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.

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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

[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

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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 Prinitng 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.

most people trust their family members to decide

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," *Gerontologst* 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 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, 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.and

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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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. Q

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 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.

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 modem 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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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. Sprjtz, "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-interpretend the law, often in ways that added to the procedures in the law. The study reults may reflect, in part, the tendency to 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 SIoan-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 Americari 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. Starter, "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 party 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. Avon 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 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 entiy of a DNR order, suggesting an unwillingness or reluctance to assume responsibility for critical health care decisions. At 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.

[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."[19] 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.

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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.

A wealth of literature describing how the 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. A1985 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.

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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.

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 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*, 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 Cdnsent," *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," *Hasting Cento- 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 ail 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

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]

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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 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* u *Nicoleau*, 75 N.Y.2d 218,551 N.Y.S.2d 876 (1990).

[6] 110S.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 NJ. 10,355 A.2d 647, *cert denied sub nont 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 NJ. 335, 529 A2d 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* u *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 NJ. 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 parent- less 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 without holding of feeding by artificial means should be evaluated in the same manner as any other distinction between artififical nutrition and hydration and other life-sustaining measueres. 110 S. Ct. at 2851-2856. New York's health care proxy law does distiniguish artififical 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.2d218, 551 N.Y.S.2d876 (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."[1217] 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

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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 norru 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.LJ., 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."

to make an informed decision about health care — has critical 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 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.

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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[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 mil, the court also specified that oral evidence can satisfy the standard.

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 534N.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 Drocedures 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* u *Grace Plaza of Great Neck, Inc.,* 148 AJD.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., and 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

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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

the delegation of all healthcare 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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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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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 (Bums Supp. 1990), as construed by the Indiana Supreme Court in *In re Lawrence,* 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 111 (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.

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ARIZONA, *Rassmussen v. Fleming,* 154 Ariz. 207, 741 P.2d 674 (1987); DELAWARE, *Sevems v. Wilmington Medical Center, Inc.,* 421 A^2d 1334 (Del. 1980); GEORGIA, *In re LII.R,* 253 Ga. 439, 321 S.E2d 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 NJ. 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. (111. 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 treatment, or an effort to picture what a hypothetical "reasonable person" would choose in the patient's circumstances.

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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 NJ. 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

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 surrogate 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

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48 [46]See *Superintendent of Belchertown State School v. SaiJcewicz,* 373 Mass. 728, 370 N.K2d 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.

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For example, in *Rasmussen* v. *Fleming,* 741 P.2d 647 (Am. 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.

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.

Kg., *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.

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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.

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.[53] 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.[54] 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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[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).

[53] Tor 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

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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 maybe 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 extraordinaiy 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).

Surrogate's Court Procedure Act authorizes courts to 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,* underscores the deference accorded parental decisions. In *Hofbauer,* the

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

[61] See *Grmker* v. *Rose,* N.Y.LJ., 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 contraty, 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).

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 with severe

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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 bom 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.

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 CF.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 legitimate

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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 arid 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 haw 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, "Earfy Emancipation Statutes: Should They Protect Parents as Well as Children?," *Family Law Quarterly* 20 (1986): 358-63.

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, 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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[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* u *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.LJ., 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

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90 111. 2d 98,549 N.E.2d 322 (1990).

91 N.Y.LJ., May 23,1990, at 26 (Sup. Ct., Queens County 1990).

92 Ibid.

that both constitutions recognize that competent adults possess this right suggests that decisions by mature minors to forgo treatment maybe accorded constitutional protection- albeit of a more qualified nature than decisions by competent adults.[93]

[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* u *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 Cento' 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 III 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 surrogate decision makers and physicians have special obligations to promote the

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for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Bebnont 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 UniversityPress, 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 derisions 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.

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 polity 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, NJ.: 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 Tecimologies 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 Ilf* 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 prior

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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 primaiy 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.

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. Reiman, "The *Saikewicz* Decision: A Medical Viewpoint," *American Journal of Law and Medicine A* (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.

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

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[18] Nathanson, 'The Values History: An Innovation in Surrogate Medical Decision-

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

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.

basis for deciding what the patient would have chosen was actually quite limited. This propensity to justify 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

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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.

interventions, and the possibility of needlessly prolonging the dying 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

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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 waiy 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 \1* (1989): 264-68.

patient's life, but at the cost of burdening the patient with 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 in- vasiveness 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]

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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 obligatoiy.

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

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

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[29] L. R. Kass, "Ethical Dilemmas in the Care of the 111: 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."

personal 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 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 Modem 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 that the well-being of these

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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. Wilder, "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.

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

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Arras argues that the substituted judgment and best interests standards represent appropriate criteria for decision making for purposes of public policy.

[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.

biological life as "inherently a good of the person," despite

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? IWo 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

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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.

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 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.

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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.

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

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 refusing would be the same. In general, however, surrogates are not

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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).

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 decisional- ly 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 treatment. This presumption assumes that life-sustaining treatment,

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

[55] See Weir, 121-22.

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

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

[60] Rhoden, "Litigating," 379, 419; Arras, "Severely," 94243. See also President's Commission, *Forego*, 217-23.

presented to the surrogate and generally recommend a course of 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] PeIlegrino 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 NJ. 10, 355 A.2d 647, *cert denied sub nont 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.

Part II

Devising Public Policy for Surrogate Decisions

Introduction

Every year in health care facilities across New York State thousands of decisions are made for patients unable to decide for themselves — the young, the old, infants, those temporarily impaired, those who will not regain capacity, and those never able to decide about treatment. The question for New York State policy is not whether surrogate decisions will be made, but who will make them and by what criteria.

Society has an obligation to protect the wishes and interests of patients dependent on surrogate decisions to guide the course of their medical treatment. Illness itself brings vulnerability — patients often experience a loss of autonomy, self-assurance, and identity. When illness renders a person unable to decide about treatment, or when individuals such as children or the developmentally disabled have not attained the capacity to decide, that vulnerability is more acute. Society has a special duty to incapacitated patients — an obligation to respect them as individuals, to preserve their own religious and moral values in these intensely personal choices, and to promote their well-being by facilitating responsible decisions about their medical care.

In fashioning public policy, society must address the harm caused to patients by both undertreatment, the failure to provide needed beneficial treatment, and overtreatment, the provision of treatment that is useless or that harms the patient. The risks of undertreatment, especially in the face of increasing medical options for cure and relief of suffering, have long been at the forefront of public debate and consciousness. Proliferating medical technologies have also heightened awareness of the harm caused by overtreatment. When unnecessary tests or procedures are performed, the outcome may be benign, although costly, for the patient. Yet, some tests and many treatments carry significant risks of morbidity and mortality and offer little if any hope for restoring or sustaining function. The Task Force believes that society must acknowledge both undertreatment and over-treatment as critical problems in the delivery of modern medical care.

The problems call for different solutions, and the tension between the two must be balanced in policies for surrogate decisions.

The United States Supreme Court, in ***Cruzan*** v. ***Director, Missouri Department of Health,*** affirmed that each state has the authority and responsibility to fashion policies for surrogate decisions. In many states, policies have been established by case law. The courts have recognized that family members and others may decide about life-sustaining measures, in accord with specified standards. In other states, legislatures have granted family members the authority to decide about life-sustaining treatment, subject to substantive and procedural requirements.

In opinions issued over the past decade, the New York Court of Appeals has consistently affirmed that the obligation to establish policy for surrogate decisions rests with the legislative, not the judicial, branch. Under existing New York law, only one avenue exists for decisions to forgo life-sustaining treatments for adult patients who lack decision-making capacity and have not appointed a health care agent — clear and convincing evidence of the patient's wish to refuse the same or similar treatment under specified medical circumstances. With the exception of decisions about do-not-resuscitate (DNR) orders, New York stands alone with Missouri as a state where legal precedents expressly deny family members the authority to refuse life-sustaining treatment for incapacitated patients.

In practice, the clear and convincing evidence standard is often unworkable and inhumane. It is a legal standard that translates poorly at the bedside where families and health care professionals must confront the hard choices that incurable illness and medical advances present.

The standard requires that patients forecast in advance what their medical condition will be at some future time and the treatments that will be available. In an age of rapid medical advances, this is a difficult task even for medical experts. It is simply unrealistic and unfair for the vast majority of the public. Even for those who are sophisticated about medical choices, the standard poses problems; it forces individuals to make specific hypothetical judgments about future care that are often best made at the time illness arises, in consultation with health care professionals.

Once patients lose decision-making capacity, many families find themselves unable to satisfy the demands of New York law, in part because our legal framework for decisions about life-sustaining treatment thwarts commonly held assumptions. The premise that families

and others closest to patients have no authority to decide about life-sustaining treatment when patients are too ill to decide for themselves flies in the face of personal and social expectations. Family members and, increasingly, others intimately connected by life experience, are entrusted to care for and nurture one another. Our laws on inheritance, marriage, and parental rights and responsibilities are founded on this assumption.

Many adults will never sign a health care proxy or provide clear and convincing evidence of their wishes. They assume that relationships which have sustained them throughout life will also accompany them in the face of illness and death.

Moreover, neither a health care proxy nor clear evidence of wishes is a possibility for children, for infants, or for many mentally ill and developmentally disabled adults. Existing New York law does not clearly authorize and guide parental decisions to forgo life-sustaining treatment for minor children or decisions by parents or others for developmentally disabled adults.

In this legal vacuum, some families and physicians make private decisions to withdraw or withhold life-sustaining treatment. But they do so without the guidance and sanction of New York State law. In many cases, facilities and physicians abide by existing law, leaving families and others stranded at the bedside, unable to refuse life-sustaining treatment despite their deep commitment to respect the patient's values or their desire to discontinue treatment that imposes excessive burdens on the patient without offering hope for cure, recovery, or relief of suffering.

The legislature has acted twice to facilitate decisions about life-saving or life-sustaining treatment for patients unable to decide for themselves, once when it passed DNR legislation in 1987 and again in 1990 when it enacted the health care proxy law. The DNR law authorizes family members to decide about CFR for incapacitated patients. The health care proxy law encompasses all treatment decisions but only for those who sign a health care proxy appointing a health care agent before they lose decision-making capacity. Each law is a milestone for New York State. But neither addresses decisions about life-sustaining treatments other than CPR for adults who fail to sign a proxy, for children, or for infants. Nor does either law create a mechanism for consent to treatment for patients who have no family members or health care agent available to consent.

As the Task Force recognized in proposing the law on DNR orders, legislation is not always the best or preferable means to establish public policy, especially when policies entail sensitive and controversial moral questions. Although powerful, legislation can be a blunt instrument. Uniformity of fundamental, sound principles for health care decisions in facilities across the state confers obvious benefits. It also carries significant difficulties. Health care facilities have diverse resources, practices, and patient populations; they also have varying degrees of experience and commitment in grappling with the dilemmas posed by medical advances. Policies designed to address problems at some facilities will be intrusive at others that forged ahead to establish their own approach without the prod of state mandates.

In New York State, judicial decisions have rendered the debate about alternatives to legislation on surrogate decisions academic. In the face of legal precedents established by the New York Court of Appeals, only the legislature can authorize family members and others close to the patient to decide about life-sustaining treatment. Legislation is also essential to establish policies for decisions on behalf of patients who have no family members or others to act as their surrogate.

The Task Force has devised a proposal for legislation on surrogate decisions. The proposed legislation seeks first and foremost to promote the wishes and interests of incapacitated patients. It is premised on the notion of family as a fundamental institution in our social and private lives, but it acknowledges that family members are not always available or able to speak on the patient's behalf. The proposal also affirms society's obligation to adopt responsible policies for patients who have no natural surrogates and are therefore, most vulnerable.

Looking at the two poles of decision-making models for incapacitated patients — the medical model of informal decisions at the bedside and the judicial model with all its procedural and evidentiary requirements — the Task Force has carved a middle path between the two. In doing so, it seeks to balance the need to protect patients from poor decisions with the need for policies that work in the context of medical practice. Some will feel that we erred too far in one direction or the other. Their position too must be weighed on the twin scales of prudence and principle. Procedures that prove unmanageable in the clinical setting will either delay attention to the patient's medical needs or be ignored altogether.

The proposed legislation sets forth standards for surrogate decisions, a priority list of those who may act as surrogate, and proce-

dural and substantive safeguards for the decisions. Many of the policies are designed to satisfy the need for standards while accommodating the diverse sizes and staffing patterns of health care facilities throughout New York State. Where appropriate, rather than specifying the content of procedures, the proposed legislation requires facilities to develop their own procedures. This approach ensures that facilities will address important issues in a way that is public and accountable but allows the flexibility needed to encompass all hospitals and nursing homes in New York State under the umbrella of one legislative scheme.

This section of the report presents the policies embodied in the Task Force's legislative proposal: the social and ethical values that animate the proposal, the alternative policies considered, and the rationale for the policies chosen. The proposed legislation appears as Appendix A.

4

Deciding in Advance

Society has increasingly recognized the personal dimension of treatment choices and the importance of enabling patients to choose for themselves. Two vehicles have been created to empower competent adults to protect their health care choices and interests beyond the loss of decision-making capacity. Commonly referred to as advance directives, these legal instruments for advance planning are the health care proxy, otherwise known as a durable power of attorney for health care decisions, and the living will.[1] Research about advance directives reveals that individuals, when informed about these options, generally desire the opportunity to plan in advance.[2]

The surrogate decision-making proposal presented in this report does not diminish the importance or value of advance guidance from the patient directly. 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, adults should be educated about advance directives and encouraged to appoint a health care agent. Planning in advance is not just for the ill or the elderly. In particular, physicians should initiate discussions with all patients about advance directives, including patients who are healthy.[3]

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[1] See discussion of New York law on advance directives in chapter 2, 29-33.

[2] A study by L. L. Emanuel et al. found that approximately 90% of the patients and general public surveyed were interested in some form of advance directive — a conversation with a physician, a living will, or a health care proxy. L. L. Emanuel et al., "Advance Directives for Medical Care — A Case for Greater Use," *New England Journal of Medicine* 324 (1991): 889-95.

[3] Emanuel et al., 893-94. The Emanuel et al. (891) study also identified the reasons patients who expressed an interest in advance directives had not completed one: 'The two most frequently cited barriers were the patient's expectation that the physician should take the initiative and the sense that such issues were only relevant for those who were older or in worse health." In addition, younger patients desired advance directives and discussions with physicians more often than older patients. Another study found that a majority of elderly patients (70% of respondents) thought discussions about CPR should take place during periods of good health.

The Task Force believes that appointment of an agent is the best vehicle to foster a person's rights and an informed decision-making process following the loss of decision-making capacity.[4] A copy of the proxy form and instructions developed by the New York State Department of Health appears as Appendix D in this report. While this form will be recognized most readily by health care providers, individuals may use another form when designating an agent so long as it meets legislative requirements. Designating a health care agent avoids the difficulty inherent in the use of living wills of trying to anticipate future medical circumstances and make treatment choices at a time that may be far removed from the actual events. An agent can instead make contemporaneous decisions in consultation with health care professionals based on all available medical information.

Individuals who sign a health care proxy may provide oral or written instructions to the person appointed as agent but need not do so.[5] The Task Force believes that it is unfortunate that individuals are sometimes urged to leave detailed instructions about treatment when they sign a health care proxy. The Task Force favored the proxy approach, in part, because the proxy does not force people to confront the difficult task of prescribing specific treatment decisions in advance.[6]

R. H. Shmeriing ct al., "Discussing Cardiopulmonary Resuscitation: A Study of Elderly Outpatients," *Journal of General Internal Medicine* 3 (1988): 317-21.

4 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).

5 Although individuals are sometimes advised to leave specific guidance as a legal precaution, the health care proxy law expressly empowers the agent to decide without such instructions. Even for decisions to forgo artificial nutrition and hydration, the agent must have reasonable knowledge of a patient's wishes, not clear and convincing evidence. That knowledge may be established by prior oral statements by the patient as well as an agent's knowledge of the patient's overall personal values and goals.

6 Task Force, 75-83. As pointed out by one author, "lists of interventions may shift attention away from overall treatment goals or may prescribe inappropriate medical care." A. S. Brett, "Limitations of Listing Specific Medical Interventions in Advance Directives," *Journal of the American Medical Association* 266 (1991): 825-28. See also G. J. Annas, "The Health Care Proxy and the Living Will," *New England Journal of Medicine* 324 (1991): 1210-13; J. Lynn, "Why I Don't Have a Living Will," *Law, Medicine and Health Care* 19 (1991): 101-4. Under New York's law, a health care agent has the authority to interpret written instructions from the patient and can override instructions based on a good faith judgment that the patient did not intend that they apply in the actual circumstances that arise, see N.Y. Pub. Health Law § 2985(d) (McKinney Supp. 1992), but specific instructions may still generate conflict or confusion.

Under the health care proxy law, unless an adult expressly limits the agent's authority, the agent stands in the patient's shoes, with the same authority that the patient would have when competent to decide about treatment. Decisions by an appointed health care agent should take priority over decisions by any other surrogate appointed under the proposed policies for surrogate decisions. If an agent has been appointed, health care professionals should seek the agent's consent under the policies in the health care proxy law, turning to a surrogate only if the agent is unavailable or unwilling to serve.

Some people who have no one to appoint as agent or who do not want to delegate authority for health care decisions rely on a living will or oral instructions about treatment. Under the Task Force's proposal, if the patient's prior statements about treatment provide a decision by the patient that meets the clear and convincing evidence standard, health care professionals need not seek the consent of a surrogate. Indeed, when the patient's advance written or oral statements are specific enough to meet the clear and convincing standard, health care providers have the same duty to honor the statements as if they had been made by the patient while competent. Existing New York law protects such statements as an exercise of the patient's common law and constitutional right to decide about treatment.[7]

As a practical matter, health care professionals must often consult with family members when determining whether clear and convincing evidence of the patient's wishes can be established. In this process, health care professionals may learn that the patient's statements are general or unclear. When this occurs, the statements do not stand on their own as a prior decision by the patient but guide the surrogate's decision. Hence, in speaking with family members or other surrogates, health care professionals should distinguish cases when a surrogate decision is unnecessary because the patient actually made a prior choice, from cases when a surrogate should decide, relying on the patient's prior statements to approximate the choice they believe the patient would have made.

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[7] See chapter 2, 29-32, and appendix C, containing the New York State Department of Health statement on the Patient Self-Determination Act. See also Department of Health regulations implementing the health care proxy law and the Patient Self-Determination Act, N.Y. Comp. Codes R & Regs. tit. 10, §§ 400.21 and 700-5 (1991).

Recommendation

The surrogate decision-making proposal does not diminish the importance or value of advance guidance from the patient directly — either the appointment of a health care agent or written or oral instructions. Decisions by a health care agent should take priority over decisions by any surrogate appointed under the proposed legislation. In addition, if a patient's prior oral or written statements about treatment provide a decision that meets the clear and convincing evidence standard, health care professions should not seek a surrogate's consent for the decision.

See Appendix A, proposed legislation, Sections 2(1) and 4(3).

5

Initiating the Surrogate's Authority: The Determination of Incapacity

The loss of decisional capacity is a critical turning point in a patient's care and in the process for making treatment decisions. Once determined incapable, patients no longer participate directly in decisions about their treatment. Both the standard and the process for determining incapacity must therefore be carefully defined and implemented.

What Is Capacity?

In recent years, the notion of capacity to make health care decisions has emerged as an alternative to the traditional standard of competence.[1] While used in many contexts, "competence" refers most accurately to a judicial determination about a person's decision-making ability. Competence generally describes a status, the ability to make all or, conversely, no decisions for oneself. "Capacity" has been understood as a more limited and specific concept that refers to a person's ability to make a particular decision.

First proposed by ethicists and philosophers, the notion of capacity has gained widespread support. In a 1986 case, ***Rivers*** v. ***Katz,*** the New York Court of Appeals relied upon the capacity concept in holding that involuntarily committed mental patients may refuse antipsychotic medication unless they lack capacity to decide about the treatment.[2] Based on recommendations by the Task Force, the DNR and health care proxy laws call for a bedside judgment about capacity, not competence, as the trigger for an agent's or surrogate's authority.

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[1] For an extensive discussion of the limitations of the competence standard see, e.g., W. Gaylin, "Competence, No Longer All or None," in *Who Speaks for the Child: The Problems of Proxy Consent,* ed. W. Gaylin and R. Macklin (New York: Plenum Press, 1982), 27-54.

[2] 67 N.Y.2d 485,504 N.Y.S.2d 74 (1986).

Choosing a particular standard for evaluating capacity calls for an ethical judgment that weighs two risks: the risk that a capable patient will be denied the right to decide about a treatment and the risk that a patient without capacity will be harmed by his or her decision. At one extreme would be a minimal standard of capacity that looks only at whether the patient expressed a choice. This standard maximizes autonomy but fails to assess the patient's ability to decide or to protect the patient from the risk of a harmful decision. At the other extreme would be a standard that sacrifices autonomy by resting the determination of capacity on a judgment about the decision itself. Under this kind of "outcome" standard, the patient would be deemed capable if he or she made the "right" decision and incapable otherwise. This is, in fact, the standard employed by health care professionals when they accept a patient's decision-making capacity if the patient agrees with their recommendation, and conclude that the patient lacks decision-making capacity if he or she disagrees. This standard effectively denies patients who make unconventional choices the right to decide, and renders the determination of capacity subject to the personal values and judgments of the individual conducting the assessment. Like the standard that relies solely on mere expression of a preference, an outcome standard offers no basis for evaluating the patient's ability or cognitive process in making the choice.[3]

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See A. E. Buchanan and D. W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989), 48-51. Several authors also suggest a standard that varies depending on the interests at stake. They argue that a lower standard should apply to decisions of minimal consequence, with more stringent standards applying as the risk of harm from a poor choice increases. For example, under this approach, decisions to forgo life-sustaining treatment would require a far higher threshold for capacity than a decision to delay elective surgery. Gaylin, 27-54; J. Drane, "Competency to Give Informed Consent: A Model for Clinical Assessments," *Journal of the American Medical Association* 25 (1984): 925-27; L. Roth, A. Meisel, and C. W. Lidz, "Tests of Competency to Consent to Treatment" *American Journal of Psychology* 134 (1977): 279-84; M. Munetz, C. Lidz, and A. Meisel, "Informed Consent and Incompetent Medical Patients," *Journal of Family Practice* 20 (1985): 273-79. However, Edmund Pellegrino argues that a "situation-based scale" confuses the competency [capacity] of the patient with the competency of the decision" and creates a rationalization for imposing a decision upon a patient. "Informal Judgments of Competence and Incompetence," Paper presented at a conference, "When Are Competent Patients Incompetent?" Texas Medical Center, Houston, Texas, May 1984 (manuscript available from the Center for the Advanced Study of Ethics, Georgetown University, Washington, D.C.). See also S. Kloezen, L. J. Fitten, and A. Steinberg, "Assessment of Treatment Decision-Making Capacity in a Medically 111 Patient," *Journal of American Geriatrics Society* 36 (1988): 1055-58, arguing that a sliding scale in capacity assessments is overly subjective and ambiguous, as well as unnecessary.

The Task Force proposes a standard of capacity that falls between these two ends of the spectrum, balancing the right to decide against the need to protect patients from harm. The Task Force recommends that the capacity standard focus on the patient's ability to understand and appreciate the nature and the consequences of proposed health care, including the benefits and risks of, and alternatives to, any such proposed health care, and to arrive at an informed decision. Under this standard, patients must have the ability to understand information about treatment and the alternatives, relate that information to their own medical condition, and weigh the risks and benefits of treatment in terms of their personal values or some identified goal of treatment.

The determination of capacity should establish the patient's incapacity for specific proposed treatment options. For future health care decisions, the attending physician should determine if the patient has capacity at that time and for the treatments under consideration. For some patients, such as those diagnosed as permanently unconscious or severely demented, successive confirmations of incapacity will be redundant. The Task Force believes, however, that this burden is outweighed by the protection afforded patients who have marginal or fluctuating capacity — the ability to make only some treatment decisions or to decide at one time of day or under certain circumstances and not others. Similar policies are included in the health care proxy law to preserve the patient's right to participate in decisions whenever possible.

Determining Incapacity

In New York State, under certain circumstances, nonjudicial procedures are available to determine that a patient lacks capacity to decide about health care, although generally only a court can curtail or remove a patient's right to decide about treatment.[4] The Task Force proposes a procedure for health care professionals to assess capacity.

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4 Physicians are permitted to determine that a patient lacks capacity for purposes of seeking a surrogate decision about CPR. Physicians may also determine that a patient lacks capacity to initiate a health care agent's authority to make treatment decisions. See discussion in chapter 2, 28. See also ibid., for a discussion of *Rivers v. Katz*, and principles concerning judicial findings of incapacity. Interdisciplinary committees appointed by the New York State Commission on the Quality of Care for the Mentally Disabled use a quasi-judicial proceeding to declare certain residents of mental hygiene facilities incapable of making decisions about major medical treatments. The decisions of these committees stand, unless a court determines otherwise.

The procedure builds on the experience attained with the capacity determination under the laws governing DNR orders and health care proxies.

All adults should be presumed to have decision-making capacity, unless determined otherwise by the procedure described below or by court order. This presumption respects the patient's right to decide, and mirrors legal and social presumptions about the capacity of adults to make fundamental personal decisions. The patient's attending physician should determine if the patient lacks capacity and state the reasons for the determination in the patient's medical record. Requiring a statement of reasons promotes well-founded decisions and enables those affected to understand the determination, and challenge it if necessary.

One other health care professional, authorized by the facility, should provide a written confirmation of the determination. This second opinion will minimize the risk of error and the possibility that the attending physician's judgment is based on disagreement with the patient's treatment choice, rather than on the patient's capacity to choose.

Under the health care proxy law, a second assessment of capacity is required only for decisions to forgo life-sustaining treatment. The Task Force proposes that for surrogate decisions, a second health care professional should participate in assessing capacity, even if the surrogate's initial or subsequent decisions do not encompass life-sustaining measures. The Task Force's surrogate decision-making proposal would empower a surrogate to make treatment decisions in cases where the patient has not agreed to, or perhaps even anticipated, a surrogate decision. The surrogate's authority would be derived entirely from statute, not from the patient's advance consent as it is with a health care proxy. Surrogate decisions therefore justify greater precaution in determining capacity.

Each health care facility should identify the credentials of the health care professionals who maybe called upon to provide a second opinion about a patient's capacity. The Task Force believes that qualified health care professionals, including nurses and social workers, can fulfill this responsibility instead of physicians in appropriate cases.

In many instances, the determination of incapacity does not entail a uniquely medical judgment. Rather, it calls for a commonsense assessment of the patient's ability to comprehend his or her present

situation and the factors involved in a treatment decision.[5] It is unnecessary, and not always feasible, to require a second physician to assess capacity in all cases.

Equally important, patients often have far more contact with other health care professionals, such as nurses and social workers, than with physicians, especially in long-term care facilities. Through this interaction, health care professionals learn information about the patient that may be pivotal to the determination: the patient's daily activities, his or her interaction with others, his or her communication skills and variations in alertness, including the effect of medication. These professionals are often in a better position to assess capacity than a physician who has had little or no previous interaction with the patient.[6] Hence, in addition to their professional training and experience, other qualified health care professionals bring an important dimension to the capacity determination.

Finally, permitting the designation of credentials by facilities, rather than by state mandate, accommodates diversity among facilities, including the fact that in some health care settings, such as long-term care, physicians are not always available when treatment decisions arise. It also recognizes that in some cases the second determination should be made by a physician. Each facility's policies should identify those circumstances when a physician is needed because the determination rests principally on medical factors, such as a neurological assessment. Facilities should also specify the qualifications and credentials of the other health care professionals who can provide a second opinion about the determination.

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[5] See, for example, Buchanan and Brock, 81-82; G. Annas and J. Densberger, "Competence to Refuse Medical Treatment: Autonomy vs. Paternalism," *Toledo Law Review* 15 (1984): 584.

[6] As explained by Nelly Peissachowitz speaking on behalf of the Nursing Home Community Coalition, the state-mandated visit by physicians eveiy 30 or 60 days does not "make a relationship possible. The doctor knows the diagnosis, but rarely gets to know the person with the diagnosis. It is because of the just-mentioned fact that we feel that in determining capacity in making this crucial judgment, a second person is needed, together with the physician. We feel that ideally a health care staff member who has a close relationship with the patient resident, one that has daily contact and knows the person more intimately, knows their strength and, importantly, their fluctuating alertness and capacity for decision making." N. A. Peissachowitz, Testimony on behalf of the Nursing Home Community Coalition of New York State, New York State, Assembly and Senate Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resuscitate Orders*, New York, February 12,1987,124. See also N. Rango, "The Nursing Home Resident with Dementia: Clinical Care, Ethics and Poli<y *Implications," Armais of Internal Medicine* 102 (1985): 835-41.

If the attending physician concludes that a patient lacks capacity due to mental illness or developmental disability, special requirements should apply. These conditions raise complex issues, including a tendency to underestimate the capacity of the developmentally disabled and the mentally ill. The attending physician should have, or consult with a health care professional who has, specialized training or experience in diagnosing or treating mental illness or developmental disabilities of the same or similar nature.[7]

Informing the Patient

Health care professionals should inform the patient when the surrogate's authority begins and should tell the patient about the determination of incapacity, if the patient has any ability to understand this information. Otherwise, patients will be denied the opportunity to object and to challenge the determination of incapacity or the treatment decision at issue.

To health care professionals, this duty to inform patients may seem counterintuitive; why tell a patient already determined incapable of deciding about treatment that he or she is incapacitated? Clearly, some persons, such as those who are unconscious or severely demented, are incapable of understanding the information. Neither the Task Force's proposal nor the proxy and DNR laws require health care professionals to inform these patients, as there is no indication that they could understand. But individuals with marginal capacity can comprehend that someone else close to them will decide about treatment. Talking with these patients will prevent mistaken judgments in some cases, and respects these patients as individuals. It also acknowledges the right to decide about treatment as a basic right. Like other such rights, including the right to decide about property or to vote, the right to decide about treatment is constitutionally protected and cannot be removed without procedures that afford "notice and an opportunity to be

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[7] This procedure lacks the detailed requirements of the health care prosy law, Sections 2983(l)(b) and 2983(l)(c), but is consistent with the Task Force's initial proposal for the proxy law. The Task Force has been informed that the requirements, especially the obligation to select a professional from a list prepared by OMRDD, have created delay and difficulty in making decisions for developmentally disabled patients. See 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), 127-28,152. The Massachusetts Legislature adopted the Task Force's proposal when it enacted health care proxy legislation in December 1990. See Mass. Ann. Laws ch. 201D, § 6 (Law. Coop. 1992).

heard."[8] Tailored to the demands of the clinical setting, the information about the determination of capacity for patients able to understand provides a valuable safeguard.

Priority of the Patient's Decision

Persons for whom a surrogate has been appointed have not relinquished their right to make health care decisions. A physician's determination of incapacity, while sufficient to trigger the participation of a surrogate, is not an adequate basis for overriding the patient's constitutional and common law right to decide about treatment if the patient expresses a treatment decision or objects to the surrogate's authority. For this reason, a facility-based determination that a patient lacks capacity should not terminate the patient's right to make health care decisions. Instead, if the patient objects to the determination of incapacity or to the surrogate's decision, the patient's wishes should be honored. Health care professionals, family members, or others close to the patient who wish to override the patient's decision, should seek a judicial determination of the patient's incapacity to make the particular decision or of the patient's incompetence to make all personal decisions.

If the patient regains the ability to decide about treatment, the surrogate's authority should cease. Accordingly, if health care professionals determine that the patient's capacity has returned, the surrogate and patient should be informed. The patient should make health care decisions as long as he or she is able, with the surrogate available if the patient subsequently loses capacity temporarily or on a longterm basis.

In some cases, an adult patient may experience a temporary loss of decision-making capacity that could be reversed if treated. For example, treatment for a reversible condition such as infection, bleeding, or fever can sometimes restore the decision-making capacity of terminally ill patients but cannot cure the underlying illness. The Task Force proposes that health care professionals should evaluate the likelihood that the patient will regain decision-making capacity. For decisions about life-sustaining treatment, this possibility should be

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For a discussion of the due process considerations raised by a facility-based determination of incapacity, see New York State Task Force on Life and the Law, *Do Not Resuscitate Orders: The Proposed Legislation and Report of the New York State Task Force on Life and the Law,* 2d ed. (New York: New York State Task Force on Life and the Law, 1988), 34-36.

weighed in determining whether the surrogate could refuse treatment on the patient's behalf.[9]

Factors to Consider

As the Task Force observed in its reports on DNR orders and the health care proxy, no settled guidelines exist about how to determine a person's incapacity to make health care decisions. Reflecting this uncertainty, practices vary considerably among institutions, ranging from psychiatric testing to informal evaluations based on casual examination.

As indicated in a 1986 and 1988 survey of hospitals and nursing homes in New York State, many health care facilities do not have written guidelines for determining incapacity. In 1986, 29 percent of the hospitals that responded to the survey and 12 percent of the nursing homes indicated that they had written guidelines for the determination. In 1988, 48 percent of the responding nursing homes had written guidelines, while the percentage of hospitals with written guidelines did not change in any statistically significant manner.[10]

Over the last few years, a growing body of literature addressing the philosophical, clinical, and legal dimensions of the incapacity determination has become available. The Task Force urges health care providers to use this valuable resource to develop and improve guidelines for determining incapacity. For example, some articles discuss the ethical questions related to choosing an incapacity standard,[11] Other studies explore different models and criteria for determining incapacity,[12] including the usefulness and limitations of mental status

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9 For a discussion of this factor in the overall standards for surrogate decisions, see chapter 7, 113-14.

10 See appendix E, table C. See also T. Miller and A.M. Cugliari, "Withdrawing and withholding Treatment: Policies in Long –Term Care Facilities," Gerontologist 30 (1990): 462-68, an anlysis of the Task Force survey data concerning long-term care facilities.

11 See, for example, Buchanan and Brock; Gaylin; B. Lo, "Assessing Decision-Making Capacity *" Law, Medicine and Health Care* 18 (1990): 193-201.

12 See, for example, M. Freedman, D. Stuss, and M. Gordon, "Assessment of Competency: The Role of Neurobehavioral Deficits," *Annals of Internal Medicine* 115 (1991) : 203-8; P. Appelbaum and T. Grisso, "Assessing Patients' Capacities to Consent to Treatment," *New England Journal of Medicine* 319 (1988): 1635-38; S. Kloezen, L. J. Fitten, and A Steinberg, "Assessment of Treatment Decision-Making Capacity in a Medically 111 Patient," *Journal of the American Geriatrics Society* 36 (1988) : 1055-58 ; J. Mahler and S. Peny, "Assessing Competency in the

and cognitive function tests such as the Mini-Mental Status Examination.[13] Researchers have also examined the impact on capacity of reversible conditions, such as depression,[14] and the influence of antipsychotic drugs, medications that are administered to an alarmingly high percentage of the long-term care population.[15] Other studies explore how health care providers' perceptions of patient incapacity may be influenced by characteristics such as a patient's age or physical disability, which may have no bearing on the patient's actual capacity to make decisions.[16]

Physically 111:
Guidelines for Psychiatric Consultants," *Hospital and Community Psychiatry* 39 (1988) : 856-61; V. Abernethy, "Compassion, Control, and Decisions About Competency" *American Journal of Psychiatry* 141 (1984): 53-58; P. Appelbaum and L. Roth, "Clinical Issues in the Assessment of Competency," *American Journal of Psychiatry* 138 (1981): 1462-67; L. Roth, A. Meisel, and C. Lidz, "Tests of Competency to Consent to Treatment," *American Journal of Psychiatry* 134 (1977): 279-84.

13 A. Siu, "Screening for Dementia and Investigating Its Causes," *Armais of Internal Medicine* 115 (1991): 122-32; M. R Somerfield et al., "Physician Practices in the Diagnosis of Dementing Disorders," *Journal of the American Geriatrics Society* 39 (1991) : 172-75; S. Kafonek et al., "Instruments for Screening Depression and Dementia in a Long-Term Care Facility," *Journal of the American Geriatrics Society* 37 (1989): 29-34; L. R Tancredi, "The Mental Status Examination," *Generations* 12 (1987): 24-31.

14 See B. V. Reifler et al., "Double-Blind Trial of Imipramine in Alzheimer's Disease Patients With and Without Depression," *American Journal of Psychiatry* 146 (1989) : 45-49; H. Koenig et al., "Self-Rated Depression Scales and Screening for Major Depression in the Older Hospitalized Patient with Medical Illness," *Journal of die American Geriatrics Society* 36 (1988): 699-706.

15 See R Beardsley et al., "Prescribing of Psychotropics in Elderly Nursing Home Patients," *Journal of the American Geriatrics Society* 37 (1989): 327-30; J. Buck, "Psychotropic Drug Practice in Nursing Homes," *Journal of the American Geriatrics Society* 36 (1988): 409-18; Mark Beers et al., "Psychoactive Medication Use in Intermediate-Care Facility Residents," *Journal of the American Medical Association* 260 (1988): 3016-20.

16 See M. R Haug and M. G. Ory, "Issues in Elderly Patient-Provider Interactions," *Research in Aging* 9 (1987): 3-44; D. Morgan, "Nurses' Perceptions of Mental Confusion in the Elderly: Influence of Resident and Setting Characteristics," *Journal of Health and Social Behavior* 26 (1985): 102-12.

Recommendation

A facility-based procedure should be used to determine that the patient lacks capacity to make treatment decisions and that the surrogate's authority should begin. Health care professionals should inform both the patient and the surrogate of the determination insofar as practical.

All adults should be presumed capable of deciding about treatment, unless determined otherwise by court order. The patient's attending physician should make the initial determination of incapacity, and another qualified health care professional should provide a second opinion. Facilities should adopt written policies identifying the credentials of health care professionals qualified to provide this second opinion. This facility-based procedure should initiate the surrogate's authority but should not deny the patient's right to make health care decisions if the patient objects to the determination of incapacity or to the surrogate's treatment decision.

See Appendix A, proposed legislation, Section 3.

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Identifying the Surrogate

Many adults do not specify their health care wishes in advance of illness or designate someone to decide about treatment. Infants and young children have not yet attained the capacity to provide this guidance while adolescents may have the maturity to make some decisions for themselves and not others. For all patients unable to decide for themselves, the question of who should decide is best answered by looking to basic values that inform individual and social expectations in the health care arena.

Ordinarily, when patients are unable to decide about treatment, health care professionals turn to family members as surrogates. Although New York law does not expressly grant family members the authority to consent to treatment, long-standing social and medical traditions have conferred this role on family members.

Several factors justify this general presumption in favor of family members as surrogate decision makers. Some are matters of custom, culture, and tradition. Others derive from clinical practice and traditions. Still others stem from the independent value of the family in our society.

Most people would want family members to decide about treatment on their behalf. Family members are usually the most personally involved with the patient and the most deeply committed to the patient's well-being. Family members are also most likely to know the patient’s wishes. The patient may have expressed treatment preferences in conversations with family members or others who enjoy a close relationship to the patient. Familiarity with the patient’s religious and moral beliefs may also provide important guidance. In addition, the patient’s life-style, personal goals, and plans may be central to understanding how the patient would choose among treatment alternatives.

As demonstrated by recent studies, family members called upon to act as surrogates do not always approximate patients’ wishes. In fact, one study found that many surrogates relied upon their own health care preferences as a frame of reference rather than focusing on the

patient's wishes and values.[1] This shortcoming points to the need for public education and guidance from health care professionals and others about how the decisions should be made. It also suggests that family members should be urged by physicians, clergy, and others to talk openly about their health care preferences, especially when one member of the family is seriously ill. The study findings do not, however, support the notion that individuals outside the patient's circle of family or close friends should be designated to act as surrogate.

Although family members do not always approximate the patient's wishes, they are more likely than others to do so. Studies have shown that family members are more familiar with the patient's health care wishes than physicians or other health care professionals.[2] They also know far more about the patient than state-appointed representatives, judges, or others who will otherwise be called upon to make surrogate decisions. Family members are also generally those most concerned about and dedicated to the patient's well-being. Connected to the patient by bonds of kinship and caring, family members often play a crucial role as advocate for the patient.

The special status of family life in our society also favors empowering family members as surrogates. The family is a basic social unit, a purveyor of values, identity, and culture. The individual's values are also often shaped by family life, and family members may recognize in one another unexpressed but shared aspirations, preferences, and beliefs. For this and other reasons, society has recognized the family as an appropriate source of authority for intensely personal and private decisions.

This recognition of family authority, and the corresponding vision of family life upon which it rests, is accompanied by the realization that some families do not match these expectations. Kinship creates an assumption, but no guarantee, of caring. Although the close-knit nuclear family remains a paradigm, it bears little resemblance to the reality of daily life for some families. Adult children may be estranged from their parents. Young children may have no parent who actively cares for them.

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[1]The study suggests that family members and others chosen as surrogates try in good faith to further the patient's well-being but often fail to use the patient's own wishes as the guidepost to decisions. N. R. Zweibell 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.

[2]These studies are discussed in chapter 1,6-8.

Even within the nuclear family, tension may arise between the patient's welfare and the emotional or financial burden of the patient's illness upon the family. Conversely, some family members, unable to reconcile themselves to the patient's impending death, may insist on prolonging treatment that harms the patient and offers no benefit. In either case, the ordinary presumption favoring the family's role must be tempered by the primacy of the patient's welfare.

Equally significant, patterns of family life and intimate relationships are now more diverse than at any other time in our history. For some individuals, those most central to their life are bound to them by life experience, not by blood or marriage. For this reason, public policies and laws increasingly accord intimate relationships outside the family similar deference to that traditionally reserved for family members.

Choosing the Surrogate

The Task Force proposes that family members and others close to the patient should be granted legal authority to decide about treatment as surrogate decision makers. This authority should encompass decisions about health care generally, including decisions about life- sustaining measures.

In practice, family members have long been accorded the right to consent to treatment.[3] The Task Force proposes that this authority should be rendered explicit under New York law. The Task Force believes that family members and others close to the patient should also have the authority to decide to forgo life-sustaining measures, subject to the standards and safeguards in the proposed legislation.

A surrogate should be chosen from a list that includes individuals appointed by the courts to oversee the patient's personal affairs, family members, and individuals closely connected to the patient by life experience. The list should operate as a priority list, with those highest given first priority to act as surrogate if they are available, willing, and competent to fulfill that role. Conflict among individuals on the list should be referred to a mediation process established within each health care facility.[4]

If an adult patient has designated a health care agent, that person has priority over anyone on the surrogate list. The health care agent,

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3 See the discussion in chapter 2,33 ff.

[4] This approach is based upon similar policies in New York's DNR law. N.Y. Pub. Health Law § 2965(4) (McKinney Supp. 1992).

like the patient himself or herself, should not appear on the surrogate list; an agent's decisions should be governed by the policies set forth in the health care proxy law, not by the policies proposed for nonappointed surrogates.

A Committee or Guardian off the Person

The first person on the surrogate list should be any person appointed by a court as a committee of the person pursuant to Article 78 of the Mental Hygiene Law or as a guardian of the person of a mentally retarded or developmentally disabled individual pursuant to Article 17-A of the Surrogate's Court Procedure Act. Such a committee or guardian assumes responsibility for the health and general welfare of the ward. That responsibility ordinarily includes the duty and authority to make health care decisions. The involvement of a committee or guardian can provide the benefit of judicial oversight without the need to initiate proceedings solely for that purpose.

In many instances, a committee or guardian of the person will be a family member. However, in cases where this is not so, this judicially appointed person nonetheless should have higher priority than family members. Article 78 of the Mental Hygiene Law and Article 17-A of the Surrogate's Court Procedure Act generally require the appointment of a family member unless the appointment would be contrary to the patient's best interests.[5] Accordingly, appointment of a nonfamily member when family members are available expresses a judicial determination of the patient's interests that should not be disregarded.

In the 1992 legislative session, the legislature will consider a proposal to replace Article 78 of the Mental Hygiene Law and Article 77 of the Mental Hygiene Law (governing conservatorships to manage the property of an incapacitated person) with a unified adult guardianship statute.[6] Under the proposal, guardians would have the authority to make treatment decisions with court supervision. If this proposal is enacted, the Task Force recommends that the adult guardian should appear first on the surrogate list, with the authority to decide about

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[5] See, e.g., *In re Klein*, 145 A.D.2d 145, 538 N.Y.S.2d 274, *appeal denied*, 73 N.Y.2d 705,539 N.Y.S.2d. 298 (1989).

[6] See New York State Senate Bill Number 4498 and New York State Assembly Bill Number 7343, proposing new Article 81 of the Mental Hygiene Law to establish proceedings for appointment of an adult guardian for personal needs or property management. See also J. C. Spring and N. N. Dubler, "Conservatorship in New York State: Does It Serve the Needs of the Elderly? A Report of The Committee on Legal Problems of the Aging," *Record of the Association of the Bar of the City of New York* 45 (April 1990): 288-338 (proposing adult guardianship legislation).

life-sustaining treatment as well as major medical treatment, subject to the standards and procedures that apply to all surrogates and the fiduciary duties established by the guardianship law.

The Person Designated by Others

The remaining individuals on the surrogate list should be family members or others who share a close personal relationship to the patient. For some patients, those on the surrogate list may agree that one person is best suited or best able to act as surrogate. This designated person should be the next person on the priority list.

A person may be chosen based on his or her professional training or personal relationship to the patient. For example, if the daughter or sister of an elderly patient is a physician, that person may be a logical choice to others. Alternatively, one person may be selected because he or she generally handles family matters or lives near the patient and can stay in closest touch with health care professionals.

The opportunity for those on the surrogate list to designate one person serves the interests of patients, family members, and health care professionals. It makes the hierarchy of individuals more flexible and responsive to the patient's needs and life circumstances. Designating one person facilitates communication with health care professionals and may alleviate tensions that might otherwise arise among family members.

Immediate Family

The next four categories of surrogates should be immediate family members — the spouse, children 18 years of age or older, parents, and siblings. This priority list of family members seeks to mirror the expectations or choices of most people, although it will not correspond to the life circumstances or preferences of all. This approach of a priority list of family members has been embodied in other New York statutes concerning health care decisions, including the law on DNR orders and consent to organ donation.

The legislation would distinguish among family members based on the type of relationship, e.g., sibling, child, but would not choose among individuals such as siblings or children who stand in the same relationship to the patient. In some families, one person will clearly emerge as the person most responsible for the patient's care and most involved in the patient's life. Physicians or other members of the health care team will identify this person in the course of caring for the patient. The Task Force believes that the process of identifying a surrogate must remain

flexible to accommodate the diverse personal circumstances of patients and those close to them.

Severe illness, especially if unexpected, can provoke a crisis within families, exposing or exacerbating tensions about the roles and responsibilities of family members. Disagreement among family members in some cases is inevitable. A mechanism should be created within facilities to address these conflicts, either through mediation or consultation with a committee. The process should be designed to clarify information about the patient's care — the diagnosis, prognosis, and treatment alternatives — to enhance communication among family members, and to provide social work or religious counseling, when appropriate. Facilities have different resources to deliver this assistance, and each facility should devise policies to guide facility responses to conflict among family members.

Close Friends and the Extended Family

Under the health care proxy law, competent adults can designate an individual from within or outside of their family as health care agent, giving that person sole legal authority to decide about health care. If the patient has not designated an agent, immediate family members should be given priority as surrogates as that would correspond to the wishes of most people. However, other individuals close to the patient should also be authorized to act as surrogates when immediate family members are not willing or available to assume that responsibility. These individuals should be entrusted as surrogates for the same reasons that , extend to family members; they are most likely and best able to safeguard the patient's preferences and interests.

The Task Force proposes that a category of "close friend" should be included on the surrogate list, encompassing individuals who have a close personal relationship to the patient but are not related by blood or marriage. The category should also include members of the extended family — close adult relatives outside the immediate family such as aunts, uncles, grandparents, and grandchildren. A category of "close friend" is included in New York's law on DNR orders, and has worked well in that context.

Individuals who have maintained regular contact with the patient and are familiar with the patient's activities, health, and religious or moral beliefs should be authorized to serve as a close friend surrogate. Persons seeking to act as surrogate should inform health care professionals about the facts and circumstances that comprise their relationship to the patient and the basis for their claim to serve as surrogate.

As a practical matter, this information may be presented to a social worker or other member of the health care team, but should be reviewed by the attending physician. If uncertainty arises about the person's participation as surrogate, the physician, any person on the surrogate list, or the person seeking designation may refer the matter for dispute mediation or review by a facility committee.

Health Care Professionals as Surrogates

Physicians, nurses, social workers, and other health care professionals, as well as administrators or legal counsel at a health care facility, may be the surrogate for a patient by virtue of their family relationship. Their professional experience can be a powerful asset to them in their capacity as surrogate. If they are employed by or affiliated with the hospital or nursing home caring for the patient, they should not be precluded from serving as a surrogate because of the potential conflict of interest; in general society can and should assume that individuals will regard their family member, not the institution, as their primary obligation.

Physicians and other health care professionals are also potential candidates for surrogates under the broad category of close friend. For some nursing home residents or long-term hospital patients, health care professionals may be the only individuals in their lives familiar with their health care goals and personal values. Nonetheless, the Task Force believes that health care professionals, including physicians, and administrators employed by or affiliated with the facility caring for the patient, should not serve as a close friend surrogate. The potential conflict of interest is direct and inevitable in some cases. Moreover, the proposed procedures establish a decision-making process for patients without surrogates that affords greater openness and scrutiny of the decisions. That process is designed to elicit the knowledge that nurses or other professionals may have about the patient as a resource in the decision-making process. Significantly too, adults who would like a health care professional from outside their family to decide on their behalf can fill out a health care proxy, although they must do so prior to admission to the facility where the health care professional is employed or affiliated.[7]

[7] N.Y. Pub. Health Law § 2981(3) (McKinney Supp. 1992).

Serving as a Surrogate: Obligations and Immunities

Those who accept the responsibility of acting as a surrogate must make decisions in good faith that are consistent with what the patient would have chosen or with the patient's interests. They must also provide informed consent on the patient's behalf. Surrogates therefore have a duty to seek all relevant medical information about the patient's condition, including the diagnosis, the prognosis, the associated risks and benefits of available treatment alternatives, and their costs. The surrogate should seek necessary medical consultations and strive to understand the medical facts and the consequences of different alternatives for the patient.

Surrogates assume tremendous responsibility for the patient. They may be called upon to make difficult treatment choices in complex medical circumstances. It is important and appropriate for surrogates who carry out their decision-making responsibilities in good faith to be protected from liability. Surrogates should remain personally liable, however, if they act in bad faith or fail to perform their obligations under the law, such as the duty to make a decision based on reasonably available medical information.

The financial protection extended to surrogates should also be clear. A surrogate's health care decisions may result in the provision of expensive medical treatment to the patient. By virtue of their willingness to serve as surrogate, individuals should not become liable for the cost of medical treatment. A health care decision by a surrogate should create the same financial obligations as if the decision had been made by the patient. Thus, when a surrogate consents to treatment, the patient or a third party payer will ordinarily be obligated to pay for the treatment. Legal responsibility for the cost of treatment may arise from the surrogate's relationship to the patient as spouse or parent, but the surrogate should not become responsible for the cost of care solely by acting as surrogate.

Recommendation

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 decisions about life-sustaining treatment.

Individuals should be chosen to act as surrogate from the following priority list:

(1) a committee or guardian of the person

(2) a person designated by others on the list

(3) the spouse

(4) a son or daughter 18 years of age or older

(5) a parent

(6) a sibling 18 years of age or older

(7) a close friend or close relative, 18 years of age or older.

Health care professionals or others employed by or affiliated with the hospital or nursing home caring for the patient should not act as surrogate as a "close friend" but may do so as family members. All those who serve as surrogates have an obligation to consult with health care professionals in seeking the information necessary to make an informed judgment. They should be protected from liability when they act in good faith and should not be liable for the cost of treatment solely by virtue of their role as surrogate.

See Appendix A, proposed legislation, Sections 4, 13, and 14.

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Guidance for Surrogate Decisions

Standards for surrogate decisions offer guidance for the surrogate in making treatment decisions for an incapacitated patient. They also provide a framework within which others, such as physicians and family members, can contribute to the surrogate's decisions. If the surrogate's choice violates established standards, others can seek to persuade the surrogate to revise his or her decision or, in extreme cases, can challenge the decision by seeking dispute mediation or judicial relief.

Over the past decade, two standards for surrogate decision making, "substituted judgment" and "best interests," have been embraced by commentators, policy makers, and the courts.[1] Based on the Task Force's recommendations, the standards have been embodied in New York's laws on do-not-resuscitate orders and the health care proxy. The Task Force proposes that these standards should guide surrogate decisions for health care generally.

Both standards focus on the patient. Respect for personal autonomy forms the primary basis for the substituted judgment standard, which requires the surrogate to decide as the patient would if he or she were capable. The obligation to promote the patient's well-being underlies the best interests standard. The Task Force recommends that the surrogate decide in accord with the patient's wishes or, if the patient's wishes are not reasonably known, in accord with the patient's best interests.

The Task Force recognizes that there is no bright line between the substituted judgment and best interests standards. A determination under the best interests standard will draw upon some consideration of the patient's preferences and concerns. Conversely, substituted judgment is not a license to choose unwisely. Even when deciding within the context of the substituted judgment standard, surrogates are not granted the same latitude as competent patients deciding for themselves. Self-determination is accorded greater deference when it is exercised by the person directly. Moreover, the process of discerning the patient's wishes and giving them meaning in an unprecedented context is inherently uncertain.

[1] The ethical and legal support for these standards is discussed in chapters 2 and 3.

Nevertheless, adopting separate standards of substituted judgment and best interests serves two important purposes. On the level of principle, it promotes the value of respect for autonomy where that value can be meaningfully applied. As a practical matter, the standards provide a frame of reference that shapes the surrogate's inquiry and decision. Under the substituted judgment standard, a surrogate seeks to answer the question, "What would the patient choose?" For a best interests determination, the surrogate must ask, "What is best for the patient taking the patient's values and beliefs into account insofar as possible?"

Regardless of the standard applied, surrogates' choices should be based on a firm understanding of the patient's medical condition, the expected benefits and risks of treatment, and the underlying goals of medical intervention. Thus, the surrogate always has a duty to ascertain the medical facts. The Task Force recommends that the surrogate should consult with health care professionals and should have the right to obtain all medical information necessary to make an informed decision.

Substituted Judgment

The substituted judgment and best interests standards exist in a hierarchical relationship to each other, with substituted judgment as the preferred standard whenever possible. The Task Force believes that all those who act as surrogate, as well as health care professionals, have an ethical duty to ensure that decisions reflect the patient's wishes and values, including the patient's religious and moral beliefs, to the extent they are reasonably known or can be identified. In this way, surrogates show their respect not only for the patient as a sick person, but for the patient as a person integrally connected to his or her previous healthy self — the goals, preferences, and beliefs by which the patient defined himself or herself.[2] Without this respect, patients are severed from their former lives, and stripped of the values and beliefs they had embraced.

[2] See N. K. Rhoden, "Litigating Life and Death," *Harvard Law Review* 102 (1988): 375-446; N. Rhoden, "How Should We View the Incompetent?" *Law, Medicine and Health Care* 17 (1989): 264-68.

Many sources of information will guide the surrogate's exercise of substituted judgment. In the most straightforward case, the surrogate can appeal to the patient's prior medical choices or statements about particular treatments.[3] These statements may have been made in response to actual choices presented to the patient, or as part of a discussion about hypothetical decisions that might lie ahead. The patient's prior attitudes about pain and sickness, as well as his or her earlier choices about activities and general life-style, may also inform the surrogate's decision. For example, what is the patient's tolerance for pain or a life beset by severe disability? Should treatment seek the prolongation of life as the primary value? What is the importance for the patient of independence, the capacity to meet one's own daily needs, physical comfort, or the ability to communicate with others?

Even when surrogates have no knowledge of the patient's expressed wishes, they may have a strong intuitive sense of what the patient would have wanted. As expressed by one commentator: "A parent may understand a child's values because she helped to form them, a child may grasp a parent's values because the parent imparted them to her, and a couple may have developed and refined their views in tandem."[4]

Best Interests

The substituted judgment standard has little meaning for persons who never indicated their treatment preferences or never had the capacity to do so. The Task Force proposes that the best interests standard should apply to decisions for these patients. This standard incorporates judgments about the risks and benefits of treatment for the patient and serves primarily to promote the patient's well-being. The course of treatment that most people would choose for themselves under the same medical and personal circumstances -can serve as an important guidepost for the surrogate.

Even when information about the patient's preferences cannot establish the foundation for a substituted judgment, it may contribute to an assessment of the patient's interests and the overall goals of health care. Indeed, particular treatment decisions can often be made only in relation to some notion of the goals of treatment or the patient's well-

[3] If the patient's prior oral or written statements clearly cover the treatment decision that must be made, they stand on their own, much like contemporaneous decisions by a patient with capacity. See the discussion of clear and convincing evidence in chapter 2,29-32, and of advance directives in chapter 4.

[4] Rhoden, "Litigating," 438-39.

being. This is especially true when the aims of medicine — care, prolongation of life, restoration of function, and relief of suffering — do not coincide, and a choice must be made among them.

For patients who have never developed the ability to formulate personal values and preferences, including young children and severely retarded adults, a surrogate may have little or no guidance based on his or her knowledge of the patient. The repeated actions of an elderly demented patient in removing a nasogastric feeding tube, or a young child's fears about chemotherapy, may suggest the burdens of treatment. Still, they cannot substitute for an overall calculus about the burdens and benefits such treatment affords.

No simple formula can serve as the benchmark for treatment decisions or define the welfare of patients in these cases. A judgment about best interests must be developed in light of the circumstances of particular cases. Nevertheless, the Task Force believes that some factors are generally important in this assessment. These include the possibility and extent of preserving life; the preservation, improvement, or restoration of health or functioning; and relief of suffering. In addition, the Task Force believes that the assessment of best interests should begin with a recognition of the dignity and uniqueness of each person; decisions should not relate to abstract categories but to the individual himself or herself.

The Task Force also recommends that the best interests standard should be understood and applied to encompass other factors that a reasonable person in the patient's circumstances would wish to consider. This approach allows for the possibility that intangible values, such as human dignity, may inform treatment decisions. The factors contributing to an assessment of best interests from the point of view of a "reasonable person" are likely to evolve over the course of time, reflecting developments in societal expectations and judgments.

Admittedly, it may be difficult to assess the implications of a value such as dignity in particular cases or to articulate a societal consensus about the significance of the value in general.[5] Ignoring these values,

[5] Consider, for example, the complex and potentially divergent understandings of dignity articulated by the Vatican in its "Declaration on Euthanasia" (in 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), 300-302), and by Justice William Brennan in his dissent in *Cruzan v. Director, Missouri Department of Health,* 110 S. Ct. 2841, 2863-78 (1990).

however, impoverishes and distorts an assessment of the patient's well-being, making it less likely that the decision will accord with what most people would choose for themselves under similar medical and personal circumstances.

Reliance on the best interests standard does not mean that the standard will always yield one "right" answer or one decision that is best for all patients in similar circumstances. Instead, the standard must be understood to confer on the surrogate, by virtue of his or her relationship to the patient, the authority to make a judgment about the patient's interests, so long as that judgment falls within a range of reasonable alternatives. As discussed below, the Task Force has proposed additional standards and procedures that will delineate the scope of the surrogate's authority for decisions to forgo life-sustaining treatment.

For routine decisions, the best interests standard may be easy to apply. When decisions arise concerning highly debated measures, the patient's perspective assumes much greater significance. These controversial measures include abortion, psychosurgery, and artificial nutrition and hydration. Decision makers confronting these difficult choices should undertake special efforts to identify the patient's preferences and values, rather than assuming that the appropriate decision is a matter of "common sense."

Relying on the Standards

It will be important for health care professionals to inform family members that they are obligated to make a substituted judgment whenever possible. The impact of this information on surrogates has been demonstrated by several studies. In one study, elderly persons and relatives were asked about treatment choices in hypothetical scenarios. The study found that family members who were asked to make a substituted judgment came significantly closer to the elderly person's preferences than others who were asked only to make a recommendation.[6]

In some cases, the question of what the patient would have wanted cannot be meaningfully answered. Surrogates must then rely upon the best interests standard. Under either the substituted judgment or best interests standard, significant deference should be accorded a surrogate's decision when that decision is informed by a prior relationship between the surrogate and the patient, and the decision falls

[6] Tom Tomlinson et al., "An Empirical Study of Proxy Consent for Elderly Persons," *Gerontologist* 30 (1990): 54-64.

within a range of acceptable treatment alternatives.

The Interests of Others

Consideration of the interests of others poses a special challenge for surrogate decision making. For many people, the emotional and financial burden of their illness and treatment on family members and others close to them would be an important factor in choosing their course of treatment. Some people would not want family assets depleted to pay for care that can prolong their life but cannot cure their underlying illness. Others will be deeply concerned about the emotional toll of their illness on those around them. Some patients might want treatment continued if family members derive emotional solace from continuing care. Others might want to receive experimental treatment, even if it is burdensome and offers them little benefit, if the treatment protocols would yield insight or information that might help others. A substituted judgment should incorporate these concerns in attempting to decide as the patient would have.

At the same time, surrogate decisions that consider the interests of others call for great caution. It may often be difficult for a surrogate to gauge the balance that a patient would make between the patient's own interests and the interests of others. This assessment is especially precarious, and open to question, because those closest to the patient, including family members, are generally both decision makers and the persons whose interests are most important to the patient.

Assessing the interests of others under the best interests standard presents especially complex problems. The weight that people would accord the interests of others that conflict with their own interests varies widely among "reasonable people." Unless knowledge of the patient's preferences is available, only general assumptions about kinship and other close relationships can guide the assessment. Appealing to psychological benefits that an individual would gain by helping others, such as family members, is often speculative. Nonetheless, to exclude a patient's interests in others, especially when information about the patient's preferences and values is available, isolates the patient from those closest to him or her. It creates a fiction by denying the human connections central to the lives of most people.

The Task Force recommends that both substituted judgment and best interests assessments should focus on the patient, but may include the interests of others from the patient's perspective. Because of the need for caution and the potential conflict of interest, consideration of the interests of others under the substituted judgment standard should

be premised on clearly articulated information about the patient's own evaluation of those interests and their significance for treatment decisions. An even stronger showing about the weight that the average person would give to the interests of others (or the benefits that a particular patient would gain from helping others) should be required to justify including those interests in a best interests assessment. Moreover, surrogates should not be allowed to make decisions based on the interests of others that would harm the patient.

Deciding to Forgo Life-Sustaining Treatment

For decisions regarding life-sustaining treatment, as for other treatment decisions, health care professionals have a responsibility to further the well-being of patients. The physician formulates the medical diagnosis and prognosis and presents treatment options. The physician must also seek to ensure that decisions by surrogates are informed. If the surrogate makes a decision that would harm the patient, health care professionals should seek to dissuade the surrogate.

In addition to this safeguard and the guidance offered by the substituted judgment and best interests standards, decisions to forgo life-sustaining treatment should be made in accord with other policies that constrain and guide the surrogate. As proposed by the Task Force, these policies include substantive limits on the authority to forgo treatment and procedures to promote sound decision making.

The Task Force recommends that family members and others on the surrogate list should be empowered to forgo life-sustaining treatment only if the treatment would be an excessive burden to the patient, ***and*** one of the following conditions is satisfied: (i) the patient is terminally ill; (ii) the patient is permanently unconscious; (iii) the patient's attending physician confirms that the decision satisfies the substituted judgment/best interests standards, and an interdisciplinary review committee approves the decision; or (iv) a court issues an order approving the decision.

Terminal illness and permanent loss of consciousness are the most common conditions under which people would choose to discontinue treatment.[7] This choice rests upon an acceptance of the limitations of

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[7] As noted in chapter 3 (60, n. 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

treatment in these circumstances. In the event of terminal illness, treatment may prolong but cannot reverse the dying process, while in cases of permanent unconsciousness, treatment may continue biological functions but cannot restore consciousness or the ability to relate to others. Although the Task Force members hold differing views about whether permanently unconscious individuals can benefit from continued treatment, they agree that society should grant family members and others close to the patient the authority to decide to forgo treatment for patients who are either terminally ill or permanently unconscious, in accord with the standards proposed.

Recognizing that treatment may be forgone for such patients, however, does not mean that it ***should*** be withheld or discontinued for all such patients. Family members, or others who act as surrogates, must make a judgment, in consultation with health care professionals, about the appropriateness of withholding or stopping treatment for each patient.[8]

Medical Guidelines

The determination that a patient is terminally ill or permanently unconscious should be made in accord with accepted medical standards. For a finding of terminal illness, the Task Force proposes that two physicians must determine, to a reasonable degree of medical certainty, that the patient has a terminal condition such that death is expected within six months even if life-sustaining treatment is provided. The expectation of death within six months establishes a general benchmark

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intracranial mass lesions, and patients with congenital hypoplasmia of the central nervous system.

[8] The Task Force rejects the position of ethicists and physicians in the Wanglie case who urged that treatment was medically futile, and that the decision called for only a medical judgment. Decisions for permanently unconscious patients are inherently social and ethical as well as medical. For further discussion of Helga Wanglie's case, see chapter 14, 195. Studies suggest that many, but not all, people would want treatment discontinued if they became permanently unconscious, but that people vary widely in the choices they make for family members who have permanently lost consciousness. For example, L. L. Emanuel et al. reported that 80% of those surveyed said that they would not want artificial nutrition provided if they were in a persistent vegetative state, 8% would want to receive these measures, and 5% would want a trial intervention. "Advance Directives for Medical Care — A Case for Greater Use," *New England Journal of Medicine* 324 (1991): 889-95. A study of family members of patients in a persistent vegetative state found that 29 of 33 family members agreed retrospectively with the insertion of a feeding tube. Eight family members wished respirator treatment to be provided, while 23 opposed this intervention. D. D. Tresch et al., "Patients in a Persistent Vegetative State: Attitudes and Reactions of Family Members," *Journal of the American Geriatrics Society* 39 (1991): 17-21.

for physicians and surrogates, without requiring a degree of certainty not afforded by medical practice.

The diagnosis of permanent unconsciousness similarly should require the agreement of two physicians and determinations to a reasonable degree of medical certainty. Through reliance on clinical criteria and tests developed by the medical community, permanent unconsciousness can now be diagnosed with a high degree of certainty. A large body of data provides the basis for determining whether a patient's unconsciousness is permanent, depending on such factors as the length of time of unawareness, the patient's age, and the nature of the disease or injury.[9] Certainty about the diagnosis increases with the passage of time. For example, the chance of regaining consciousness after three months of unconsciousness is about 1 in 100 and less than 1 in 1,000 after six months. For some younger patients, a waiting time of 12 months of observed unawareness has been suggested.[10]

In several highly publicized cases, patients diagnosed as permanently unconscious later regained consciousness. For example, in one case that arose in Albany, New York, a woman regained consciousness after a court had approved the removal of life-sustaining treatment. In that case, the diagnosis of permanent unconsciousness was made, and the court order was sought, well short of the time frame generally relied upon for the diagnosis.[11] Reliance on proven clinical criteria can virtually

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9 See 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 0k American Medical Association* 263 (1990): 426-30. Information on permanent unconsciousness was also provided to the Task Force by Dr. Fred Plum in a presentation on May 12,1987.

10 Ibid. The few patients who have regained consciousness after being determined to be in a persistent vegetative state suffer from severe and permanent disabilities. At least some of these patients may have been misdiagnosed and may have in fact been suffering from paralysis associated with the Iocked-in syndrome.

11 See *Gannon* v. *Albany Memorial Hosp.*, No. 89-757, slip. op. (N. Y. Sup. Ct., April 3, 1989); R. E. Cranford, "Neurological Syndromes and Prolonged Survival: When Can Artificial Nutrition and Hydration be Forgone?" *Law, Medicine and Health Care* 19 (1991): 13-22; B. Steinbock, "Recovery from Persistent Vegetative State?: The Case of Carrie Coons," *Hastings Center Report* 19, no. 4 (1989):14-15; S. H. Verhovek, "Right-to-Die Order Revoked as Patient in Coma Wakes," *New York Times,* April 13, 1989, sec. B, p. 3. Carrie

eliminate the risk of mistaken diagnosis, although it will not preclude the possibility of recovery in extremely rare cases.

The New York State Department of Health or professional organizations could prepare guidelines to help assure the accuracy of determinations that a patient is terminally ill or permanently unconscious. For example, guidelines could specify particular tests and criteria for the determination of permanent unconsciousness.[12] The qualifications of one or both physicians making the determination that a patient is permanently unconscious could also be specified. Within these guidelines, health care facilities could formulate policies that would best assure careful determinations of these conditions.

Other Cases

Decisions to forgo life-sustaining treatment may also be appropriate for some patients who are neither terminally ill nor permanently unconscious.[13] For example, an aggressive and painful course of chemotherapy might extend the life of a patient with a chronic degenerative illness who has irreversibly lost the ability to speak or to recognize people. A surrogate might decide that the chemotherapy would be excessively burdensome to the patient, based on the patient's prior wishes or an assessment of the patient's interests.

Decisions to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious require heightened scrutiny. Mistaken decisions for these patients pose the greatest danger

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Coons was not examined by a neurologist, and a recommended confirmatory computerized tomography (CT) scan was not performed because of the family's objection. Cranford (18) states that the diagnosis was premature given the cause of the patient's loss of consciousness.

[12] Some criteria are suggested in the statement of the American Medical Association, 427-28.

[13] At least seven states have statutes authorizing surrogate decisions to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious. The surrogate decision-making statutes of Arkansas, Iowa, Louisiana, Maine, Montana, Nevada, and Texas permit surrogates to forgo life-sustaining treatment for patients with a "terminal condition" broadly defined as a condition where death will occur shortly *without* the provision of treatment. These states do not require either judicial or institutional review or approval for the decisions. See chapter 2,33 ff.

of significant harm.[14] Caring for profoundly disabled or "pleasantly senile" patients is often personally difficult as well as expensive for family members and health care providers. While some adults who were once fully capable might not want to live with severe mental handicaps, adults who are profoundly retarded have never known or aspired to a different kind of life. Their disability alone should not serve as the basis for discontinuing treatment, although others might be prone to dismiss continued life for them as offering no benefit. Likewise, many elderly nursing home residents have diminished capacity to think, relate to others, or engage in the activities that once filled their lives. These vulnerable patients cannot speak for themselves and may be regarded by some solely as a burden to others, even though the benefits of treatment and continued life would outweigh the burdens from their perspective.

The Task Force proposes that decisions to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious should require approval by an interdisciplinary committee at the facility or by a court. The composition and role of these committees, known as bioethics review committees, are discussed in Chapter Nine below. Oversight could also be provided directly by a court, with judicial review of the surrogate's decision to determine if the decision satisfies the proposed standards. In these cases, the courts should make an explicit finding that the standards have been met and should create a record that serves as precedent for subsequent cases.

Excessive Burden

For patients in any medical circumstances, life-sustaining treatment should only be withheld or withdrawn if it would be an "excessive burden" to the patient. The concept of excessive burden requires a prudential judgment that the patient would have rejected treatment as excessively burdensome or that continued treatment contravenes the patient's interests. It recognizes that treatment cannot be withheld or withdrawn simply because the patient falls within a particular diagnostic or prognostic category. Instead, the benefits and burdens of treatment must be evaluated for each patient on a case-by-case basis.

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[14] The case of Earle Spring illustrates the potential for error or abuse. Earle Spring was senile and chronically ill, but not terminally ill, when his family requested that kidney dialysis be discontinued. Commenting on the case, George Annas argued that life-sustaining treatment may have been burdensome to Spring's family and health care providers, but did not seem to have been burdensome to the patient. Annas suggested that the decision to forgo treatment may have reflected a bias that senile or troublesome patients do not "deserve" expensive health care. G. J. Annas, "Quality of Life in the Courts: Earle Spring in Fantasyland," *Hasting? Center Report* 10, no. 4 (1980): 9-10.

The term "excessive burden" should be understood to reflect the past values, wishes, and preferences of the patient to the extent that these are reasonably known or can be identified. Hence, under the substituted judgment standard, the provision of life-sustaining treatment, including artificial nutrition and hydration, for a permanently unconscious patient might be judged excessively burdensome for a patient who would have viewed continued treatment as an affront to his or her dignity. Conversely, it might be considered beneficial for a patient whose values and wishes would support the prolongation of life despite the loss of consciousness. Best interests decisions would seek to identify any relevant personal information about the patient and ascertain whether treatment would be considered excessively burdensome, and rejected, by a "reasonable person" in the patient's medical and personal circumstances.

An assessment of excessive burden should also include consideration of the possibility that the patient could regain the capacity to decide about treatment for himself or herself. This possibility should be weighed as one factor among other important variables including the extent to which the patient's wishes are already known, whether continued treatment would violate those wishes, and the overall burdens and benefits treatment may confer. A rule requiring continued treatment in all cases when the patient might regain capacity would impose serious hardship for some patients, especially those at the end-stage of the dying process.

While decisions about life-sustaining treatment demand great caution, they must be made with the recognition that overtreatment as well as undertreatment may violate the wishes and well-being of patients. The Task Force believes that the proposed decision-making standards, together with substantive and procedural safeguards, provide an appropriate framework for protecting and promoting the interests of vulnerable patients.

Recommendation

The Task Force recommends that, after consultation with health care professionals, the surrogate should make health care decisions 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. In either case, health care decisions should reflect the values of the patient to the extent they are reasonably known. 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.

A surrogate should be authorized to refuse consent to initiating life-sustaining treatment or consent to withholding or withdrawing life-sustaining treatment once it has begun, if: (i) the treatment would be an excessive burden to the patient in the light of the substituted judgment and best interests standards, and (ii) one of the following circumstances is present: the patient is terminally ill; the patient is permanently unconscious; a physician agrees that the decision complies with mandated standards and a bioethics review committee approves the decision; or a court finds that the decision to forgo life-sustaining treatment meets the proposed standards and issues an order approving the decision.

See Appendix A, proposed legislation, Section 4.

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Deciding for Children and Newborns

Parental decisions for minor children represent a special subset of surrogate health care decisions. Public policies and laws on parental decisions are informed by respect for the special bond between parents and children and by the responsibility of parents to care for their children.

Existing laws grant parents broad authority to rear and nurture their children free from state intrusion. This parental authority, including the right to make treatment decisions for minor children, is protected by the United States Constitution, as well as New York law.[1]

Despite its breadth, parental authority to decide about treatment is not absolute. A parent's failure to provide adequate or acceptable medical treatment for a child can constitute child neglect, triggering governmental intervention.[312] New York law also constrains parental decisions to forgo life-sustaining treatment.[3]

In general, the New York courts have interpreted the neglect standard to give parents broad latitude to decide about treatment, allowing a greater range of parental discretion than would be extended under

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1 See chapter 2, 39-40. See also N.Y. Pub. Health Law § 2504(2) (McKinney 1985). As explained by the New York Court of Appeals in a case concerning parental rights to custody: "The state is parens patriae and always has been, but it has not displaced the parent in right or responsibility. Indeed, the courts and the law, would, under existing constitutional principles, be powerless to supplant parents except for grievous cause or necessity." Bennett v. Jeffreys, 40 N.Y.2d 543, 545, 367 N.Y.S.2d 821, 824 (1976). The clear legal authority of parents to make treatment decisions for their children stands in marked contrast to the lack of explicit legal authority for other surrogates to make health care decisions under New York law, except for surrogates deciding about CPR or appointed health care agents.

2 See, e.g., *Matter of Gault,* 387 U.S. 1 (1967); N.Y. Fam. Ct. Act Article 10 (McKinney 1983 & Supp. 1992). Parental authority may also be limited in a different way by the authority of emancipated minors and mature minors to make some health care decisions for themselves. See chapter 2,40.

3 See chapter 2,40.

the best interests standard. In some cases, courts have recognized that parents may choose unconventional medical treatments for their minor children, allowing parents to opt for recommended treatments that might not maximize their child's chance for survival.[4]

If a child's natural parents die or are unable or unfit to care for the child, a court can appoint another adult as guardian of the child.[5] Often this legal guardian is a member of the child's extended family, such as an aunt, uncle, or grandparent, or has a prior relationship to the child. These guardians stand ***in loco parentis,*** in the parent's place, in terms of their responsibility for and relationship to the child. They generally possess the same authority as parents to decide about medical treatment.

Treatment Decisions by Parents

The Task Force believes that existing state law governing parental treatment decisions for minor children establishes sound policies and should not be changed, except for legal precedents concerning parental authority to forgo life-sustaining treatment. Parents are generally the persons most committed to their child's well-being, and the best judges of their child's interests. Parents also have special rights and responsibilities in raising their children. While most surrogates make health care decisions for a patient only when the patient loses decision-making capacity, parents ordinarily decide about treatment for their children. Parents also shape a child's development and have discretion in imparting their values to the child and making choices for the child based on those values.[6]

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[4] See *In re Hofbauer,* 47 N.Y.2d 648, 419 N.Y.S.2d 936 (1979) and *Weber* u *Stony Brook,* 95 A.D.2d 587, 467 N.Y.S.2d 686 (2d Dep't 1983). In *Hofbauer,* the court upheld the parents' right to refuse conventional radiation treatment for their son suffering from Hodgkin's disease. They opted for laetrile and nutritional therapies proposed by the boy's physician but rejected by most medical authorities.

[5] An individual ordinarily becomes the guardian of the person of a minor by means of a proceeding in the Surrogate's Court, pursuant to the procedures and standards of Article 17 of the Surrogate's Court Procedure Act. Determinations about guardianship are made based on the court's assessment of the child's best interests. However, if a parent contests the appointment of a nonparent, the court will not appoint the nonparent unless the parent is unfit or there exists some other extraordinary circumstance. See *Merritt* v. *Way,* 85 A.D.2d 666, 445 N.Y.S.2d 205 (2d Dep't 1981), *affd,* 58 N.Y.2d 850,460 N.Y.S.2d 20 (1983).

[6] See, e.g., A. E. Buchanan and D. W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989), 232-34.

Reliance on the abuse and neglect standard respects the parent-child relationship and the constitutional right of parents to make fundamental decisions for their minor children. As an ethical matter, parents should seek to make treatment decisions that serve their child's best interests. As a legal matter, however, the state should show significant deference to parental authority before intruding into the intimacy of the parent-child relationship.

Current laws limiting state intervention to instances of actual or suspected child abuse should not deter health care professionals from relying on the best interests standard as a guidepost when interacting with parents. Courts become involved in the process of deciding for children only when parents' choices endanger the child's health or welfare. Health care professionals, in contrast, routinely interact with minor patients and their parents in the course of delivering medical care. The best interests of the child should provide a benchmark for this interaction, shaping the way physicians frame treatment options and their recommendations to parents.

Ongoing discussion among health care professionals and parents is essential to assess which course of action best serves the child's interests. In addition, children should be informed, in a manner appropriate to their developmental level and preferences, about their condition, proposed treatments, and likely outcomes, especially in cases of severe illness or major medical interventions. The experience of chronic or terminal illness often confers on young children maturity or understanding generally not associated with children their age. Moreover, when parents and physicians don't talk to a child about his or her illness, they risk leaving the child feeling isolated and helpless.

Children should be asked about their perceptions of treatments and medical conditions. Even young children may contribute to treatment decisions, at least to the extent of determining the order or manner in which some procedures are performed. Children should be involved in decisions in a way that respects their developing capacity and maturity.

Parental Decisions to Forgo Life-Sustaining Treatment

While New York law recognizes the right of parents to make most health care decisions on behalf of their children, like other surrogates, parents are not clearly authorized to decide to forgo life-sustaining treatment, except for cardiopulmonary resuscitation. Yet for children, as for adults, the provision of life-sustaining treatment may contravene

the patient's interests. Aggressive courses of treatment may in some cases cause pain or psychological suffering and offer little hope of benefit. At the same time, deciding to forgo life-sustaining treatment is especially painful for parents because of the tragedy and depth of personal loss they experience. The death of a child is traumatic for them, for other family members, and for health care professionals.

Surrogates for adults can often look to the patient's previously expressed wishes and to the totality of the person's life in making treatment decisions. Although parents must attend carefully to the views and preferences expressed by children, they must assume a fuller burden of responsibility for the decision. This can heighten the anguish of parents, whether they decide to provide painful procedures to prolong their child's life or to refuse life-sustaining treatment.

These factors make decisions to forgo life-sustaining treatment on behalf of children even more difficult than for adult patients, but do not call for different procedures or substantive standards. The Task Force proposes that parents and legal guardians should decide about life-sustaining treatment for minor children, in accord with the same standards as surrogate decisions for adults.

Under the Task Force's proposal, surrogate decisions for adults are guided by the patient's wishes when possible and by the best interests standard otherwise. Minors generally lack both the capacity and the legal authority to make their own health care decisions.[7] Accordingly, while parents should take the views and preferences of children into account, parental decisions to forgo life-sustaining treatment for minor children usually will be guided by the best interests standard.[8]

The best interests standard grants parents less discretion than the neglect standard that governs other parental decisions about treatment under existing law. The Task Force believes that the nature of the decisions and the magnitude of the interests at stake provide a basis for distinguishing parental decisions about life-sustaining treatment from other treatment decisions. Decisions to forgo life-sustaining treatment affect the child's most fundamental interests and are generally irreversible. The decisions call for a different balancing of society's responsibilities to respect the choices of parents and to protect the health and welfare of children.

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7 The special case of mature minors is discussed on pp. 129-32.

8 The patient’s wishes should become increasingly central to the decision-making process for older children and adolescents as they develop and mature.

Reliance on the best interests standard for parental decisions about life-sustaining treatment would not disrupt well-established or settled legal precedents. Parental decisions to refuse life-sustaining treatment have not been granted the same deference as other treatment decisions by parents. Like surrogate decisions to forgo life-sustaining treatment generally, parental decisions have been sharply constrained by legal precedents established by the New York Court of Appeals.[9]

As with adults, the assessment of the child's best interests should include consideration of the uniqueness and dignity 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 factors as a reasonable person in the patient's medical and personal circumstances would want considered. Decisions for adults often look back to the adult's life to determine the values or views that should inform decisions. In contrast, a judgment for children is more forward-looking: it focuses on the child's potential and the opportunity for future development. Whenever possible, the child's own perceptions of treatment and medical conditions should be taken into account, although they may not in themselves be decisive.

Life-sustaining treatment should only be withheld or terminated if it would be an excessive burden to the child under the best interests standard. In addition, parents should be authorized to refuse life-sustaining treatment only if the medical criteria for surrogate decisions are satisfied: the child is terminally ill; the child is permanently unconscious; the child's attending physician confirms that the decision satisfies the best interests standard, and a bioethics review committee approves the decision; or a court finds that the decision complies with the proposed surrogate standards and issues an order approving the decision.[10]

While a decision to forgo life-sustaining treatment requires only the formal consent of one parent, any objections raised by another parent of the child must be considered. If an attending physician learns that one parent opposes a decision by the other parent concerning life-sustaining treatment, and the disagreement cannot be resolved, the physician should refer the matter to a review committee for dispute mediation.

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9 See Chapter 2, 40.

10 See chapter 7. Bioethics review committees are discussed in chapter 9.

In some cases, physicians may have contact with only one parent. Indeed, a growing number of children are raised by single parents. While some children have a significant ongoing relationship with a noncustodial parent, others may have little or no contact. If an attending physician has reason to believe that there is a parent, including a noncustodial parent, who has not been informed of a decision to refuse life-sustaining treatment, health care professionals should make reasonable efforts to determine if the parent has maintained "substantial and continuous contact" with the minor.[11] If so, the physician should make diligent efforts to contact the parent. This provision preserves the rights and responsibilities of parents to make health care decisions for their children. At the same time, it recognizes that when a noncustodial parent has become estranged from or hostile to the custodial parent or to the child, informing that parent may only lead to conflict that ultimately harms the child and the custodial parent.

Deciding for Newborns

Beginning in the early 1970s, ethical dilemmas in the neonatal nursery have been the focus of intensive public scrutiny and debate.[12]

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[11] The standard of substantial and continuous contact is drawn from New York's DNR law and the law on parental consent to adoption. The DNR law requires physicians to attempt to inform a parent of a pending DNR order if the physician knows that the parent has maintained substantial and continuous contact with the child. N.Y. Pub. Health Law § 2967(2)(b) (McKinney Supp. 1992). Under the Domestic Relations Law, a determination about "substantial and continuous" contact examines such factors as a parent's financial support for, visitation of, and communication with, the child N.Y. Dom. Rel. Law § 111 (McKinney 1988 & Supp. 1992).

[12] An article by two physicians describing a policy marked by great deference to parental decisions sparked discussion of these issues as early as 1973. R. F. Duff and A. G. M. Campbell, "Moral and Ethical Dilemmas in the Special-Care Nursery," *New England Journal of Medicine* 289 (1973): 890-94. In another early article, James M. Gustafson discussed and criticized a decision to allow the death of a newborn with Down syndrome. "Mongolism, Parental Desires, and the Right to Life," *Perspectives in Biology and Medicine* 16 (1973): 529-57. Physicians continue to embrace widely varying approaches to treatment decisions for newborns. Some see preserving the infant's life as central, while others are more willing to make judgments about whether the newborn would have an acceptable quality of life. Physicians also vary in their responsiveness to parental concerns and their deference to parental decisions that they believe fail to promote the infant's interests. See E. Rosenthal, "As More Tiny Infants Live, Choices and Burden Grow," *New York Times*, September 29, 1991, 1, and R. F. Weir, *Selective Nontreatment of Handicapped Newborns* (New York: Oxford University

Dramatic advances in neonatal medicine have not changed the fact that some infants are born dying or face a highly uncertain prognosis for survival.[13] In fact, social trends, including the use of crack and cocaine, have made the hard choices faced in the nursery more prevalent.

Newborns may face life-threatening conditions as the result of many factors, including congenital defects, maternal disease, labor-related complications, and prematurity. Unfortunately, neonatal complications are not uncommon, especially those caused by prematurity. In 1988,10.7 percent of newborns in New York State, and 12.9 percent of newborns in New York City, were born premature (gestation less than 37 weeks); 7.8 percent of newborns in New York State, and 9.8 percent of newborns in New York City, had a low birth weight (less than 2,500 grams, or about 51/2 pounds).[14] Both low-birth-weight and premature newborns face increased risk of medical complications, with the degree of risk depending on the extent of prematurity and low birth weight, as well as other factors.

The severity of risks that newborns face, and the certainty of their prognosis, vary widely. Anencephalic infants, who lack a developed brain, are likely to die within the first hours or days after birth and have no potential for consciousness. Infants with some severe congenital abnormalities, such as trisomy 13, suffer from profound mental and physical defects and often die within a few months. In contrast, infants with trisomy 21, commonly known as Down syndrome, while often facing serious medical complications, generally have good prospects for a prolonged life. The mental deficiency associated with Down syndrome varies, with an IQ generally ranging between 25 and 60.

Press, 1984). Among the many discussions of health care decisions for newborns, see also 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), 197-229; Hastings Center Research Project on the Care of Imperiled Newborns, "Imperiled Newborns," *Hastings Center Report* 17, no. 6 (1987): 5-32; A. R. Fleischman, "Ethical Issues in Neonatology: A U.S. Perspective," in *Biomedical Ethics: An Anglo-American Dialogue,* ed. D. Callahan and G. R Dunstan (New York: New York Academy of Science, 1988), 83-91.

[13] As articulated by Paul Ramsey in 1970: "Life in the first of it and life in the last of it are both prismatic cases of human helplessness. The question is, What does loyalty to the newborn and to the dying require of us? ... If a balancing judgment is permitted — even morally required — concerning whether proposed remedies will be beneficial to the adult dying, the same reasoning cannot be peremptorily excluded from our care of the newborn." *The Patient as Person* (New Haven: Yale University Press, 1970), 131-32.

[14] New York State, Department of Health, *County Data Book,* December 1990,45.

The prognosis for newborns who are premature and of low birth weight is often highly uncertain, especially in the long term. Continuing advances in neonatology over the last three decades have made possible the survival of newborns who are increasingly smaller, of younger gestational age, and more severely ill[15] These developments have reduced infant mortality and improved the quality of life for many infants, especially for newborns who weigh 750 grams (one pound and 10 ounces) or more. A significant number of newborns of gestational age 24-28 weeks and birth weight of 500-1,000 grams now survive.

At the same time, efforts to save babies at younger and younger gestational ages have increased the number of children who survive with severe disability. While neonatal intensive care and other treatments show remarkable power to support newborns of only six months gestational age, they are imperfect substitutes for the natural gestational environment. The smallest newborns are extremely vulnerable to severe complications such as respiratory disorders and brain hemorrhage leading to neurological damage, blindness, and seizures. Although some of these infants grow up to lead lives without significant handicaps, others survive with the most profound disabilities or die a prolonged death.

Decisions to forgo life-sustaining treatment may reflect a judgment about whether the infant's survival despite severe disabilities would be in the infant's interests, introducing further complications. Parents deciding for newborns with a potentially handicapping condition are also likely to consider the child's interests in the context of the family's life and the impact of the child's illness on them and their other children.

While many parents find reward and meaning in caring for severely ill and disabled children, immense personal and financial sacrifices are required. Moreover, for adults who have lived a life unencumbered by handicaps, a life burdened by severe or even moderate disabilities might not seem acceptable. Yet those lives may be worth living from the perspective of those who have known no other condition. [16] Ul-

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The capacity of medicine to preserve the lives of the most premature newborns is discussed in New York State Task Force on Life and the Law, Committee on Fetal Extrauterine Survivability, *Fetal Extrauterme Survivability* (New York: New York State Task Force on Life and the Law, 1988). The report concluded that 23-24 weeks represents a threshold of fetal survivability; technological advances are likely to improve the rate of survival for newborns above this threshold but will not in the foreseeable future make survival at younger gestational ages possible.

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As one commentator notes: "Even individuals with serious, ongoing handicaps

timately, treatment alternatives must be weighed to consider the child's strong interest in continued life as well as the limited benefits and potential harm that advanced medical treatment may confer on infants.

The Task Force believes that the interests of newborns will generally be served best by authorizing parents to decide on their behalf. Parental decisions for newborns should be made in accord with the standards and procedures for other surrogate decisions, recognizing that the best interests standard will always apply to newborns who have not developed their own views or values.

The participation of health care personnel in the decision-making process, the requirement that decisions further the newborn's best interests, and the medical circumstances that define the limits of surrogate authority will promote sound decisions by parents for their newborn children. For newborns as for other patients, in many cases the best interests standard will not yield a single correct decision, but will be consistent with a range of reasonable alternatives.[17]

The newborn's prognosis and the outcome of interventions are often uncertain. This uncertainty makes the option of a trial period of treatment especially critical for newborns. Parents and physicians should explore the benefits and burdens of a trial period of treatment. If they later decide that the treatment is excessively burdensome to the newborn, treatment could be withdrawn or withheld at that time.

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[17] Decisions to forgo life-sustaining treatment for newborns who are neither terminally ill nor permanently unconscious include those decisions that present the greatest danger of mistaken judgment or abuse. For example, in one much publicized case, the Bloomington Baby Doe case, parents accepted medical advice to refuse surgery to correct an esophageal blockage for their newborn son with Down syndrome, solely because the child had Down syndrome. See Weir, 128-129; J. E. Pless, "The Story of Baby Doe," *New England Journal of Medicine* 309 (1983): 664. Under the Task Force's proposal, these cases will be reviewed automatically by the bioethics review committee.

Children in Foster Care

A substantial number of children in New York State do not reside with their parents, but instead live in institutions, group homes, or with relatives or unrelated families, placed there under the auspices of state and local government. The children are part of New York State's foster care system. At the end of 1991, 64,445 children had entered this system. The vast majority of children are placed in foster care because of abuse, neglect, or abandonment by parents or other caretakers. Approximately 38 percent of foster care children are placed with relatives, sometimes referred to as "kinship" foster parents.[18]

If a court determines that a child has been abused or neglected, or if a public agency removes a child from parental custody on grounds of abuse or neglect, New York law authorizes local commissioners of social services and local commissioners of health to "give effective consent for medical, dental, health and hospital services "[19] State and local agencies generally assume that this authority does not include the power to forgo life-sustaining measures. Nor have they construed it as a basis to act as a decision maker under New York's DNR law, which authorizes a minor's "legal guardian" to consent to a DNR order.[20]

Private agencies or foster parents caring for children that have been removed from their parents and entered the foster care system have no

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[18] New York State Department of Social Services, *Monthly Summary Characteristics of Children in Foster Care* (Albany, N. Y.: New York State Department of Social Services, December 1, 1991); New York State Department of Social Services, Division of Family and Children's Services, Bureau of Services Information Systems, *Special Report*, (Albany, N. Y.: New York State Department of Social Services, October 31, 1991). Of the 64,445 children in foster care as of November 30, 1991, 50,770 were from New York City. Statewide, approximately 73% of the children were in foster care following a judicial finding of abuse or neglect and 21% were voluntarily placed by parents. Most voluntary placements arise because of abuse and neglect, but placements are negotiated between local departments of social services and parents and do not involve the courts.

[19] N.Y. Soc. Serv. Law (&) 383-b (McKinney Supp. 1992)

[20] N.Y. Pub. Health Law § 2967(2) (McKinney Supp. 1992), Some of the local agencies interpret the DNR law as limiting decisional authority for minors to parents or to court-appointed guardians of the person. These agencies attain this guardianship only if a court terminates all parental rights, freeing the child for adoption. A local agency does not serve as legal guardian for the vast majority of children in foster care; the children are in the care and custody of the state, but parental rights have not been terminated.

authority to make major treatment decisions. The local department of social services and the child's natural parents, if available, generally decide about treatment. Even if a child has spent years with a foster parent or a foster parent is a close relative, that adult cannot make health care decisions for the child. Nor can foster parents seek court approval for particular treatment decisions unless they forfeit the programmatic and financial support they receive for participating in the foster care system. Foster care is regarded as temporary, with the assumption that children should be returned home or adopted as soon as possible.

If only natural parents or judicially-appointed legal guardians are authorized to decide about life-sustaining treatment, many foster care children will be left without anyone to decide on their behalf. Parents are not available to decide about treatment for many children in foster care, some of whom are abandoned at birth in the hospital. Legal guardianship for a minor is rarely transferred to a private individual or to a local department of social services solely to authorize medical decisions for a dying child.

Unfortunately, the circumstances of their lives place foster care children at special risk for severe or terminal illness. Some are born dying because of AIDS or conditions associated with extreme prematurity. Others may be the victims of abuse or violence. An increasing number are born addicted to crack-cocaine or other substances.

These children are among the most vulnerable members of our society. The obligation to care for them encompasses the duty to assure that they receive compassionate, appropriate medical care. Unless sound policies for decisions about life-sustaining treatment are adopted, these children will not only have more difficult lives, but also more difficult and painful deaths; they will undergo aggressive interventions that most parents would refuse on behalf of their children.

For this reason, the courts should be authorized to appoint a special limited guardian of a minor, called a "health care guardian," empowered to decide about life-sustaining treatment in accord with the same standards that would apply to parents and legal guardians for a minor under the Task Force's proposal. The appointment of a health care guardian should only be an option if no parent is available, willing and competent to exercise his or her right to decide on the child's behalf. In all cases, the natural parents and responsible governmental

agencies should be notified at the beginning of the appointment process.[21]

Only persons with a direct relationship to the child should be permitted to seek appointment as a health care guardian. The hospital administrator and the attending physician should be authorized to petition for this guardianship. The local commissioner of health or local commissioner of social services should also be permitted to seek appointment as health care guardian for children removed from their parents due to abuse or neglect. Finally, private individuals who have cared for the child for a substantial and continuous period of time should be allowed to seek this authority. This may include foster parents who care for the child through formal, compensated placements, as well as relatives who have cared for or raised the child through informal arrangements. The law should grant these individuals only the right to petition the court. The appointment itself should rest on existing guardianship principles, including respect for parental rights and the court's obligation to protect the child's best interests.

Seeking appointment or being appointed as a health care guardian should not otherwise affect the legal status or rights of a person who seeks the appointment. For example, financial and other support received by a foster parent should not cease if he or she undertakes this responsibility. Some foster parents, including family members such as a grandmother or aunt, develop a substantial relationship with a child and may have raised the child since birth. They should not be discouraged from seeking appointment as a health care guardian for fear of losing foster parent status. While the underlying goals of the foster care system are generally adoption or return home, these goals should not interfere with the delivery of appropriate medical care for dying or severely ill children. Clearly for these children, a compassionate decision-making process responsive to their medical needs should be the paramount consideration.

The legislation proposed by the Task Force would allow a court to appoint a health care guardian only for the purpose of deciding about life-sustaining treatment. The Task Force urges the legislature, and those concerned about the well-being of children in foster care, to consider whether this authority should be extended to encompass all health care decisions, if necessary to serve the best interests of the

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21 Specifically, the Task Force recommends notifying those persons who would be served with process of a proceeding to appoint a guardian of a minor under section 1705 of the Surrogate's Court Procedure Act (McKinney 1967 & Supp. 1992).

child. While the local departments of social services can consent to treatment for children in foster care, an individual at the health care facility appointed by the court and in close contact with health care professionals may provide more timely decisions and the intensive involvement required for a severely or terminally ill child.[22] In each case, the court could determine whether a parent is available to fulfill this role, or whether the child's needs would be better served if the local department of social services retained sole responsibility for these decisions. Public discussion of the proposed legislation should explore this option, and seek to assess the need for and benefits of this alternative for children in foster care.

Mature Minors

The laws governing the rights of minors to participate in or make health care decisions reflect a complex balancing of the developing rights of the minor and parental rights. A minor's interest in autonomy must be weighed against the risk of harm from his or her own poor decisions and the rights and interests of parents. Society also has an interest in promoting the autonomy and well-being of minors.

As established by statutes and judicial opinions in New York State, a minor's right to decide about treatment depends on the minor's status and the nature of the decision. For some treatment decisions, a minor is categorically excluded, while for others a minor's right to participate may depend on a determination of his or her maturity and ability to appreciate the risks and benefits of a particular course of action.[23]

New York statutes expressly grant minors the right to decide about treatments for certain conditions, such as venereal disease, mental illness, prenatal care, and drug abuse. These laws reflect judgments about parental authority and the rights and well-being of minors in relation to specific treatments. For example, without parental consent or knowledge, a physician may treat a minor who has been infected by or exposed to a sexually transmitted disease; a minor who is 17 years

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In his article on treatment decisions for foster care children, Jonathan D. Moreno acknowledges that he has no data about the harm caused children under the existing system of consent, but reports anecdotal evidence that treatment has been delayed by the need to obtain consent from the responsible social services agency. He argues for broader, supervised authority for faster parents to consent to treatments that clearly would benefit the child and present little or no risk. "Foster Parents as Surrogates for Infants and Young Children," *Mount Sinai Journal of Medicine* 58 (1991): 393-97.

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See discussion in chapter 2,42^45.

or older may donate blood in a voluntary and noncompensatory program without parental permission.[24]

These specific policies should not be disturbed or replaced with all-encompassing standards for decisions without thorough review, consideration, and debate. While the Task Force believes that existing policies for decisions by and for mature minors might benefit from a more comprehensive approach, it has concluded that the issue is too complex to be addressed in the context of this proposal.[25] Accordingly, as with decisions for children generally, the Task Force's proposal for treatment decisions by or on behalf of mature minors addresses only decisions to forgo life-sustaining treatment.

The Task Force recommends that the determination of a minor's capacity to participate in a decision about life-sustaining treatment should be made on a case-by-case basis. Each determination should carefully assess the minor's maturity, conceptual ability, and experience in making important life decisions. In addition, in contrast to adults who are presumed capable of deciding about treatment, minors should generally be presumed incapable, unless the physician determines that the minor possesses capacity. Like the policy embodied in New York's DNR law, this approach recognizes that the decisional capacities of adolescents vary widely.[26]

The Task Force concluded that lowering the age of majority for deciding about health care or extending the presumption of capacity accorded adults to minors, would not be appropriate. Even adolescents with significant cognitive abilities may have difficulty in assessing future consequences of their choices or anticipating changes in their values and preferences. At the same time, some minors do have the maturity and decisional capacity to participate in decisions about life-sustaining treatment. These minors should not be excluded from the decision-making process because of a categorical determination based on age,

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[24] N.Y. Pub. Health Law §§ 2305(2) and 3123 (McKinney Supp. 1992).

[25] See, e.g., U. S. Congress, Office of Technology Assessment, *Adolescent Health*, vol. 1, *Summary and Policy Options* (Washington: U.S. Government Printing Office, 1991), 57, which states, "The body of law that determines the extent of adolescents' involvement in decisions about their own health care is large and complicated because it is an amalgam of common law, State and other statutes, Supreme Court decisions, the decisions of other Federal and State courts, and regulations issued by government agencies. From the standpoint of adolescents, their parents, and health care providers, among others, the law in this area is often unclear and inconsistent."

[26] N.Y. Pub. Health Law § 2967 (McKinney Supp. 1992).

unrelated to their individual emotional development and cognitive capacities.

Rather than an assessment by a physician and a second health care professional as proposed for adults, the Task Force recommends that an attending physician, in consultation with a minor's parent or legal guardian, should determine whether a minor has the capacity to decide about life-sustaining treatment. Parents are usually most familiar with the minor's emotional and cognitive development — information that is critical to the assessment. Ultimately, however, the attending physician must utilize his or her clinical experience to determine capacity, based on observations of the patient and information provided by the parents and by others such as health care professionals.

The Task Force proposes that minors found to have decisional capacity should be accorded a substantial, although not exclusive, role in decisions about life-sustaining treatment. If a minor has decision-making capacity, the minor's consent should be required to withhold or withdraw life-sustaining treatment. After weighing the rights and responsibilities of parents and the consequences of a decision to refuse life-sustaining treatment, the Task Force also concluded that the minor's right to refuse life-sustaining treatment should depend on parental consent. Under this policy, parental consent is not required if the minor chooses to have treatment continued, but would be necessary to forgo treatment, unless a court order is obtained.

The Task Force recognizes that in some cases, it will be ethically acceptable and appropriate to respect the choice of a capable uneman-dpated minor to withhold or to stop life-saving or life-sustaining treatment, even in the face of parental objections. For example, an adolescent, dying of AIDS or cancer, may come to grips with and accept his or her impending death more readily than a parent. In such cases, an aggressive course of chemotherapy, or experimental treatment for AIDS that prolongs the adolescent's dying but offers slim if any chance of saving his or her life, may impose enormous suffering. As a practical matter, however, the Task Force believes that few hospitals would remove treatment in the face of parental opposition and that granting minors the right to decide over the objection of parents will also yield poor decisions in some cases.

Important too in considering this issue is the realization that dis-agreements about life-sustaining treatment between minors who have decision-making capacity and their parents will be rare. In most cases, disputes will be resolved through communication among the patient, parents, and health care professionals. For cases of ongoing conflict,

participation by a bioethics review committee may also contribute to a resolution. If informal mediation fails to resolve the conflict, the committee can issue a nonbinding opinion about the appropriate course of action. However, as proposed by the Task Force, if the minor is not emancipated, decisions to forgo life-sustaining treatment, even if agreed to by the committee, cannot be implemented without the consent of a parent as well as the patient, unless a court approves the decision.

The Task Force anticipates that a review committee recommendation supporting a minor's decision to refuse life-sustaining treatment will generally help to persuade parents to consent to that decision. In the unusual event that parents continue to insist on treatment, the review committee or health care facility should refer the case to the Legal Aid Society or otherwise help the patient to arrange for legal counsel, so that the dispute between the minor and his or her parents can be resolved by a court. The Task Force recognizes that these policies leave unemancipated, mature minors dependent upon their health care facility or professionals for assistance, but it believes that this approach is preferable to a blanket policy favoring decisions by minors or by their parents in all cases.

Emancipated Minors

Special issues are raised by patients who are not yet adults but are no longer part of an established parent-child relationship. The personal circumstances of these patients vary widely. One patient may be an adolescent runaway who has left behind an untenable family situation and, of necessity, made a life for herself on the streets. Another may be a member of the armed services, raised in a supportive family but now beyond the bounds and controls of his parents. The health needs of homeless and runaway adolescents are of particular concern, given the often troubled circumstances of their lives.[27]

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[27] Covenant House, an organization that provides a shelter and services for homeless adolescents in New York City, operates a medical clinic that has served approximately 28,000 minors since 1984. About 60% are treated for sexually transmitted diseases. Other common conditions treated include mental illness, substance addiction, pregnancy, and trauma. Interview with James Kennedy, Medical Director, Covenant House, in New York City (November 26, 1990). These adolescents' high-risk behavior also makes AIDS a substantial health threat. New York State, and, in particular, New York City, have been described "as the epicenter of the epidemic of HIV in adolescents." As of March 1990,20% of all reported cases of AIDS among persons aged 13 to 21 in the United States were diagnosed in New York City. See Ad Hoc Committee on Adolescents and HIV of the New York State

Like other minors, emancipated minors may give valid consent to treatment for certain conditions, such as sexually transmitted diseases. Health care providers may also rely on other legal bases for consent, such as the emergency exception, which authorizes the provision of care in cases when delay would endanger the patient's life and health.[28] The emancipated minor doctrine, a developing area of New York law, may also empower these minors to consent to treatment. The doctrine applies in cases where both a minor and his or her parents have intentionally ended the parent-child relationship.[29] Some health care providers accept the mature minor doctrine, allowing minors to consent to treatment if they understand the nature and consequences of treatment and can make an informed decision.[30]

Despite different legal bases for consent, some health care providers are reluctant to treat any minor, even an emancipated minor, without the consent of a parent or legal guardian. As a result, the minor's access to health care may be impeded. Many of these minors lack health insurance or other financial resources, creating another barrier to adequate medical care.[31]

The health care needs of emancipated minors and policies to promote their access to treatment raise complex questions. These issues, and the effect of existing law on the treatment of emancipated minors, merit further study [32] In this proposal, however, as it has with other minors, the Task Force limits its recommendations to decisions about life-sustaining treatment.

Minors who have decision-making capacity, and other indicia of independence and adulthood, should be accorded the right to decide about life-sustaining treatment, with review of their decisions to refuse

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AIDS Advisory Council, *Illusions of Immortality: The Confrontation of Adolescence and AIDS* (New York: New York State AIDS Advisory Council, 1991), 18-19.

[28] See N.Y. Pub. Health Law § 2504(4) (McKinney 1985).

[29] See discussion in chapter 2, 42-43.

[30] See discussion in chapter 2, 43-44.

[31] The Office of Technology Assessment reports that "[o]ne out of seven adolescents, 4.6 million overall, are without a key ingredient to access to health care: health insurance coverage. This includes one out of three poor adolescents who are not covered by the Medicaid program." Office of Technology Assessment, 110.

[32] For a cogent discussion of some of these issues, see the report by the Ad Hoc Committee on Adolescents and HIV of the New York State AIDS Advisory Council.

treatment. The Task Force proposes that a minor should be considered emancipated if he or she is 16 years of age or older and living independently from his or her parents or legal guardian. Moreover, for purposes of a decision to forgo life-sustaining treatment, the Task Force believes that the current legal presumption in New York that "the parent of a child" is capable of consenting to treatment on his or her own behalf is overly broad.[33] A very young parent, such as a 13- or 14-year-old, should not be presumed capable of deciding to refuse life-sustaining treatment for himself or herself.[34] The Task force proposes that parents who are younger than 18 years of age should be considered emancipated minors, not adults, under its decision-making proposal.

If an attending physician determines that a minor has decision-making capacity and is emancipated, the minor should have authority to consent to life-sustaining treatment. The minor should also be permitted to decide that life-sustaining treatment should be withheld or withdrawn, but not with the same degree of latitude accorded capable adults. To minimize the risk of harm from a poor decision, the minor's choice should fall within the parameters proposed for surrogate decisions for adults. The minor should be terminally ill and treatment must pose an excessive burden to the minor, or, for minors who are not terminally ill, treatment must be an excessive burden. In either case, the bioethics review committee should approve the decision.

Particularly when considering decisions by homeless and runaway adolescents to forgo treatment, the review committee should help ensure that chronically or terminally ill minors do not refuse treatment and choose to die because they feel they have limited options for continuing their lives. Health care professionals should try to secure all available psychosocial support and encourage the minor to separate the despair that may accompany life on the streets from the burdens associated with the provision of life-sustaining treatment.[35]

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

[34] The Task Force does not propose setting special limits on such parents' rights to decide for their own children. The safeguards contained in the Task Force proposal for all parental decisions to forgo life-sustaining treatment, as well as the separate laws and policies protecting against child abuse and neglect, provide sufficient protection against poor decisions.

[35] Leon Kass describes the physician's responsibility to provide this support to all chronically and terminally ill patients: "Instruction, support, and encouragement become all the more part of the doctor's professed business in the face of chronic illness and incurable disease Concretely, this means that the physician is obligated

Health care professionals should also ensure that the parents or legal guardian are not inappropriately excluded from the decision-making process, by notifying the parents or legal guardian of an emancipated minor, if the hospital can readily ascertain their identity. If a parent or legal guardian objects to the minor's decision or to a judgment that the minor is emancipated, the review committee should consider the matter. If the review committee concludes that the minor is not emancipated, the parent or guardian's consent would be necessary to withdraw or withhold treatment, as with other mature minors. If the committee finds that the minor is emancipated and approves the minor's decision, the minor's decision should be honored, unless the parent or legal guardian seeks a court order.

Recommendation

The Task Force recommends that a minor's parent, legal guardian, or special health care guardian should have the authority to decide about life-sustaining treatment on behalf of the minor, according to the same standards and limitations that apply to surrogate decisions for adults. A health care guardian would be an individual, with a direct relationship with the minor, who has been appointed by a court solely for the purpose of deciding about life-sustaining treatment. An attending physician, in consultation with a minor's parent, legal guardian, or health care guardian, should determine whether a minor has the capacity to decide about life-sustaining treatment. If the minor has decision-making capacity, the minor's agreement should be required to withhold or withdraw life-sustaining treatment.

Minors who are 16 years of age or older and living independently from a parent or legal guardian, and minors who are the parent of a child, should be authorized to decide about life-sustaining treatment, if an attending physician determines that the minor has decisionmaking capacity. An emancipated minor's decision to forgo life-sustaining treatment should meet the same standards that govern surrogate decisions for adults and should require the approval of a bioethics review committee.

~~to learn and advise about ways of *living* better with~~ illness, through means not generally thought to be medical — involving advice about improved and more encouraging living situations, family support, alternative employment, transportation, etc." *Toward a More Natural Science: Biology and Human Affairs*

Health care professionals should notify the parents or legal guardian of an emancipated minor patient prior to implementing a decision to forgo

treatment, if they can readily ascertain their identity. If a parent or legal guardian objects to the minor's decision to refuse treatment, the bioethics review committee should consider the matter. If the minor, attending physician, and bioethics review committee still agree that treatment should be withheld or withdrawn, the minor's decision should be honored, although a parent or legal guardian may seek judicial intervention.

See Appendix A, proposed legislation, Section 5.

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Bioethics Review Committees

The Task Force believes that treatment decisions for patients without decision-making capacity should generally be made by family members or others close to the patient, in consultation with physicians and other health care professionals. By and large, decisions made in accord with the proposed law will be private bedside decisions by those closest to the patient. In some circumstances, however, additional review or consultation will be necessary. In particular, consultation and review should be available if conflict arises or if surrogates wish to forgo life-sustaining treatment on behalf of patients who are not terminally ill or permanently unconscious, but who may be severely and chronically ill.

The Task Force proposes that multidisciplinary committees based in health care facilities, referred to as "bioethics review committees," would best fulfill these functions. In addition, the Task Force proposes that the review committees should also be authorized to review and approve proposed treatment decisions for patients without family or others to serve as surrogates and for emancipated minors.[32]

Establishing Bioethics Review Committees

The Task Force recommends that each health care facility should establish a bioethics review committee or participate in a review committee that serves more than one facility.[33] While these committees would share some of the characteristics of ethics committees, the authority of the review committees would be greater than that generally exercised by ethics committees.[34]

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[32] See chapter 10 for discussion of policies proposed for patients without surrogates and chapter 8,132-35, for policies for emancipated minors.

[2] Facilities may also establish or participate in more than one review committee. For example, a large hospital might choose to establish separate review committees for infants or for other groups of patients.

[34] See chapter 1 for discussion of ethics committees.

The Task Force's recommendations for review committees draw not only upon the experience of ethics committees, but also upon institutional review boards (IRBs). Federal regulations mandate that IRBs review proposals for federally funded research involving human subjects.[35] New York State law requires a similar review procedure for any research with human subjects not covered by federal regulations.[5] Federal regulations set minimal standards for the composition of IRBs and specify criteria that IRBs must consider in their evaluations. IRBs have the power to approve, require modifications in, or disapprove any research activities they consider.

Under the Task Force's proposal, bioethics review committees would be mandated by state law and, like IRBs, would have to meet certain requirements. Review committees would be distinguished from IRBs most clearly in that review committees would consider treatment decisions for particular patients, while IRBs examine research programs as a whole. State law would frame the review committees' function and operation, but would be less specific than the regulations governing IRBs.

Bioethics review committees would also share some characteristics of surrogate committees for the mentally disabled established under Article 80 of New York's Mental Hygiene Law. Under Article 80, multidisciplinary committees make treatment decisions for mental hygiene facility residents who lack available surrogates. Bioethics review committees would also be multidisciplinary committees charged to promote the interests of vulnerable patients. However, under Article 80, the committees decide only for patients who have no natural surrogate, while the committees proposed by the Task Force would review certain decisions by family members or other surrogates.[6]

In developing its recommendations, the Task Force also examined the role the courts might and should play in surrogate decisions. It concluded

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45 C.F.R.§ 46 (1991). See L. H. Glantz, "Contrasting Institutional Review Boards with Institutional Ethics Committees," in *Institutional Ethics Committees and Health Care Decision Making,* ed. R. E. Cranford and A E. Doudera (Ann Arbor. Health Administration Press, 1984), 129-37.

[5]N.Y. Pub. Health Law § 2444 (McKinney 1985).

[6] Another major difference is that bioethics review committees would be facility-based, while Article 80 committees are organized by the State of New York Commission on Quality of Care for the Mentally Disabled and operate as quasi-judicial authorities, independent of any health care or mental hygiene facility. The Task Force's proposal for bioethics review committees would not encompass decisions for patients covered by Article 80. See chapters 2 and 10 for further discussion of Article 80 committees.

that the courts should always remain available as an alternative for those who do not want to participate in a facility-based process, and as a last resort for disputes or cases that cannot be resolved at the health care facility. The Task Force believes, however, that courts should not be the avenue of first resort, either as the sole alternative to address conflict or as the primary decision maker on behalf of all patients who are neither terminally ill nor permanently unconscious.[7] The courts would be overwhelmed by this responsibility, and patients would be ill-served by the delays and demands of the judicial process. This approach would also intrude unnecessarily on the privacy of the family unit and relationships.

Membership

The membership of the review committee should be diverse, in order to provide a range of experience and expertise and to ensure that a variety of perspectives inform committee deliberation. The composition of review committees will vary with the type and size of institution and the sorts of cases reviewed most often. The Task Force proposes that review committees should consist of at least five individuals; at many institutions, committees will be much larger.

Mandatory Members

Each review committee should include at least one physician; one registered nurse; one certified social worker or other person with training or expertise in providing psychosocial services to patients; one individual with training or expertise in bioethics, moral philosophy, or theology; and one lay community member unaffiliated with the facility. In long-term care facilities, at least one representative of the residents' council and one advocate for elderly or nursing home residents should participate on the committee. In addition, the Task Force encourages nursing home committees to include either a member of the bioethics review committee at an acute care hospital with which the nursing home is affiliated or to

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As observed in a report on guidelines for state court decisions authorizing the withholding of life-sustaining treatment, "The court should not be used as a clearinghouse for the rendering of medical decisions which are best made by the patient and family and the physician of the patient. A trial court must protect itself from inappropriate involvement in a life-sustaining medical treatment case and should decline jurisdiction if there is no justifiable controversy." National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment* (Williamsburg, Va.: National Center for State Courts, 1991), 36. The guidelines were prepared by a council that advised the National Center for State Courts. Sol Wachtler, Chief Judge of the New York Court of Appeals, served as vice-chairman of the council. See also J. Kaye, "Staking Out the Law," *Mount Sinai Journal of Medicine* 58 (1991): 369-74.

participate in a review committee that serves more than one nursing home.[8]

Most committees will have more than one physician, representing different specialties and experience. The scientific and technical knowledge of physicians, as well as their clinical experience in caring for patients, is essential to committee deliberations. As the committee considers individual cases, it should begin by clarifying the medical facts, including the patient's diagnosis and prognosis, and treatment alternatives.

Nurses, like physicians, bring both clinical knowledge and experience with patients to committee discussion. Nurses spend extensive time with patients, caring for their personal and medical needs. Although nurses cannot serve on the committee when it considers a case involving one of their patients, this experience still informs their professional perspective. As suggested by a study of New York's DNR law, nurses may be more likely than many physicians to regard the promotion of patient rights as part of their professional mission.[9]

Social workers and other persons with training or expertise in providing psychosocial services to patients also have a vital role in committee discussion, especially concerning the personal, social, and psychological dimensions of each case. They can help to clarify the preferences of patients and the roles and views of family members and others close to the patient. Information about social support and resources available to the patient and family may be critical in some cases.

Review committees should also include at least one individual with training or expertise in bioethics, moral philosophy, or moral theology. These individuals bring skill and experience in identifying ethical

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[8] New York State Department of Health regulations require each long-term care facility to maintain a transfer agreement with one or more general hospitals as required to meet the medical needs of residents. N.Y. Comp. Codes R. & Regs, tit* 10, § 415.26(g) (1991).

[9] Robert Baker et al. report that critical-care nursing directors surveyed "see themselves as having special obligations to protect the individual's right to self-determination." Thirty-seven percent of nursing directors providing written comments reported a need to advocate for patients' rights when physicians fail to discuss DNR orders. Only 3% of hematologists and oncologists surveyed explicitly mentioned patients' rights. 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: A Study of New York's DNR Law,* ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers, forthcoming).

problems and analyzing critically the ethical claims and interests of all involved in the case.[10] They can assist the committee to develop clear principles to guide decision making. Ethicists and chaplains may also be well versed in the literature on medical ethics and have experience applying ethical principles in the context of medical cases.

In many facilities, individuals with training or expertise in bioethics, philosophy, or theology will be members of the clergy. In addition to their contribution in evaluating ethical problems, clergypersons, including chaplains, may assist the committee to address religious issues that may be critical for some patients. A clergyperson can help identify the patient's religious values and ensure that the personal and religious views of all concerned are respected.

This responsibility must be approached with sensitivity to the religious and moral diversity likely to be encountered in health care facilities throughout New York State. A member of the clergy must be careful not to promote decisions based on his or her own religious convictions when these diverge from the patient's religious or moral outlook. Even if the patient and clergyperson share the same religious affiliation, their interpretations of that tradition may differ.

The Task Force recommends that review committees also include at least one community member who is not otherwise affiliated with the institution. These individuals should not participate as a "community representative" in the sense of promoting the interests of a group outside the institution, but rather should provide an independent perspective in advocating for patients. These individuals may notice practices and patterns that those affiliated with the facility might overlook or take for granted. They also add to the accountability and credibility of the committee. Their independence distances them from potential conflicts of interest, and enhances their freedom to take positions differing from those of facility administrators or others in a position of authority at the facility.

In acute care hospitals, the lay community member could be an individual who has recognized expertise or demonstrated interest in patient welfare or individual rights. Members of civic organizations and groups that advocate for the elderly or for patients generally could serve as the lay community member.[11] Committees that review cases involving newborns might

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[10] Some philosophers might have little interest in resolving particular cases, focusing their concerns on abstract theory. They would be less likely than other philosophers to seek to participate on a review committee or to contribute fruitfully to its deliberations.

[11] The diversity of organizations whose members might volunteer for this responsibility is suggested by the many organizations that supported enactment of New York's health care proxy law. Among the measure's proponents were the National Organization of Women-New York State, the Association of the Bar of the City of New York, the New York Civil Liberties Union, the Lutheran Office of Governmental Ministry, the Gay Men's Health Crisis Center, the Junior League of Long Island, Citizen Action of New York, the Episcopal Diocese of New York, and the League of Women Voters.

include the parent of a disabled child, an adult with a congenital disability, or a special education teacher. Retired physicians, nurses, judges, university professors, and others might also be willing to serve on the committee. In order to assure the availability of volunteer community members, several individuals could be selected.

In long-term care facilities, the lay community member should be an advocate for persons in long-term care or the elderly. This person could be a representative from the New York State Long Term Care Ombudsman Program. The Ombudsman Program, administered by the New York State Office of the Aging, provides advocacy services for older residents of long-term care facilities. The program relies on trained volunteers as well as state staff to receive, investigate, and resolve complaints. The lay community member might also be a member of a not-for-profit organization that has as part of its mission advocacy for long-term care residents or the elderly, such as the Nursing Home Community Coalition or the state chapter of the American Association of Retired Persons.

The Task Force recognizes that the participation of lay community members raises potential problems. These individuals may be unfamiliar with the clinical setting in general and the facility in particular, making it difficult for them to understand and contribute to committee discussion. They also may be intimidated or ignored by other committee members. Some commentators have expressed concern that patient confidentiality might be compromised by the participation of an individual unaffiliated with the institution, especially one who might not be sensitive to legal requirements or professional standards of confidentiality. Some individuals might be more devoted to general social goals or a personal agenda than to the wishes and interests of individual patients. Finally, some committee members might feel that the participation of a community representative lessens their own responsibility as an advocate for the patient.[12]

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[12] Some commentators assert that the participation of an individual unaffiliated with the institution may complicate liability concerns; the legal protection proposed for committee members and others addresses this concern.

Despite these difficulties, the Task Force believes that the participation of lay community members who are not affiliated with the facility adds to committee deliberation and on balance makes an essential contribution. An individual unaffiliated with the institution can bring a critical independent perspective. The individual will also enhance the committee's accountability and public trust in the committee process.

In long-term care facilities, committees should also include at least one member of the residents' council. Required in all facilities by New York State Department of Health regulations, residents' councils are designed to provide a forum for resident participation in devising facility programs and policies.[13] A member of the council can provide insight about treatment alternatives from the perspective of a patient at the facility. In addition, the resident can help to ensure that the patient's interests in each case are fully explored.

Additional Members

The participation of more than one individual from some of the above categories will generally enhance committee deliberation. Facilities can increase the expertise or perspectives available to the committee by inviting individuals affiliated with another health care facility or local institution such as a university to join the committee. Including individuals from another facility is especially important for nursing homes, which often have a more centralized administration than hospitals and may lack the independent viewpoints that coexist in many hospitals. The Task Force encourages committees in long-term care facilities to participate in a committee with another nursing home. When a single bioethics review committee serves more than one long-term care facility, the perspectives of members from different facilities are likely to enrich committee deliberation, and help guard against excessive deference to any one committee member or point of view.

Establishing a review committee with another facility may not be feasible for some nursing homes, particularly those in rural areas. Committees that serve a single nursing home, as well as others, should seek to include a health care professional from the acute care facility with which the nursing home is affiliated. This individual would provide an informed and independent perspective. The nursing home review committee would especially benefit from the experience of a member of the hospital review committee; the hospital committee's policies, decisions in particular cases, and procedures could serve as a resource for the nursing home.

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[13] See N.Y. Comp. Codes R. & Regs. tit. 10, § 415.26(b)(8) (1991), mandating residents' councils.

Review committees at both general hospitals and long-term care facilities may also be strengthened by other individuals from within the facility. For example, facilities that have a patient representative or patient-advocate program should consider appointing individuals from the program.

Attorneys can be a valuable resource for a committee. In addition to their familiarity with the law, lawyers are trained to identify principles and distinguish cases. They can help the committee apply relevant legal doctrines and assure that like cases are treated alike. Lawyers can also serve as an independent source of authority or opinion for a committee that might otherwise be dominated by one individual. Finally, lawyers can assist the committee to find a common ground between the interests of the patient and the legal concerns of the facility. However, if an attorney or risk manager participates on a review committee, special care must be devoted to clarifying his or her role. Facility counsel and risk managers often define their responsibility as finding the "safest" alternative, rather than as identifying a range of treatment options supported by existing case law and statutes. This focus on the institution may conflict with the committee's principal role of protecting patients. Without participating on the committee, attorneys or risk managers can still fulfill their traditional function by advising the facility once the committee has developed its recommendations.

A facility administrator can provide an overall perspective of the institution, as well as familiarity with institutional policies and resources. In some cases, administrative arrangements, like transferring care of the patient to another physician or different nurse on duty, might resolve the conflict. Like all other committee members, administrators who serve on a committee must accept the patient's needs as the committee's primary concern.

Training

The Task Force recognizes the importance of preparation and education for review committee members. Those without a medical background should gain familiarity with the clinical setting. Physicians and other health care professionals must be educated about the right of patients to decide about treatment, and the authority granted to family members and other surrogates under the law. The ethical premises underlying state policies and laws should be examined. Committee members must also develop a sense of the committee's role within the institution and its mandate under state law.

Education must be not only a central focus of the committee's early activity but an ongoing concern for committee members. Training is especially important for lay community members; they may have little background in medical decisions and must speak with an independent voice on the committee. The Task Force urges that an educational program should be developed for lay committee members, especially in the early stages of the committee's work.[14]

The program should focus on the standards and procedures embodied in the law, the ethical principles underlying the law, and basic facts about hospital services and organization. Modest financial and personal resources will be required for this purpose. While institutions and professional organizations should contribute to this effort, funding should also be provided by state government or by grants from the private sector. Training programs designed for surrogate decision-making committees for the mentally disabled under Article 80 of New York's Mental Hygiene Law could serve as a model. A study of that program found a high level of satisfaction with the training of committee members.[15]

Beyond any particular training provided, the ability of a committee to function well will hinge on intangible factors that cannot be regulated or mandated. Those factors include the tone established by the committee chairperson, the dedication of those who participate, and the support extended by the facility to the committee. At a minimum, each committee member must respect the contributions of members with different areas of expertise and be committed to promoting the wishes and interests of the patients whose cases are reviewed.

Procedures

Facilities should adopt a written policy governing committee functions, composition, and procedures. This policy should contain procedures for responding promptly to a request for a case consideration, informing appropriate persons of the case, and providing them with access to the committee. It should also specify the circumstances that would trigger the committee's participation or review.

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[14] See, e.g., J. W. Ross, *Handbook for Hospital Ethics Committees* (Chicago: American Hospital Publishing, 1986), 49-50; B. Hosford, *Bioethics Committees: The Health Provider's Guide* (Rockville, Md.: Aspen Systems, 1986), 153-59; R. Macklin and R. B. Kupfer, *Hospital Ethics Committees: Manual for a Training Program* (Bronx, N.Y.: Albert Einstein College of Medicine, 1988).

[15] M. Gold and L. Torian, "The Surrogate Decision Making Program: Final Evaluation Report." January 29,1988,20,70.

The committee should inform the patient, when possible, the surrogate and involved family members, the attending physician, the facility, and other appropriate individuals of a pending case review, and provide information about the committee's procedures and function. These individuals should also be promptly informed of any decision or recommendation by the committee and should have the opportunity to present their concerns and views to the committee.

Patients and surrogates should also be allowed to bring a person with them to the meeting to assist them in understanding the issues discussed or in presenting their views. This person may be a family member, lawyer, member of the clergy, or simply a close friend. Especially for those who may be intimidated by the process, this is an important option.

While all persons connected with a case may present information to the review committee, health care professionals should not participate as committee members in a case that concerns them directly. For example, physicians caring for the patient whose case is under consideration should present their views to the committee in the same manner as individuals involved with the case, but should not otherwise participate in committee deliberations. This policy will facilitate frank discussion among committee members and enhance the fairness of committee review.

A quorum of the full committee should review surrogate decisions to withdraw or withhold life-sustaining treatment from a patient who is neither terminally ill nor permanently unconscious, or a decision to withhold or withdraw life-sustaining treatment from an emancipated minor or a patient without a surrogate. At a minimum, the proposed requirements for committee membership should be met: at least five members with the professional and other qualifications for committee composition should be present. A health care facility should identify the number of individuals that constitute a quorum of the committee. The presence of a quorum would help assure that cases are treated in a consistent manner and that principles or precedents reflected in the decisions are embraced by the review committee as a whole, not just by a few members.

The facility should make reasonable efforts to inform all committee members of the pending consideration of these sensitive cases. Decisions reviewed by the committee should not be implemented until the committee informs the patient, the surrogate and family members,

the facility, the attending physician, and other appropriate persons of the committee's recommendation. In these cases, the committee should also provide the surrogate and other appropriate individuals with a written statement of the reasons for approving or disapproving the decision to forgo life-sustaining treatment.

In general, facilities should maintain written records of committee decisions. The records will contribute to the continuity of the committee's activities, enabling the committee to examine its previous recommendations and to modify its decisions or procedures where appropriate. Maintaining records will also contribute to the committee's accountability.

Except for cases mentioned above when a quorum of the committee should always be present, committees should be allowed to delegate the review of cases to subcommittees. The full committee may be unable to consider every case, because of the frequency of decisions requiring review or the urgency of a particular case. Particularly in situations of conflict between family members or among members of the health care team, a subcommittee may be able to address the issues as well as a larger group and in a more timely way. Except for dispute mediation, which would not require any fixed number of individuals, at least three review committee members, including at least one physician, should participate in each case. Subcommittees should routinely report their activities to the review committee to maintain accountability and to allow the full committee to identify any patterns in subcommittee review that seem problematic.

Functions

Education and Policy Review

In addition to case consultation and review, bioethics review committees could undertake other responsibilities as authorized by the facilities they serve. Review committees could naturally fulfill other roles associated with ethics committees, such as education and policy development. In addition to their intrinsic importance, these activities generally strengthen the ability of committees to engage in case consultation and review. For facilities that already have ethics committees, those committees would probably provide the basis for or serve as the bioethics review committee.

Responding to Conflict or Requests for Consultation

Conflict among family members and others close to the patient will inevitably arise in some cases. For example, the children of an elderly

patient may disagree about which course of treatment would best accord with the patient's wishes and interests. In other cases, the surrogate and the physician or other health care professionals may disagree about the course of treatment.

The Task Force recommends that review committees should be available for consultation and advice upon the request of persons involved with the case. In addition, it proposes that committees should seek to resolve cases whether a decision to provide treatment or a decision to withdraw or withhold treatment triggers the conflict. When disagreements arise between or among the physician or other health care professionals caring for the patient, family members, other persons on the surrogate list, or the facility, they should be brought to the committee. For example, the committee should consider any of the following cases:

- A physician objects to a surrogate's decision to discontinue life-sustaining treatment and refers the matter to a review committee rather than implement the decision or transfer the patient's care to another physician.
- A close family member (or other individual on the surrogate list) objects to a surrogate's decision to provide life-sustaining treatment for a dying patient.
- A parent objects to another parent's or guardian's decision to refuse life-sustaining treatment for a minor child, or a minor refuses life-sustaining treatment despite the objection of a parent or guardian.
- An attending physician and other health care professionals disagree about surgery for a patient who has no surrogate.

In these types of cases, the most appropriate role for the committee may be dispute mediation. The committee may be able to resolve a conflict by improving communication among those involved or exploring alternative courses of action. The committee should also identify disputes that arise because a proposed course of treatment conflicts with the substituted judgment and best interests standards or with the medical predicates for surrogate decisions.

Reviewing Sensitive Treatment Decisions

The Task Force believes that three kinds of cases are so sensitive that they should be reviewed routinely by a bioethics review committee, even in the absence of disagreement among those close to the patient and health

care professionals: when a surrogate decides that life-sustaining treatment should be withdrawn or withheld for a patient who is neither terminally ill nor permanently unconscious; when a decision is made to forgo life-sustaining treatment for a patient without a surrogate; and when an emancipated minor wishes to forgo life-sustaining treatment. These types of cases present difficult treatment decisions for patients who are extremely vulnerable.[16]

Under the Task Force's proposal, decisions by family members or other surrogates to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious would not be authorized unless reviewed and approved by the committee or by a court. Committee review and approval would not change the fact that the surrogate and physician remain the decision makers, although it does establish a constraint on their authority. In essence, the committee should function in these sensitive cases to confirm that the decision-making standards have been met and that a surrogate's decision is made in good faith. For emancipated minors, the committee can serve as an advocate, assuring that health care professionals have explored the options for available care and informed the minor fully. For minors as well as surrogates, the committee can also determine whether the choice falls within a range of acceptable alternatives.

The review committee may enhance the surrogate's or minor's decision by seeking additional medical information, clarifying available alternatives, and raising issues that might have been overlooked in previous discussions. The committee should also issue a recommendation about the surrogate's or minor's decision, presenting a statement of the reasons for its recommendation. The statement may persuade the surrogate or minor to accept the committee's recommendation. The statement of reasons would also provide a basis for the surrogate, minor, or attending physician to respond to the committee or to challenge the committee's position. Surrogates, minors, or physicians acting on behalf of their patients can also bypass the committee altogether and seek judicial approval of the decision.

Extending Legal Protection

The Task Force proposes that individuals who serve on bioethics committees in good faith in accord with the proposed legislation should

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[16] The special role of the committees for patients without surrogates and the policies proposed for emancipated minor patients are discussed fully in other chapters of this report. See chapters 8 and 10.

be protected from liability.[17] It is appropriate to extend this legal protection. It is also essential to encourage individuals to serve on the committees. Given the authority vested in the committees, the potential for liability would be more real than when ethics committees perform a purely consultative role, as they do now. Fears of liability, if unaddressed, would not only discourage persons from participating on committees, but would also would inhibit free and open discussion among committee members.

The Task Force proposes that individuals should be granted legal protection for actions taken in good faith as a member of or consultant to a review committee or as a participant in a review committee meeting. The protection proposed is broad but not unlimited; it would not encompass either activities outside the scope of committee duties or actions taken in deliberate disregard of the standards and requirements of the proposed legislation.[18] For example, committee members who place the interests of the health care facility ahead of those of the patient whose case is considered would not be protected from liability.

This proposed protection from liability resembles protections afforded under New York law to participants in other health care committees that also function to improve patient care. For example, persons who participate in good faith in dispute mediation under the DNR law are protected from civil liability, criminal prosecution, and professional misconduct sanctions.[19] Likewise, if a person's participation on a facility's quality assurance committee meets a good faith standard, New York law extends immunity from any action for civil damages or other relief as a result of the activity.[20]

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[17] The law firm of Kalkines, Arky, Zall & Bernstein provided the Task Force with a legal analysis of New York law and the law in other states relating to the confidentiality and immunity protections extended to ethics committees. That analysis of existing law informed the Task Force's judgments presented in this chapter.

[18] Although few states have statutes on hospital ethics committees, of those that do, almost all provide liability protection. See, e.g., Section 19-374 of the Maiyland Health-General Code, providing immunity for advice provided in good faith; Section 37-2-201 of the Montana Code, providing immunity for any action taken within the scope of the functions of the committee, if without malice and in the reasonable belief that it is warranted by the facts; and Section 663-1.7 of the Hawaii Revised Statutes, providing immunity for acts done in the furtherance of the purpose for which the committee was established, if done without malice and within the authority of the particular member.

[19] N.Y. Pub. Health Law § 2974(3) (McKinney Supp. 1992).

[20] N.Y. Pub. Health Law § 2805-j(2) (McKinney Supp. 1992).

Maintaining Confidentiality

Confidentiality for committee deliberations is also crucial to foster committee activity and to protect the privacy of patients whose cases are reviewed. The Task Force recommends that internal committee discussions and records should remain confidential, except for the cases and circumstances specified below.[21] As a general matter, neither the proceedings nor the records of the committee should be released by committee members, consultants, or others privy to such information, nor should the information be accessible to others for use in legal proceedings or government agency investigations. Under this standard, minutes, memoranda, or other written materials prepared for the committee would be kept confidential. Internal committee deliberations and views expressed at committee meetings would also remain private. This confidentiality should be accomplished in two ways. Committee members, consultants, and others with access to these materials and discussions should have a duty to maintain confidentiality. Also, persons external to the committee process, such as individuals who bring a legal action against a physician or the facility, generally should be unable to gain access to documents and discussions by means of subpoenas or other methods.

This confidentiality protection should be subject to two important exceptions. First, committee records and proceedings that address the withdrawal or withholding of life-sustaining treatment from a patient without a surrogate, an emancipated minor patient, or any patient who is neither terminally ill nor permanently unconscious, should be subject to review by the New York State Department of Health. The nature of these sensitive treatment decisions calls for greater oversight and openness about the decision-making process. Also, confidentiality protections should not prevent the patient, the surrogate, other persons on the surrogate list, or the parent or guardian of a minor patient from speaking about the committee proceedings to which they have access, if they choose to do so. For example, a spouse acting as the surrogate for her husband should not be

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[21] See A. Mcisel, *The Right to Die* (New York: John Wiley and Sons, 1989), 485 (§ 15.9), emphasizing the importance of ethics-committee confidentiality: "Ethics committees do not merely discuss issues of ethics, law and medicine, but they are also concerned with equally if not more delicate issues, such as errors in professional judgment, personality clashes, professional misconduct, and quality of care. Without a vow of confidentiality to which all ethics committee members subscribe, the functioning of ethics committees can only suffer; individuals may be reluctant to serve or to participate fully and health care professionals maybe reluctant to bring cases to the committee or to be forthcoming with the committee."

constrained from describing the comments made by committee members during any part of a review committee meeting she attended.

Policies preserving the confidentiality of committee proceedings are also important to protect the privacy of patients. In order for the bioethics review committee to perform its function, committee members, consultants, and others must have access to relevant medical records and information. This access entails a duty to respect the patient's privacy and the confidentiality ordinarily accorded medical information.[22] Any patient-specific information should be disclosed only to the extent strictly necessary to accomplish the purposes of the surrogate decision-making proposal or as otherwise provided by law.[23] For example, the committee should be permitted to inform appropriate persons of a pending case, but should only give individuals the medical information necessary to foster decision making under the standards of the proposal. The patient's privacy should remain of utmost concern.

Health care facilities or the committees themselves should make special efforts to explain the confidentiality requirements to community members and long-term care residents who serve on the committees. These individuals, like others on the committee, should have a clear legal duty to respect the patient's privacy, but may not be familiar with the confidentiality that extends to medical information.

Mandating Committees

The growing presence of interdisciplinary ethics committees in hospitals and nursing homes in New York State attests to their value and acceptance.[24] Nonetheless, the Task Force recognizes that mandating

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[22] The common law and state and federal statutes and regulations, as well as the constitutional right of informational privacy, impose duties of patient confidentiality upon health care providers. Private accreditating bodies, such as the Joint Commission on the Accreditation of Healthcare Organizations, also require providers to respect patient confidences. See, e.g., M. C. Macdonald, K. C. Meyer, and B. Essig, *Health Care Law: A Practical Guide* (New York: Matthew Bender, 1989), chapter 19, for a full discussion about medical information and confidentiality.

[23] Otherwise confidential medical information may be subject to release to governmental agencies pursuant to laws governing, for example, child abuse and neglect. See, e.g., N.Y. Soc. Serv. Law §§ 411 to 428 (McKinney 1983 & Supp. 1992) ("Child Protective Services").

[24] A 1988 Task Force survey of New York health care facilities found that 51% of responding hospitals had an ethics committee, and an additional 6% were in the process of developing one. A lower percentage of nursing homes (27%) had established a committee. However, this represented an increase of 14% over the number of nursing homes that had an ethics committee in a 1986 Task Force survey.
See discussion of ethics committees, chapter 1 and appendix E.

bioethics review committees would constitute a major policy shift. In general, the committees that exist today in hospitals and nursing homes in New York State are voluntary, not mandated by legislation.[25] Indeed, only the state of Maryland has affirmatively required facility-based ethics committee.[26] Also, unlike the purely advisory function fulfilled by existing ethics committees, bioethics review committees would have the authority to approve or disapprove certain proposed decisions to forgo life-sustaining treatment.

Some individuals have cautioned against requiring health care facilities to establish ethics committees. Concerns have been raised about mandating committees that lack a clear role and specific guidelines. Some have suggested that even when committees are purely advisory, they violate patients' rights because they do not accord patients and those close to them adequate information, notice, or access.[27]

The Task Force's proposal addresses many of these concerns. It not only requires facilities to establish review committees, but delineates the functions of the committees and sets minimum standards for their composition and process. Many of the proposed procedures are designed to make the committee process open and accessible. The committees would be required to function according to a written policy and to consider and respond to health care matters presented by patients, a person on the list of potential surrogates, health care providers, or an authorized state agency. They must also inform patients and those close to them that a matter is under consideration and tell them about the committee's function and procedures. Moreover, the proposed decision-making process, including the participation of committees, represents an alternative for patients and their family members. It would not prevent them from bypassing the committee altogether and seeking judicial intervention at any time.

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25 One important exception concerns level III perinatal care programs, which are required to establish an infant bioethical review committee. These committees are authorized to provide guidance to family and staff, to ensure that parents are given medical information and that decisions by competent parents to continue life-sustaining treatment are implemented, and to intervene when parents lack decisional capacity or make a decision "manifestly against the infant's best interests." N.Y. Comp. Codes R. & Regs., tit. 10, § 405.21(h)(3)(ii)(1989).

26 See Sections 19-370 to 19-374 of the Maryland Health-General Code.

27 See, for example, the symposium in the *Maryland Law Review* on hospital ethics committees and the law. *Maryland Law Review* 50 (1991): 742-919.

The Task Force believes that review committees are the best available option for meeting the identified needs and gaps in the current decision-making process for incapacitated patients. Undoubtedly, some facilities will be better prepared than others to establish committees able to meet their responsibilities under the law. Nonetheless, in all hospitals and nursing homes, the committees will offer a greater degree of openness and scrutiny for the decisions they are charged to review.

Recommendation

The Task Force recommends that each health care facility should establish one or more bioethics review committees or participate in a review committee that serves more than one facility. Each review committee should include at least one physician; one registered nurse; one certified social worker or other person with training or expertise in providing psychosocial services to patients; one individual with training or expertise in bioethics, moral philosophy, or theology, and one lay community member unaffiliated with the facility. In long-term care, the community member should be a representative of the Long- Term Care Ombudsman Program or of a not-for-profit organization that promotes the rights and interests of the elderly or nursing home residents as part of its mission. Review committees at long-term care facilities should also include at least one representative of the residents' council. Long-term care facilities should be encouraged, but not required, to include either a member of the bioethics review committee at the acute care hospital with which the facility is affiliated or representatives of more than one long-term care facility in a review committee serving more than one facility.

Facilities should adopt a written policy governing committee functions, composition, and procedures. This policy should include procedures for responding promptly to a request for case consideration and should permit persons connected with a case to present their views to the committee. The proceedings and records of the review committee should generally be kept confidential. All committee members have a duty to respect the confidentiality of patient information.

Review committees should be consulted in the event of conflict between and among health care professionals, family members, and others close to the patient or the facility. Committees should also review and be authorized to approve decisions to forgo life-sustaining treatment by

emancipated minors and for patients who are neither terminally ill nor permanently unconscious, even in the absence of conflict. In both types of cases, review committees should determine whether the decision satisfies the standards for surrogate decisions and should issue a recommendation. Review committees should also review and be authorized to approve recommendations to forgo life-sustaining treatment for patients who do not have a family member or friend willing and able to serve as surrogate.

See Appendix A, proposed legislation, Section 11.

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Deciding for Adults Without Surrogates

Every day, hospitals, nursing homes, and health care professionals face the formidable problem of how treatment decisions should be made for patients who lack capacity and have no family members or close friends to act as "natural" surrogates. These individuals are among New York's most vulnerable patients: elderly nursing home residents without involved family members, AIDS patients predeceased by loved ones, drug abusers, and homeless persons estranged from relatives and companions.

Family members and close friends play a critical role as surrogates for incapacitated patients by promoting the patient's values and preferences, and assessing the proposed course of treatment. This balance, and the dialogue about treatment it entails, are not available for individuals without natural surrogates.[1]

Many physicians and health care facilities now make decisions for isolated patients, including decisions to forgo life-sustaining treatment, without review or consultation. Other providers, more wary of the absence of legal authority for such decisions, find themselves paralyzed, unable to give isolated patients the same timely care that other patients receive, or to stop treatment that they believe imposes an excessive burden on the patient.

In rare cases, a health care facility or public official seeks a court order authorizing treatment, or a committee or guardian of the person has been appointed and decides about treatment. More often, the expenses and delays associated with court proceedings are avoided.
Sometimes health care professionals wait until a patient's condition deteriorates and major medical interventions are authorized under the

[1] An incapacitated patient who lacks a family member or close friend to make treatment decisions, but has a court-appointed committee of the person, or guardian of the person for a mentally retarded or developmentally disabled person, would not lack a surrogate decision maker under the Task Force's proposal. These court-appointed individuals are included as the first potential surrogates on the Task Force's proposed surrogate list. See chapter 6.

emergency exception to the requirement of informed consent.[2] Other times, a patient receives treatment, but health care providers proceed without a clear legal substitute for patient or family consent. In either case, decisions are routinely made on an informal basis, without prospective or retrospective review.

Existing informal practices for deciding about treatment for isolated patients do not adequately protect these patients' interests. Nor, in all cases, are the practices supported by established legal principles. The Task Force proposes a decision-making process for this patient population that seeks to facilitate their access to needed treatment and to permit the discontinuation of life-sustaining measures in accord with publicly approved standards and procedures.

In devising its recommendations, the Task Force examined policies in other states to identify precedents and possible models. Remarkably few exist. Apart from traditional guardianship proceedings and the availability of a court order to authorize treatment decisions, most states have no explicit policies for deciding on behalf of patients without a surrogate.

Oregon and North Carolina are exceptions. Both states authorize the patient's physician to make decisions for incapacitated patients who have no surrogate, including decisions to forgo life-sustaining treatment.[3] The Task Force concluded that this process is not sufficient to preserve the interests of incapacitated patients, especially for decisions to withdraw or withhold life-sustaining treatment. Unless treatment is futile, as narrowly defined and understood, decisions to forgo life-sustaining treatment involve judgments that are principally social and ethical, not medical.[4] Physicians acting alone should not be empowered to decide for isolated patients.

The Task Force considered three decisional paradigms for isolated patients: a judicial model, a nonjudicial system centered outside of health care facilities, and a facility-based approach. The Task Force concluded that hospitals and nursing homes are the appropriate locus for decision making so long as decisions are made in accord with publicly accepted standards and are open to public scrutiny.

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[2] N.Y. Pub. Health Law § 2805-d (McKinney 1985 & Supp. 1992).
[3] N.C. Gen. Stat. § 90-322(b) (1989); Or. Rev. Stat. § 127.635(3) (1990).
[4] See below, chapter 14 on medical futility.

Alternative Approaches

Relying on the Courts

The Task Force considered, and rejected, mandating court review in all cases or requiring a court-appointed legal guardian for each isolated patient. It determined that the disadvantages of a judicial model outweigh the advantages. Under the Task Force's proposal, the courts will remain an important alternative for those who seek the judicial appointment of a guardian or for any case challenging decisions made on behalf of an isolated patient.

The judicial process entails a high degree of public accountability and our society's most extensive due process protections, including important fact-finding powers. Judicial decisions must satisfy societal requirements for the particular case and in terms of the decision's role as precedent. Judicial proceedings also provide a neutral forum and an impartial decision maker. However, court proceedings are often cumbersome and time-consuming. They are almost always adversarial and public. As such, they are at odds with the timely, private, and collegial model of medical decision making.

It is also unclear that court decisions would be qualitatively better than decisions reached at the facility level, subject to publicly approved standards. In cases about treatment decisions, judges tend to defer to physicians' recommendations.[5] Judges are at a disadvantage, as compared with health care professionals and others who are close to the treatment setting and patient, have ready access to medical expertise, and can respond to the patient's changing medical needs. Under the Task Force's proposal, the courts will remain an important forum for deciding disputes and controversies that are not resolved within health care facilities. The courts, however, cannot be expected to evaluate and monitor treatment plans for all patients without surrogates in New York State.

This approach is supported by the guidelines on life-sustaining treatment cases prepared for state court judges. The commentary that

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See commentary for guidelines for state court judges on life-sustaining treatment cases, acknowledging that judges are inexperienced at handling these cases and tend to defer to medical authority. National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment* (Williamsburg, Va.: National Center for state Courts, 1991), 36, n. 61. As explained by Judge Judith S. Kaye, "it may be difficult — perhaps more so than in other litigation — to replicate in the courtroom the critical reality that may become evident over time at the bedside." "Staking Out the Law," *Mount Sinai Journal of Medicine* 58 (1991): 372.

accompanies the guidelines notes that most "guardianship petitions filed with the court do not appear to raise complex issues of law or facts, thereby adding to the costs and delays in what might otherwise be relatively simple decision-making. Courts lack the personnel and resources to develop, calculate and monitor complex plans for services."[6]

Nonjudicial Models

The Task Force considered several alternatives for a nonjudicial system centered outside of health care facilities that could make decisions on behalf of isolated patients. Under one approach, a public guardianship program would assume responsibility for treatment decisions. Some states currently rely upon public guardians to decide about treatment for isolated patients. However, the experience of these efforts suggests that their effectiveness is too often hampered by chronic underfunding.[36] The Task Force concluded that the cost of creating a sufficiently large public guardianship program in New York State would be inordinate. The Task Force also has strong reservations about relying on public guardianship because such a program would essentially vest a small office or one individual with both broad policymaking authority and responsibility for thousands of cases.[9]

Another approach would rely on committees similar to surrogate decision-making committees for the mentally disabled established by

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[6] Ibid, 36-37.

7 See 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), 130.

8 Ibid.

9 In New Jersey, the courts mandated a role for the State Ombudsman's Office in cases where life-sustaining treatment is withheld or withdrawn from an elderly, incompetent nursing home patient. *In re Conroy*, 98 NJ. 321, 486 A.2d 1209 (1985) and *In re Peter*, 108 NJ. 365,529 A.2d 419 (1987). In 1989, the Ombudsman informed all New Jersey nursing homes that every proposal to forgo life-sustaining treatment from an elderly nursing home resident would be considered "a possible case of patient abuse," and that all such proposals must be reported to the Ombudsman's Office. The policy was widely rejected by both health care professionals and advocates for patients, leading ultimately to the Ombudsman's resignation. See "Controversial Patient Abuse Policy Chills NJ Nursing Home Decisions," *Medical Ethics Advisor* 5 (1989): 8; "NJ Hospital Association Sues Ombudsman Over 'Abuse' Guidelines," *Medical Ethics Advisor 5* (1989): 38.

Article 80 of New York's Mental Hygiene Law.[10] Under Article 80, multidisciplinary committees decide about treatment for mentally ill and developmentally disabled individuals who reside in mental hygiene facilities and lack natural surrogates. Article 80 committees are organized and operated by the New York State Commission on Quality of Care for the Mentally Disabled. The committees function as quasi-judicial authorities, independent of any health care or mental hygiene facility.

Article 80 committees have provided a responsible and important forum for decisions for the special patient population they serve, helping to ensure that patients are not denied needed treatment because of the expense and delay of obtaining court approval. The program has been recognized as a model for decisions on behalf of the institutionalized mentally ill and developmentally disabled. It is unlikely, however, that the system could be expanded successfully to make decisions for all isolated patients in New York State. The interdisciplinary panels that function as decision makers under the Article 80 program are comprised of volunteers. Given the volume of cases that would arise if the program's jurisdiction were expanded to encompass all persons without surrogates in general hospitals and nursing homes, administration of the program would be unwieldy. The Task Force also believes that such an extensive system could not depend principally on donated service.[11] The lack of adequate resources for a statewide program represents another significant hurdle. Sufficient resources to

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See N.Y. Mental Hyg. Law Article 80 (McKinney 1988 & Supp. 1992); M. Gold and L. Torian, 'The Surrogate Decision Making Program: Final Evaluation Report," January 29,1988; C. J. Sundram, "Informed Consent for Major Medical Treatment of Mentally Disabled People: A New Approach," *New England Journal of Medicine* 318 (1988): 1368-73

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From May 1986 to July 1991, Article 80 committees considered 168 major medical treatment cases from the downstate areas of Bronx, Kings, Richmond, and Rockland counties. CQC, *Surrogate Project Report (May 1986 - July 1992)* (July 15, 1991) (available from CQC), 1. The number of cases would increase exponentially if the program covered all incapacitated patients statewide. Not only would the number of patients covered expand enormously, but their need for decisions would be dramatically higher. Unlike mental health facilities, which are homes for many individuals, patients admitted to an acute care facility are admitted to receive major medical treatment.

serve Article 80's existing target population, the residents of mental hygiene facilities, are not available.[12]

Finally, decisions by a committee outside the hospital or nursing home might not substantially improve decisions reached at the facility level. For example, data on the Article 80 program show that the committees have followed physician recommendations in all but a few cases.[13]

The Task Force Proposal: Deciding Within Health Care Facilities

The Task Force recommends that a facility-based procedure should be developed to make health care decisions for isolated, incapacitated individuals. The decision-making process should vary depending upon the nature of the treatment decision presented, with more serious decisions triggering more extensive review. The Task Force proposes three distinct processes for decisions depending on whether the decision involves routine treatment, major medical treatment, or a decision to forgo life-sustaining measures.

As with all patients, the decision-making procedures should be initiated only if health care professionals determine that the patient lacks capacity. If the patient objects to the determination of incapacity or to any treatment decisions made thereafter, the patient's objection or decision should prevail unless a court determines otherwise.

Physicians and facilities that now make treatment decisions for isolated patients without consultation or review may regard the proposed procedures as burdensome. However, the Task Force believes that many health care providers will welcome the policies as a vehicle to improve decision making by creating a clear, workable system. The policies also resolve the dilemma that confronts health care providers who care for isolated patients: the clear professional obligation to care for these patients and the inadequate legal basis for obtaining consent to treatment short of judicial intervention.

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12 In 1990 the New York Legislature authorized expansion of the Article 80 program beyond the geographic areas where it functioned as a demonstration project, but public funds have not yet been appropriated to finance this expansion.

13 CQC, 3.

The Decision-Making Standard

The Task Force proposes that the decision-making standards for isolated patients should be the same as those recommended for patients with surrogates. Treatment decisions should, to the extent possible, reflect the patient's health care wishes, preferences, and values. If these are not reasonably known, decisions should be made in accord with the patient's best interests. Decisions should not be based on a facility's or health care provider's financial or administrative concerns, although the Task Force does not intend by this to suggest that hospitals or nursing homes should be required to expand their existing equipment and facilities solely to provide treatments to isolated patients beyond the treatments provided to other patients.

In order to promote decisions based on patient preferences, hospitals and nursing homes should identify patients who appear to have no natural surrogate. As far as practicable, facilities should elicit these patients' preferences about the goals of treatment and pending health care decisions. The results of this discussion should be recorded in the medical record and should guide treatment decisions if the patient loses capacity. Health care providers should also make reasonable efforts to determine whether a patient who appears to have no involved family members or friends has appointed a health care agent or can identify a potential surrogate.[14]

Routine Treatment

Some medical procedures, such as drawing blood for tests or providing medication for high blood pressure, are minimally invasive, involve little or no risk to the patient, and are clearly beneficial. For procedures of this kind, physicians generally do not obtain a specific consent from the patient or others. Such treatments could be characterized as "routine." They involve judgments that are primarily medical in quality, although they may touch upon personal preferences or value judgments at the margin. In general, the greatest risks are posed when routine treatment is delayed or denied, not when it is provided.

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[14] A University of New Mexico project has developed, tested, and disseminated a "values history" document, designed to record isolated patient's health care wishes and to become a part of the admissions and medical record. See "Values History Project Confronts Questions Before Crisis Occurs," *Medical Ethics Advisor* 5 (1989): 155; 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.

The Task Force proposes that the attending physician should be authorized to decide about routine medical treatment for patients without surrogates, a proposal that would bring existing law into line with existing practice. This policy would facilitate access to routine treatments for isolated patients without presenting a risk of serious harm.

Routine medical treatment should be defined as any routine health care, such as the administration of medication, the extraction of bodily fluids for analysis, or dental care performed with a local anesthetic, for which physicians do not ordinarily seek specific consent. This definition recognizes that some medication, as well as the extraction of bodily fluids for diagnostic purposes, such as a spinal tap or the removal of fluid from the pleural space surrounding the lungs, may involve serious risks. For this reason, physicians do not perform these tests without specific consent. In addition, some treatments are appropriately considered routine if intended for short-term use, but are invasive and burdensome if used for prolonged periods. For example, a nasogastric tube would be routine if needed for a brief period following recovery from surgery, but should be considered a judgment about major medical treatment if provided as a long-term solution to a permanent medical condition. The Task Force proposes that the concept of routine treatment should encompass consideration of the intended or actual duration of the treatment.

Major Medical Treatment

Apart from treatments that might be considered routine, most medical interventions are invasive. Many carry potential risks and entail the loss of privacy and autonomy. In each case, these burdens should be assessed in light of the benefits and overall goals of treatment. The Task Force proposes that decisions about treatments considered "major medical treatments" should be made by the attending physician in consultation with others.

Decisions about major medical treatment require substantial medical judgment but also incorporate important nonmedical considerations. One patient with a serious heart condition may choose a surgical intervention, while another favors long-term medication. The reasons may be more personal than medical. The deliberative process about major medical treatment is informed by individual judgments or attitudes about pain, disfigurement, disability, and risk. The value-laden nature of these decisions, as well as the greater risks and burdens imposed by major medical interventions, call for input beyond a unilateral decision by the attending physician.

The Task Force proposes that major medical treatment should be defined as any treatment, service, or procedure to diagnose or treat an individual's physical or mental condition: (i) where a general anesthetic is used; (ii) which involves any significant risk; (iii) which involves any significant invasion of bodily integrity requiring an incision, producing substantial pain, discomfort, or debilitation, or having a significant recovery period; or (iv) which involves a significant period of chemical or physical restraint.[15] Thus, for example, if the administration of medication involves serious risks, such as a course of cancer chemotherapy, the medication should be considered major medical treatment.

In deciding about major medical treatment, the attending physician should consult with the staff, such as the nurses, social workers, and nurses aids, who care for and know the patient best. Particularly in nursing homes, the attending physician may be far more distant from the patient than nurses and social workers who have regular, daily contact with the patient. These members of the health care team may be an important repository of information about the patient's preferences, personal needs, and values.

In nursing homes, the personnel consulted would most likely be members of the resident's interdisciplinary care team, the individuals responsible under New York State regulations for developing and implementing the resident's plan of care.[16] Although state regulations do not establish similar teams in hospitals, physicians should identify the nurses and others who have had regular contact with the patient. These professionals can help assure that physicians consider the personal dimension of the decisions and the patient's own preferences. If any of the individuals consulted by the attending physician conclude that the physician's decision does not reflect the patient's preferences or best interests, they should bring the case to the attention of the facility's bioethics review committee.

The Task Force also proposes prospective review and confirmation of the physician's medical judgment before decisions about major

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This definition is similar to and drawn from the definition of major medical treatment in Article 80 of the Mental Hygiene Law. N.Y. Mental Hyg. Law § 80.03(a) (McKinney Supp. 1992)

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N.Y. Comp. Codes R. & Regs. tit. 10, § 415.11 (1991). Pursuant to this regulation, the members of the interdisciplinary care team must include "the attending physician, a registered professional nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs." § 415.11(c)(2)(ii).

medical treatment are authorized and carried out for patients without a surrogate. Specifically, a second physician, designated by the hospital or nursing home, should evaluate the attending physician's recommendation. The second physician should examine the patient's diagnosis, prognosis, and treatment alternatives, as in an ordinary second opinion. In essence, this opinion gives isolated patients the benefit of the second opinion that many individuals pursue before undertaking surgery or other major interventions. The review also creates a check on the practice of allowing physicians to authorize unilaterally the often costly services for which they will be remunerated. If an unresolved difference of opinion arises between the attending and the confirming physician, the case should be brought to the bioethics review committee, which should issue a recommendation.

As defined by the Task Force, treatment involving any significant period of chemical or physical restraint would also be included in the category of major medical treatment. Both types of restraints can be extremely coercive, denying patients their dignity and the most basic human freedoms of thought and movement. Restraints may also impose significant medical risks.[17] New York State Department of Health regulations establish specific, detailed safeguards for the use of restraints in nursing homes.[18] Those safeguards, including the prohibition against using restraints for purposes of discipline or staff convenience, establish criteria and a process for decisions about restraints. The regulations require that the patient, or a person authorized to consent on the patient's behalf, provide consent before physical restraints may be administered, except in an emergency. The Task Force recommends that the attending physician should seek the consultation and confirmation needed for other major medical treatments before prescribing or authorizing physical or chemical restraints for a significant time period.

Forgoing Life-Sustaining Treatment

Decisions to forgo treatment that might prolong the patient's life present the greatest risk of harm from a wrongful choice and require the most profound judgments about the benefits and burdens treatment affords. These decisions pose more serious risks than decisions to provide major medical treatment that are also value-laden and

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17See the discussion above, chapter 1,14.

[18]N.Y. Comp. Codes R & Regs. tit. 10, § 415.4 (1991). The proposed legislation would not eliminate or diminish these safeguards but would provide a mechanism for consent within the framework established by the regulations.

subjective. For example, a decision to amputate a leg to prevent a deadly case of gangrene is an intensely personal choice; some patients would rather die than live without a limb. But the decision to provide a major medical treatment differs fundamentally from the refusal of the same treatment. The patient's continued life is the expected outcome of one, while the patient's death is the likely result of the other. The Task Force proposes that decisions to withhold or withdraw life-sustaining treatment should be subject to the closest scrutiny.

The treatments characterized as life-sustaining should not be restricted to those, such as dialysis or the artificial respirator that are ordinarily included in this category. The Task Force recommends that life-sustaining treatment should be understood more expansively as any treatment or procedure without which the patient will die within a relatively short time, as determined by the attending physician, to a reasonable degree of medical certainty. Under this formulation, whether a particular treatment choice constitutes a decision to forgo life-sustaining treatment turns on the consequences of the treatment decision, not on the type of treatment. Returning to the case above, for example, a decision not to undergo a leg amputation, where the result will be death from gangrene within a relatively short period of time, would be considered a decision to forgo life-sustaining treatment. In contrast, the amputation, if provided, would be classified as major medical treatment. Likewise, if a patient would be likely to die within a relatively short time unless antibiotics are provided, a decision to refuse the antibiotics would be a judgment to forgo life-sustaining treatment, while a decision to provide antibiotics to cure an acute condition would constitute a decision about routine treatment.

Decisions to forgo life-sustaining treatment for isolated patients should be made in a process that draws upon the physician's medical judgment, a second medical opinion, the knowledge of other facility staff who have cared for the patient, and full consideration and approval of the decision by the bioethics review committee. The decision-making process will ordinarily begin with the attending physician. The attending physician should consult with health care personnel to gather all available medical and personal information about the patient. In developing a recommendation, the physician should also determine whether continued treatment would be an excessive burden to the patient in light of the substituted judgment and best interests standards. A second physician, designated by the facility, should review the attending physician's diagnosis and prognosis.

The committee's review should focus on these questions: Is the physician's recommendation to forgo life-sustaining treatment consistent with the patient-centered standards for surrogate decisions? Would treatment be an excessive burden for the patient? Does the decision comport with available knowledge about the patient's wishes, or if the patient's wishes are not reasonably known, the patient's best interests? Committee review should differ from the review that would take place for patients with a surrogate. The committee not only must decide whether the physician's recommendation meets the proposed standards and falls within the range of acceptable decisions but, in effect, acts as the decision maker. The committee should evaluate the physician's recommendation as a patient or surrogate ordinarily would, engaging in a discussion with the attending physician and others to ensure that its judgment is informed by the relevant medical and personal information available.

For some patients at the end stage of the dying process, physicians may recommend that all interventions to prolong the patient's life should stop and that the goal of treatment should be solely to care for the patient with palliative measures to ease pain and discomfort. In these cases, not just one but several technologies to sustain life may be withdrawn or withheld over time.[19] Physicians effectively are making a judgment about the overall course of care, not just individual treatments. Physicians should not have to seek committee review of each discrete treatment decision as it arises but should instead be able to obtain review of the decision to provide only palliative care. This option should be available for all patients, and is especially important to avoid unnecessary delay for patients without a surrogate.

The Task Force recommends that a hospital review committee considering a decision to forgo life-sustaining treatment for an isolated patient who has been transferred from a nursing home should consult with the nursing home staff that have known the patient. The potential to improve the quality of decision making at the hospital outweighs the administrative burden of this requirement. Members of the nursing home staff may spend years caring for residents who lack family or close friends and may come to know these residents well. If a nursing home resident is transferred to a hospital during his or her final illness,

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Many hospitals, for example, have long had policies establishing different levels of care, including "palliative care only." See, for example, S. H. Miles and C. F. Gomez, *Protocols for Elective Use of Life-Sustaining Treatments* (New York: Springer Publishing Company, 1989),

the knowledge of the nursing home staff should be available as a resource for decisions at the hospital.

The full review committee, not just a subcommittee, should consider decisions to withdraw or withhold life-sustaining treatment for patients who have no surrogate. At a minimum, at least five committee members who meet the categories of membership required for any bioethics review committee, as well as a quorum of the entire committee, should participate in reviewing decisions to forgo life-sustaining treatment for these patients. In the unusual case that a review committee approves a decision that violates the decision-making standards or required procedures, members of the committee should inform the facility administration. Members should also be authorized to seek judicial intervention based on a good faith belief that the treatment decision and the committee's recommendation do not satisfy the standards and procedures set forth by the law.

The committee should issue a statement of reasons for its decision, and unlike cases where the committee acts in an advisory manner, committee records of decisions about life-sustaining treatment should be subject to review by the New York State Department of Health. These procedures will afford openness and accountability for these sensitive decisions.

Treatment Without Medical Benefit

The Task Force identified a narrow category of decisions that, like a decision about routine treatment, call for judgments and evaluations that are primarily medical in character. During the final days and hours of the dying process, many treatments offer no benefit for the patient. For some patients, treatments are continued in the final days of their dying process for the benefit of grieving family members who have not **reconciled themselves to the patient's death. In rare cases, treatment** to prolong the patient's life even at the end stage of the dying process corresponds to the patient's preferences. The Task Force recommends that decisions to forgo such treatments for patients in this condition who have no family members or others to act as surrogate should not require review by a bioethics review committee. Like all health care decisions, these decisions should accord with the patient's wishes or, if these cannot be ascertained, with the patient's interests.

The attending physician should determine whether the patient will die within a short time period even if treatment is provided. This finding should be made in accordance with accepted medical standards and to a reasonable degree of medical certainty. In light of the vulnerability of

isolated patients, a second physician should be consulted and confirmation of the attending physician's decision should be required. This second opinion will minimize the risk of error and the likelihood that physicians will rely upon an expansive or value-laden notion of futility in making these judgments. Unresolved differences of opinion between the attending physician and the consulting physician should be referred to the bioethics review committee for prospective review. Committee review of decisions for all patients who are imminently dying is not necessary and is likely to result in the provision of unnecessary, harmful treatment.

Recommendation

The Task Force recommends that a process based in health care facilities should be created to decide about treatment for adult patients who lack capacity and have no available surrogate. The process should provide an alternative for making decisions, but should not preclude health care professionals or other appropriate parties from seeking a court appointed guardian or judicial approval for a recommended course of treatment or for a particular treatment decision.

Decisions should conform to the patient-centered standards proposed for patients with surrogates, including, when applicable, the standards for withholding or withdrawing life-sustaining treatment. To facilitate decisions based on patient preferences, facilities should identify patients without involved family or friends and elicit their treatment wishes or the name of a surrogate if possible.

The attending physician should decide about routine medical treatment. A decision to provide major medical treatment should be authorized if the attending physician makes a recommendation, in consultation with other health care personnel directly involved in the patient's care, and a second physician concurs in the recommendation. The bioethics review committee should review disputes that arise among health care personnel about the decision.

A decision to forgo life-sustaining treatment should be authorized if (i) the attending physician recommends the withdrawal or withholding of treatment, in consultation with other health care personnel directly involved in the patient's care; (ii) a second physician concurs in the recommendation; and (iii) the bioethics review committee approves the recommendation. The review committee should issue a statement of its reasons for approving or disapproving the recommendation, and

committee records concerning the decision should be subject to review by the New York State Department of Health. If a general hospital patient has been transferred from a nursing home, a representative of the review committee should consult with nursing home personnel who cared for the patient.

A decision to forgo treatment should also be authorized if the attending physician determines, in accord with accepted medical standards and to a reasonable degree of medical certainty, that the patient will die within a short time even if treatment is provided, and a second physician concurs in this medical determination. The bioethics review committee should review the case if the attending physician and the physician consulted disagree about the imminence of the patient's death or other clinical judgments.

See Appendix A, proposed legislation, Section 7.

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Patients with Mental Disabilities

Each year, more than 500,000 persons receive treatment for mental illness in New York State. Approximately 25 percent are cared for in residential facilities.[1] Residential treatment is provided in diverse settings: state-operated psychiatric centers, psychiatric units in general hospitals, private psychiatric hospitals, community residences, family care homes, residential care centers, and special facilities for children.

More than 68,300 individuals receive services provided, funded, or certified by the Office of Mental Retardation and Developmental Disabilities.[2] These individuals have a broad range of chronic conditions that arise prenatally or in childhood and that substantially impair an individual's intellectual functioning or adaptive behavior. Conditions commonly identified as developmental disabilities include autism, cerebral palsy, epilepsy, mental retardation, and muscular dystrophy. The most profoundly impaired developmentally disabled persons usually reside in state-operated facilities that provide total care. Persons with the mildest impairments often live independently or with their families. Some reside in group homes. Fewer than 8,000 individuals still reside in developmental centers. Another 24,000 live in. various types of community-based residential services. Most developmentally disabled persons live independently or with their families.[3]

Residents of Mental Health Facilities

Existing state statutes, as well as constitutional principles and regulations, guide and constrain decisions for the mentally disabled and, in particular, for residents of mental hygiene facilities. State laws authorize health care decisions by a court-appointed committee or

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1 New York State, Office of Mental Health, *Annual Report,* 1987,29-32.

2 New York State, Office of Mental Retardation and Developmental Disabilities, *The Community Challenge,* July 1991, p. 49, fig. 3-15.

3 New York State, Governor Mario Cuomo, *Message to the Legislature,* January9, 1991, 55.

guardian.[4] Regulations issued by the Office of Mental Retardation and Developmental Disabilities and the Office of Mental Health allow family members and others on a list of potential surrogates to consent to proposed medical treatments for residents of mental hygiene facilities.[5] Treatments such as psychotropic medication are covered by specific regulations.[37] In addition, Article 80 of the Mental Hygiene Law establishes quasi-judicial committees to decide about major medical treatment for incapable residents of mental hygiene facilities who lack an available surrogate.[7]

The Task Force's current proposal does not encompass surrogate decisions for residents of mental hygiene facilities, except for decisions authorized by court order. Polities for mental hygiene residents must rest on a careful understanding and assessment of relevant state statutes, judicial decisions, and constitutional law. The special needs and concerns of mental hygiene residents must also be explored in relation to the particular problems presented by long-term care for mental illness.

The Task Force will deliberate about guidelines for surrogate decisions on behalf of mental health facility residents, in conjunction with those most concerned about the residents, including the appropriate executive agencies of state government and advocates for the mentally disabled. It does not believe that these policies must necessarily be considered and debated at the same time as the broader surrogate proposal.[38]

Currently, decisions about CPR for mental hygiene facility residents at certain facilities and in hospitals are governed by New York's DNR law. The Task Force proposes that these policies should remain in place until they are merged with comprehensive policies for surrogate decisions.

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[4] See discussion above, chapter 2, 38-39.

[5] See, e.g,. N.Y. Comp. Codes R & Regs. tit. 14, § § 527(9)(b)(2)(i) and 633 (H)(a)(l)(iii)(b) (1991).

[37] E.g., N.Y. Comp. Codes R & Regs. tit. 14, § 527(8)(c)(2)(ii)(1991).

[7] Article 80 committees are discussed in Chapters 2,9, and 10.

[8] The Task Force took this same approach in relation to decisions about CPR proposing policies for general hospitals and nursing homes and then turning to the more complex questions presented in mental hygiene facilities. When the legislature passed the DNR law in July 1988, policies for the mental hygiene facilities had already been incorporated.

At this time, the Task Force recommends one crucial change in state law on surrogate decisions for residents of mental hygiene facilities. Current New York law provides no legal foundation for decisions to forgo life-sustaining treatment for patients who do not have, and never possessed, the capacity to decide for themselves. Existing law requires clear and convincing evidence of a wish to forgo treatment. This standard is unattainable for -those without the capacity to formulate such wishes. It is also inhumane, substituting a legal imperative to treat in all cases for a judgment about the limitations and benefits of modern medical technology for each patient.

The Task Force proposes that courts should be empowered to authorize decisions to forgo life-sustaining treatment for residents of mental hygiene facilities, as for all other individuals in New York State. The courts should assess the decisions under the substituted judgment and best interests standards embodied in the proposed legislation.[9]

The Mentally Disabled in the Community

Many individuals who are mentally disabled do not reside in mental health facilities — they live at home or in group homes. In New York City, a high percentage of the homeless are mentally ill. These individuals are routinely treated in hospitals, but are not covered by the same laws or regulations that apply to mental hygiene facility residents transferred to a hospital. The Task Force recommends that these individuals should be covered by the proposed surrogate policies, with special requirements for determining their capacity to decide about treatment.

Under this approach, the decision-making process for mentally disabled individuals in hospitals will depend on whether or not the individual has been transferred from a mental hygiene facility. Existing law and policies already distinguish the mentally disabled on this basis. In contrast to the body of statutes and regulations that apply to decisions for mental hygiene facility residents, a vacuum exists for individuals admitted to hospitals and nursing homes whose mental disability is recognized in the course of caring for them. The Task Force believes that these individuals are extremely vulnerable at present. They will be better served by the general surrogate policies proposed,

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The majority of state courts in the country evaluate and authorize surrogate decisions relying on standards similar to those in the proposed legislation. See chapter 2,35-36.

with special procedures for determining capacity, than by existing practice.

The DNR and health care proxy laws incorporate specific requirements for determining incapacity for patients who are mentally disabled.[10] Both require the participation of physicians or psychologists with specialized expertise and training to determine that a patient lacks decision-making capacity due to mental illness or developmental disability. Persons without the necessary expertise may err in two directions. They may too readily presume that persons are incapable because of their disability, or conversely, they may not appreciate the limitations of patients who appear lucid and capable.

The Task Force recommends similar requirements for surrogate decisions. A determination that a patient lacks capacity due to mental illness or developmental disability should require the participation of a health care professional who has specialized training or experience in diagnosing or treating mental illness or developmental disability of the same or similar nature.

Recommendation

Surrogate policies for residents of mental hygiene facilities raise complex legal, ethical, and social questions. The Task Force will recommend policies for these patients after examining existing New York law and policies and the particular problems presented for surrogate decisions by long-term mental illness. At this time, the Task Force proposes that at least one forum, the courts, should be authorized to approve decisions to withdraw or withhold treatment for residents of mental hygiene facilities, subject to standards in the proposed legislation. In addition, the DNR law should remain in effect for residents of mental hygiene facilities until comprehensive surrogate legislation is adopted.

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[10] The fact that an individual has a mental illness or developmental disability does not in itself establish that the individual lacks capacity to make health care decisions. In many cases, a mental disability affects some mental abilities without undermining others. For example, persons who are schizophrenic or have other serious mental disorders may be fully capable of making some or all health care decisions. A. Stone, "Informed Consent: Special Problems for Psychiatry," *Hospital and Community Psychiatry* 30 (1979): 326; S. Reiser, "Refusing Treatment for Mental Illness: Historical and Ethical Dimensions," *American Journal of Psychiatry* 137 (1980): 331. See N.Y. Pub. Health Law §§ 2963(3) and 2983(1) (McKinney Supp. 1992). New York's highest court has upheld the right of persons in mental health facilities to make treatment decisions unless the person has been determined to lack capacity by a judicial finding. *Rivers v. Katz,* 67 N.Y.2d 485,504 N.Y.S.2d 74 (1986).

Mentally disabled individuals who are patients in a general hospital and have not been transferred from a mental hygiene facility are not covered by many of the same laws and regulations that apply to residents of mental hygiene facilities. The policies proposed for surrogate decisions generally should apply to these patients, with special requirements for determining incapacity.

See Appendix A, proposed legislation, Sections 2(2), 3(3), and 16(2).

12

The Obligations of Health Care Professionals

Under the Task Force's proposal, physicians and other health care professionals have specific obligations, including the duty to determine incapacity and diagnose the medical conditions under which surrogates may decide to forgo life-sustaining treatment.[1] Health care professionals also have more general responsibilities to the surrogate, arising from their primary duty to care for the patient.

Talking to Patients

The availability of surrogate decisions for patients who have lost capacity does not diminish the duty of physicians to discuss treatment alternatives with the patient directly whenever possible. Physicians who have an ongoing relationship with patients should ask them about their wishes and values regarding treatment and encourage them to discuss their preferences with family members. Even if patients opt not to provide specific advance instructions, physicians can greatly enhance surrogate decisions and diminish the burden of decision making by engaging the patient in a dialogue about the goals of treatment.[2]

For patients with chronic and progressive diseases, physicians can often anticipate that the patient may lose decision-making capacity and that certain treatment choices are likely to arise. With these patients in particular, the physician should discuss treatment options and suggest that they appoint a health care agent or decide in advance about a course of treatment. Nurses and other health care professionals often play a

[1] See above, chapters 5 and 7.

[2] As discussed above in chapter 1, studies have consistently shown that patients want to discuss treatment alternatives, including life-sustaining treatment, and many expect their physician to initiate the conversation.

critical role in this dialogue, encouraging both physicians and patients to start the conversation and assisting patients when necessary.[3]

Although some individuals who lack decision-making abilities are not able to communicate at all, others can converse on some level about their condition and care. Indeed, they often have questions and concerns and may have important information to offer. The existence of a surrogate does not relieve health care professionals of the obligation to communicate with the patient to the extent possible.

Patients should also be encouraged, if able, to make nonmedical decisions about their care. Allowing a patient to decide, for example, whether to take two injections at once or at separate times, expresses respect for the patient and may enhance a sense of control. It also reinforces the decision-making abilities of patients who may be able to regain capacity, or of minors who may come to develop such capacity.

Communicating with Surrogates

When a patient lacks capacity and a surrogate begins to decide about treatment on the patient's behalf, the obligations of health care professionals to care for the patient remain undiminished. However, the patient's loss of capacity triggers the surrogate's authority and responsibility to decide about treatment. Health care professionals must relate to and communicate with the surrogate accordingly. The physician must provide information to the surrogate, frame treatment options, and contribute an independent perspective in promoting the patient’s wishes and interests.

The physician should provide a complete and straightforward explanation of the relevant medical circumstances to the surrogate. That explanation should include a discussion of the risks and benefits of any proposed treatment, as well as information about available alternatives. While the physician’s recommendation about proposed treatment is an integral part of medical care, that recommendation should be distinguished from a clear statement of the medical facts necessary for the surrogate to make an informed judgment.

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[3] In a recent study of New York’s DNR law, 37% of critical care nursing directors offering comments reported that they frequently urge physicians to initiate discussions about DNR orders with their patients, despite physician reluctance. R. Baker et al., “Legal and Professional Enforcement of Bioethical Reform: A Comparative Study of the 1988 NY and JCAHO DNR Reforms,” in *Legislating Medical Ethics: A Study of New York’s DNR Law,* ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers, forthcoming).

Formulating a Care Plan

The physician and surrogate should discuss the patient's overall course of care on an ongoing basis. Together they should formulate a comprehensive care plan based on treatment objectives that are appropriate in light of the patient's medical condition, as well as his or her wishes and preferences. Each patient's plan should be carefully tailored to reflect the medical and personal circumstances of that patient and should be reviewed regularly. The care plan offers a valuable framework for communication between the surrogate and health care professionals and allows for a coordinated course of treatment.

The comprehensive care plan also provides the context for particular treatment decisions. Physicians should seek the surrogate's consent whenever significant health care decisions arise. These decisions include the provision of major medical treatments, decisions not to provide treatments that could offer significant benefits to the patient, decisions among medically acceptable alternatives that entail differing risks and benefits, and decisions to withdraw or withhold life-sustaining treatment.

When patients have no surrogate, they do not have the benefit provided by two independent perspectives, that of the surrogate and the physician. A care plan may be even more important for these patients to assure that the overall goals of treatment have been identified and that decisions are not made by default. As discussed in Chapter Ten, health care professionals have special obligations for these patients.

Responding to Surrogate Decisions

The Task Force's proposal would grant surrogates the legal authority to make health care decisions following specified guidelines and procedures. Physicians and other health care professionals must honor surrogate decisions made in accord with these policies, unless they take steps to challenge the surrogate's decision or transfer the patient's care.

Disagreements between physicians and surrogates are bound to arise. In some cases, a surrogate may opt for a combination of treatments that would be inconsistent with good medical practice or insist on a treatment decision that a physician believes would harm the patient. In these and other circumstances, health care professionals may conclude that the surrogate's decision violates the proposed standards, either

because the surrogate is seriously mistaken or because the surrogate is acting in bad faith.

Whenever disagreement arises, the health care professional should discuss the matter with the surrogate. An unsound decision by a surrogate may well be changed by a conversation with a physician or other health care professionals. If the surrogate is not persuaded, physicians and other health care professionals have a professional, ethical, and legal obligation to challenge the surrogate's decision. The physician or any other health care professional responsible for the patient's care may ask the facility's bioethics review committee to consider the case. The attending physician must also refer a disagreement about life-sustaining treatment among the patient's family members or other potential surrogates to the review committee, if the dispute cannot be otherwise resolved.

In some cases, physicians or other health care professionals may believe that the surrogate's decision, although consistent with the proposed decision-making standards, violates their own religious beliefs or sincerely held moral convictions. When this occurs, health care professionals have the same obligations they would have if it were a patient's decision to which they objected. Health care professionals should inform the surrogate of their beliefs and cooperate in transferring care of the patient to another health care professional.[4]

Managing the Withdrawal or Withholding of Life-Sustaining Treatment

Physicians and other health care professionals must ensure that treatment orders are understood and communicated to all health care professionals responsible for the patient's care. A decision to withhold one life-sustaining treatment should not be interpreted as a decision not to provide other treatments. Too often, for example, a DNR order is interpreted as a "do not treat" order, denying patients with a DNR order the option to decide about other medical treatments.[5] As a result, patients or surrogates who would otherwise refuse resuscitation may be

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[4] See chapter 13, discussing conscience objections of health care providers and facilities.

[5] Numerous studies as well as personal observations indicate that such misunderstanding of DNR orders is widespread. C Joseph and W. Wanlass report: "When nursing home patients are transferred to the hospital, we have sometimes found that hospital staff: (1) express reluctance about admitting acutely ill DNR patients after emergency department evaluation, (2) are reluctant to offer surgery to patients with a DNR order, (3) require reversal of the DNR order prior to any

unwilling to consent to a DNR order because of fears that the patient will be abandoned. In some cases, the same considerations that lead to a DNR order would suggest other measures to limit aggressive treatment. In other cases, CPR may be ineffective, but antibiotics or other life-sustaining procedures would offer clear benefits. Physicians should engage surrogates in a dialogue about specific life-sustaining measures. A decision to forgo one or more forms of life-sustaining treatment must not be viewed as a signal to abandon the patient.[6]

Physicians should also review any orders or plan to forgo life-sustaining treatment, in accord with good medical practice. The Task Force recommends that hospitals and nursing homes should prepare written guidelines for this review. In addition to periodic review, physicians should note any change in the patient's condition that might prompt reconsideration of the decision to forgo treatment and should cancel the decision when appropriate.

Health care professionals also have an obligation to convey complete and accurate medical information whenever a patient is transferred from their care. If the patient is transferred to another health care facility, the transferring facility should assure that any orders or plan to withhold or withdraw life-sustaining treatment, such as a DNR order, accompany the patient. The order should remain effective at the receiving facility until the patient is examined by an attending physician, who must either reissue the order or cancel it and inform the person who consented to the order and the facility staff directly responsible for the patient's care.

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surgery, and (4) deny admission to the intensive care unit for patients who have a DNR order." "DNR Orders," *Journal of the American Geriatrics Society* 39 (1991): 1142. Baker et al. found that over 40% of health care professionals surveyed in New York reported that a DNR order is interpreted as a signal to withhold life-sustaining measures other than CPR Similar responses to DNR orders are documented by, e.g., H. L. Lipton, "Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications, and Outcomes," *Journal of the American Medical Association* 256 (1986) : 1168; and D. R. Berlowitz, S. V. B. Wikling, and M. A. Moskowitz, "Do-Not-Resucitate Orders at a Chronic Care Hospital," *Journal of the American Geriatrics Society* 39 (1991): 476.

[6]As eloquently stated by ethicist Paul Ramsey: "Desertion is more choking than death, and more feared. The chief problem of the dying is how not to die alone. To care, if only to care, for the dying is, therefore, a medical-moral imperative: it is a requirement of us all in exhibiting faithfulness to all who bear a human countenance." *The Patient as Person* (New Haven: Yale University Press, 1970), 134.

These proposed policies are identical to those now embodied in New York's DNR law.[7] They are designed to ensure continuity of care and to avoid the necessity of obtaining a new consent for decisions to forgo treatment when patients are transferred. The policies also recognize that physicians at the receiving facility may identify legitimate reasons for canceling the order and that they cannot in any event be bound by an order or plan of care entered by a physician at another facility.

Protection from Liability

In recent years, concerns about liability have asserted greater influence over the practice of medicine. While health care professionals must be aware of their legal responsibilities, fear of criminal and civil liability can distort the decision-making process by displacing patient care as the pivotal focus of the decision.[8]

Protecting health care professionals and facilities from liability in appropriate cases, while beneficial for providers, also confers tangible benefits for patients. Equally important, health care professionals and facilities should not be forced to choose, as they must now in some cases, between appropriate medical treatment for their patients and the risk of civil or criminal liability.

The Task Force believes that health care professionals and facilities who honor in good faith treatment decisions made by surrogates and others in accord with the policies proposed, should be protected from criminal sanctions, civil liability, and professional penalties. This protection, however, should extend only to claims based on the professional's good faith reliance on a surrogate's decision. For example, physicians should be required to obtain informed consent from a surrogate, as they would from a patient. Moreover, all health care professionals should remain obligated to provide medical treatment in accordance with applicable standards of care. Thus, a physician would

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[7] N.Y. Pub. Health Law § 2971 (McKinney Supp. 1992). In 1991, this provision was amended to underscore the fact that physicians need not obtain a new consent to enter the DNR order at the receiving facility. Instead, if they do not reissue the order, they must inform the person, patient or surrogate, who consented to the order.

[8] For example, the Harvard Medical Practice Study Group conducted a series of physician surveys, which revealed that the overall perceived risk of being sued in a given year was 20%, approximately 3 times the actual-risk of being sued. Physicians who perceived themselves to be at greater risk of suit said that in the past 10 years they had ordered more tests and procedures and reduced their practice scope more than had their colleagues with less perceived risk. "Patients, Doctors, and Lawyers: Medical Injury, Malpractice Litigation, and Patient Compensation in New York," Report of the Harvard Medical Practice Study to the State of New York, 1990,9-10.

not be protected from liability if he or she failed to meet applicable standards of skill and care in making the medical diagnoses required by the legislation or in carrying out the surrogate's decisions.

Recommendation

Physicians and other health care professionals should assist patients to plan in advance by choosing a health care agent, and discussing their treatment values and preferences, and decisions. Once the patient has lost decision-making capacity, the physician should communicate effectively with the surrogate, enabling him or her to make an informed decision on the patient's behalf.

The physician and surrogate, in conjunction with other health care professionals, should formulate a care plan based on treatment objectives that are appropriate in light of the patient's medical condition as well as his or her wishes and preferences. Physicians should review an order or plan to forgo life-sustaining treatment in accord with accepted medical standards and facility guidelines for this review. If the patient is transferred from one facility to another, an order or plan to forgo treatment should remain effective unless canceled.

Health care professionals and facilities that honor surrogate decisions in good faith in accord with the standards proposed, should be protected from civil and criminal liability and from penalties for professional misconduct.

See Appendix A, proposed legislation, Sections 6,9,10, and 13.

13

Responding to Conscience Objections

In some cases, treatment choices by patients or surrogates conflict with the moral, religious, or professional convictions of those who provide health care, including physicians and nurses. Health care facilities may also object to honoring certain treatment decisions because of religious or moral principles embraced by the facility.

Generally, professionals or facilities object on grounds of religious or moral conscience to decisions about life-sustaining treatment. Initially, conscience objections focused on withdrawing artificial respiration. Currently, objections are more likely to arise in response to decisions about artificial nutrition and hydration.

In the past several years, a different kind of conscience case has also emerged. Health care professionals and facilities have begun to object on grounds of professional or moral conviction to decisions to continue life-sustaining treatment that they regard as futile or not medically indicated. These objections reflect a judgment that the provision of treatment would violate the provider's professional integrity and commitment to the patient.[1]

Objections by Health Care Professionals

Physicians are not legally required to honor a treatment decision that contravenes their religious, moral, or professional convictions.[392]

1
See chapter 14 for discussion of medical futility.

2
New York law formally recognizes that physicians do not engage in unprofessional conduct if they refuse to perform an act that constitutes medical practice because of their religious belief or training. N.Y. Educ. Law § 6527(4)(c) (McKinney 1985). Explicit legal protection extends to all health care professionals for decisions not to honor a DNR order. N.Y. Comp. Codes R. & Regs. tit. 10, §§ 405.43(e) (2)(v) and 405.43(f)(6Xv) (1988). Section 79-i of the New York Civil Rights Law bars facilities from discriminating against employees who refuse to participate in an abortion because it violates their moral or religious beliefs. (MeKinney 1976).

Instead, physicians may withdraw from the case and transfer care of the patient to another physician willing to honor the patient's or surrogate's decision. Physicians may not simply abandon patients; they remain responsible for a patient's care until transfer to another physician has occurred.[3] Special legal protection exists for health care professionals who decide not to assist or perform an abortion.[4]

Under New York's health care proxy law, health care professionals may refuse to honor a decision by an appointed health care agent on grounds of religious or moral belief, provided the professional would object to the same decision if made by the patient when competent. Professionals must inform the agent and the health care facility promptly of their objection and cooperate in transferring the care of the patient to another professional.[5]

The Task Force believes that individual health care professionals should not be legally obligated to carry out decisions that contravene their religious or moral convictions. This respect for individual convictions should extend to decisions to provide treatment as well as decisions to refuse. The Task Force recommends that a policy similar to the policy in the health care proxy law should be adopted for individual conscience objections to surrogate decisions.

A health care professional should be required to inform the surrogate and the facility promptly of an objection and should cooperate in transferring care of the patient to another health care professional. The burden of effecting the transfer should rest on the facility, recognizing that for some professionals responsibility for carrying out the transfer would also violate their convictions.

In cases involving claims by individuals seeking to exercise their First Amendment right to free exercise of religious belief, the courts have consistently examined the sincerity of the individual's religious beliefs, but not the content of the beliefs.[6] The Task Force endorses this

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[3] See, e.g., *Shapira v. United Medical Service, Inc.*, 15 N.Y .2d 200, 213-14, 257 N.Y.S.2d *150(1965).*

[4] See above at note 2, N.Y. Educ. Law § 6527(4)(c), N.Y. Civ. Rights Law § 79-i.

[5] N.Y. Pub. Health Law § 2984(4) (McKinney Supp. 1992).

[6] See, e.g., *United States v. Ballard*, 322 U.S. 78 (1944); *Int'l Soc'y for Krishna Consciousness, Inc. v. Barber*, 650 F.2d 430 (2d Cir. 1981); *Sherr v. Northport-East Northport Union Free School Dist*, 672 F. Supp. 81, 94 (E.D.N.Y. 1987). The health care proxy law requires that moral convictions must be "sincerely held" but does not impose the same requirement on religious convictions. Consistent with First Amendment principles, the courts are likely to conduct the inquiry of sincerity in a contested case. In any event, the Task Force believes that convictions that are not "sincerely held" should not be protected.

approach for conscience objections on religious or moral grounds by health care providers. Refusals on grounds of conscience should be based on clearly articulated and sincerely held moral or religious convictions; they should not be used to mask other personal interests, such as the desire to avoid a situation that the physician or other health care professionals may find difficult or demanding.

The Task Force does not propose restricting conscience objections to cases when the health care professional would object if the same decision had been made by a patient. That provision in the proxy law reflects the special status of decisions made by a health care agent, selected by the patient and explicitly authorized to decide on his or her behalf.

Objections by Health Care Facilities

Like principles underlying First Amendment protection for religious belief, conscience objections in the health care context are premised on the notion that individuals cannot be forced to engage in conduct that violates personal, religious, or moral beliefs. However, questions about how institutions "hold" beliefs, and how those beliefs are identified, are complex. Institutions do not have the same personal rights as individuals, although some legal commentators have argued that institutions can be understood to hold beliefs as an aggregate of the individuals that belong to the institution. Institutions may also be seen to have a sense of integrity or mission that reflects a particular moral or religious vision.[7]

In New York State, both the courts and the legislature have addressed the right of institutions to object on grounds of conscience to treatment decisions. Court cases involving decisions to withdraw life- sustaining treatment have yielded diverse precedents. Two decisions — ***Delio*** v. ***Westchester County Medical Center*** and ***Elbaum v. Grace Plaza of Great Neck, Inc***. — illustrate the diverse approaches adopted by New York courts.

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[7] See, e.g., I. C Lupu, "Free Exercise Exemption and Religious Institutions: The Case of Employment Discrimination," *Boston University Law Review* 67 (1987): 391-442; S. H. Miles, P. A. Singer, and M. Siegler, "Conflicts Between Patients' Wishes to Forgo Treatment and the Policies of Health Care Facilities," *New England Journal of Medicine* 321 (1989): 48-50; K. W. Wildes, "Institutional Integrity: Approval, Toleration and Holy War or Always True to You in My Fashion," *Journal of Medicine and Philosophy* 16 (1991): 211-20.

In *Delio,* [8] the court authorized the withdrawal of artificial nutrition and hydration from a permanently unconscious patient, but permitted the facility to decline, on conscience grounds, to terminate treatment at the facility. Instead, the court ordered the hospital to cooperate in transferring the patient to another facility where treatment could be discontinued.[409]

In Elbaum,[10] a facility also objected to the removal of a feeding tube from a permanently unconscious patient. In that case, the court upheld the family's request to withdraw artificial feeding and hydration from Ms. Elbaum and ordered the facility to carry out the decision within 10 days if it could not transfer the patient to a facility willing to honor the family's wishes. In reaching its decision, the court noted that the facility did not have a written policy against discontinuing artificial nutrition and hydration and that the facility had not informed the patient's family of the policy prior to admission or in a reasonable time thereafter.[11]

The legislature has also addressed the issue of conscience objections by health care facilities. New York's health care proxy law specifies the conditions under which facilities can object, on religious or moral grounds, to treatment decisions by a health care agent.[12] The proxy law recognizes that private facilities may object to an agent's decision if the facility would object to the same decision by the patient. Health care facilities must assert that the decision is "contrary to a formally adopted policy that is expressly based on religious beliefs or sincerely held moral convictions central to the facility's operating principles" and the hospital or nursing home would be permitted by law to refuse to honor the decision if made by the patient.[13] Facilities must also inform patients or the agent prior to or upon admission about their conscience policy. If a conflict arises, the facility must cooperate in transferring the patient to a facility willing to honor the decision. If no such facility is available or the transfer is not accomplished for other reasons, the facility must seek judicial relief.

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8 129 A.D.2d 1, 516 N.Y.S.2d 677 (2d Dep't 1987)

9 Similar decisions from other states include *Brophy v. New England Smai Hosp., Inc.,* 398 Mass. 417, 497 N.E.2d 626 (1986) and *In re Morrison,* 206 Cal. App. 3d 304, 253 Cal. Rptr. 530,535 (1st Dist. 1988).

10 148 A.D.2d 244,544 N.Y.S.2d 840 (2d Dep't 1989).

11 Similar decisions from other states include *In re Jobes,* 108 NJ. 394,529 A.2d 434 (1987) and *McConnell* v. *Beverly Enterprises,* 209 Conn. 692,553 A.2d 596 (1989).

12 N.Y. Pub. Health Law § 2984(3) (McKinney Supp, 1992). For a further discussion of the proxy law's provisions on institutional conscience objections see 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): 363-64.

13 Ibid.

The Task Force believes that significant respect should be accorded convictions identified by private health care facilities as fundamental or essential to their mission and continued operation. This respect acknowledges the personal commitments of the individuals that manage and work for the facility. It also allows a facility as a community of individuals to embrace a distinctive set of religious commitments or a particular moral vision that guides their collective enterprise. The same deference should not be extended to public institutions. Supported entirely by society at large, public health care institutions should be obligated to honor the full spectrum of choices recognized in our laws and public policies.

As with individual conscience objections, the Task Force suggests that policies for institutional conscience objections should be similar to policies currently embodied in New York's health care proxy law. Conscience objections should reflect a formally adopted policy expressly based on sincerely held religious beliefs or moral convictions central to the facility's operating principles.[41] Facilities should be obligated to inform patients or their surrogates about the policy in advance of admission whenever possible. The facility must also cooperate in transferring the patient to a facility willing to honor a decision to which it objects. In contrast to the proxy law, conscience objections should not be restricted to cases when the health care facility would object to the decision if it had been made directly by the patient.

For health care facilities operated or sponsored by religious communities, beliefs are defined by a body of authoritative teaching or religious doctrine, although the particularized facts of medical cases frequently call for an interpretation of general principles, and interpretations may differ. Moral convictions vary more widely and are not constrained or delineated by reference to one particular body of beliefs. Sincere moral convictions that are central to a facility's operation should be respected. The broad rubric of moral convictions, however, should not serve as a placeholder for policies motivated by concerns about liability or other administrative interests.

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41 As with individual beliefs, the proxy law requires that moral, but not religious, beliefs must be "sincerely-held." Consistent with and drawn from First Amendment principles, the sincerely held requirement should apply equally to objections based on religious as well as on moral convictions.

The Task Force believes that recognizing the moral convictions of private facilities creates the potential for abuse, especially in New York State, where fears about liability often drive the decision-making process. The Task Force recommends that stringent standards and procedures should be applied in assessing the legitimacy of institutional conscience objections. Facilities generally have greater resources and access to legal counsel than individuals. A facility invoking conscience in refusing the request of a surrogate should therefore be responsible for initiating legal proceedings, if the dispute cannot otherwise be resolved. The facility should also bear the burden of showing that the surrogate's decision contravenes a formally adopted policy that is expressly based on sincerely held religious beliefs or on sincerely held moral convictions central to the facility's operating principles. In this inquiry, the actions of the facility in other cases and in response to other patients should be assessed carefully to determine if the stated conscience objection is consistent with the overall pattern of practices at the facility.

The right of facilities to refuse to honor a treatment decision on grounds of conscience must be balanced against the rights of patients or their surrogates to decide about treatment. Accommodating facility objections by transferring a patient to another institution can impose significant burdens on a patient and family. This is especially true for long-term care residents who may have lived in a facility for months or years and developed personal attachments to the institution, other residents, and the staff. In some instances, another facility willing to honor the resident's or surrogate's decision may not be available or accessible to the resident's family. In such cases, or if the transfer is not accomplished for other reasons, the facility should honor the surrogate's request or seek judicial relief.

Recommendation

Nothing in the Task Force's proposal should be construed to require a health care professional to carry out a treatment decision that contravenes the individual's sincerely held religious or moral convictions. In these cases, the health care professional should promptly inform the person who made the decision, and the facility, of his or her refusal to honor the decision. With the cooperation of the health care professional, the facility should then promptly transfer responsibility for the patient to another health care professional willing to honor the decision.

Nothing in the proposal should be construed to require a private hospital or nursing home 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. This provision applies only if the hospital or nursing home has informed the patient or family of the policy prior to or upon admission, if reasonably possible, and the patient is transferred promptly to another facility that is reasonably accessible under the circumstances and willing to honor the decision. If the patient's family is unable or unwilling to arrange such a transfer, a hospital or nursing home may intervene to facilitate such a transfer. If such a transfer is not effected, the facility must seek judicial relief or honor the decision.

See Appendix A, proposed legislation, Section 12.

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Medical Futility: Defining the Limits of the Duty to Heat

Increasingly, physicians and hospitals have asserted a right not to provide treatment they consider medically futile. Discussion of the duty of physicians to talk to patients or families about treatment they regard as futile, or to provide such treatment, often focuses on decisions about cardiopulmonary resuscitation. In New York, debate has centered on New York's law on DNR orders.

Recent cases have highlighted the significance of the issue for other treatments. For example, in a case reported in 1990, physicians refused to provide artificial respiration to assist the breathing of a severely handicapped, two-year-old girl. The girl's mother requested the treatment, but physicians asserted that the treatment would be futile and inconsistent with the child's best interests.[1] In the case of Helga Wanglie, an 86-year-old woman who was permanently unconscious, the Hennepin County Medical Center in Minneapolis sought a court order to discontinue artificial respiration. Physicians at the hospital maintained that treatment was medically futile because it could no longer serve the personal interests of a patient in Ms. Wanglie's condition. Ms. Wanglie's husband and children wanted treatment continued, stating that the patient had previously expressed the wish that "she did not want anything done to shorten or prematurely take her life."[2]

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[1] J. Paris, R. K. Crone, and F. Reardon, "Physicians* Refusal of Requested Treatment: The Case of Baby L," *New England Journal of Medicine* 322 (1990): 1012-15. Baby L suffered from extensive neurological impairment. Hie authors report that her care was transferred to another physician. Two years later, Baby L had survived and was living with her parents but required intensive home nursing care; she was blind, deaf, and quadriplegic, with the mental status of a three-month-old infant. Responses to this case are found in "Point-Counterpoint: Physicians* Refusal of Requested Treatment," *Journal of Perinatology* 10 (1990): 407-15.

[2] "Hospital Opposes Family, Seeks Termination of Treatment," *Medical Ethics Advisor* 7 (1991): 17-19; L. Belkin, "As Family Protests, Hospital Seeks an End to Woman's Life Support," *New York Times* January 10, 1991, sec. A, p. 1. On July 1,1991, a

Defining Futility

Any discussion of medical futility is complicated by the diversity of physicians' understandings of the term. As noted by the Council on Ethical and Judicial Affairs of the American Medical Association: "The term ***futility*** does not express a discrete and identifiable quantity, but rather encompasses a range of probabilities and is likely to be interpreted in different ways by different physicians. Determinations of futility also may vary from one physician to another based on the perceived objectives of medical treatment and the criteria that are used to evaluate outcome"[3]

Some physicians use "futile" narrowly, considering treatments to be futile if they would be physiologically ineffective or would fail to postpone death, "by even a few minutes." [4] New York State's DNR law defines "medically futile" to mean that "cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time before death occurs."[5]

Many physicians embrace a broader, more elastic understanding of the term. Assessments of futility may represent a judgment that a given result is highly unlikely, even if not absolutely impossible. Commentators report that "some physicians may only invoke futility if the success rate is 0 percent, whereas others invoke futility for treatments with success rates as high as 13 percent."[6]

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court rejected a petition to appoint an independent conservator and designated Ms. Wanglie's husband, Oliver, as conservator. Helga Wanglie died three days later. For further discussion of the case, see A. M. Capron, "In Re Helga Wanglie," *Hasting? Center Report* 21, no. 5 (1991): 26-28; S. H. Miles, "Informed Demand for 'Non-Beneficial' Medical Treatment," *New England Journal of Medicine* 325 (1991): 512-15. For further discussion of decisions about life-sustaining treatment for permanently unconscious patients, see above, chapter 3.

[3] "Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders," *Journal of the American Medical Association* 265 (1991): 1870.

[4] S. J. Youngner, "Who Defines Futility?," *Journal of the American Medical Association* 260 (1988): 2094-95. See also "Point-Counterpoint," statements by A. R. Fleischman (407), and by R. H. Perelman and N. C. Fost (413).

[5] N.Y. Pub. Health Law § 2961 (McKinney Supp. 1992).

[6] J. D. Lantos et al., "The Illusion of Futility in Clinical Practice," *American Journal of Medicine* 87 (1989): 82. These authors argue that "futility cannot be defined with precision, but is simply the end of the spectrum of low-efficacy therapies." Others propose that a treatment should be regarded as futile if it has not worked in the last hundred cases. L. J. Schneiderman, N. S. Jecker, and A. R. Jonsen, "Medical Futility:

Some physicians might regard a treatment as futile if it could not preserve a patient's life for what they consider a significant length of time; for example, if CPR could prolong life for a few days or weeks but would not allow a patient to survive until discharge from the hospital.[7] Some broadly define treatment as futile if it cannot improve "the patient's prognosis, comfort, well-being, or general state of health. A treatment that fails to provide such a benefit — even though it produces a measurable effect — should be considered futile."[8]

Following this approach, a treatment might be seen as futile if it does not offer what physicians consider an acceptable quality of life. For example, in one survey, a majority of physicians agreed that for a severely demented patient with Alzheimer's disease, CPR would be "so clearly inappropriate or futile on medical grounds that physicians should be permitted to institute DNR status based on clinical judgment, without obtaining consent."[9]

The Significance of Futility

Underlying the debate about medical futility are basic assumptions about the ability of patients and family members to decide about treatment, the importance of their participation in treatment decisions, and the balance that should be struck between the authority of patients and the authority of physicians. Concerns about resource allocation have also fueled the futility debate.

Several approaches to futility have been proposed. Under one approach, physicians may decide not to provide a treatment on grounds of futility without informing the patient or family. Some agree that physicians have the authority to make decisions based on futility,

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Its Meaning and Ethical Implications," *Annals of Internal Medicine* 112 (1990): 951-52.

7 See, e.g., American Medical Association, 1870.

8 Schneiderman, Jecker, and Jonsen, 950. See also L. J. Blackhall, "Must We Always Use CPR?," *New England Journal of Medicine* 317 (1987): 1284; and the statement of Stanley J. Reiser, quoted in Belkin.

9 N. Spritz, "Views of Our Membership Concerning the DNR Issue and the New York State DNR Law," in *Legislating Medical Ethics: A Study of New York's DNR Law,* ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers, forthcoming). Seventy-seven percent of respondents agreed that physicians should be able to institute DNR status unilaterally based on futility in some cases, and 75% of that group believed that they should be able to do so for the patient with severe Alzheimer's disease.

but urge that they should discuss their decisions with the patient or surrogate. Others argue that the patient or surrogate should make most significant treatment decisions, even when futility is invoked, with the physician playing an advisory role.

At one extreme, some contend that physicians need not discuss treatments that they consider futile with a patient or family members. Responding to New York's DNR law, some physicians have urged that physicians should be granted unilateral authority to decide about CPR because severely ill patients or those close to them cannot make a rational choice. As stated by Dr. Kenneth Praeger, "Critically ill patients often cannot cope with the stress of discussing the possibility of their imminent death and of rationally weighing the pros and cons of CPR. They often have no idea of what the procedure involves and of the possible state to which they might be restored in the event of a 'successful resuscitation."[10]

Other physicians echoed these concerns about the DNR law. asserting that discussions about CPR cause therapeutic harm.[11] Some physicians asserted that doctors could know their patients' wishes and need not ask when they determine that CPR is not medically appropriate in their judgment.[12]

The Task Force rejects each of these arguments as a basis for granting physicians unilateral authority to decide about CPR or other treatments on the grounds of medical futility. The paternalistic notion that physicians should make decisions without consulting their patients because patients are incapable of making an informed or rational choice flies in the face of principles embraced in the past decade of discussion about medical advances.[13] It is also at odds with professional standards

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[10] K. Praeger, "How CPR Can Threaten the Desperately 111," *Walt Street Journal*, March 9,1989,16. See similarly D. J. Murphy, "Do-Not-Resuscitate-Orders: Time for Reappraisal in Long-term —Care Institutions," *Journal of the American Medical Association* 260 (1988): 2099. While Murphy acknowledges that discussion even about these decisions would provide some benefits to patients and family members, he suggests that "time would be better spent discussing other therapies and plans."

[11] F. Rosner, "Must We Always Offer the Option of CPR The Law in New York," *Journal of the American Medical Association* 260 (1988): 3129.

[12] P. Swender, "Reflections on the New York Do-Not-Resuscitate Law," *New York State Journal of Medicine* 89 (1989): 57-58.

[13] Testifying about the therapeutic exception to consent at hearings on New York's DNR law on behalf of a coalition of organizations that advocate for nursing home residents, Nelly Peissachowitz stated: "The aged have, during their lifetime, faced traumatic experiences, they have suffered losses, but they have coped and they have

of practice.[14] This position should not be condoned or adopted in the context of policies about medical futility.

The fact that some patients facing imminent death may find it difficult to decide about CPR does not suggest their failure, but the failure of physicians to raise the issue at an earlier time. Indeed, Dr. Praeger's comments beg the question of why he, and other physicians, wait until their patients enter the last stages of the dying process before raising the question of CPR. Some patients might want to refuse the treatment earlier. As shown by many studies, most would appreciate the respect and control such a conversation accords.[15]

Studies have also shown that unless physicians ask patients about their treatment wishes, they fare no better than chance alone at estimating what their wishes might be. Surrogates are not always familiar with the patient's wishes, but are more likely than physicians to approximate the patient's choice.[16]

In addition, studies of the DNR law do not support either the assumption that patients and families make poor choices by routinely opting for futile treatment or that involving patients and families in the decision-making process will lead to more futile treatment. Studies of actual practices before and after implementation of the DNR law consistently show that the provision of CPR did not increase after the

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survived. Most of the aged have made, or are in the process of making, their own decision regarding disposal of their belongings. They've arranged for a burial place and have expressed their wishes regarding disposal of their remains. We know that many have donated their organs, they have executed their will and indicated whether they wish to be cremated or not. The same individuals, we feel, can be trusted to express their wishes should they be faced with cardi[a]c or respiratory arrest in ca[s]e of hopeless illness. The medical assumption of possible harm in raising this issue is really, at best, an assumption." N. A. Peissachowitz, Testimony on behalf of the Nursing Home Community Coalition of New York State, New York State, Assembly and Senate Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resuscitate Orders,* New York, February 12,1987,125.

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As stated by the American Medical Association Council on Judicial and Ethical Affairs in its most recent guidelines on DNR orders (1871): "Patients who are at risk of cardiac or respiratory failure should be encouraged to express, in advance, their preferences regarding the use of CPR. These discussions should include a description of the procedures encompassed by CPR and, when possible, should occur in an outpatient setting when general treatment preferences are discussed, or as early as possible during hospitalization, when the patient is likely to be mentally alert."

15See chapter 1, 8-10,15.

16 See chapter 1,6-8.

law was implemented.[17] The largest study conducted to date also found that the law did not significantly alter the medical condition of the patients for whom the orders were entered, with the sickest patients most likely to have DNR status before and after the law.[18]

Some of those who have advocated a medical futility exception to the duty to provide treatment, or to consult patients or surrogates about decisions, have explicitly urged that the need to ration medical care justifies this approach.[19] The Task Force agrees that our current health care system lacks coherent, equitable policies to allocate health care resources. It does not believe, however, that such allocation should or can be achieved by the judgments of individual physicians or that the concept of medical futility should be a placeholder for those rationing choices. Rationing by individual physicians cannot yield coherent, fair policy. The judgments of individual physicians about the quality of life achieved by treatment are likely to vary as much as the views of patients. Access to treatment will then depend on the personal, religious, and moral views of each doctor, under the broad rubric of "medical futility."

A final major force driving the debate about medical futility is the growing body of data available about the poor outcomes of treatment for patients in certain medical conditions. Based on this data, physicians are able to determine that for certain patients, such as those in the final stages of a terminal illness, certain treatments offer no hope of cure or improvement and limited, if any, chance for prolonging life.[20]

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17 Based on anecdotal evidence, physicians and others have asserted that the DNR law increased futile CPR. No studies of the law support this claim. The studies do suggest, however, that physicians hostile to the notion of talking to patients or family members about CPR are most likely to report an increase in futile CPR By their silence, some physicians effectively opt to impose CPR they deem futile on their patients.

18 J. C. Ahronheim, S. Maheswaran, and C. Rosenberg, "Impact of Do-Not-Resuscitate Legislation on the Use of Cardiopulmonary Resuscitation in Three Teaching Hospitals," *New York State Journal of Medicine*, forthcoming. The authors stated that they undertook the study to confirm the "impression on the part of some of our colleagues that the DNR law was leading to an increase in the number of medically inappropriate resuscitations." They concluded that the study failed to confirm that observation. See similarly 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.

19 See, e.g., Murphy, 2100. Others who agree that physicians should be able to withhold treatment based on futility insist that resource considerations must remain separate from the futility debate. Schneiderman, Jecker, and Jonsen, 953.

20 See American Medical Association, 1868-69.

In light of this data, some commentators have argued that physicians should be able to decide not to provide treatment they judge to be futile, although they should first talk with the patient or surrogate. Most treatments impose risks and harms to patients. These commentators urge that physicians should be able to refrain from performing interventions when they determine that the risk of significant harm far exceeds potential benefits. Physicians and other health care professionals feel frustrated when forced to provide treatment that they deem futile. Health care professionals may also believe that providing such treatment violates their personal and professional integrity.[21]

Commentators have also argued that physicians should not "offer" treatments to patients or surrogates that they believe to be futile, because this falsely implies that the physician believes the treatment is a reasonable option. At the same time, some have noted that conversations between physicians and patients or surrogates, even about futile treatments, can provide important benefits and safeguards.[22] Discussion with patients and family members manifests respect for them, promotes trust in the patient-physician relationship, and gives patients and surrogates the opportunity to seek a second opinion or to transfer care of the patient.[23]

Asserting that judgments about futility of treatment for particular patients are often value-laden, some commentators emphasize that the patient's own wishes and values must play a central role in the decision-making process.[24] For patients who lack decision-making capacity,

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[21] Some physicians have recognized that the provision of "futile" treatment could be indicated by the duty to serve the best interests of the patient or by compassion in some cases, but assert that decisions about providing treatment on these grounds fall within the domain of professional authority. Schneiderman, Jecker, and Jonsen, 952- 53; T. Tomlinson and H. Brody, "Futility and the Ethics of Resuscitation," *Journal of the American Medical Association* 264 (1990): 1277-79.

[22] As stated by Tomlinson and Brody (1279-80): "[The] goal in rejecting the consent process for futile CPR is to place the discussion in a meaningful context, not to avoid the emotional pain of discussing terminal illness with patients."

[23] Youngner, "Futility in Context," *Journal of the American Medical Association* 264 (1990): 1296. See also American Medical Association, 1871.

[24] As Stuart Youngner observes: "Living for five more days might give some patients the opportunity to say good-byes, to wait for the arrival of a loved one from another city, or to live to see the birth of a grandchild. For one patient, a life with extreme disability and pain might be quite tolerable; for another, it might be totally unacceptable. Risk takers might see a *3%* chance as worth taking, while others might

family members and other surrogates are generally best able to articulate the patient's wishes through substituted judgment. Significant deference should be accorded surrogates' assessments of the best interests of patients as well.[25] At the least, patients and surrogates should participate in the decision-making process, so that the special values of the patient and family can be taken into account.[26]

Some are more adamant about the authority of the patient or surrogate. One physician urges that while a physician can explain why a DNR order seems appropriate, "it is up to the patient to decide whether to be resuscitated The physician's decision ought only to be that in his or her judgment there is no medical benefit, not that the patient will not be resuscitated."[27] A unilateral decision by the physician would violate the rights and dignity that physicians should accord their patients.

Many commentators note that defining the authority of physicians, patients, and surrogates to make treatment decisions based on futility raises important concerns for public policy. Some assert, however, that physicians may withhold treatment on the grounds of futility based on a clear consensus in the medical community that a treatment is futile or on a socially shared understanding that a treatment is unreasonable.[28]

The Task Force believes that neither patients nor those who decide on their behalf have, or should be granted, the right to insist on treatment that offers no physiological benefits in terms of cure, care, or the prolongation of life. At the same time, it has concluded that policies on

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give more weight to the *97%* chance of failure." "Who," 2095. See similarly Lantos et al., 82-84.

The American Medical Association "Guidelines" (1870-71) state that, unless CPR would be physiologically ineffective, "judgments of futility are appropriate only if the patient is the one to determine what is or is not of benefit, in keeping with his or her personal values and preferences."

25 See, e.g., Fleischman, 407-8, and discussion above, chapters 1 and 3.

26 Youngner, "Context," 1296.

27 S. J. Faiber, Letter on "Ethics of Life Support and Resuscitation," *New England Journal of Medicine* 318 (1988): 1757-58. Most of those who emphasize the role of the patient and family in assessing futility agree that it is appropriate for physicians to recommend a course of treatment and seek to persuade the patient or surrogate about the appropriate treatment choice.

28 2o Schneiderman, Jecker, and Jonsen, 949,952-33; Tomlinson and Brody, 1279; G. B. Avery, statement in "Point-Counterpoint," 410. These commentators acknowledge that if futility simply represents a vague appeal to physician discretion, it may be abused. They also warn that physicians should not "impose unsubstantiated claims of certainty" in assessing futility.

medical futility must account for the diverse understandings of futility among physicians, the persistent reluctance of physicians to discuss end-of-the decisions with patients, and the importance of the dialogue between the physician and the patient or someone authorized to decide on the patient's behalf.

The Task Force proposes that legislation on surrogate decisions should recognize the limits of surrogate authority to insist upon treatment. This constraint on surrogate authority should be coextensive with the limits on the right of competent patients. Policies for surrogate decisions should provide that a request for treatment by a surrogate shall not create any greater duty to provide treatment than a request by a competent patient.

This policy creates no hard-and-fast rule about when treatment can be deemed futile; it recognizes that a societal consensus about the term, except in its strictest, most limited sense, has not yet developed and is still evolving. It also establishes that a determination that treatment is futile under appropriate standards constrains the choices of both competent adults and surrogates.

Physicians currently have no duty to provide treatment that is futile in the narrow sense of the term — treatment that will not achieve any identified medical benefit, including the prolongation of life. A broader definition that encompasses perhaps the last few days or possibly weeks of the dying process would have to await the consensus of society at large, not just physicians. The Task Force did not reach a consensus on whether the definition of futility should be broadened, and believes that such a consensus has not yet emerged.[29]

In all cases, however, the Task Force believes that a conversation between the physician and the patient or surrogate is crucial before the physician unilaterally withdraws or withholds life-sustaining treatment on grounds of futility. The conversation will shore up the trust between patient and physician; it will avoid the silence and secrecy that accom-

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[29] Some Task Force members believe that physicians should provide any life-sustaining treatment that is not physiologically futile and that is requested by a surrogate in accord with decision-making standards. Other members feel that, after informing a patient or surrogate, physicians should be able to refuse to provide treatment that might extend the life of a dying patient by hours or days without any chance of cure. Task Force members agree that if a patient without decision-making capacity lacks a surrogate, and the attending physician and a second physician determine that the patient will die within a short time even if treatment is provided, a decision to withhold or withdraw treatment should not require review by a bioethics review committee. Like all health care decisions, this decision should accord with the patient's wishes or, if these cannot be ascertained, the patient's interests.

panied DNR decisions before the DNR law was enacted. The conversation also affords patients, or those deciding for them, an opportunity to seek a second opinion and to inquire about the physicians' assessment of futility. Given the expansive, variable notion of futility among physicians, this option is critical for individual cases and as an overall check upon reliance on futility as a basis to deny treatment according to the subjective judgments of each physician. Without this conversation, the futility concept would undoubtedly become, for some physicians, a way to avert conversations they find difficult and have long avoided.[30]

Recommendation

Neither patients nor surrogates have the right to insist on physiologically futile treatment. The Task Force proposes that legislation for surrogate decisions should recognize that 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, futility must be carefully defined, and the physician should talk with the patient or surrogate before treatment is withheld or withdrawn on grounds of medical 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.

See Appendix A, proposed legislation, Section 4(3)(a)

30 See T. E. Miller, "Do-Not-Resuscitate Orders: Public Policy and Patient Autonomy," *Law*; *Medicine and Health. Care* 17 (1989):245-54.

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Some Special Issues

Several special issues are central to decisions to forgo life-sustaining treatment. These include the distinction some health care professionals draw between stopping and not starting treatment, the moral significance of intentions, and euthanasia. Decisions about artificial nutrition and hydration also touch upon important values.

These issues help to define the ethical duties of health care professionals and the parameters of surrogate authority. They arise in many sensitive cases, in which medical and personal judgments about treatment benefits, intentions, and responsibilities may dramatically affect decisions at the end of life. In our pluralistic society, the diversity of beliefs about some of these issues poses additional challenges for public policy.

A. Withdrawing and Withholding Treatment

Health care professionals often distinguish between withholding treatment and withdrawing treatment after it has been initiated. As a result, health care professionals and facilities are sometimes willing to honor decisions by patients or family members not to start treatment, but will not allow them to refuse treatment once it has begun.[1] Another consequence of the distinction is that physicians may discuss decisions to withdraw treatment with patients and surrogates, but may decide to withhold treatment without consulting the patient or family.

Underlying the distinction is an understanding by some health care professionals that withholding treatment is an omission while withdrawing treatment is a positive action and is therefore more culpable.

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[1] See, e.g., 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), 73-75; T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 3d ed. (New York: Oxford University Press, 1989), 147-50; and R. F. Weir, *Abating Treatment with Critically IU Patients: Ethical and Legal Limits to the Medical Prolongation of Life* (New York: Oxford University Press, 1989), 147-48,401-3.

Some regard the distinction as harshly as that between "letting die" and "killing."[2] Some professionals may also believe that actions to remove treatment have graver legal consequences.

Over the past decades, a consensus has emerged in the bioethics literature that withdrawing and withholding treatment should not be morally distinguished.[3] As often characterized, withdrawing life-sustaining treatment in response to the request of a patient or surrogate is best seen as allowing rather than causing the patient's death; the underlying disease, not the removal of treatment, remains the cause of death.

The Task Force shares the widely articulated belief that withholding and withdrawing treatment are morally equivalent. Whether treatment is stopped or never initiated, all relevant moral factors are the same, including health care professionals' duty to respect the patient's wishes, the consequences, the intentions, the cause of death, and the potential for abuse. Hence, if a patient is dying of cancer, either withholding or removing a respirator allows the disease to take its natural course; neither the omission nor the withdrawal of treatment causes the patient's death.[4]

The Task Force's 1988 study of health care facilities examined whether facilities would oppose, on religious or moral grounds,

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[2] President's Commission, 73-74; L. Baer, "Nontreatment of Some Severe Strokes," ***Annals of Neurology*** 4 (1978): 381-82. Some Jewish authorities argue that from the perspective of traditional Jewish law, the physician's obligations in approaching a decision to withhold or withdraw treatment may be distinct in some cases. See, e.g., F. Rosner and M. D. Tendler, ***Practical Medical Halacha,*** 3d ed. (Hoboken, N.J.: Association of Orthodox Jewish Scientists in association with Ktav, 1990), 54. Others, though, argue that any such distinction should not be decisive. "At the outset, the physician should connect the support systems of respiration or circulation; he should not decline to do so on the grounds that this may be prolonging death. He must give the patient every chance for life. Having connected the systems conditionally, however, he may remove them if he then determines that their function was not prolongation of life but of death." D. M. Feldman, ***Health and Medicine in die Jewish Tradition*** (New York: Crossroad, 1986), 95. See also I. Jakobovits, ***Jewish Medical Ethics***, 2d ed. (New York: Bloch, 1975), 121-25,275-76.

[3] See, e.g., President's Commission, 73-77; American Medical Association, Council on Ethical and Judicial Affairs, ***Current Opinions*** (Chicago: American Medical Association, 1989), sec. 2.20, p. 13; P. Ramsey, ***The Patient as Person*** (New Haven: Yale University Press, 1970}, 121.

[4] See Weir, 310-17. A different case would be presented if an otherwise healthy patient is left untreated (deliberately or negligently) and dies. In this type of situation, either the withholding or withdrawal of standard therapy would be considered a contributing cause of death from a moral and legal perspective.

decisions to either withhold or withdraw life-sustaining treatment. In a majority of the cases presented, respondents distinguished between decisions to withhold and to withdraw treatment. For example, facilities were more likely to have a religious or moral objection to withdrawing treatment than to withholding treatment.[5] Anecdotal evidence and public discussion of decisions about life-sustaining treatment in the State suggest that the distinction between not starting and stopping treatment is widespread in health care facilities.

The Task Force urges all health care facilities to review their policies and practices for decisions about life-sustaining treatment, and to abandon distinctions based solely on the difference of whether or not treatment has already been started. The distinction cannot be supported on moral grounds. It also contravenes New York legal principles specified in judicial decisions and statutes. Neither the common law right to refuse treatment nor the authority of a duly appointed health care agent turns on whether treatment has been initiated for patients. The relevant legal benchmark is the patient's consent or, for health care agents, the agent's authority and duty to promote the patient's wishes whenever possible and otherwise to decide in accord with the patient's interests. The liability of health care providers for withholding or withdrawing treatment does not depend on the distinction, but on the duty to provide the treatment and the validity of any consent that may be required to stop or not to start treatment.

Those who adhere to the distinction should recognize that it may prompt poor medical practice in some cases. For certain patients, a trial period of treatment may yield clinical information about the efficacy of the treatment or the patient's willingness to accept the burdens that treatment imposes. For example, physicians may not know how a sick newborn will respond to a respirator. An elderly patient may wish to experience dependence on a gastrostomy tube before deciding about long-term treatment. If parents, other surrogates, or patients are told that, once initiated, treatment is irreversible, they will in some cases opt not to start. In an emergency, the distinction places even greater pressure on the difficult, emotionally charged choices that must be made in the immediate aftermath of an unexpected injury or illness.

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The survey explicitly instructed facilities to disregard concerns about liability as a basis for refusing to honor decisions to forgo treatment. In actual practice, legal considerations may drive many decisions to continue or to forgo life-sustaining treatment. New York State Task Force on Life and the Law, survey data. See appendix E.

The Task Force recognizes that the distinction between not starting treatment and stopping has proven tenacious, persisting now for many years despite a broadly articulated consensus that rejects the distinction on moral grounds. At the least, health care professionals should recognize that they have neither the moral nor the legal right to refuse to honor a decision to stop treatment by a competent patient or duly authorized health care agent, unless they have specific grounds for doing so, such as the patient's incapacity to decide or bad faith by the agent. The same would hold true for surrogate decisions under the proposed legislation. If health care professionals do not want to participate in removing treatment on grounds of conscience, they need not participate, but they must inform the health care facility and the patient or person deciding for the patient and cooperate in transferring care of the patient.

B. The Moral Significance of Intentions

For some treatment decisions, a surrogate's choice to relieve pain may conflict with the value of preserving or extending life. For example, a potentially beneficial treatment such as heart surgery or chemotherapy may carry a high risk of mortality. Likewise, effective doses of pain medication for a terminally ill patient may depress respiration and risk hastening a patient's death. In such cases involving conflicting values and obligations, some commentators distinguish intended consequences from those consequences that are not intended but can be foreseen.[6]

This distinction is supported by Roman Catholic teaching, as well as other religious and secular traditions, and is often expressed in terms of "the principle of double effect." An action with both good and evil effects is permitted if the action is not intrinsically wrong, the agent intends only the good and not the evil

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[6] The ***Ethical and Religious Directives for Catholic Health Facilities*** states that "it is not euthanasia to give a dying person sedatives and analgesics for the alleviation of pain, when such a measure is judged necessary, even though they may deprive the patient of the use of reason, or shorten his life " National Conference of Catholic Bishops (St. Louis: Catholic Health Association of the United States, 1975), 13-14, par. 29. See similarly the Vatican's 1980 "Declaration on Euthanasia," in President's Commission, 304-5.
A Jewish ***Compendium on Medical Ethics*** agrees that "relief of pain is adequate reason to assure palliation therapy, even with attendant risk." D. M. Feldman and F. Rosner, ed., 6th ed. (New York: Federation of Jewish Philanthropies, 1984). See similarly Jakobovits, 276.

effect, the evil effect is not the means to the good effect, and a favorable balance exists between the good and evil effects.[7]

Under this analysis, a decision to provide pain medication in the case of the terminally ill patient described above would be ethically acceptable. The administration of medication is not intrinsically wrong, and is intended to alleviate the patient's pain, although the risk of death could be anticipated. Respiratory failure and the patient's death are not intended, nor are they necessary to relieve pain. In addition, in certain cases, such as when the patient is terminally ill and in pain, the good achieved would outweigh the risk of harm.

This type of case is distinct from the intentional termination of life by lethal overdose. Active euthanasia relieves suffering by a deliberate action with the primary intention of ending the patient's life. In contrast, palliative medication in the case above may risk hastening death, but it is not intended to cause death.[8]

This distinction between intended and foreseen consequences has been criticized as irrelevant, especially as expressed in the doctrine of double effect. Some argue that if consequences, actions and all other factors are the same, it makes no difference whether the patient's death is intended or not. Critics note problems in applying the distinction to actual cases, in which it is often difficult to discern exactly what a physician or others intended, and what counts as a means or a side effect. Some emphasize that those who act are responsible for all consequences of their actions that can be anticipated.[9]

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See, e.g., Beauchamp and Childress, 127-28. Evaluation of the balance of good and evil effects is classically phrased in terms of proportionality. Most instances of causing unintended but foreseeable deaths would be judged morally wrong on this basis because the negative effect of the patient's death would outweigh any good effects. Various formulations of the principle (or doctrine) of double effect have been developed by philosophers and moral theologians. Recent essays on this topic may be found in ***Journal of Medicine and Philosophy*** 16, no. 5 (1991): 465-585.

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Some commentators also distinguish between intended and foreseen consequences when decisions are made to forgo life-sustaining treatment. They accept the withholding or withdrawal of treatment with the intention to alleviate burdensome treatment. However, they oppose the denial of treatment intended to lead to the patient's death, as passive euthanasia. W. E. May et al., "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," ***Issues in Law and Medicine*** 3 (1987): 204,207-9.

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President's Commission, 77-82; Beauchamp and Childress, 130-34; A. R. Jonsen, M. Siegler, and W. J. Winslade, ***Clinical Ethics,*** 2d ed. (New York: Macmillan, 1982), 120-21.

Several commentators, while criticizing the intended/foreseen distinction and the doctrine of double effect, acknowledge that intentions may be a significant factor in moral deliberation. For example, they note that many medical interventions, intended to cure the patient or relieve pain, entail some finite risk to life. Society has granted physicians the authority to evaluate risks and benefits, to recommend a course of treatment, and to implement treatments chosen by a patient or surrogate in pursuit of accepted medical goals. While potentially risky interventions intended to cure the patient or relieve pain are within the scope of the physician's professional role, actions that are intended directly to cause death fall outside the physician's special authority. Commentators argue that allowing physicians to act with the intention of causing death raises problems for the way physicians view themselves and the practice of medicine and poses dangers of abuse for society as a whole.[10]

Some members of the Task Force embrace the principle of double effect. Others stress that intention is one, but not the primary, factor in determining the moral acceptability of providing pain relief; they believe that the decision should focus on the overall risks and benefits of the treatment. All agree that 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.

Pain relief is of vital, and often overwhelming, importance to patients. Of the many disabilities and discomforts associated with illness and the dying process, patients often fear the experience of pain most. The popularity of the book ***Final Exit,*** instructing people how to kill themselves, attests to the public's anxiety about a lingering, painful death. This fear can be attributed, in part, to the medical profession's recognized failure to make adequate pain relief available to patients facing painful terminal or chronic illness. As characterized by an editorial in the ***New England Journal of Medicine***, pain relief for hospital patients is "regularly and systematically inadequate."[11]

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[10] President's Commission, 77-82. See also E. Y. Waldenberg, ***Tzitz Eliezcr,*** vol. 13, no. 87; discussed in B. A. Brody, [W]A Historical Introduction to Jewish Casuistiy on Suicide and Euthanasia," in ***Suicide and Euthanasia***, ed. B. A. Brody (Dordrecht: Kluwer Academic Press, 1989), 73.

[11] M. Angell, "The Quality of Mercy," New ***England Journal of Medicine*** 306 (1982): 98-99. See also K. M. Foley "The Relationship of Pain and Symptom Management to Patient Requests for Physician-Assisted Suicide," ***Journal of Pain and Symptom Management*** 6 (1991): 289-97; "Will Doctors Hear the Wake-Up Call?" ***American Medical News***, December 9, 1991, 3; D. M. Gianelli, "Euthanasia Opponents Urge
Pain-Control Education." ***American Medical News,*** January 20, 1992, 9.

Various reasons have been offered to explain why physicians fail to provide sufficient pain relief, including lack of training in advanced pain relief techniques, patients* reluctance to complain, physicians* failure to acknowledge patients* pain, and physicians' fear of side effects, including addiction and the possibility that pain medication will hasten the patient's death. Studies have shown, however, that concerns about addiction or hastening death from pain medication are not supported by medical evidence; patients receiving medication for chronic pain generally do not become addicted or suffer serious or fatal respiratory distress. The rare case when aggressive analgesia would pose significant risks should be resolved through careful discussion between the patient or surrogate and health care professionals. When the goals of prolonging life and alleviating suffering conflict, the values of the patient should generally be decisive.[12]

C. Deciding about Artificial Nutrition and Hydration

Throughout the public deliberation leading up to passage of New York's health care proxy law, decisions about artificial nutrition and hydration generated the most extensive debate. The Task Force recognizes that as the legislature considers its proposal for surrogate decisions, policies on these measures will once again receive close scrutiny.

The term "artificial nutrition and hydration" refers generally to the provision of food and water through tubes inserted in the patient's veins, nose and throat, stomach, or intestine. Artificial feeding is used to supplement nutritional intake or to provide total nutritional support on a short-term or long-term basis. As long-term measures, artificial nutrition and hydration are usually provided through a tube inserted in the nose and esophagus or surgically inserted into the stomach or a portion of the small intestine.[13] While such nutritional support is usually highly effective, potential complications, including the risk of serious

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[12] See American Medical Association, ***Current Opinions,*** sec. 2.20, p. 13. See Bioethics Committee, Montefiore Medical Center, "Ethical Issues in Pain Control" (Bronx, N. Y., 1991), for a helpful and comprehensive summary of medical and ethical issues.

[13] U.S. Congress, Office of Technology Assessment, ***Life-Sustaining Technotopes and the Elderly***, OTA-BA-306 (Washington: U.S. Government Printing Office, 1987), 275-93; C M. Lewis, ***Nutrition and Nutritional Therapy in Nursing***, (Norwalk, Ct.: Appleton Century-Crofts, 1986). Total parenteral nutrition (TPN) is another means of artificial feeding that involves the provision of nourishment through a central venous catheter. The risks and high cost of TPN, however, make tube feeding the

infection, are numerous and vary according to the feeding method chosen.[14]

The issue of withdrawing artificial nutrition and hydration arises most frequently for patients who have permanently lost consciousness. It is also considered for some patients who are irreversibly ill and do not tolerate the procedure well.[15] If artificial nutrition and hydration as well as other nursing and medical care are provided to patients who have permanently lost consciousness, their vital bodily functions may be maintained for many years[16] Karen Ann Quinlan, for example, lived for 10 years following removal of the artificial respirator that assisted her breathing. When artificial nutrition and hydration are withdrawn, patients usually die within a period of time ranging from two to ten days.[17]

Existing medical opinion suggests that patients who have permanently lost consciousness do not experience pain or discomfort following the withdrawal of artificial nutrition and hydration.[43] For some permanently unconscious patients,

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treatment of choice for most patients who can process food in some portion of their gastrointestinal tract. See C H. Bastian and R. H. Driscoll, "Enteral Tube Feeding at Home," in ***Clinical Nutrition,*** vol. 1, ***Enteral and Tube Feeding,*** ed. J. L. Rombeau and D. M. Caldwell (Philadelphia: W. B. Saunders Co., 1984), 494-512; S. A. Chiysomilides and M. V. Ka miniski, "Home Enteral and Parenteral Nutritional Support: A Comparison," ***American Journal of Clinical Nutrition*** 34 (1981): 2271-75.

[14]Tube feeding, especially among the elderly, can be continued for long periods but is associated with a high frequency of complications. For a detailed discussion of the potential complications and side effects associated with different methods of providing artificial nutrition and hydration, see M. Bernard and L. Forman, "Complications and Their Prevention," in ***Clinical Nutrition***, vol. 1,542-69; Office of Technology Assessment, 280-86; J. O. Ciocon et al., "Tube Feeding in Elderly Patients," ***Archives of Internal Medicine*** 148 (1988): 429-43.

[15]J. Lynn and J. F. Childress, "Must Patients Always Be Given Food and Water?" ***Hasting? Center Report*** 13, no. 4 (1983): 17-21; P. Schmitz and M. O'Brien, "Observations on Nutrition and Hydration in Dying Cancer Patients," in ***By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water,*** ed. J. Lynn (Bloomington: Indiana University Press, 1986), 29-38; H. Brody and M. B. Noel, "Dietitians' Role in Decisions to Withhold Nutrition and Hydration," ***Journal of the American Dietetic Association*** 91 (1991): 580-85.

[16]i n one recorded case', the patient survived in a permanently unconscious state for 37 years; in another, for 18 years. President's Commission, 181*82.

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Conversation with Fred Plum, M.D., Chairman, Dept, of Neurology, Cornell-New York Hospital Medical Center, April 15,1987.

however, the provision of artificial nutrition and hydration leads to numerous complications. Less information is available about the experience of greatly debilitated patients or those suffering from severe illness who are in the end stage of the dying process. Available information, however, suggests that these patients appear to experience little, if any, discomfort when routine comfort measures are provided.[19] Finally, in some cases, the provision of artificial nutrition and hydration very close to the time of death may increase the patient's discomfort. Some patients are more likely to experience pulmonary edema, nausea, and mental confusion when artificial nutrition and hydration are maintained in the last stages of the dying process.[20]

Ethical Considerations

Discussions about artificial nutrition and hydration often center on whether these measures should be distinguished from other treatment on medical or clinical grounds. Some insist that artificial nutrition and hydration constitute "basic care" rather than medical treatment. They describe nutrition and hydration, whether provided directly or by artificial means, as universal needs, not just as needs of the sick. Artificial nutrition and hydration are not administered in order to cure or control disease, but rather to sustain the patient's

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Patients who are permanently unconscious have lost all thought, sensation, and awareness. This includes patients in a persistent vegetative state, patients who are totally unresponsive following brain injury or hypoxia, and patients at the end stage of certain degenerative neurological conditions. See President's Commission, 177. See also Brief for Amicus Curiae American Academy of Neurology, 10-29; ***Brophy v. New England Sinai Hospital***, 398 Mass. 417,497 N.R2d 626(1986).

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Schmitz and O'Brien, 29-38; P. Schmitz, "The Process of Dying with and without Feeding and Fluids by Tube," ***Law, Medicine and Health Care*** 19 (1991): 23-26; J. A. Billings, "Comfort Measures for the Terminally 111: Is Dehydration Painful?" ***Journal of the American Geriatrics Society*** 33 (1985): 808-10. Billings reports that the only troubling and commonly encountered symptoms that can be attributed to dehydration in terminally ill patients are thirst and dry mouth. He suggests that these symptoms can be relieved by small amounts of oral fluid or by keeping the patient's mouth moist with water, ice chips, or artificial saliva. A study by Ciocon et al. that examined the complications of tube feeding, indicated that patients frequently experienced problems of agitation, extubation, and aspiration pneumonia. Weight loss was common among patients who had been tube fed for more than six months. See also "Terminal Dehydration," ***Lancet*** no. 8476 (1986): 306; D. J. Oliver, "Terminal Dehydration," (letter) ***Lancet*** no. 8403 (1984): 631.

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Lynn and Childress, 19.

life. While some patients require assistance to receive nutrition and hydration, dependence on others for the provision of nutrition is an accepted part of the human condition.[21]

Some commentators also emphasize the symbolic and affective meanings associated with providing nutrition and hydration and the effects upon society of allowing persons to die by starvation or dehydration [22] A practice of forgoing artificial nutrition and hydration could undermine the self-image of health care professionals as well as the trust of patients.[23]

Perhaps the strongest concerns about forgoing artificial nutrition and hydration are that such procedures intentionally cause death, at least in some cases. Commentators point out that while death does not always occur after the withdrawal of other treatments such as artificial respiration, death is inevitable if nutrition and hydration are withheld. Lack of nutrition and hydration become the cause of death.[24]

Some commentators argue that the certainty of death following the forgoing of nutrition makes the intention of death inescapable, especially for patients who are not terminally ill. Some assert that artificial nutrition and hydration should be withheld or withdrawn only when the measures are absolutely futile or when the aim is to avoid burdens caused by the treatment itself. It is wrong, though, to withhold nutrition and hydration from patients simply because others regard

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[21] G. Meilaender, "On Removing Food and Water Against the Stream," ***Hastings Center Report*** 14, no. 6 (1984), 11-13; P. Derr, "Why Food and Fluids Can Never Be Denied," ***Hastings Center Report*** 16, no. 1 (1986), 28-30; W. B. Smith "Is a Decision to Forgo Tube Feeding for Another a Decision to Kill?" ***Issues in Law and Medicine*** 6 (1991): 388-90.

[22] As stated by A. J. Weisbard and M. Siegler "Although the techniques for providing such supports may be medical, and thus logically associated with other medical interventions, the underlying obligations of providing food and drink to those who hunger or thirst transcend the medical context, summoning up deep human responses of caring, of nurturing, of human connectedness, and of human community." "On Killing Patients with Kindness: An Appeal for Caution," in *By No Extraordinary Means*, 112.

[23] D. Callahan, "On Feeding the Dying," ***Hastings Center Report*** 13, no. 5 (1983): 22; D. Callahan, "Feeding the Dying Elderly" ***Generations*** 10, no. 2 (1985): 15-17; Derr, 29-30; Smith, 391.

[24] Deliberately to deny food and water to such innocent human beings in order to bring about their death is homicide, for it is the adoption by choice of a proposal to kill them by starvation and dehydration." May et al., 207. See also Weisbard and Siegler, 111-112; Derr, 28-29; Meilaender, 12; B. A. Brody, "Ethical Questions Raised by the Persistent Vegetative Patient," *Hastings Center Report* 18, no. 1 (1988): 35.

their lives as valueless.[25] Withholding nutrition on that basis is regarded as the intentional achievement of death or deliberate killing. Some commentators warn of the dangers of abuse, and the consequences to society, of a widespread practice of decisions to forgo artificial nutrition and hydration.[26]

In contrast, others argue that artificial nutrition and hydration should not be distinguished from other medical treatments. This position is reflected in statements by the American Medical Association's Council on Ethical and Judicial Affairs and the New York Academy of Medicine, recent court decisions, and other public commentary.[27] Advocates of this position maintain that, like other treatments and in contrast to ordinary feeding, artificial nutrition and hydration are not universal needs for all persons, but interventions in response to an underlying disease or condition. While nutrition and hydration provided without medical intervention are basic needs, air is an equally basic need; providing air by artificial respiration is properly understood as medical treatment. Artificial nutrition and hydration require the assistance of medical personnel, entail risks, discomfort and complications for the patient, and in some cases require surgery.[28]

Responding to concerns about the symbolic significance of nutrition and hydration, commentators emphasize the differences between medical nutrition and hydration on the one hand and food and water on the other. Starvation is repugnant because it causes suffering, but when artificial nutrition and hydration are appropriately forgone, the patient's suffering diminishes. Some

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[25] May et al., 206.

[26] As stated by Daniel Callahan: "A denial of nutrition and hydration may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die. Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it could well become the nontreatment of choice." Callahan, "On Feeding," 22. See also Meilaender, 12; May et. al., 207; Derr, 29-30; R. M. Veatch, ***Death, Dying and the Biological Revolution***, 2d ed. (New Haven: Yale University Press, 1989): 84-85.

[27] American Medical Association, Council on Ethical and Judicial Affairs, "Withholding or Withdrawing Life Prolonging Medical Treatment," March 14, 1986; "Statement of the Joint Subcommittee on the Care of the Terminally 111 of the Committee on Public Health and the Committee on Medicine in Society," approved by the Council of the New York Academy of Medicine, April 22,1987. See also, Weir, 409-10; Lynn and Childress, 17-21; G. J. Annas, "Do Feeding Tubes Have More Rights than Patients?" ***Hastings Center Report*** 16, no. 1 (1986): 26-28; S. Wanzer et al., "The Physician's Responsibility Toward Hopelessly 111 Patients," ***New England Journal of Medicine*** 310 (1984): 955-59.

[28] Annas, 28-30; Lynn and Childress, 17-19; Weir, 409-13.

commentators argue that the interests of particular patients cannot be sacrificed in order to maintain a general symbol. It is further claimed that people can clearly differentiate the withholding and withdrawal of artificial nutrition and hydration from allowing the poor to starve to death.[29]

Commentators assert that forgoing artificial nutrition and hydration remains essentially similar to forgoing other types of life-sustaining treatment and differs crucially from intentional and active killing. While death is certain in some cases following the withdrawal of artificial nutrition and hydration, death may also be certain when other life-sustaining treatments are withdrawn. From this perspective, the abatement of artificial nutrition is no more the cause of death than the discontinuance of artificial respiration or antibiotics. In all of these cases, the cause of death remains the disease or injury that brought about the need for life-sustaining treatment.[30]

Additionally, forgoing artificial nutrition and hydration remains the refusal of treatment. Among those who reject the distinction between artificial nutrition and hydration and other treatment, some advocate that, like other treatment, artificial nutrition and hydration cannot and should not be imposed over the wishes of a competent patient.[31] Others focus on the standard of proportionality and maintain that a competent patient may appropriately refuse artificial nutrition and hydration when the burden of treatment outweighs the benefits it offers the patient.[32] Under

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[29] Lynn and Childress, 20-21; J. F. Childress, "When Is It Morally Justifiable to Discontinue Medical Nutrition and Hydration," in *By No Extraordinary Means,* 74-76; Veatch, 84. Some commentators also suggest that words like "kill" or "starve" obscure rather than advance meaningful discussion* As stated by Dennis Brodeur, "'Starvation' and 'murder' are morally charged words that conjure up deliberate, and by definition, immoral actions. These words do not suggest moral dialogue. Rather they present moral conclusions* When discussing respirators, for example, the moral question is not asked: 'Can we turn off a ventilator and suffocate a person to death?'" Brodeur, "Is a Decision to Forgo Tube Feeding a Decision to Kill?" *Issues in Law and Medicine* 6 (1991): 397.

[30] Lynn and Childress, 20; Weir, 413-14.

[31] Annas, 27; Childress; D. Brock and J. Lynn, "The Competent Patient Who Decides Not to Take Nutrition and Hydration," in *By No Extraordinary Means,* 202-15.

[32] See G* Kelly, "The Duty of Using Artificial Means of Preserving Life," *Theological Studies* 11 (1950): 203-20; J. J. Walter, "Food and Water An Ethical Burden," *Commonweal* 113 (1986): 616-19. This approach has been espoused by some within the Roman Catholic tradition, although debate continues about the given explicit delegation regarding nutrition and hydration, no other party is able to make decisions in this regard." He suggests that surrogate decision makers should be authorized to decide to forgo artificial nutrition and hydration based on a calculus of benefits and burdens for the particular patient, with safeguards to prevent abuse. "Context," p. 19 of manuscript.
Society of New York State, New York State, Assembly and Senate Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resusciate Orders,* New York, February 12,1987,227; J. Linville, Testimony on behalf of Health and Hospitals Corporation, *Public Hearing?,* 176.

either analysis, the symbolic importance of providing

nutrition and hydration does not outweigh other considerations: either the patient's right to self-determination or, ***under*** the proportionality standard, the patient's interest in the appropriate course of medical treatment.[33]

Proposed Policy for Surrogate Decisions

Members of the Task Force hold diverse views on many issues posed by decisions to forgo artificial nutrition and hydration. They concur,

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implications of Catholic teaching for decisions about artificial nutrition and hydration. In a statement of guidelines for legislation on life-sustaining treatment, the United States Bishops' Committee on Pro-Life activities urged that laws about life-sustaining treatment should establish a strong presumption in favor of providing artificial nutrition and hydration, but it recognized that "Laws dealing with medical treatment may have to take account of exceptional circumstances, when even means for providing nourishment may become too ineffective or burdensome to be obligatory." "The Rights of the Terminally 111," ***Origins*** 16 (1986): 222-24. Commentators within the Roman Catholic tradition generally agree with this statement and the principles articulated in the Vatican's 1980 "Declaration on Euthanasia," but they vary in their interpretation of these guidelines.
Msgr. William B. Smith, for example, argues that in most cases, artificial nutrition and hydration represent basic care that should be provided to conserve and sustain life. He further notes the symbolic significance of providing life-sustaining measures. "Supporting life . . . does benefit that person even if only minimally because it expresses love of that person (neighbor). One benefit is care of the comatose rather than their abandonment. And this maintains human solidarity which affirms their dignity as persons and our dignity as personal caregivers." Smith, 391,385-94.
Within the Catholic tradition, others argue that commitment to the intrinsic value of human life is compatible with the forgoing of "disproportionately burdensome" treatment in a broader range of cases. A joint statement of 16 of the 18 Texas Catholic bishops and the Texas Conference of Catholic Health Facilities states that permanently unconscious patients, while human persons with inherent dignity, suffer from a lethal pathology. "The morally appropriate forgoing or withdrawing of artificial nutrition and hydration from a permanently unconscious person is not abandoning that person. Rather, it is accepting the fact that the person has come to the end of his or her pilgrimage and should not be impeded from taking the final step. The forgoing or withdrawing of artificial nutrition and hydration should only occur after there has been sufficient deliberation based upon the best medical and personal information available." "On Withdrawing Artificial Nutrition and Hydration," ***Origins*** 20 (1990): 53-55.
See also Joseph Cardinal Bemadin, "Context for and Moral Principles Guiding Catholic Conference of Illinois' Position on Senate Bill 2213," address to a meeting of the Pro-Life Department, Catholic Conference of Illinois, September 11, 1990; Brodeur, 395-406; Kelly, 203-20; and the discussion 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), 43-44.

[33] Brock and Lynn, 202-15; Annas, 26-28.

however, on two basic recommendations for public policy. First, decisions about artificial nutrition and hydration are highly sensitive, requiring caution and careful attention to the personal and medical circumstances of each particular patient. Second, legislative provisions for these measures that differ from the policies proposed for other decisions about life-sustaining treatment are not needed to address these concerns.

While court cases have found that no legal distinction can be drawn between artificial nutrition and hydration and other life-sustaining treatments, a diversity of opinion prevails about the measures. Some individuals in our society distinguish artificial nutrition and hydration on personal, religious, and moral grounds and would want the measures provided, unless they are futile or themselves cause physical harm. Others firmly reject that distinction and would frame their treatment wishes accordingly.

Many people, perhaps most, do not think about their wishes in relation to artificial nutrition and hydration or other particular treatments; they concentrate on the outcomes of treatment. For example, many individuals may not even know that artificial nutrition and hydration, along with treatments such as antibiotics, are used to sustain the lives of patients who are permanently unconscious, although they may have strongly held views about whether they would want to live under such circumstances.[34]

Policies for surrogate decisions must accommodate these diverse views and understandings of artificial nutrition and hydration. Our social and religious pluralism does not lend itself to a single resolution of this personal question. Instead, those who act as surrogates should devote special efforts to ascertaining the patient's own preferences and values.

Public policies should also take into account the fact that individuals dependent on artificial nutrition and hydration are often frail and vulnerable. They have lost many of the qualities and abilities commonly prized in our

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[34] The case of Helga Wanglie, for instance, turned on her general desire to have her life sustained as long as possible, not on her specific wishes or beliefs about artificial nutrition and hydration. See discussion above, chapter 14,195. Likewise, in the case of Nancy Cruzan, her parents did not assert that Nancy had particular views about artificial nutrition and hydration but that she would not have wanted to survive in a state of unconsciousness. *Cruzan v. Director, Mo. Dep't of Health,* 110 S. Ct 2841 (1990). Indeed, the fact'that most people do not focus on or talk specifically about artificial nutrition and hydration or other treatments highlights the failing of the clear and convincing evidence standard; people generally think about their future treatment in terms of outcomes, not interventions.

society, such as their self-reliance and the ability to communicate. They depend on others, often strangers or heavily burdened family members, for care that is demanding and expensive. Decisions to forgo artificial nutrition and hydration for these individuals would potentially affect thousands of nursing home residents.

The Task Force's proposal includes substantive and procedural standards to protect the interests of patients requiring surrogate decisions, especially for decisions about life-sustaining treatment. While policies are needed to prevent inappropriate decisions to forgo artificial nutrition and hydration, decisions to forgo other life-sustaining treatments, such as antibiotics, pose similar risks and can also be wrongful. The Task Force believes that the safeguards it has proposed for decisions about other life-sustaining treatments are appropriate and sufficient for decisions about artificial nutrition and hydration.

The Task Force did not distinguish artificial nutrition and hydration from other life-sustaining measures in its proposed legislation for the health care proxy law, although it did acknowledge special social concerns raised by artificial nutrition and hydration in its accompanying report.[35] Ultimately, the legislature decided that decisions to forgo these measures should meet an additional requirement, beyond those proposed for treatment decisions generally. It chose to require reasonable knowledge by the agent of the patient's wishes to forgo these measures.[36]

Under the Task Force's proposal, the authority conferred upon a surrogate would be far more constrained than the authority granted to health care agents. Medical circumstances define the limits of the surrogate's authority to forgo life-sustaining treatment. Only if the patient is terminally ill or permanently unconscious and treatment would be an excessive burden can the surrogate decide, in conjunction with the physician, to forgo artificial nutrition and hydration. In any other medical circumstance, decisions to forgo these measures or other life-sustaining treatment, would require approval by a bioethics review committee, or by a court. Records of committee decisions would then be available for review. These requirements assure heightened scrutiny of the decisions likely to pose the greatest danger of abuse.

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35 Task Force, 36-40.
36 N.Y. Pub. Health Law § 2982(2) (McKinney Supp. 1992).

Furthermore, decisions by a surrogate may be more readily challenged than those by a health care agent. In general, the agent has the same authority to make decisions as the patient would have had if capable. While agents must act in good faith and decide in a manner consistent with the patient's wishes and interests, their decisions can only be challenged in court. In contrast, health care professionals caring for the patient, as well as family members and others on the list of potential surrogates, can challenge decisions made by surrogates that they believe violate the proposed decision-making standards. Conflicts that cannot otherwise be resolved must be considered by a bioethics review committee.[37]

In the context of the proxy law, the requirement for reasonable knowledge of the patient's wishes regarding artificial nutrition and hydration represents a more appropriate safeguard than a similar requirement for surrogate decisions. Adults who create a proxy are informed that they should communicate their wishes about artificial nutrition and hydration to the agent; the proxy form and instructions prepared by the New York State Department of Health specify this information.[38] Patients who have not appointed an agent, however, are not likely to know or to have ever been told about the importance of articulating their preferences concerning these measures.

For patients whose wishes are not known, and for children and adults who never had the ability to formulate and express their own values and preferences, the health care proxy law would not provide the basis to forgo artificial nutrition and hydration under any circumstances. Almost all commentators agree that, in at least some cases, decisions to forgo these measures are mandated by consideration of the patient's best interests. For example, most would agree that artificial nutrition and hydration should be withheld or withdrawn when the measures cause additional suffering to a dying patient by increasing edema, nausea, and abdominal pain [39]

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[37] See chapter 9.

[38] See appendix D.

[39] See May et al., 208-9; Schmitz and O'Brien, 29-30. Joseph Cardinal Bemadin writes: "It does not seem justified to argue, as some have, that unless a person has

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

D. Euthanasia

In its report recommending the health care proxy law, the Task Force urged that existing New York laws prohibiting the taking of human life should not be modified and that euthanasia, understood as direct measures intended to cause a patient's death, should remain illegal. The Task Force recognized that euthanasia would provide a less painful, prolonged dying process for certain patients, but it concluded that compassion for these patients could not justify a change in public policy that would allow one human being intentionally to kill another.[41]

Since the Task Force issued that broad statement, national events have focused debate on the narrower question of physician-assisted suicide. In 1990 and 1991, Dr. Jack Kevorkian helped patients to die using suicide devices that he invented.[42] In the March 7,1991, issue of the *New England Journal of Medicine*, Dr. Timothy Quill described the case of Diane, a patient with leukemia who committed suicide using barbiturates prescribed by Dr. Quill. In August of that year, the New York State Board of Professional Medical Conduct decided not to refer Dr. Quill's case for misconduct charges. It distinguished Quill's actions from those of Kevorkian, stating that it "does not condone so-called assisted suicide, which remains a crime under New York law." The Board called upon the Task Force to examine the social and ethical issues posed when physicians assist a competent adult to commit

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The Task Force's full statement is found in ***Life-Sustaining Treatment***, 40-42. As proposed by the Task Force, the health care proxy law granted agents the same, but no greater, legal authority than that extended to competent adults, thereby incorporating existing legal prohibitions against assisted suicide and homicide into the proxy law. As enacted, the proxy law expressly states that it is not intended to permit or promote suicide, assisted suicide, or euthanasia. N.Y. Pub. Health Law § 2989(3) (McKinney Supp. 1992).

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L. Belkin, "Doctor Tells of First Death Using His Suicide Device," ***New York Times***, June 6, 1990, sec. A, p. 1; M. Williams, "Dr. Kevorkian's Future Without a License Is Uncertain," ***American Medical News,*** December 9, 1991, 9. In 1991, Washington State voters considered and defeated a referendum initiative that would have allowed physicians to provide "aid-in-dying" when requested by terminally ill patients. This provision would have legalized physician-assisted suicide as well as direct active euthanasia.

suicide, suggesting that both patients and physicians need guidance.[42] The Task Force has agreed to assume this charge and will address these issues in a future report.

The Task Force's recommendations in this report do not encompass decisions by adults with decision-making capacity, but decisions by others on behalf of those unable to decide. Few commentators have proposed that active measures such as a lethal injection should be used to end the life of a person without the capacity to make an informed request to have his or her life ended, although some have argued that honoring the requests of competent adults will extend inevitably to substitute consent for the incapacitated.

In proposing public policy for surrogate decisions, the Task Force affirms the position expressed in the health care proxy report; the Task Force does not recommend any change in current New York State law prohibiting active measures to cause a patient's death. It again distinguishes active measures such as lethal injection from legitimate, reasoned decisions to withdraw or withhold treatment made in accord with appropriate standards.

The Task Force's proposal addresses the need for policies to provide sound, responsible decisions for patients who cannot decide for themselves. It is not intended either as a step on the road to assisted suicide or as a vehicle to extend the authority of family members beyond the traditional boundaries established by consent to provide treatment or not to treat. The Task Force proposes that the legislation on surrogate decisions should, like the health care proxy law, state that the law is not intended to permit or promote euthanasia, assisted suicide, or suicide.

Recommendation

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

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[42]New York State, Board for Professional Medical Conduct, "Dr. Timothy Quill," August 16, 1991; T. E. Quill, "Death with Dignity: A Case of Individualized Decision-Making," *New England Journal of Medicine* 324 (1991): 691-94.

Health care professionals have a duty to offer aggressive 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 Ihsk Force urges health care professionals and facilities to accord pain control a higher priority in medical practice and education.

Decisions about artificial nutrition and hydration are highly sensitive, requiring caution and careful attention to the personal and medical circumstances of each particular patient. Surrogates should make special efforts to identify patients' wishes about artificial nutrition and hydration, but legislative provisions distinct from the policies proposed for other life-sustaining treatments are not necessary. The safeguards proposed for decisions about other life-sustaining treatments are appropriate and sufficient for decisions about artificial nutrition and hydration.

The Task Force's proposal responds to the need for policies that provide a sound, responsible decision-making process for patients who lack capacity. The proposed legislation is not intended to permit or promote suicide, assisted suicide, or euthanasia. Nor does the Task Force recommend any change in current New York State law that prohibits active measures to cause a patient's death.

See Appendix A, proposed legislation, Section 15(3).

16

Merging the DNR Law with Policies for Surrogate Decisions

The Task Force first approached the issue of surrogate decision making in the context of decisions about cardiopulmonary resuscitation (CPR) and the issuance of DNR orders. Based on recommendations by the Task Force, New York's DNR law was enacted in 1987 and amended in 1991.[1]

The Task Force addressed decisions about CPR apart from other treatment decisions because problems and confusion about the legality of DNR orders appeared to be widespread. Equally significant, a broader societal consensus existed about surrogate decisions for CPR than for other life-sustaining measures.[2]

The DNR law has achieved important goals. It granted surrogates clear authority to decide about CPR for incapacitated patients, removed the secrecy that had surrounded the decision about CPR in many hospitals and nursing homes, and reinforced the right of adult patients with decision-making capacity to decide for themselves. One ancillary but significant benefit of the law is that it has served as a testing ground for policies on surrogate decisions. The proposed surrogate decision-making legislation encompasses the basic principles and procedures established in the DNR law, with some modifications to accommodate the broad range of decisions covered and to reflect experience and insight gained from the DNR law.

The Task Force recommends that the DNR law should be integrated with the proposed legislation, with specific policies for DNR orders retained where appropriate. For the most part, separate policies for CPR and other treatments are not necessary. In addition, the existence

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1 N.Y. Pub. Health Law Article 29-B (McKinney Supp. 1992).

2 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), 6-8; T. E. Miller, "Do-Not-Resucitate Orders: Public Policy and Patient Autonomy," *Law, Medicine and Health Care* 17 (1989): 245-54.

of two laws and sets of policies would be unworkable for health care professionals.

In the clinical setting, decisions about CPR are best made in the context of an overall plan about the course of the patient's care. The patient's wishes and needs for CPR should be explored in relation to other treatments. Combining CPR decisions with discussions about other treatment is also likely to minimize misunderstandings and the tendency to equate a DNR order with an order "not to treat."

Building on the DNR Law

Many of the basic policies in the surrogate proposal are drawn from New York's DNR law: the list of surrogate decision makers, reliance on the patient's wishes and interests to guide surrogate decisions, and the establishment of a facility-based determination of patient incapacity, subject to judicial review when necessary. The standard for incapacity, like the standard in the health care proxy law, potentially addresses the capacity for all treatment decisions, not just decisions about CPR. A definition of "best interests" has been added to provide further guidance for surrogates and health care professionals.

The conditions under which surrogates may decline life-sustaining treatment are more rigorous under this proposal than under the DNR law, to reflect and address the broad scope of treatments covered by the proposal. In addition to the mediation process established under the DNR law to resolve conflict, this proposal recommends a more formal committee structure authorized to review decisions under specified circumstances.

The Task Force proposes that certain policies in the DNR law should be retained for decisions about CPR, but should not be extended to other treatment decisions. Specifically, the Task Force recommends that the therapeutic exception should apply to decisions for CPR but not to decisions about other life-sustaining treatment. Under the DNR law, physicians may seek consent to a DNR order from a surrogate even if the patient has the capacity to decide, if two physicians determine that discussing CPR with the patient would cause therapeutic harm, defined in the law as "severe and immediate" injury.[3] Inclusion of the exception in the DNR law was the subject of considerable debate within the Task Force and by the public at large.[4]

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N.Y. Pub. Health Law § 2964(3) (McKinney Supp. 1992).

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Task Force, 26-27, 66-68. Sec also C. Rogers, Testimony on behalf of Medical

Since the law has become effective, some physicians have urged that it should contain a broad therapeutic exception because the discussion of CPR can be traumatic for some patients.[5] The Task Force rejected this proposal in considering amendments to the DNR law and continues to believe that broadening the exception is unwise. Studies have consistently shown that many patients are eager to discuss CPR, while many physicians often opt not to do so.[6] Given the reluctance of physicians to discuss CPR with their patients, an expansive therapeutic exception would seriously diminish the right and opportunity for patients to participate in decisions about CPR.

Although narrowly drawn, the therapeutic exception in the DNR law should not apply to other life-sustaining treatments. Consent to a DNR order entails an advance decision that will be relevant only if an intervening event arises — the patient suffers cardiopulmonary arrest. In contrast, for other life-sustaining treatments, the withholding of treatment is contemporaneous, not future oriented, and the harm of withdrawing or withholding treatment is immediate. The Task Force believes that the potential harm caused by excluding the patient from the decision-making process would in virtually all cases outweigh the potential harm of a discussion.

In discussing the issue of medical futility in this report, the Task Force also underscored the importance of the patient-physidan dialogue. Guidelines on the DNR law from the Health Department clarify that physicians are not obligated to provide medically futile CPR, but they must inform patients, the health care agent, or a surrogate before entering an order on grounds of futility.[7] The Task Force recommends that this requirement of informing patients, agents, or surrogates should remain explicit for DNR orders, either in legislation, regulation, or guidance from the department.

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[5] F. Rosner, "Must We Always Offer the Option of CPR: The Law in New York," *Journal of the American Medical Association* 260: (1988): 3129; P. Swender, "Reflections on the New York DNR Law," *New York State Journal of Medicine* 89 (1989): 57-58.

[6] See chapter 1,8-9, for discussion of studies.

[7] New York State Department of Health, Medical Society of the State of New York, and Hospital Association of New York State, *Do Not Resuscitate Orders: Questions and Answers for Health Care Professionals* (Albany: New York State Department of Health, 1990), 20.

Based on recommendations by the Task Force and the Department of Health, the legislature amended the DNR law in 1991 to establish policies for honoring DNR orders for patients cared for at home or in other community settings.[8] The law requires emergency medical services (EMS) personnel to honor DNR orders issued by physicians based on consent by the patient, an appointed health care agent, or a surrogate identified under the provisions of the DNR law. The policies were devised in response to concerns expressed by physicians, patient advocates, and EMS representatives that existing laws and practices did not adequately protect decisions to withhold CPR for terminally ill patients cared for in the community.

The problems posed by other treatment decisions in outpatient settings appear less urgent, in part because CPR is one of the more common, and most invasive, life-saving treatments provided by EMS. The Task Force proposes that policies for DNR orders in community settings should be retained, but should not encompass other treatments. Reliance on advance decisions in an emergency, and the process of surrogate decision making, are more complex and more varied for patients in the community than in a health care facility. The Task Force recommends that New York State, as it did with DNR orders, should implement surrogate decision-making policies in health care facilities first and then turn to identified problems for patients at home and in other community settings.

New York's DNR law also covers decisions in certain mental health facilities. As discussed in Chapter 11, the Task Force recognizes the special issues raised by surrogate decisions in these facilities and the considerable body of statutes and regulations that currently governs many surrogate decisions for residents of mental health facilities. It proposes that the DNR law should continue to apply to these facilities, until such time as comprehensive surrogate policies for mental health facilities are enacted.

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[8] N.Y. Pub. Health Law § 2977 (McKinney Supp. 1992). These policies cover CPR decisions for patients in a wide variety of settings including, for example, individuals living at home, with or without home care support, those living in a group home, and prisoners.

Recommendation

The DNR law should be merged with broader surrogate decision-making legislation, with specific policies retained for DNR orders where appropriate. Specifically, the therapeutic exception to consent to forgo treatment, the duty to inform patients or surrogates of a DNR order entered on grounds of futility, and policies for patients in community settings should be retained for DNR orders, but should not be extended to other treatment decisions.

See Appendix B, Policies for DNR Orders: Existing Law.

17

Promoting Surrogate Decisions

While some aspects of the law governing life-sustaining treatment remain unclear or undeveloped in New York State, judicial decisions, statutes, and regulations have accorded patients, and those authorized to decide for them, certain basic rights.[1] The impact of these rights is undermined when health care providers misunderstand or misconstrue the laws governing treatment decisions. In addition to complying with ethical and professional standards for good medical practice, providers owe a duty to patients and surrogates to understand and abide by the law.

Bridging the Gap Between Theory and Practice

Educating Health Care Professionals

Confusion about the law on treatment decisions appears to be widespread among health care professionals in New York State. A1990 study assessing New York's law governing DNR orders revealed that two years after the law's passage, a significant percentage of physicians misunderstood some of the law's basic requirements.[2] Important common law principles are also not well understood. For example, many health care professionals believe that New York law establishes a right to withhold life-sustaining treatment, such as an artificial respirator, but not the right to have treatment stopped once it has begun, a right clearly recognized by judicial decisions.[3]

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[1] See discussion, chapter 2.

[2] Baker et al., "Legal and Professional Enforcement of Bioethical Reform: A Comparative Study of the 1988 NY and JCAHO DNR Reforms," in ***Legislating Medical Ethics: A Study of New York's DNR Law,*** ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers, forthcoming).

[3] See discussion, chapter 2.

A broad educational effort is essential to clarify misconceptions about the law on treatment decisions and the legal obligations and protections afforded health care professionals, The Task Force urges health care lawyers and administrators to create a process by which medical professionals can be educated and advised on a regular basis about the law on decisions about life-sustaining treatment and health care more generally. In addition, associations representing health care facilities and professionals, as well as patient advocacy groups, should continue their support for this educational effort.

Health care organizations have already undertaken cooperative educational efforts, as evidenced by recent publications describing New York's health care proxy and DNR laws.[4] New federal and state mandates have also prompted public and professional education about the rights of patients and families to make health care decisions.[5] Future educational initiatives should build on past efforts and seek new avenues to inform physicians about the laws that are critical to them and to their patients.[6]

Available Remedies

Health care professionals and facilities are understandably cautious in framing policies and responding to individual decisions about life- sustaining treatment. In addition, some legal doctrines such as the requirement of clear and convincing evidence of a patient's wishes call for hard judgments. It appears, however, that some physicians and facilities do not struggle to apply the law in good faith, but allow concerns about liability to preclude a reasonable or informed legal judgment. This undue caution penalizes patients and those deciding on their behalf.

For some physicians, risk managers, and hospital lawyers, the assessment of

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[4] For example, the 1991 guidebook on the health care proxy law was prepared by the New York State Department of Health and the Task Force, in consultation with the Association of the Bar of the City of New York, the Greater New York Hospital Association, the Hospital Association of New York State, the Medical Society of the State of New York, the New York Academy of Medicine, and the New York State Nurses Association.

[5] See, e.g., the Patient Self-Determination Act of 1990, §§ 4206 arid 4751 of the Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, codified at 42 U.S.C. §§ 1395cc(f), 1396a(a)(57), 1396a(a)(58), and 1396a(w)(l), requiring Medicare and Medicaid providers to educate patients and th?ir families, staff, and the community about advance directives; and N.Y. Pub. Health Law § 2992 (McKinney Supp. 1992), requiring hospitals and nursing homes to educate patients and their families and staff about New York's health care proxy law.

[6] Professional organizations such as the Hospital Association of New York State hold regular educational conferences for their members. In general, these conferences are well attended by social workers, nurses, and administrators, but rarely attended by physicians. While studies of the DNR law suggest that other hospital staff, especially nurses, may prod physicians to comply with the law, including the duty to honor patients' decisions about treatment, lack of understanding or ignorance of the law by physicians imposes obvious burdens on patients.

potential liability for honoring decisions to forgo life-sustaining treatment is one-sided; not only is the risk of liability for stopping treatment exaggerated, but the logical corollary in the equation, the risk of providing treatment without consent or in the face of an explicit refusal, appears to carry little, if any, weight.[7]

If treatment is provided without consent or following an explicit refusal, patients or those authorized to decide on their behalf may seek judicial redress for medical battery or for the violation of informed consent requirements or the constitutionally-based right to refuse medical treatment. Health care providers found liable may lose the right to collect a fee for the medical services rendered without consent,[8] may pay monetary damages,[9] or may be held responsible for attorneys' fees. Under Section 2801-d of the Public Health Law, residents of

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[7] See R. Weir and L. Gostin, "Decisions to Abate Life-Sustaining Treatment for Nonautonomous Patients: Ethical Standards and Legal Liability for Physicians after Cruzan," *Journal of the American Medical Association* 264 (1991): 1846, 1847, 1852, arguing (1852) that the perception of risk felt by providers for decisions to forgo life-sustaining treatment is ungrounded in existing judicial precedents. See also, e.g., M. Kapp and B. Lo, "Legal Perceptions and Medical Decision Making," *MiUbank Quarterly* 64 (1986): 163, 179. The authors observe, "[M]any attorneys and risk managers who advise medical professionals and institutions in life-sustaining situations err greatly on the side of legal conservatism, to the point where their caution in seeking absolute legal immunity before any action is taken wastes time, energy, and emotion in a way that is a disservice to both the client and affected patients and families."

[8] Existing law establishes that competent patients have no obligation to pay for treatment provided over their express objection. See *Shapira* v. *United Medical Service, Inc.* 15 N.Y.2d 200,257 N.Y.S.2d 150 (1965). This same principle applies to the refusal of treatment by a health care agent that meets the standards of the health care proxy law. See N.Y. Pub. Health Law §§ 2982(1) and 2987. In *Grace Plaza of Great Neck, Inc. v. Elbaum,* N.Y.LJ., Jan. 19,1990, at 26 (Sup. Ct., Nassau Co.), the trial court ruled that a nursing home could not collect fees of over $100,000 after providing life-sustaining treatment to a permanently unconscious patient over the objections of her husband that providing treatment would violate her clearly expressed wish. The nursing home appealed the ruling, arguing, in part, that the le^l remedy of nonpayment should not apply because of the uncertainty of existing law on decisions to forgo treatment for incapacitated patients.

[9] In two reported cases concerning the right to refuse life-sustaining treatment, the courts approved monetary settlements: In re A.C., 573 A.2d 1235 (D.C. App. 1990) and *Leach v. Shapiro,* 13 Ohio App. 3d 393,4% N.E.2d 1047 (Ct. App. 1984).

nursing homes may collect statutory damages,[9] as well as punitive damages and attorneys' fees, when appropriate, for violation of their rights.

Nonetheless, patients or their family members rarely sue to enforce the right to refuse treatment.[43] It is possible that they are unaware of their rights or are too exhausted or emotionally drained by the patient's illness to pursue judicial relief. Generally, patients and surrogates also have limited access to the financial resources required for legal redress. Thus far, refusal of treatment cases have not generated large monetary outcomes in the form of damages or attorneys' fees.[44] As a result, few lawyers may be willing to take similar cases on a contingency-fee basis. Persons of moderate or low income, who depend upon such arrangements to gain access to the courts, cannot seek judicial intervention unless they find an attorney willing to take their case on a ***pro bono*** or reduced-fee basis.

The Task Force believes that the unlawful refusal to honor a decision to forgo life-sustaining treatment is a serious harm. Whether brought as a battery action or as a violation of the constitutional right to refuse treatment, the harm to the patient should be assessed not only in terms of physical injury, but as a violation of the patient's dignity and person.

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[9] In two reported cases concerning the right to refuse life-sustaining treatment, the courts approved monetary settlements: In re A.C., 573 A.2d 1235 (D.C. App. 1990) and *Leach v. Shapiro,* 13 Ohio App. 3d 393,4% N.E.2d 1047 (Ct. App. 1984).

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In at least three cases to date the courts have awarded attorneys' fees to patients who sued to enforce their right to refuse life-sustaining treatment**.** *Bouvia v. Glenchur,* 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (1987); *Hoffmeister v. Coler,* 544 So. 2d 1067 (Fla. D.C. App. 1989); *Gray* **v.** *Romeo,* 709 F. Supp. 325 (D.R.1.1989).

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See, for example, National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Treatment,* 13 (1991), presenting data from a survey of state court judges indicating how rarefy courts decide these cases. The low percentage of suits indicates little about the extent of the injury or harm. Indeed, it may say far more about the lack of accessible remedies. For example, the 1990 Harvard Medical Practice Study estimated that 8 times as many patients suffered an injury from negligence as filed a malpractice claim, and about 16 times as many patients suffered an injury from negligence as received compensation from the tort liability system. "Patients, Doctors, and Lawyers: Medical Injury, Malpractice Litigation, and Patient Compensation in New York," Report of the Harvard Medical Practice Study to the State of New York, 1990,6.

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It appears that no reported case nationwide has resulted in monetary damages awarded after final judgment. Notes 9 and 10, above, indicate how few cases have resulted in monetary settlements or the award of attorneys' fees.

The Task Force deliberated about the possibility of specifying statutory damages or making the remedies under Section 2801-d of the Public Health Law available for hospital patients, as well as nursing home residents. Some of the members believe that replacing the clear and convincing evidence standard with policies allowing surrogate decisions under different standards, as proposed in the legislation, would address the underlying problem.[13] Others suggested that initial implementation of the legislation will necessarily entail an adjustment and some uncertainty on the part of providers about their obligations. Overall, however, many of the Task Force members remain concerned that patients and those close to them should not be left helpless when physicians or facilities unlawfully refuse to respect their rights.[14]

The Task Force members did *not* reach a resolution on the question of statutory remedies or damages for this harm. They agree, however, that as a matter of equity, any physician or health care facility that unlawfully refuses to honor an explicit request to withhold or withdraw treatment should not be entitled to compensation for the treatment provided in violation of the patient's right or the authorized decision of a health care agent or surrogate. Existing case law recognizes this principle for decisions by a patient.[15] The Task Force proposes that the legislation on surrogate decisions should provide that any physician or

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[13] In *Elbaum,* discussed above at note 8, the Grace Place nursing home asserted that its refusal to honor Murray Elbaum's decision on behalf of his wife was appropriate in light of the uncertainty of existing law and the difficulties of applying the clear and convincing evidence standard. Reply Brief for Plantiff-Appellant at 16-26, *Grace Plaza of Great Neck, Inc. v. Elbaum,* No. 90-01888 (N.Y. App. Div., 2d Dep't, dated Aug. 13, 1990). The proposed legislation would eliminate the clear and convincing evidence standard and drastically reduce legal uncertainty, although it would still require health care providers to exercise professional judgment in applying the standards set forth in the law.

[14] The fact that patients or their families can seek injunctive or other judicial relief offers little comfort for the vast majority of individuals. As argued by organizations that submitted an amicus brief in *Elbaum,* "Patients typically lack the physical capacity and they and their families typically lack the emotional and financial resources required to obtain court approval for what should be a self-executing right." Brief of Proposed Amici the Coalition of Institutionalized Aged and Disabled, Inc., Friends and Relatives of Institutionalized Aged, Inc., and the Nursing Home Community Coalition of New York State at 8-9, *Grace Plaza of Great Neck, Inc.* **v.** *Elbaum,* No. 90-01888 (N.Y. App. Div., 2d Dep't, dated July 18,1990).

[15] See note 8.

facility that refuses to honor a surrogate's decision that accords with the standards of the legislation should not be entitled to compensation for treatment provided in violation of the statute. Consistent with the terms of the proposed legislation, health care providers may exercise a conscience objection to treatment decisions, challenge the surrogate's decision under standards set forth in the proposed legislation, and rely on procedures such as dispute mediation. But a physician or hospital that refuses to honor an authorized decision, not the patient or family member responsible for the patient's medical bills, should bear the financial burden of the provider's failure to comply with the decision-making process and standards in the statute. This relief should be available in addition to the remedies under existing law, including injunctive relief, damages for battery, and administrative penalties.

The actual cases that rely upon this remedy may be few. Many people are intimidated by the prospect of a judicial action and will simply not have the resources either to bring a suit against a physician or health care facility or to defend themselves in an action for nonpayment of medical bills. But explicit recognition of the remedy alone will prompt some physicians and facilities to weigh more carefully the consequences of treating a patient if the patient or a legally authorized representative expressly refuses treatment. In this regard, the proposed policy will lead to judgments that are more balanced, benefiting the patients and those close to them who lack the resources to pursue and preserve their rights.

Recommendation

Any physician or health care facility that refuses to honor a surrogate decision authorized by the proposed legislation should not be entitled to compensation for treatment provided in violation of the standards and decision-making process of the legislation. This remedy should not limit other rights or remedies under existing law, including administrative remedies.

See Appendix A, legislative proposal, Section 17.

Conclusion

Upon completing the proposal for health care proxy legislation in 1987, we began our deliberations on surrogate decisions. We recognized at the outset that patients without decision-making capacity who did not or could not leave advance guidance of their wishes present society with profound social and ethical questions. We also understood that any policies proposed would touch the lives of most New Yorkers. Virtually all of us, as a parent, spouse, sibling, or friend, will be called upon to act as surrogate for someone close to us or will have decisions made on our behalf.

The United States Supreme Court, in the case of Nancy Cruzan, affirmed that each state has the responsibility to fashion policies for surrogate decisions. Those policies must foster the wishes and interests of incapacitated patients. They must make it possible for family members and others close to the patient to decide about treatment in a way that expresses their caring, their compassion, and their affirmation of the values and life the patient chose for himself or herself. Public policy should also promote sound decisions for patients who have no natural surrogate to decide on their behalf.

The Task Force believes that the proposed legislation will achieve these goals. The legislation will also respond to the legal vacuum that surrounds many surrogate decisions today. Legal hurdles now deny some patients ready access to treatment. For others, treatment is determined by what is technologically possible, rather than by a judgment of what is humanly and medically desirable. Society should fulfill its responsibility to these individuals, and to those standing at their bedside.

Minority Report

J. David Bleich

The report of the Task Force and its proposals for legislation governing health care decision-making address two entirely distinct issues, each of which is deserving of examination, analysis and debate on its own merits. Linkage of the two can only lead to obfuscation of the issues and dereliction in candid confrontation of moral concerns.

The law, as it presently stands, does not permit a physician to treat a patient without the patient's consent. Next of kin have no formal standing to grant consent — or to withhold consent — even if the patient lacks decision-making capacity. Although, in theory, a physician has no right to treat without consent of the patient, in practice, this requirement does not serve to bar treatment of patients lacking decision-making capacity since, in cases of emergency or serious illness, the law presumes that, were the patient capable of giving consent, he or she would do so. Thus, in practice, such patients do receive treatment.

Since, in such circumstances, the consent of the patient is presumed as a matter of law, consent of next of kin is not required. Many, and probably most, physicians are under the impression that consent of next of kin is required, at least in situations in which next of kin are available, and hence, as a matter of practice, they seldom make treatment decisions without such consent. Although not legally required, it is probably prudent for physicians to seek such consent since, arguably, under estoppel doctrine next of kin who grant consent are effectively precluded from later claiming that the physician acted improperly. Formal establishment of authority to provide routine medical treatment in non-life-threatening situations is certainly a legal ***desideratum***. Yet the Task Force recognizes that "[i]n practice, family members have long been accorded the right to consent to treatment" (Part II, Chapter Six). Thus the Task Force's justificatory statement in the preface to its report claiming that "existing law presents a hurdle for some patients in gaining access to needed treatment" and that "[individuals without family available to consent to treatment are especially vulnerable" by its own admission must be taken ***cum grano satis.***

This is not to say that problems do not exist. They do. They are more likely to arise, not in the context of a decision to treat or not to treat, but in the context of how to treat when a choice between different treatments is available. Consider the case of a patient lacking decision making capacity afflicted with a malignant tumor. The tumor can be removed surgically, or it can be treated by means of chemotherapy or radiation. Since the condition is life-threatening, even under current law, the physician may treat the patient despite the absence of consent and, presumably, he may choose the mode of therapy as well. Although few physicians would make such a choice without consultation with, and the consent of, next of kin, much can be said for making such a procedure a legal requirement. Yet, doing so generates still another problem. What shall the physician do when members of the same surrogate class disagree? What shall the physician do when one child demands surgical excision while the other insists upon chemotherapy? Although Solomonic wisdom may be required to solve such dilemmas it is somewhat strange that the report of the Task Force does not explicitly address the issue of dispute resolution with regard to choice of treatment.

This lacuna is symptomatic of the fact that the real concern of the Task Force is not surrogate decision-making in the treatment of incompetent patients but the entirely different issue of surrogate decision-making regarding withholding of treatment and termination of life-support systems.

During recent years, there has been a steady, linear progression in the erosion of the value associated with preservation of human life in the mores of our society. There was a time when whether or not withholding nonhazardous treatment by a physician at the request of a patient would constitute manslaughter was a matter of serious consideration by legal scholars. Today, not only would the very suggestion be dismissed out of hand but the converse has become the accepted legal norm, The physician dares not preserve the life of his patient against the latter’s wishes. Upon acceptance of the view that a patient can refuse even nonhazardous life-preserving therapy, attention focused upon withholding of artificial hydration and nutrition. Judicial decisions then established that refusal of artificial nutrition and hydration is to be equated with refusal of medical treatment and medical personnel who comply with such directives are not to be regarded as assisting in the patient's suicide. Legislation recommended by the Task Force has been enacted making it possible for such decisions to be made not only by the patient himself but also by an agent designated by the patient. The present recommendation would not only enable a person specifically designated by the patient and explicitly charged with that responsibility to make a decision to allow the patient to die, but would, by operation of law, automatically grant such power to a surrogate in situations in which the patient cannot himself or herself make such decisions.

This recommendation marks a new ideological departure from previously accepted moral principles. In expressing earlier adopted moral positions, society was well aware of an often existing tension between two conflicting moral values, preservation of life and respect for personal autonomy. In retaining a prohibition against attempted suicide or assisting a suicide, society — at least for the present — continues to accord precedence to preservation of life over personal autonomy or "the right to die," at least in non-medical contexts. Acceptance of a patient's right to demand passive euthanasia does not deny the value of preservation of human life but instead reorders priorities in assigning precedence to patient autonomy. Granting the patient the right to delegate such decisions to a health-care proxy, it might be argued, is merely an extension of the exercise of individual autonomy. It is the patient who designates the health-care proxy and empowers the agent to authorize withholding or withdrawal of treatment. That the act of the agent is the act of the principal is well-established as a legal principle in other areas of human endeavor. It may be argued with some cogency that refusal to permit such delegation of authority would itself be a constraint upon a person's free choice to designate an agent.

Provision for surrogate decision-making by operation of law, rather than by designation of the patient, is not a victory of individual liberty over preservation of life. In the absence of the expressed or otherwise known desire of the patient there exists no conflict between two competing values, each of which is independently entitled to respect and protection. Permitting a surrogate to refuse life-sustaining treatment without the patient's authorization constitutes stark abnegation of preservation of life as a value in and of itself. The proposed limitations upon the powers of the surrogate are predicated upon quality of life considerations and clearly assume that not every human life is possessed of intrinsic value. Adoption of these proposals would constitute far more than a reordering of priorities; it would signify a renunciation of hitherto accepted values.

The gravity of this step dare not be minimized. There may be room for debate with regard to whether human life constitutes an absolute value or whether its acceptance as a value is to be qualified by a ***ceteris paribus*** clause. But, if so, one should be prepared to spell out in precise detail the conditions and circumstances in which life need not be preserved. In effect, such an exercise serves to establish values that may be granted precedence over preservation of life. A benefit-burden or best interests test falls short of doing so unless it spells out clearly and precisely what is to be recognized as a countervailing burden or as an adverse interest. Even among those willing to accept such a test in principle, there will assuredly be disagreement with regard to precisely which factors may be considered in subordination of human life. The present recommendations give the surrogate full decision-making powers and hence, in effect, permit him to assign zero value to human life in balancing preservation of life against other considerations.

It is readily acknowledged that these recommendations are limited to decisions made by a surrogate on behalf of a terminally ill patient, defined as a patient who is presumed to have a maximum longevity anticipation of six months, or on behalf of a patient judged to be permanently unconscious. Translated into value terms, the Task Force recommendations render virtually nugatory the moral significance of all but the final six months of the life of a patient incompetent with regard to independent decision-making. But there is nothing sacrosanct with regard to that time frame. Six months may readily be expanded to one year, two years or ten. After all, life itself is a terminal condition. Similarly, the Task Force's recommendations render nugatory the moral significance of the life of a permanently unconscious patient. Moreover, the distinction between the moral significance of the life of a permanently unconscious person and a person who is permanently insane is far from clear. If decisions to permit passive euthanasia may be made by a surrogate on behalf of the permanently unconscious, why may such decisions not be made on behalf of persons deemed to be permanently demented? Once it is accepted that life per se is no longer a transcendental value, may society not dispense with the surrogate and his services and determine by operation of law that life-sustaining treatment be withdrawn from any permanently unconscious or terminally ill patient incapable of independent decision-making or even from a non-terminally ill mentally incompetent person?

In an earlier minority report I wrote: "I fully concur in the recommendation that competent patients be accorded the opportunity to designate an agent for purposes of making health-care decisions — so long as the proxy is designed to be only for the purpose of achieving a therapeutic result." I also fully concur in the recommendation that provisions be made for designation of a surrogate for purposes of making health-care decisions on behalf of incompetent patients — so long as the surrogate's decision-making authority is designed to be exercised for the purpose of preservation of life.

Designation of a surrogate is justifiable only for the purpose of weighing the pros and cons of alternatively available therapies or of weighing the risk-benefit factors inherent in a proposed treatment. Such decisions are predicated upon one prior assumption: the desired goal is cure or, *de minimis*, maximum prolongation of life. The decision itself is simply with regard to the means of achieving that end. Decisions for the withholding of potentially life-prolonging treatment are based upon an entirely different premise: they are designed to result in the patient's early demise.

Even in the extremely limited circumstances under which some ethicists might regard such a decision to be morally justified, it would be thoroughly unconscionable to sanction such a course of action without the patient's own fully informed consent. A decision to die is far too awesome a matter to be delegated to a proxy and certainly far too awesome a matter to be delegated to a self-appointed surrogate

Appendices

Appendix A

Proposed Legislation for Surrogate Decisions

Section

1. Definitions.

2. Priority of decision by health care agent; mental hygiene facility residents.

3. Determination of incapacity.

4. Health care decisions for adult patients by surrogates.

5. Decisions about life-sustaining treatment for minor patients.

6. Obligations of attending physician.

7. Health care decisions for adult patients without surrogates.

8. Revocation of consent.

9. Implementation and review of treatment decisions.

10. Interinstitutional transfers.

11. Bioethics review committees.

12. Conscience objections.

13. Immunity.

14. Liability for health care costs.

15. Effect on other rights.

16. Special proceeding authorized; court orders; health care guardian for minor patient.

17. Remedy.

18. Regulations.

19. Rights to be publicized.

§ 1. Definitions

The following words or phrases, used in this article, shall have the following meanings, unless the context otherwise requires:

1. ***Adult*** means any person who is 18 years of age or older or has married.

2. ***Attending physician*** means a physician, selected by or assigned to a patient, who has primary responsibility for the treatment and care of the patient. Where more than one physician shares such responsibility, or where a physician is acting on the attending physician's behalf, any such physician may act as an attending physician pursuant to this article.

3. ***Bioethics review committee*** means the interdisciplinary hospital committee established in accordance with the requirements of section 11 of this article.

4. ***Close friend*** means any person, 18 years of age or older, who presents a signed, written statement to an attending physician stating that he or she is a close friend of the patient and that he or she has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs, and stating the facts and circumstances that demonstrate such familiarity.

5. ***Close relative*** means any person, 18 years of age or older, who presents a signed, written statement to an attending physician stating that he or she is a relative of the patient and that he or she has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs, and stating the facts and circumstances that demonstrate such familiarity.

6. ***Decision-making capacity*** means the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of, and alternatives to, any such proposed health care, and to reach an informed decision.

7. ***Emancipated minor patient*** means a minor patient who is the parent of a child, or who is 16 years of age or older and living independently from his or her parents or guardian.

8. ***General hospital*** means a general hospital as defined in section 2801(10) of the public health law.

9. ***Guardian of a minor*** or ***guardian*** means a health care guardian or a legal guardian of the person of a minor.

10. ***Health care*** means any treatment, service, or procedure to diagnose or treat an individual's physical or mental condition.

11. ***Health care agent*** means a health care agent designated by an adult pursuant to article 29-C of the public health law.

12. ***Health care decision*** means any decision to consent or refuse to consent to health care.

13. ***Health care guardian*** means an individual appointed by a court, pursuant to section 16(3) of this article, as the guardian of a minor patient solely for the purpose of deciding about life-sustaining treatment pursuant to this article.

14. ***Health care provider*** means an individual or facility licensed, certified, or otherwise authorized or permitted by law to administer health care in the ordinary course of business or professional practice.

15. ***Hospital*** means a general hospital as defined in section 2801(10) of the public health law, and a residential health care facility as defined in section 2801(3) of the public health law.

16. ***Life-sustaining treatment*** means any medical treatment or procedure without which the patient will die within a relatively short time, as determined by an attending physician to a reasonable degree of medical certainty.

17. ***Major medical treatment*** means any treatment, service or procedure to diagnose or treat an individual's physical or mental condition: where a general anesthetic is used; or, which involves any significant risk; or which involves any significant invasion of bodily integrity requiring an incision, producing substantial pain, discomfort, debilitation or having a significant recovery period; or, which involves a significant period of chemical or physical restraint.

18. ***Metal hygiene facility*** means a residential facility operated or licensed by the office of mental health or the office of mental retardation and developmental disabilities.

19. ***Mental illness*** means a mental illness as defined in section 1.03(20) of the mental hygiene law, provided, however, that mental illness shall not include dementia, such as Alzheimer's disease, or other disorders related to dementia.

20. ***Minor*** means any person who is not an adult.

21. ***Parent,*** for the purpose of a health care decision about a minor patient, means a parent who has custody of, or who has maintained substantial and continuous contact with, the minor patient.

22. ***Patient*** means a person admitted to a hospital.

23. ***Person connected with the case*** means the patient, any person on the surrogate list, a parent or guardian of a minor patient, the hospital administrator, an attending physician, any other health care professional who is or has been directly involved in the patient's care, and any duly authorized state agency.

24. ***Reasonably available*** means that a person to be contacted can be contacted with diligent efforts by an attending physician, another person acting on behalf of an attending physician, or the hospital.

25. ***Residential health care facility*** means a residential health care facility as defined in section 2801(3) of the public health law.

26. ***Routine medical treatment*** means any treatment, service, or procedure to diagnose or treat an individual's physical or mental condition, such as the administration of medication, the extraction of bodily fluids for analysis, or dental care performed with a local anesthetic, for which health care providers ordinarily do not seek specific consent from the patient or authorized representative. It shall not include the long-term provision of treatment such as ventilator support or a nasogastric tube that would be deemed routine if used on a temporary basis.

27. ***Surrogate*** means the person selected to make a health care decision on behalf of a patient pursuant to section 4 of this article.

28. ***Surrogate list*** means the list set forth in section 4(1) of this article.

§ 2. Priority of decision by health care agent; mental hygiene facility residents

1. A health care decision by a health care agent on a patient's behalf is governed by article 29-C of the public health law and shall have priority over decisions by any other person except the patient or as otherwise provided in the health care proxy.

Health care providers shall make reasonable efforts to determine whether the patient has appointed a health care agent and to contact the agent before relying on a decision by a surrogate under this article.

2. This article shall not apply to residents of mental hygiene facilities, except for section 16(2) of tins article governing court orders for decisions about life-sustaining treatment

§ 3. Determination of Incapacity

1. **Presumption of capacity.** For purposes of this article, every adult shall be presumed to have decision-making capacity unless determined otherwise pursuant to this section, or pursuant to court order, or unless a committee of the person has been appointed for the adult pursuant to article 78 of the mental hygiene law.

2. **Determination by attending physician.** A determination that an adult patient lacks decision-making capacity shall be made by an attending physician to a reasonable degree of certainty. The determination shall be included in the patient's chart and shall contain the physician's opinion regarding the cause and nature of the patient's incapacity, as well as its extent and the likelihood that the patient will regain decision-making capacity.

3. **Concurring opinion.**

(a) At least one other health care professional must concur in the determination that an adult patient lacks decision-making capacity. Such concurring opinion shall also be included in the patient's chart. Hospitals shall adopt written policies identifying the training and credentials of health care professionals qualified to provide a concurring opinion of incapacity.

(b) If an attending physician determines that a patient lacks decision-making capacity because of mental illness or developmental disability, an attending physician who makes the determination must have, or must consult with a health care professional who has specialized training or experience in diagnosing or treating mental illness or developmental disabilities of the same or similar nature. A record of such consultation shall be included in the patient's chart.

4. **Informing the patient and surrogate**. Notice of a determination that the surrogate will make health care decisions because the adult patient has been determined to lack decision-making capacity shall promptly be given:

(a) to the patient, where there is any indication of the patient's ability to comprehend the information; and

(b) to at least one person on the surrogate list highest in order of priority listed, when persons in prior subparagraphs are not reasonably available.

The manner of notice to the patient shall be included in the patient's chart. Nothing in this subdivision shall preclude or re- quire notice to more than one person on the surrogate list.

5. **Limited purpose of determination.** A determination made pursuant to this section that an adult patient lacks decision-making capacity shall not be construed as a finding that the patient lacks capacity for any other purpose.

6. **Priority of patient's decision.** Notwithstanding a determination pursuant to this section that an adult patient lacks decision-making capacity, if the patient objects to the determination of incapacity, or to a health care decision made by a surrogate or made pursuant to section 7 of this article, the patient's objection or decision shall prevail unless a court of competent jurisdiction determines that the patient lacks decision-making capacity or the patient is or has been adjudged incompetent for all purposes.

7. **Confirmation of lack of decision-making capacity.**

(a) An attending physician shall confirm the adult patient's continued lack of decision-making capacity before complying with health care decisions made pursuant to this article, other than those decisions made at or about the time of the initial determination. A concurring opinion of the patient's continued lack of decision-making capacity shall be required if the subsequent health care decision concerns the withholding or withdrawal of life-sustaining treatment.

(b) Any confirmation of continued lack of decision-making capacity, and concurring opinion thereof, shall be included in the patient's chart. Health care providers shall not be required to inform the patient or surrogate of the confirmation.

§ 4. Health care decisions for adult patients by surrogates

1. **Identifying the surrogate.** One person from the following list, chosen from the class highest in priority when persons in prior classes are not reasonably available, willing, and competent to act, shall be the surrogate for an adult patient without decision-making capacity:

(a) a committee or guardian of the person appointed pursuant to article 78 of the mental hygiene law or article 17-A of the surrogate's court procedure act;

(b) an individual, 18 years of age or older, designated by others on the surrogate list, provided that no person on the surrogate list objects to the designation;

(c) the spouse, if not legally separated from the patient;

(d) a son or daughter 18 years of age or older;

(e) a parent;

(f) a brother or sister 18 years of age or older;

(g) a close friend or close relative 18 years of age or older.

2. **Restrictions on who may be a surrogate.** An operator, administrator, or employee of a hospital may not serve as the surrogate for any adult who is a patient of such hospital, unless such individual is related to the patient by blood, marriage, or adoption.

3. **Authority and duties of surrogate.**

(a) **Scope of surrogate's authority.**

(i) Subject to the standards and limitations of this article, the surrogate shall have the authority to make any and all health care decisions on the adult patient's behalf that the patient could make.

(ii) Nothing in this article shall obligate a physician to provide a treatment, service, or procedure at the request of a surrogate that the physician would have no duty to provide at the request of a patient with decisionmaking capacity.

(iii) Nothing in this article shall obligate health care providers to seek the consent of a surrogate if an adult patient has already made a decision about the proposed health care, expressed orally or in writing, including a decision about withdrawing or withholding life-sustaining treatment. If an attending physician relies on the patient's prior decision, the physician shall record the prior decision in the patient's chart.

(b) **Commencement of surrogate's authority.** The surrogate's authority shall commence upon a determination, made pursuant to section 3 of this article, that the adult patient lacks decision-making capacity. In the event an attending

physician determines that the patient has regained decision-making capacity, the authority of the surrogate shall cease, but shall recommence if the patient subsequently loses capacity as determined pursuant to section 3 of this article.

(c) **Right and duty to be informed.** Notwithstanding any law to the contrary, the surrogate shall have the right to receive medical information and medical and clinical records necessary to make informed decisions about the patient's health care. The surrogate shall seek information necessary to make an informed decision, including information about the patient's diagnosis, prognosis, the nature and consequences of proposed health care, and the benefits and risks of, and alternatives to, proposed health care.

4. **Decision-making standards.**

(a) **General standard.** The surrogate shall make health care decisions:

(i) in accordance with the patient's wishes, including the patient's religious and moral beliefs; or

(ii) if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the patient's best interests.

In either case, health care decisions shall reflect the values of the patient, including the patient's religious and moral beliefs, to the extent they are reasonably known or can with reasonable diligence be ascertained.

(b) **Assessment of best interests**. An assessment of the patient's best interests shall include consideration of the dignity and uniqueness of every person, the possibility and extent of preserving the patient's life, the preservation, improvement or restoration of the patient's health or functioning, the 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.

5. **Decisions to withhold or withdraw life-sustaining treatment**

(a) **Limited application of this subdivision.** This subdivision applies only to decisions to withhold or withdraw life-sustaining treatment. Nothing in this subdivision is intended to apply to other health care decisions for patients who lack decision-making capacity, including decisions about alternative treatments that are medically accepted therapies and

decisions about the course of routine or major medical treatment.

(b) **Standards for decisions.** A surrogate shall have the authority to decide to withhold or withdraw life-sustaining treatment, if the following two conditions are satisfied:

(i) Treatment would be an excessive burden to the patient in light of the standards set forth in subdivision (4) of this section. This determination shall be made on an individualized basis for each patient and shall include consideration of the patient's preferences, values, and personal circumstances, to the extent possible, as well as the likelihood that the patient will regain decisionmaking capacity.

(ii) At least one of the following circumstances is present:

(A) **Terminal condition.** An attending physician determines, with the concurrence of another physician, that, to a reasonable degree of medical certainty, the patient has an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within six months.

(B) **Permanent unconsciousness.** An attending physician determines, with the concurrence of another physician that, to a reasonable degree of medical certainty, the patient is permanently unconscious.

(C) **Physician determination and bioethics review committee approval.** An attending physician and the bioethics review committee determine that the surrogate's decision complies with the standards set forth in subdivision (4) of this section and sub- paragraph (i) of this paragraph, and the bioethics review committee approves the decision.

(D) **Judicial approval.** A court of competent jurisdiction issues an order approving the decision, pursuant to section 16(2) of this article.

(c) **Patient's chart.** Determinations made pursuant to paragraph (b) of this subdivision shall be recorded in the patient's chart.

(d) **Expression of decisions.** The surrogate shall express a decision to withdraw or withhold life-sustaining treatment either in writing, dated and signed in the presence of one

witness, 18 years of age or older, who must sign the decision; or orally to two persons, 18 years of age or older, one of whom is a physician affiliated with the hospital in which the patient is being treated. The decision shall be recorded in the patient's chart.

§ 5. Decisions about life-sustaining treatment for minor patients

1. **Authority of parent or guardian.** The parent or guardian of a minor patient shall have the authority to decide to withhold or withdraw life-sustaining treatment, subject to the provisions of this section and the standards for surrogate decisions for adults.

2. **Decision-making standards and procedures for minor patient.**

(a) An attending physician, in consultation with a minor's parent or guardian, shall determine whether a minor patient has decision-making capacity for a decision to withhold or withdraw life-sustaining treatment. If the minor has such capacity, the minor must consent to withhold or withdraw life-sustaining treatment for decisions pursuant to this section.

(b) Where an attending physician has reason to believe that a parent of a minor patient, including a noncustodial parent, has not been informed of a decision to withdraw or withhold life-sustaining treatment, an attending physician or someone acting on his or her behalf, shall make reasonable efforts to determine if the uninformed parent has maintained substantial and continuous contact with the minor and, if so, shall make diligent efforts to notify that parent prior to implementing the decision.

3. **Decision-making standards and procedures for emancipated minor patient.**

(a) If an attending physician determines that a patient is an emancipated minor patient with decision-making capacity, the patient shall have the authority to decide about life-sustaining treatment. Such authority shall include a decision to withhold or withdraw life-sustaining treatment if, prior to implementing the decision, an attending physician and the bioethics review committee determine that the decision accords with the standards for surrogate decisions for adults,

and the bioethics review committee approves the decision. Such determinations shall be recorded in the patient's chart.

(b) If the hospital can readily ascertain the identity of the parents or guardian of an emancipated minor patient, the hospital shall notify such persons prior to withholding or withdrawing life-sustaining treatment pursuant to this subdivision.

§ 6. Obligations of attending physician

1. An attending physician provided with or informed of a decision to withdraw or withhold life-sustaining treatment made pursuant to the standards of this article shall record the decision in the patient's chart, review the medical bases for the decision, and shall either: (a) implement the decision or (b) promptly make his or her objection to the decision and the reasons for the objection known to the decision-maker, and either make all reasonable efforts to arrange for the transfer of the patient to another physician, if necessary, or promptly refer the matter to the bioethics review committee.

2. If an attending physician has actual notice of the following objections or disagreements, he or she shall refer the matter to the bioethics review committee if the objection or disagreement cannot otherwise be resolved:

(a) any person on the surrogate list objects to a surrogate's decision; or

(b) a parent or guardian of a minor patient objects to the decision by another parent or guardian of the minor; or

(c) a minor patient refuses consent to life-sustaining treatment, or consents to the withholding or withdrawal of life-sustaining treatment, and the minor's parent or guardian wishes the treatment to be provided, or the minor patient objects to an attending physician's determination about decisionmaking capacity or recommendation about life-sustaining treatment.

§ 7. Health care decisions for adult patients without surrogates

1. Identifying adult patients without surrogates. Within a reasonable time after admission to the hospital of each adult patient, the hospital shall make reasonable efforts to determine if the

patient has appointed a health care agent or if at least one individual is available to serve as the patient's surrogate in the event the patient loses decision-making capacity. If no such potential surrogate is identified, the hospital shall identify, to the extent reasonably possible, the patient's wishes, preferences, and values about pending health care decisions, and shall make a written record of its findings.

2. Decision-making standards. Any health care decision made pursuant to this section shall be made in accordance with the standards for surrogate decisions for adults and shall not be based on the financial interests of the hospital or any other health care provider.

3. Routine medical treatment. If no surrogate is available, willing, and competent to act, an attending physician shall be authorized to decide about routine medical treatment for an adult patient who has been determined to lack decision-making capacity pursuant to section 3 of this article.

4. Major medical treatment. If no surrogate is available, willing, and competent to act, a decision to provide major medical treatment, made in accordance with the following requirements, shall be authorized for an adult patient who has been determined to lack decision-making capacity pursuant to section 3 this article:

(a) An attending physician shall make a recommendation in consultation with hospital staff directly responsible for the patient's care.

(b) Prior to implementing the recommendation in a general hospital, at least one other physician designated by the hospital must concur in the recommendation.

(c) Prior to implementing the recommendation in a residential health care facility, the medical director of the facility, or a physician designated by the medical director, must concur in the recommendation; provided that if the medical director is the patient's attending physician, a different physician designated by the residential health care facility must concur in the recommendation.

5. Decisions to withhold or withdraw life-sustaining treatment. If no surrogate is available, willing, and competent to act, a decision to withhold or withdraw life-sustaining treatment, made in accordance with the following requirements, shall be authorized for an adult patient who has been determined to lack decision-making capacity pursuant to section 3 of this article:

(a) An attending physician shall make a recommendation in consultation with hospital staff directly responsible for the patient's care.
(b) Prior to implementing the recommendation in a general hospital:
(i) at least one other physician designated by the hospital must concur in the recommendation;
(ii) the bioethics review committee must determine that the recommendation accords with the standards for surrogate decisions for adults and must approve the recommendation; and
(iii) if the patient has been transferred from a residential health care facility, before the bioethics review committee approves or disapproves the recommendation, a representative of the committee must make reasonable efforts to consult with staff from the facility who were directly responsible for the patient's care.
(c) Prior to implementing the recommendation in a residential health care facility:
(i) the medical director of the facility, or a physician designated by the medical director, must concur in the recommendation; provided that if the medical director is the patient's attending physician, a different physician designated by the residential health care facility must concur in the recommendation; and
(ii) the bioethics review committee must determine that the recommendation accords with the standards for surrogate decisions for adults and must approve the recommendation.

6. Health care without medical benefit. If no surrogate is available, willing, and competent to act for a patient determined to lack decision-making capacity pursuant to section 3 of this article, a decision to withhold or withdraw life-sustaining treatment shall be authorized if:
(a) an attending physician determines, in accordance with accepted medical standards and to a reasonable degree of medical certainty, that the patient will die within a short time period despite the provision of treatment and that treatment should be withdrawn or withheld; and

(b) one other physician selected by the hospital concurs in this determination.

7. Patient's chart; physician's obligations.

(a) Recommendations and determinations made pursuant to this section shall be recorded in the patient's chart.

(b) if the following disputes cannot otherwise be resolved, they shall be referred by an attending physician to the bioethics review committee:

(1) the concurring physician objects to an attending physician's recommendation or determination;

(ii) a member of the hospital staff directly responsible for the patient's care objects to an attending physician's recommendation.

§ 8. Revocation of consent

1. A patient, surrogate, or parent or guardian of a minor patient may at any time revoke his or her consent to withhold or withdraw life-sustaining treatment by notifying a physician or member of the nursing staff of the revocation.

2. Any physician informed of a revocation of consent made pursuant to this section shall immediately:

(a) record the revocation in the patient's chart;

(b) cancel any orders or plans of care implementing the decision to withhold or withdraw treatment; and

(c) notify the hospital staff directly responsible for the patient's care of the revocation and any cancellations.

3. Any member of the nursing staff informed of a revocation made pursuant to this section shall immediately notify a physician of the revocation.

§ 9. Implementation and review of decisions

1. Hospitals shall adopt written policies requiring implementation and regular review of decisions to withhold or withdraw life-sustaining treatment, in accordance with accepted medical standards.

2. If a decision to withhold or withdraw life-sustaining treatment has been made pursuant to this article, and an attending physician determines at any time that the decision is no longer appropriate or authorized because the patient has regained decision-making capacity or because the patient's condition has otherwise improved, the physician shall immediately:

(a) include such determination in the patient's chart;

(b) cancel any orders or plans of care implementing the decision to withhold or withdraw life-sustaining treatment;

(c) notify the person who made the decision to withhold or withdraw treatment; and

(d) notify the hospital staff directly responsible for the patient's care of any cancelled orders or plans of care.

§ 10. Interinstitutional transfers

1. If a patient with any order or plan of care to withhold or withdraw life-sustaining treatment is transferred from a hospital to a different hospital, any such order or plan shall remain effective until an attending physician first examines the transferred patient, whereupon an attending physician must either:

(a) issue appropriate orders to continue the prior order or plan. Such orders may be issued without obtaining another consent to withhold or withdraw life-sustaining treatment pursuant to this article; or

(b) cancel such order or plan and immediately notify the person who made the decision to withhold or withdraw treatment and the hospital staff directly responsible for the patient's care of any such cancellation.

§ 11. Bioethics review committees

1. **Establishment of a bioethics review committee; written policy.** Each hospital shall establish at least one bioethics review committee or participate in a bioethics review committee that serves more than one hospital, and shall adopt a written policy governing committee functions, composition, and procedure, in accordance with the requirements of this section.

2. **Functions of bioethics review committee.**

(a) The bioethics review committee shall consider any health care matter presented to it by a person connected with the case.

(b) The bioethics review committee response to a health care matter may include:

(i) providing advice on the ethical aspects of proposed health care;

(ii) making a recommendation about proposed health care; (ili) providing assistance in resolving disputes about

proposed health care; or

(iv) discussing a matter without making a recommendation.

(c) Recommendations and advice by the bioethics review committee shall be advisory and nonbinding, except for committee approvals or disapprovals of the withdrawal or withholding of life-sustaining treatment from an emancipated minor patient, from an adult patient without a surrogate, or from any patient who is neither terminally ill nor permanently unconscious.

(d) The bioethics review committee may undertake other functions, such as education and policy review and development, as authorized by the hospital or hospitals it serves.

(e) The bioethics review committee may review and approve or disapprove recommendations to withhold or withdraw particular treatments or recommendations about a patient's course of treatment.

3. **Composition of bioethics review committee.**

(a) The bioethics review committee shall consist of a minimum of five individuals. It shall include at least one physician, one registered nurse, one certified social worker or other person with training or expertise in providing psychosocial services to patients, one other individual with training or expertise in bioethics, moral philosophy or theology, and one individual who is not affiliated with the hospital.

(b) In addition to meeting the requirements of paragraph (a) of this subdivision, in a residential health care facility at least one committee member must be a member of the facility's residents' council; and at least one committee member must be a certified ombudsman with the New York State Long Term Care Ombudsman Program or a representative or member of a not-for-profit organization organized and operated to promote the interests or rights of the elderly or nursing home residents. Nothing in this paragraph shall require the bioethics review committee of a residential health care facility to consist of more than five individuals, so long

as the qualifications of the members satisfy the requirements of paragraphs (a) and (b) of this subdivision.

(c) The bioethics review committee may include other individuals as chosen by the hospital.

4. **Procedures for bioethics review committee.**

(a) A minimum of three bioethics review committee members, at least one of whom is a physician, must participate in the consideration of any matter presented to it by a person connected with the case, subject to the following exceptions:

(i) Any committee member may suffice for dispute mediation.

(ii) The consideration of withdrawing or withholding life-sustaining treatment from an emancipated minor patient, an adult patient without a surrogate, or any patient who is neither terminally ill nor permanently unconscious, shall require the participation of at least five committee members who meet the requirements of subdivision (3) of this section; and the proportion of committee members that constitute a quorum of the entire review committee. The hospital shall make reasonable efforts to notify all committee members of these pending cases.

(b) A person connected with the case may not participate as a bioethics review committee member in the consideration of that case.

(c) The bioethics review committee shall:

(i) establish the proportion of committee members that constitute a quorum of the entire committee;

(ii) respond promptly, as required by the circumstances, to any request for a case consideration made by a person

* connected with the case; and

(iii) permit persons connected with the case to present their views to the committee, and to have the option of being accompanied by an advisor when participating in a committee meeting.

(d) The bioethics review committee shall promptly provide the patient, where there is any indication of the patient's ability to comprehend the information, the surrogate, other persons on the surrogate list directly involved in the patient's care, any parent or guardian of a minor patient directly involved in the minor patient's care, an attending physician,

the hospital, and other persons the committee deems appropriate, with the following:

(i) notice of any pending case consideration concerning the patient, including for patients, persons on the surrogate list, parents and guardians information about the review committee's procedures, composition and function; and

(ii) the committee's response to the case, including a written statement of the reasons for approving or disapproving the withholding or withdrawal life-sustaining treatment from an emancipated minor patient, an adult patient without a surrogate, or any patient who is neither terminally ill nor permanently unconscious.

(e) Following bioethics review committee consideration of a case concerning the withdrawal or withholding of life-sustaining treatment, treatment shall not be withdrawn or withheld until the persons identified in paragraph (d) of this subdivision have been informed of the committee's response to the case.

(f) The bioethics review committee may act through subcommittees, use different members for different types of cases and functions, and seek the advice of consultants as necessary. Any subcommittee shall routinely report its activities to the entire committee.

(g) The written policy of the bioethics review committee shall contain procedures to implement the requirements of this subdivision.

5. **Access to medical records and information; patient confidentiality.** Bioethics review committee members and consultants shall have access to medical information and medical and clinical records necessary to perform their function under this article. Notwithstanding any other provision of this article, any such information or records disclosed to committee members, consultants, or others shall be kept confidential, except to the extent necessary to accomplish the purposes of this article or as otherwise provided by law.

6. **Bioethics review committee confidentiality.** Notwithstanding any other provisions of law, the proceedings and records of a bioethics review committee shall be kept confidential and shall not be released by committee members, committee consultants, or other persons privy to such proceedings and records; the proceedings and records of a bioethics review committee shall not be subject to disclosure or inspection in any manner, including under article 6 of the public officers law or article 31 of the civil practice law and rules; and, no person shall testify as to the proceedings or records of a bioethics review committee, nor shall such proceedings and records otherwise be admissible as evidence in any action or proceeding of any kind in any court or before any other tribunal, board, agency or person, except that:

(a) bioethics review committee proceedings and records, in cases where a committee approves or disapproves of the withholding or withdrawal of life-sustaining treatment from an emancipated minor patient, an adult patient without a surrogate, or any patient who is neither terminally ill nor permanently unconscious, shall be subject to review by the department of health; and

(b) nothing in this subdivision shall prohibit the patient, the surrogate, other persons on the surrogate list, or a parent or guardian of a minor patient from voluntarily disclosing, releasing or testifying about committee proceedings or records.

§ 12. Conscience objections

1. **Private hospitals.** Nothing in this article shall be construed to require a private hospital to honor a health care decision made pursuant to this article if:

(a) the decision is contrary to a formally adopted policy of the hospital that is expressly based on sincerely held religious beliefs or sincerely held moral convictions central to the facility's operating principles;

(b) the hospital has informed the patient, family, or surrogate of such policy prior to or upon admission, if reasonably possible; and

(c) the patient is transferred promptly to another hospital that is reasonably accessible under the circumstances and willing to honor the decision.

If the patient's family or surrogate is unable or unwilling to arrange such a transfer, the hospital may intervene to facilitate such a transfer. If such a transfer is not effected, the hospital shall seek judicial relief or honor the decision.

2. **Individual health care providers.** Nothing in this article shall be construed to require an individual as a health care provider to honor a health care decision made pursuant to this article if:

(a) the decision is contrary to the individual's sincerely held religious beliefs or sincerely held moral convictions; and

(b) the individual health care provider promptly informs the person who made the decision and the hospital of his or her refusal to honor the decision. In such event, the hospital shall promptly transfer responsibility for the patient to another individual health care provider willing to honor the decision. The individual health care provider shall cooperate in facilitating such transfer.

§ 13. Immunity

1. **Bioethics review committees**. No person shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for acts performed in good faith pursuant to this article as a member of or consultant to a bioethics review committee or a participant in a bioethics review committee meeting.

2. **Providers.** No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring in good faith a health care decision made pursuant to this article or for other actions taken in good faith pursuant to this article.

3. **Surrogates, parents and guardians.** No person shall be subjected to criminal or civil liability for making a health care decision in good faith pursuant to this article or for other actions taken in good faith pursuant to this article.

§ 14. Liability for health care costs

Liability for the cost of health care provided to an adult patient pursuant to this article shall be the same as if the health care were provided pursuant to the patient's decision.

§ 15. Effect on other rights

1. Nothing in this article creates, expands, diminishes, impairs, or supersedes any authority that an individual may have under law to make or express decisions, wishes, or instructions regarding

health care on his or her own behalf, including decisions about life-sustaining treatment.

2. Nothing in this article shall affect existing law concerning implied consent to health care in an emergency.

3. Nothing in this article is intended to permit or promote suicide, assisted suicide, or euthanasia.

§ 16. Special proceeding authorized; court orders; health care guardian for minor patient

1. **Special proceeding.** Any person connected with the case and any member of the hospital bioethics review committee may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this article.

2. **Court orders to withhold or withdraw life-sustaining treatment**. A court of competent jurisdiction may authorize the withholding or withdrawal of life-sustaining treatment from a person if the court determines that the person lacks decision-making capacity, and withdrawing or withholding the treatment would accord with the standards set forth in section 4(4) of this article.

3. **Health care guardian for a minor patient**

(a) The following persons may commence a special proceeding in a court of competent jurisdiction to seek appointment as the health care guardian of a minor patient solely for the purpose of deciding about life-sustaining treatment pursuant to this article:

(i) the hospital administrator;

(ii) an attending physician;

(iii) the local commissioner of social services or the local commissioner of health, authorized to make medical treatment decisions for the minor pursuant to section 383-b of the social services law; or

(iv) an individual, 18 years of age or older, who has assumed care of the minor for a substantial and continuous period of time.

(b) Notice of the proceeding shall be given to the persons identified in section 1705 of the surrogate's court procedure act.

(c) No appointment shall be made pursuant to this subdivision if a parent or legal guardian of the person is available, willing, and competent to decide about treatment for the minor.

(d) Notwithstanding any other provision of law, seeking appointment or being appointed as a health care guardian shall not otherwise affect die legal status or rights of the individual seeking or obtaining such appointment.

§ 17. Remedy

1. Any hospital or attending physician that refuses to honor a health care decision made by a person authorized to make such decision pursuant to this article shall not be entitled to compensation for treatment, services, or procedures provided in violation of this article.

2. The remedy provided in this section is in addition to and cumulative with any other remedies available at law or in equity or by administrative proceedings to a patient, a health care agent appointed pursuant to article 29-C of the public health law, or a person authorized to make health care decisions pursuant to this article, including injunctive and declaratory relief, and any other provisions of the public health law governing fines, penalties, or forfeitures.

§ 18. Regulations

1. The commissioner of health shall establish such regulations as may be necessary to implement this article.

2. The commissioner of health, in consultation with the commissioners of the office of mental health and the office of mental retardation and developmental disabilities, shall promulgate regulations identifying the credentials of health care professionals qualified to provide a concurring opinion, pursuant to section 3(3) of this article, that a patient lacks decision-making capacity because of mental illness or developmental disability.

§ 19. Rights to be publicized

1. The commissioner of health shall prepare a statement summarizing the rights, duties, and requirements of this article and shall require that a copy of such statement be furnished to patients, or to persons on the surrogate list known to the hospital, or to the parents or guardians of minor patients, at or prior to admission to a hospital, or within a reasonable time thereafter, and to each member of the hospital's staff.

Appendix B

Policies for DNR Orders: Existing Law

The Task Force recommends that the basic policies of Article 29-B of the New York Public Health Law, governing orders not to resuscitate (DNR orders), should be merged with its legislative proposal for surrogate decisions. However, certain policies specific to decisions about cardiopulmonary resuscitation (CPR) should still be contained in legislation or New York State Department of Health regulation. This appendix sets forth these provisions from Article 29-B. Chapter 16 discusses the Task Force's recommendations for integrating Article 29-B with the proposed legislation.

Definitions

To clarify legislative provisions on DNR orders, certain defined terms set forth in Section 2961 of Article 29-B should be retained. They are as follows:

1. ***Cardiopulmonary resuscitation*** means measures, as specified in regulations promulgated by the Commissioner of the Department of Health, to restore cardiac function or to support ventilation in the event of a cardiac or respiratory arrest. CPR shall not include measures to improve ventilation and cardiac functions in the absence of an arrest.

2. ***Emergency medical services personnel*** means the personnel of a service engaged in providing initial emergency medical assistance, including but not limited to first responders, emergency medical technicians, and advanced emergency medical technicians.

3. ***Hospital*** means a general hospital as defined in Section 2801(10) of the Public Health Law or a residential health care facility as defined in Section 2801(3) of the Public Health Law or a hospital as defined in Section 1.03(10) of the New York Mental Hygiene Law or a school named in Section 13.17 of the Mental Hygiene Law.

4. ***Hospital emergency service personnel*** means the personnel of the emergency service of a general hospital, as defined in Section 2801(10) of the Public Health Law, including but not limited to

> emergency services attending physicians, emergency services registered professional nurses, and registered professional nurses, nursing staff and registered physicians assistants assigned to the general hospital's emergency service.

5. ***Hospitalization*** means the period during which a person is a patient in, or a resident of, a hospital.

6. ***Medically futile*** means that CPR will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs.

7. ***Nonhospital order not to resuscitate*** means an order, issued in accordance with Section 2977 of the Public Health Law, that directs emergency medical services personnel and hospital emergency service personnel not to attempt CPR in the event a patient suffers cardiac or respiratory arrest.

8. ***Patient*** means a person admitted to a hospital or, for the purpose of provisions in the Public Health Law governing nonhospital DNR orders, a person who has or may be issued a nonhospital DNR order.

Decisions by Patients with Capacity — The Therapeutic Exception (Section 2964(3))

In general, Article 29-B requires physicians to seek the consent of an adult patient before entering a DNR order if the patient has the capacity to decide. Section 2964(3) of Article 29-B allows physicians to seek consent from a family member or other surrogate if two physicians determine that the discussion about a DNR order would cause the patient severe, immediate injury, and other requirements are met. This provision, as set forth below, should remain in effect, and should apply only to decisions about CPR.

Section 2964(3).

(a) In the event that the attending physician determines, in writing, that, to a reasonable degree of medical certainty, an adult patient who has capacity would suffer immediate and severe injury from a discussion of CPR, the attending physician may issue a DNR order without obtaining the patient's consent, but only after:

(i) consulting with and obtaining the written concurrence of another physician selected by a person authorized by the hospital to make such selection, given after personal examination of the patient, concerning the assessment of immediate and severe injury to the patient from a discussion of CPR;

(ii) ascertaining the wishes of the patient to the extent possible without subjecting the patient to a risk of immediate and severe injury,

(iii) including the reasons for not consulting the patient in the patient's chart; and

(iv) obtaining the consent of a health care agent who is available and would be authorized to make a decision regarding CPR if the patient lacked capacity or, if there is no such agent, a surrogate pursuant to Section 2965 of Article 29-B, provided, however, that the consent of an agent or surrogate should not be required if the patient has previously consented to a DNR order pursuant to Section 2964(2).

(b) Where the provisions of this subdivision have been invoked, the attending physician shall reassess the patient's risk of injury from a discussion of CPR on a regular basis, and shall consult the patient regarding CPR as soon as the medical basis for not consulting the patient no longer exists.

Effect of DNR Order on Other Treatment (Section 2968)

Section 2968 of the DNR law expressly states that "Consent to the issuance of a DNR order shall not constitute consent to withhold or withdraw medical treatment other than CPR." This provision should remain in effect.

DNR Orders in Community Settings (Section 2977)

In 1991, Article 29-B was amended to establish a system for honoring DNR orders for patients cared for at home or in other community settings. The amendments create a "nonhospital order not to resuscitate" and require emergency medical services personnel and hospital emergency service personnel to honor nonhospital DNR orders, except under narrow circumstances as described below in Section 2977(10). The Task Force proposes that these provisions should be retained.

Section 2977(2) extends policies for DNR orders in hospitals, nursing homes, and mental health facilities to nonhospital orders, except as otherwise provided in Section 2977. Under Section 2977(3), a nonhospital DNR order may be issued for patients in a health care facility to take effect after the patient leaves the facility, or it may be issued for a person who is not a patient or resident of a health care facility. Section 2977(4) establishes that consent to a nonhospital DNR order is given in the same manner as consent to a DNR order in a health care facility, except that a surrogate may only consent to a nonhospital order for a patient at a hospital, nursing home, or mental health facility. (This limitation expires on September 1, 1992, allowing surrogate decisions in other health care settings after that date.) Also, in any health care or community setting, an adult with capacity or a health care agent may consent to a nonhospital DNR order orally to the attending physician. A third person acting as a witness is not necessary for this consent.

Section 2977(2) specifies that requirements for dispute mediation established by Article 29-B apply only to patients at a hospital or nursing home. This is because a similar dispute mediation system is not available for home care patients or other patients in the community. Similarly, if the proposed legislation is enacted, the provisions for a bioethics review committee would apply only to patients in a general hospital or residential health care facility. The remaining provisions of Section 2977 are as follows:

Section 2977(6). A nonhospital DNR order shall be issued upon a standard form prescribed by the commissioner of health. The commissioner shall also develop a standard bracelet that may be worn by a patient with a nonhospital DNR order to identify that status; provided, however, that no person may require a patient to wear such a bracelet, and that no person may require a patient to wear such a bracelet as a condition for honoring a nonhospital DNR order or providing health care services.

Section 2977(7). An attending physician who has issued a nonhospital DNR order, and who transfers care of the patient to another physician, shall inform the physician of the order.

Section 2977(8). For each patient for whom a nonhospital DNR order has been issued, the attending physician shall review whether the order is still appropriate in light of the patient's condition each time he or she examines the patient, whether in the hospital or elsewhere, but at least every 90 days, provided that the review need not occur more than once every 7 days. The attending physician shall record the review in the patient's chart or record provided, however, that a registered nurse who provides direct care to the patient may record the review in the chart or record at the direction of the physician. In such case, the attending physician shall include a confirmation of the review in the patient's chart or record within 14 days of such review.

Failure to comply with this subdivision shall not render a nonhospital DNR order ineffective.

Section2977(9). A person who has consented to a nonhospital DNR order may at any time revoke his or her consent to the order by any act evidencing a specific intent to revoke such consent. Any health care professional informed of a revocation of consent to a nonhospital DNR order shall notify the attending physician of the revocation. An attend- ing physician who is informed that consent to a nonhospital DNR order has been revoked shall record the revocation in the patient's chart or record, cancel the order, and make diligent efforts to retrieve the form issuing the order and the standard bracelet, if any.

Section 2977(10). Emergency medical services personnel or hospital emergency service personnel who are provided with a nonhospital DNR order, or who identify the standard bracelet on the patient's body, shall comply with the terms of such order; provided, however, that:

(a) emergency medical services personnel or hospital emergency service personnel may disregard the order if:

(i) they believe in good faith that consent to the order has been revoked, or that the order has been cancelled; or

(ii) family members or others on the scene, excluding such personnel, object to the order and physical confrontation appears likely; and

(b) hospital emergency service physicians may direct that the order be disregarded if other significant and exceptional medical circumstances warrant disregarding the order.

Section 2977(11). If a patient with a nonhospital DNR order is admitted to a hospital, the order shall be treated as a DNR order for a patient transferred from another hospital, and shall be governed by Section 2971 of Article 29-B ("Interinstitutional Transfers").

Section 2977(12). No person shall be subjected to criminal prosecution or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring reasonably and in good faith pursuant to this Section 2977 a nonhospital DNR order, for disregarding a nonhospital DNR order pursuant to Section 2977(10), or for other actions taken reasonably and in good faith pursuant to this Section 2977.

Residents of Mental Hygiene Facilities

Pending the development of comprehensive policies on surrogate decisions for residents of mental hygiene facilities, existing Article 29-B should apply to decisions about CPR for residents at such facilities and for those who have been transferred to a general hospital.

Medically Futile CPR

The Department of Health has clarified that Article 29-B creates no duty to provide medically futile CPR. The law defines futile CPR as CPR that will be unsuccessful in restoring cardiac and respiratory function or that will result in the patient experiencing repeated arrest in a short time period before death occurs. Under guidelines from the Department of Health, before a physician enters a DNR order because CPR would be futile, he or she must inform the patient, where there is any indication of the patient's ability to comprehend the information, or inform the person authorized to decide on the patient's behalf — a parent or legal guardian of a minor patient, a health care agent, or a surrogate for an adult patient without decision-making capacity.

This clarification about the intent and requirements of Article 29-B is important. The Task Force recommends that it should be set forth in legislation or regulation.

Appendix C

New York State Department of Health Patient Self-Determination Act Statement

PLANNING IN ADVANCE

FOR

YOUR MEDICAL TREATMENT

Your Eight to Decide About Treatment

Adults in New York State have the right to accept or refuse medical treatment, including life-sustaining treatment. Our Constitution and state laws protect this right. This means that you have the right to request or consent to treatment, to refuse treatment before it has started, and to have treatment stopped once it has begun.

Planning in Advance

Sometimes because of illness or injury people are unable to talk to a doctor and decide about treatment for themselves. You may wish to plan in advance to make sure that your wishes about treatment will be followed if you become unable to decide for yourself for a short or long time period. If you don't plan ahead, family members or other people close to you may not be allowed to make decisions for you and follow your wishes.

In New York State, appointing someone you can trust to decide about treatment if you become unable to decide for yourself is the best way to protect your treatment wishes and concerns. You have the right to appoint someone by filling out a form called a Health Care Proxy. A copy of the form and information about the Health Care Proxy are available from your health care provider.

If you have no one you can appoint to decide for you, or do not want to appoint someone, you can also give specific instructions about treatment in advance. Those instructions can be written, and are often referred to as a living Will.

You should understand that general instructions about refusing treatment, even if written down, may not be effective. Your instructions must clearly cover the treatment decisions that must be made. For example, if you just write down that you do not want "heroic measures," the instructions may not be specific enough. You should say the kind of treatment that you do not want, such as a respirator or chemotherapy, and describe the medical condition

when you would refuse the treatment, such as when you are terminally ill or permanently unconscious with no hope of recovering. You can also give instructions orally by discussing your treatment wishes with your doctor, family members or others close to you.

Putting things in writing is safer than simply speaking to people, but neither method is as effective as appointing someone to decide for you. It is often hard for people to know in advance what will happen to them or what their medical needs will be in the future. If you choose someone to make decisions for you, that person can talk to your doctor and make decisions that they believe you would have wanted or that are best for you, when needed. If you appoint someone and also leave instructions about treatment in a Living Will, in the space provided on the Health Care Proxy form itself, or in some other manner, the person you select can use these instructions as guidance to make the right decision for you.

Deciding About Cardiopulmonary Resuscitation

Your right to decide about treatment also includes the right to decide about cardiopulmonary resuscitation (CPR), CPR is emergency treatment to restart the heart and lungs when your breathing or circulation stops.

Sometimes doctors and patients decide in advance that CPR should not be provided, and the doctor gives the medical staff an order not to resuscitate (DNR order). If your physical or mental condition prevents you from deciding about CPR, someone you appoint, your family members, or others close to you can decide. A brochure on CPR and your rights under New York law is available from your health care provider.

Appendix D

Health Care Proxy Form

Health Care Proxy

a) i ----------

hereby appoint_____
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect when and if I become unable to make my own health care decisions.

(2) Optional instructions: I direct my agent to make health care decisions in accord with my wishes and limitations as stated below, or as he or she otherwise knows. (Attach additional pages if necessary.)

(Unless your agent knows your wishes about artificial nutrition and hydration [feeding tubes], your agent will not be allowed to make decisions about artificial nutrition and hydration. See instructions on reverse for samples of language you could use.)

(3) Name of substitute or fill-in agent if the person I appoint above is unable, unwilling or unavailable to act as my health care agent.

(name, home address and telephone number)

(4) Unless I revoke it, this proxy shall remain in effect indefinitely, or until the date or conditions staled below. This proxy shall expire (specific date or conditions, if desired):

(5) Signature_____

Address_ _____

Date_____

Statement by Witnesses (must be 18 or older)

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1 _____ ; _____

Add rcss _____

Witness 2 _____
Address.

Appendix E

Hospital and Nursing Home Policies on Life-Sustaining Treatment 1988/89 Survey Results

Introduction

In 1986 the Task Force conducted a survey of hospitals and nursing homes in New York State to learn about practices and policies for decisions about life-sustaining treatment.[1] In the winter of 1988-89 the Task Force conducted a second survey. The surveys covered four basic areas: (i) the existence and scope of institutional policies about withdrawing and withholding life-sustaining treatment, (ii) the procedures to determine whether patients have decision-making capacity, (iii) the prevalence of and functions served by committees that resolve conflicts or offer guidance to decision-making parties about the withholding and withdrawing of life-sustaining treatment, and (iv) the prevalence of religious or moral objections to forgoing life-sustaining treatment. The survey results are presented in tables A through E and are summarized below.

Table A: Response Rate and Profile of Respondents

In November 1988 the Task Force distributed a written questionnaire to administrators of 554 nursing homes. The questionnaire was sent to all nursing homes with only skilled beds and those with both skilled and health related beds listed in the directory of health care facilities maintained by the New York State Department of Health.

A similar survey was sent to the administrators of New York State hospitals in January 1989. The Hospital Association of New York State (HANYS) provided the Task Force with its member mailing list of 229 hospitals. The Health and Hospital Corporation of New York City hospitals were added to the list. Overall, the Task Force sent the1

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[1] Results of the 1986 survey are presented in New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent,* (New York, 1987), 161-80.

questionnaire to 243 hospitals — over 85 percent of the hospitals in New York State.

Two hundred and twelve of 554 nursing homes (38 percent) and 140 of 243 hospitals (58 percent) returned the questionnaire. Administrators completed a majority of the questionnaires: 69 percent of the nursing home responses and 64 percent of the hospital survey.

The distribution of the nursing home respondent population did not differ significantly from the actual nursing home population when analyzed by type of facility, number of beds, and whether the facility was hospital based. The sample, however, was not representative of the population by sponsorship; proprietary nursing homes were underrepresented.

The hospital respondents were representative of the HANYS hospital population in terms of geographic region and hospital size (number of beds); a breakdown for the entire hospital population was not available for the other characteristics — type of facility and medical school association. Community hospitals and hospitals affiliated with medical schools made up a majority of the respondents.

Table B: Institutional Policies for Withholding/ Withdrawing Life-Sustaining Treatment

To determine the number of facilities with institutional policies, the survey asked respondents whether they have a policy for decisions to withdraw or withhold life-sustaining measures other than CPR. Among hospitals, approximately one third had developed institutional policies. Hospitals with larger patient capacity (over 100 beds) were more likely to have an institutional policy. Geographic region, medical school affiliation, and type of hospital did not have a significant impact on whether the hospital had developed a policy.

Only 26 percent of the nursing homes had an institutional policy on life-sustaining treatment. A majority of nursing home institutional policies addressed artificial respiration and artificial nutrition and hydration. In addition, 89 percent of the nursing home policies covered decisions to transfer residents to other facilities for treatment.

Almost all survey respondents with policies (both hospital and nursing home) indicated that the policies were written.

Table C: Determining Decision-Making Capacity

Despite the importance of the determination of capacity, only 36 percent of the hospitals had a policy for the procedure to determine that a patient lacks capacity to make decisions. Tertiary care facilities, large hospitals, and hospitals affiliated with a medical school were significantly more likely to have a policy. A majority of these policies were written.

Close to one half of the nursing home respondents had written guidelines to determine capacity (a significant increase from the previous Task Force survey when only 12 percent of nursing homes had written policies[2]). Differences among nursing homes by facility characteristics such as size or sponsorship were insignificant.

The nursing home questionnaire also asked facilities to identify the person(s) responsible for determining that residents lack the capacity to decide about life-sustaining treatment. Facilities reported that the attending physician was involved in virtually all cases.

Table D: Institutional Committees

The Task Force questionnaire asked respondents whether the facility had a "committee that considers ethical issues, resolves conflicts, or offers guidance to decision-making parties regarding the withholding or withdrawal of life-sustaining or life-saving medical treatment." The question did not inquire specifically about an "ethics committee" since some facilities do not use that term but may have a committee that serves similar functions.

Twenty-seven percent of the nursing homes surveyed indicated they had a committee to address ethical issues. Size, sponsorship, type of facility, and whether the nursing home was hospital based were not significant variables. In addition, nursing homes with committees were more likely to have established institutional policies for withholding and withdrawing life-sustaining treatments than facilities without committees: 49 percent (28) of the 57 nursing homes with committees had institutional policies compared with 18 percent (29) of the 155 facilities without committees.

A majority of hospital respondents indicated that the facility had a committee. Tertiary care hospitals and hospitals affiliated with a medi

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2 For an analysis and comparison of the 1986 and 1988 nursing home survey data see T2 Miller and A. M. Cugiiari, "Withdrawing and Withholding Treatment: Policies in Long-Term Care Facilities," *Geroritologist* 30 (1990): 462-68.

cal school were more likely to have formed a committee. However, hospitals with committees were not more likely to have an institutional policy about life-sustaining treatment.

Committees at both facilities most frequently addressed ethical issues in patient care generally and decisions about life-sustaining treatment. A majority of the committees provided consultation and a forum for discussing ethical issues. In addition, a majority of the committees engaged in dispute resolution.

The committees in New York State hospitals and nursing homes were multidisciplinary. Almost all the committees included physicians, nurses, social workers, and lawyers. Members of the clergy and administrators participated on approximately half the committees. Thirty-eight percent of the hospital committees included an ethicist in contrast to 12 percent of the nursing home committees.

Table E: Institutional Conscience Objections to Treatment Decisions

In order to understand the nature and prevalence of institutional conscience objections at hospitals and nursing homes, the questionnaire sought information about facilities that refuse to honor, on religious or moral grounds, decisions to withhold or withdraw life-sustaining treatment by competent patients or patients who left clear evidence of their wishes. The questionnaire instructed respondents to exclude concerns about liability as a basis for refusing to honor decisions to forgo treatment when answering the questions.

The questionnaire asked respondents whether their facility would object on religious or moral grounds to decisions to withhold artificial respiration or artificial nutrition and hydration for patients facing three different medical conditions: (i) terminal illness, (ii) permanent unconsciousness, and (iii) severe debilitation in the absence of terminal illness and permanent unconsciousness. The questionnaire also asked for responses about withdrawing treatment in each of these circumstances.

The survey results revealed four important findings: (i) overall, 29 percent of the hospitals and 40 percent of the nursing home respondents indicated an institutional objection based on either religious or moral beliefs to at least one of the 12 treatment decisions posed; (ii) a majority of the hospitals and nursing homes with conscience objections had not expressed their policy in writing — 90 percent of the hospitals and 70 percent of the nursing homes; (iii) a higher

percentage of hospital and nursing home respondents opposed or had no policies for decisions to forgo artificial nutrition and hydration than opposed or had no policies for artificial respiration; and (iv) facilities were more likely to have "no policy" for withdrawing treatment than for withholding treatment.

Although a substantial number of nursing homes and hospitals expressed conscience objections, the study did not examine surrogate decisions for incompetent adults who left no clear guidance; the study inquired solely about objections to decisions by patients to forgo treatment. Since facilities may be more likely to raise conscience objections when surrogates decide than when competent patients choose for themselves, the actual number of facilities that opposed decisions to forgo life-sustaining treatment may have been higher than was indicated by the survey.

Table A
Response Rate and Profile of Respondents

Response Rate

	Hospital	Nursing Home
Questionnaires	243	554
Responses #		140212
Overall Response Rate	58%	38%

Profile of Respondents

1989 Hospital Survey

Type	n= 140	
Community	113	81%
Tertiary	24	17%
Region		
Nassau/Suffolk	11	8%
Northeast	16	11%
Central	24	17%
Buffalo	21	15%
Greater New York	28	20%
Northern Metropolitan	23	16%
Rochester	14	10%

Affiliation	n= =140	
Medical school	56	40%
Independent	83	59%
Number of Bed		
under 100	29	21%
100-250	46	33%
250-500	43	31%
over 500	22	16%
Position of Respondent		
Administrator	90	64%
Medical director	16	11%
Director of nursing	10	7%
Counsel	6	4%
Other	2	1%
No response	16	11%

1988 Nursing Home Survey

Type	n= 212	
Skilled	120	57%
Combined	92	44%
Number of Beds		
under 50	16	8%
50-99	54	25%
100-199	79	37%
over 200	63	30%

Sponsorship	n= 212	
Voluntary	89	42%
Public	33	16%
Proprietary	85	40%
Association		
Hospital based	40	19%
Not hospital based	172	81%
Position of Respondent		
Administrator	146	69%
Director of nursing	27	13%
Medical director	15	7%
Other	17	8%

Table B
Institutional Policies

Hospitals/nursing homes with institutional policies for withholding or withdrawing life-sustaining treatment (other than CPR)

	Hospital	Nursing Home
	n-138	n = 206
Yes	50 36%	56 *27%*
No	78 57%	131 64
In progress	10 *7%*	19 *9%*

Hospitals/nursing homes with institutional policies in writing

	n=50	n = 56
Yes	43 *86%*	52 93
No	*7* 14 *%*	4 7%

Treatments included in institutional policies

	n -50	n — 56
Artificial respiration	28 56%	30 54%
Dialysis	8 16%	12 21%
Surgery	8 16%	18 32%
Antibiotics	9 18%	22 39%
Artificial nutrition & hydration	10 20%	33 59%

Table C
Determining Capacity

Hospitals/nursing homes with a procedure or policy for determining capacity

	Hospital n = 140	Nursing Home n = 212
Yes	51 36%	102 48%
No	81 58%	68 32%
In progress	6 4%	14 7%
No response	2 1%	28 13%

Hospitals with policies that are written

	n =51
Yes	37 73%
No	14 27%

Professional who determines capacity[45]

	n	212
Attending physician	38	18
Attending physician with one health care professional No response	128	60
	46	22

45 * Nursing home survey only.

Table D
Institutional Committees

Hospitals/nursing homes that have a committee to consider ethical issues, resolve conflicts, or offer guidance to decision-making parties about the withholding or withdrawal of life-sustaining medical treatment (excluding committees that address only CPR)

	Hospital n = 140		Nursing Home n = 212	
Yes	71	51%	57	27%
No	54	38%	135	64%
In progress	8	6%	20	10%
No response	7	5%		
Issue(s) committees address	**n = 71**		**n = = 57**	
Ethical issues in patient care generally	64	90%	32	56%
Life-sustaining treatment decisions			36	63%
Only issues in neonatal and infant care	6	8%		
Other	10	14%	5	9%
Frequency of committee meetings	**n = = 71**		**n = = 57**	
Monthly	22	31%	8	14%
Bi-monthly	4	6%	1	2%
Quarterly	4	6%		
When necessary	36	51%	48	84%
Function of the committees	**n = = 71**		**n = =57**	
Prognosis determination	9	13%		
Dispute resolution	47	66%	45	79%
Retrospective case review	25	35%	13	23%
Prospective case review	14	20%	18	32%
Consultation	48	68%	36	63%
Education	49	69%	25	44%
Policy development	47	66%	27	47%
Discussing ethical issues	61	86%	33	58%
Other	9	13%		
Composition of the committees	**n = = 71**		**n = =57**	
Physicians	71	100%	54	95%
Nurses	68	96%	55	96%
Social workers	53	75%	55	96%
Lawyers	43	61%	17	30%
Ethicists	27	38%	7	12%
Members of the outside community	29	41%	15	26%
Clergy	38	54%	26	46%
Administrators	30	42%	27	47%
Other	27	38%	21	37%

Table E
Institutional Conscience Objections
to Treatment Decisions*

Hospitals/nursing homes that would object on religious or moral grounds to the following:

A. Withholding artificial respiration for patients facing the following medical conditions:

	Terminally HI		Permanently Unconscious		Severely Debilitated	
	Hospital	Nursing Home	Hospital	Nursing Home	Hospital	Nursing Home
	n = 132	n = 151	n = 131	n = 149	n = 129	n = 150
Yes	1 1%	11 7%	5 4%	12 8%	18 14%	27 18%
No	105 80%	108 72%	98 75%	103 69%	73 57%	88 59%
No policy	26 20%	32 21%	28 21%	34 23%	38 29%	35 23%

B. Withdrawing artificial respiration for patients facing the following medical conditions:

	Terminally 111		Permanently Unconscious		Severely Debilitated	
	Hospital	Nursing	Hospital	Nursing Home	Hospital	Nursing Home
	n = 132	n = 143	n = 131	n = 142	n —129	n = 140
Yes	7 5%	17 12%	14 11%	17 12%	19 15%	29 21%
No	88 67%	82 57%	80 61%	79 56%	61 47%	64 46%
No policy	37 28%	44 31%	37 28%	46 32%	49 38%	47 34%

C. Withholding artificial nutrition and hydration for patients facing the following medical conditions:

	Terminally 111		Permanently Unconscious		Severely Debilitated	
	Hospital	Nursing Home	Hospital	Nursing Home	Hospital	Nursing Home
	n -133	n-193	n = 131	n = 191	n = 130	n = 190
Yes	20 15%	51 26%	22 17%	55 29%	31 24%	72 38%
No	67 51%	103 53%	62 47%	94 49%	43 33%	75 40%
No policy	46 35%	39 20%	47 36%	42 22%	56 43%	43 23%

D. Withdrawing artificial nutrition and hydration for patients facing the following medical conditions:

	Terminally 111		Permanently Unconscious		Severely Debilitated	
	Hospital	Nursing Home	Hospital	Nursing Home	Hospital	Nursing Home
	n -133	n = 186	n = 131	n = 186	n = 130	n = 186
Yes	21 16%	54 29%	26 20%	62 33%	31 24%	73 39%
No	60 45%	83 45%	53 40%	74 40%	38 29%	62 33%
No policy	52 39%	49 26%	53 40%	50 27%	61 47%	51 27%

Other Reports by the Task Force

- Surrogate Parenting: Analysis and Recommendations for Public Policy, May 1988 (143 pp.)
- Transplantation in New York State: The Procurement and Distribution of Organs and Tissues, January 1988 (164 pp.)
- Fetal Extrauterine Survivability, January 1988 (13 pp3
- Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent, July 1987 (180 pp.)
- The Determination of Death, July 1986 (48 pp.)
- Do Not Resuscitate Orders, April 1986 (113 pp.)
- The Required Request Law, March 1986 (16 pp.)

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