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 overtreatment 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 CPR 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.

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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]

[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. Shmerling et 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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[3]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 Ill 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. The procedure builds on the experience attained with the capacity

[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.

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 may be 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 every 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 Policy Implications," *Annals 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 proxy law, Sections 2983(1)(b) and 2983(1)(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 long-term 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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[8]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

[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 analysis 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 Ill Patient," *Journal of the American Geriatrics Society* 36 (1988): 1055-58 ; J. Mahler and S. Perry, "Assessing Competency in the Physically Ill:

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]

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

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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," *Annals 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 the 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.

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.

6

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 of 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

[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.

7

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

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

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.

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.

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[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

[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.

well-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, however, impoverishes and distorts an assessment of the patient's

[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).

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

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

between the surrogate and the patient, and the decision falls 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

[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

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

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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.

[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.

within six months even if life-sustaining treatment is provided. The expectation of death within six months establishes a general benchmark 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

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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 the 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 locked-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 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

virtually 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 of significant harm.[14] Caring for profoundly disabled or "pleasantly

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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.

[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

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.

The term "excessive burden" should be understood to reflect the past values, wishes, and preferences of the patient to the extent that

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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," *Hastings Center Report* 10, no. 4 (1980): 9-10.

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.[2] 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 v. 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), *aff'd*, 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 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*

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 5 1/2 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.

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-

[15]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 Extrauterine 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.

[16]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.

(such as those associated with the more severe cases of spina bifida) rarely indicate to researchers that they would prefer no life to the life they have had. They may covet the normalcy they see in other persons, but they do not want to give up the abnormal lives they have for the alternative of death." Weir, 239. The disparity between the perspectives of the most profoundly disabled newborns and most "reasonable people" is discussed by John D. Arras, "Toward an Ethic of Ambiguity," *Hastings Center Report* 14, no. 2 (Apr 1984): 29-31.

[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 authority to make major treatment decisions. The local department of social services and the child's natural parents, if available, generally

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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.

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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[22]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 foster 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.

[23]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 unemancipated 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 disagreements 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]

[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 treatment. The Task Force proposes that a minor should be considered

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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.

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 decision-making 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.

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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* (New York: The Free Press, 1985), 223.

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.