong.[45]

Family interests. In some cases, the patient's interests diverge from important interests of others, including family members. Commentators from various perspectives have asserted that burdens on family members may be taken into account and that there are limits on the treatment that must be provided to the patient.[46] As articulated by Pope Pius XII, when treatment such as resuscitation "constitutes in reality such a burden for the family that one cannot in all conscience impose it upon them, they can lawfully insist that the doctor should discontinue those attempts, and the doctor can lawfully comply."[47]

Some commentators argue that the obligation to pursue a patient's interests or wishes diminishes when the patient is severely impaired. They claim that infants or adults who have no capacity for thought or human relationships are no longer persons, or that their interests properly count for less than those who are fully capable.[48] Others reject such claims as deeply troubling and offensive.

Other commentators, while not proposing that the interests of third parties necessarily ought to be considered, recognize that a family's

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[44] E.g., Buchanan and Brock, 132-33; U.S. Congress, Office of Technology Assessment, 118.

[45] E.g., Jonsen, Siegler, and Winslade, 133. Conflicting interests of health care professionals that take the form of conscientious objection are discussed in chapter 13.

[46] S. Hauerwas, "The Demands and Limits of Care — Ethical Reflections on the Moral Dilemma of Neonatal Intensive Care," *American Journal of the Medical Sciences* 269 (1975): 230. See also, e.g., J. Hardwig, "What About the Family," *Hastings Center Report* 20, no. 2 (1990): 5-6; Veatch, 436-38.

[47] Pope Pius XII, "The Prolongation of Life," *The Pope Speaks* 4 (1957): 397.

[48] E.g., Buchanan and Brock, 196-200. See also Arras, "Ambiguity," 31-32.

judgment will be influenced by the financial and emotional impact of decisions on themselves. These considerations are seen as acceptable so long as the family's decision falls within a range of ethically permissible choices and does not harm the patient in a clear or unreasonable way.[49]

Some commentators reject consideration of burdens on others in all cases, or at least object to their playing a decisive role. Such considerations may be viewed as intrinsically wrong or unfair to the patient or as inconsistent with proper medical practice. More commonly, it is argued that allowing the interests of others to determine treatment decisions can lead to abuse, in particular cases and as a general practice.[50]

Societal interests and the allocation of resources. In recent years, the debate about "burdens" has increasingly focused on the burden to society of treatment at a time of scarce resources. Some have argued that such burdens must be considered because society has an obligation to allocate scarce medical resources in a way that is fair and beneficial for all its members.

Others urge that allocation decisions should not focus on the unconscious or other patients who are vulnerable because of impaired or lost capacity for thought and interaction with others. They also believe that it is important to society to treat such patients in order to express and strengthen our commitment to human life.

Most commentators distinguish carefully between societal decisions to allocate resources in the context of public policy and physicians' decisions to discontinue treatment in particular cases through "bedside rationing." While the need for society to grapple with the hard questions posed by diminishing resources and rising demands has been recognized, allocation by physicians at the bedside has been widely opposed.

Physician rationing on a case-by-case basis may break an implicit promise to the patient, or undermine patient trust and the physician-patient relationship. Physicians as well as surrogates generally lack the moral authority to ration societal goods to the detriment of a particular patient. Such case-by-case allocation is likely to be inequitable; like

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[49] E.g., J. D. Arras, "The Severely Demented, Minimally Functional Patient: An Ethical Analysis," *Journal of the American Geriatrics Society* 36 (1988): 942-43.

[50] See U.S. Congress, Office of Technology Assessment, 118; Weir, 396, who objects to consideration of burdens to others playing a decisive role.

cases will not be treated alike, and the most vulnerable may be most harmed.[51]

Many commentators suggest that society should formulate policies to contain medical costs and allocate resources effectively. They caution, however, that the process of identifying priorities must be fair and the outcome consistent with basic social and ethical commitments. The President's Commission, for example, states that "the fact that a therapy is life-sustaining does not automatically create an obligation to provide it." At the same time, the Commission notes dangers in explicitly restricting treatment decisions on financial grounds and observes that there are few areas in which a strong societal consensus mandates that life-sustaining treatment should be withheld solely for financial reasons.[52]

Defining the Limits of Surrogate Authority

As discussed in Chapter One, surrogates are constrained in making decisions by several factors. Many of these are similar to the constraints posed for all health care decisions: the resources available for treatment, potential conflict among those close to the patient, and objections by health care facilities or professionals to following a particular course of treatment. Surrogates, even health care agents appointed by the patient, cannot exceed the legal limits on the authority that patients, if competent, would have if deciding for themselves.[53]

Some standards for treatment decisions might not distinguish between patients deciding for themselves and surrogates deciding for others; the moral obligation to accept treatment and the basis for

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[51] Jonsen, Siegler, and Winslade, 130-31; N. Daniels, "Why Saying No to Patients in the United States Is so Hard," *New England Journal of Medicine* 314 (1986): 1380-83. See also American Medical Association, Council on Ethical and Judicial Affairs, *Current Opinions* (Chicago: American Medical Association, 1989), 2.03, p. 3.

[52] President's Commission, *Forego*, 97, 95-100. The President's Commission (100) observes that, even aside from the symbolic importance of life-sustaining treatment, many routine tests and procedures are less beneficial and less cost-effective than more dramatic life-sustaining procedures. "Although society might be justified in limiting access for some very costly forms of life-sustaining treatment, the Commission does not believe it would now be wise to focus decisions about such therapy on the issue of cost-containment. Nor should discussions of cost-containment begin with consideration of life-sustaining treatments. If potential benefits must be foregone, they should first be in areas that allow more dispassionate reflection and opportunity to rectify errors."

[53] See N.Y. Pub. Health Law Article 29-C (McKinney Supp. 1992).

refusing would be the same. In general, however, surrogates are not granted the same latitude in making decisions as competent patients deciding for themselves. Usually, a competent patient's choices are honored even if others believe they are idiosyncratic, unwise, or detrimental to the patient's well-being. In contrast, surrogate decisions are not accorded the same deference. One reason for the discrepancy involves the practical difficulties of determining the wishes of a now incompetent patient. Additionally, respect for the patient's self-determination, which may override concerns about the patient's well-being when competent patients decide for themselves, is absent or attenuated when someone else decides on the patient's behalf.[54]

In the context of proposals for public policy, limits on surrogate authority often rest on judgments about how our reverence for human life is best expressed or sustained. Treatment decisions are assessed not just in terms of the outcome for particular patients but as societal practices, and as symbolic gestures that both reflect and shape our aspirations and values. Some criteria for guiding these decisions have been expressed in terms of ethical norms or obligations while others have been articulated in the context of public policy and law. The limits proposed for surrogate decisions are shaped by implicit or explicit assumptions about the benefits and burdens of treatment under certain circumstances as well as the potential for abuse when family members or others decide about life-sustaining measures on behalf of decisionally incapable patients.

The Parameters of Surrogate Choice

One central set of issues concerns the degree of deference that should be given to the surrogate and the criteria for intervening or overriding the surrogate's decision. At one extreme, surrogates might have virtually no authority. The right to decide about treatment, especially life-sustaining treatment, might be seen as purely personal: a competent patient may decide to forgo life-sustaining treatment, but others may not make that decision on the patient's behalf. Once patients become incompetent and have not left clear instructions about treatment, no one else has the moral authority to forgo measures to sustain the patient's life.[55]

Others would allow some surrogate decisions to forgo life-sustaining treatment but would maintain a strong presumption for providing

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[54] President's Commission, *Forego*, 133; Veatch, 434-35.

[55] See Weir, 121-22.

treatment. This presumption assumes that life-sustaining treatment, even for dying patients, generally serves their best interests. Mistaken decisions to forgo life-sustaining treatment are less susceptible to correction than mistaken decisions to continue treatment. For these reasons and others, some commentators insist on "erring on the side of life." A strong presumption for treatment places upon the surrogate the burden of proving that it is permissible to withdraw or withhold treatment.[56]

A presumption for treatment can also be compatible with accepting decisions to forgo treatment in clearly defined situations. Many laws and policies allow for decisions to forgo life-sustaining treatment when substantive medical standards are met, such as when the patient is terminally ill and treatment would only prolong dying, when the patient is permanently unconscious, or when the treatment would be absolutely futile. In other cases, life-sustaining treatment would be presumed to be in accordance with the patient's interests and wishes unless it would manifestly conflict with such criteria; for example, if the patient's wishes to forgo treatment are known, or the treatment is "virtually futile . . . and the treatment itself under such circumstances would be inhumane."[57]

Other commentators argue that establishing too strong a presumption in favor of life-sustaining treatment results in decisions that violate the wishes and interests of patients. Some propose the criterion of "reasonableness" to establish the parameters of permissible surrogate decisions. One approach might require surrogates to reach the "most reasonable" decision, with limited discretion. A decision about which course of treatment is most reasonable, however, calls for a judgment about which people will differ strongly. This standard might, in some cases, overrule surrogate decisions to refuse treatment, and might in others forbid requested treatment that health care professionals or others find unreasonable from their own perspective.[58]

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[56] Rhoden ("Litigating," 419-37) argues that physicians and courts are unduly influenced by a presumption for providing life-sustaining treatment. See also Chief Justice William Rehnquist's opinion in *Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990).

[57] May et al., 205; 42 U. S. C. A. §§ 5101 to 5106g (West Supp. 1991), the Child Abuse Prevention and Treatment Act of 1984, as amended. See also American Medical Association, Council on Ethical and Judicial Affairs, *Current Opinions*, 2.21; and the discussion in chapters 2 and 14.

[58] Veatch, 466-67.

Many argue that surrogates should be granted the discretion to decide within a range of acceptable alternatives as long as the decision is "reasonable" and informed. This understanding of a reasonableness standard does not dictate a single conclusion in most cases. Instead, it sets general limits of moral permissibility, recognizing that a range of choices within those parameters are acceptable and should be respected because of the surrogate's special relationship to the patient.[59]

Some commentators have urged that certain cases, including many when patients are permanently unconscious or severely debilitated, fall into an ethical gray zone in which several choices are ethically acceptable but there is no clear "right" answer. Patients rarely provide an advance decision that applies directly, and often a surrogate cannot know with certainty what a patient would want or what is best. Instead of demanding a degree of certitude that cannot be achieved, society should presume that decisions by family members or others close to the patient are acceptable unless others can show that a decision exceeds the boundaries of reasonableness. This presumption reflects the belief that treatment choices are inherently value-laden and should be made by those most intimately involved with the patient and most likely to realize the patient's values.[60]

Reviewing and Challenging the Surrogate's Decisions

In conjunction with or as an alternative to substantive limits on surrogate authority, procedures are often relied upon as a check upon surrogate decisions. Such procedures, implicit in medical practice or explicit in hospital or public policy, often focus on the selection of a surrogate and mechanisms to override or remove surrogates who place the patient's interests at risk. In some cases, family members may be incapable of deciding on the patient's behalf, may act irresponsibly, or may disregard the patient's wishes and interests. Health care professionals often challenge particular surrogate decisions that they believe endanger the patient. Intervention to establish a new surrogate, including legal action in rare cases, may also be undertaken.

Discussions among physicians, other health care professionals, and surrogates play an important role in safeguarding the well-being of patients. In the first instance, physicians frame the treatment options presented to the surrogate and generally recommend a course of

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[59] Veatch, 447-57, 465-66.

[60] Rhoden, "Litigating," 379, 419; Arras, "Severely," 942-43. See also President's Commission, *Forego*, 217-23.

treatment. They also have an obligation to promote informed decisions by surrogates. If the surrogate makes a decision that would harm the patient, health care professionals may seek to dissuade the surrogate through informal and formal discussion.[61]

Institutional consultation or review committees such as ethics committees, discussed in Chapter One, provide another forum for challenges to surrogate decisions. In many cases, better communication or dispute mediation may resolve the problem. In other cases, the ethics committee can perform a consultative function, offering advice to patients, family, and health care professionals. If these activities fail to resolve the problem, an ethics committee can inform a government agency or institute legal proceedings. An ethics committee might also regularly review some sorts of cases with sensitive treatment decisions, even in the absence of conflict.

The courts have ultimate authority and responsibility for protecting vulnerable patients. Courts are generally viewed as a last resort for disputes about treatment decisions because the proceedings are often cumbersome, expensive, and adversarial. In some cases, court proceedings are unavoidable, although significant debate continues about which cases require judicial scrutiny.[62]

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[61] Pellegrino and Thomasma, 162 ff.; President's Commission, *Making Decisions*; Childress, "Protecting," 276-77. See also Faden and Beauchamp's discussion distinguishing among persuasion, manipulation, and coercion, 346-54.

[62] President's Commission, *Forego*, 154-60; *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); A. M. Capron, "The Burden of Decision," *Hastings Center Report* 20, no. 3 (1990): 36-41.