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## Patient Groups Raising Special Concerns



During the Commission's hearings and deliberations on this Report, several groups of patients were identified whose situations are currently raising questions about the decision-making process. Part II applies the more general analysis of the preceding chapters to the situations of patients who are incapable of deciding about medical care for themselves— with special attention to those who have permanently lost consciousness and to newborn children with potentially fatal illnesses— and to decisionmaking about resuscitating hospitalized patients who have a cardiac arrest.

The decision about whether or not to undertake life-sustaining treatment is more difficult to make when a patient cannot assess the options and make the choice. Chapter Four explores how these treatment decisions should be made for such patients. The first section of the chapter examines the problem of decisional incapacity itself: what does decision-making capacity entail, and who is to determine its absence or presence? The next section looks at the process of making decisions for such patients. Who is to serve as a surrogate decisionmaker? How is the surrogate to be designated? What standards should the surrogate use to make a decision? The role of "advance directives" in helping surrogates and health care providers make decisions on behalf of incapacitated patients is then examined. The procedures for this decision-making, especially the roles of the courts, health care institutions, and intrainstitutional ethics committees, are considered in the final section.

The particularly tragic circumstances of patients who have permanently lost consciousness prompted vigorous public discussion at the time of the *Quinlan* case.<sup>1</sup> These patients are

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<sup>1</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922

not dead, yet they cannot experience any of the activities of the world around them. How should such a patient be treated? What role should the family play in decisionmaking about the person's health care? What role, if any, should the law have in this process? To find answers to these questions, as the Commission attempts in Chapter Five, the general principles of this Report must be applied to circumstances in which patients' interests in health care are very attenuated.

While the Commission was working on this Report, several cases involving nontreatment of seriously ill newborn babies received wide publicity.<sup>2</sup> Chapter Six develops an analysis of the issues involved and recommends procedural and substantive policies to guide the decisionmaking in a manner that is protective of the interests of this special group of very vulnerable patients.

In Chapter Seven, the Commission recommends prudent policy for decisionmakers, care giving institutions, and the legal system in responding to the issue of when, why, and how it is appropriate for a physician to order that no attempt be made to resuscitate a patient. In the past two decades, hospitals have developed special teams that intervene rapidly to try to restore heartbeat when a patient's heart stops. Some hospitals have begun developing policies on decisions not to automatically attempt resuscitation, but much professional and public uncertainty persists about how such a practice should develop and be regulated.

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(1976) (a period of interrupted breathing caused Karen Quinlan to sustain brain damage that left her in a persistent vegetative state; her father successfully sought appointment as her guardian for purposes of authorizing removal of her respirator).

<sup>2</sup> See, e.g., Jay Mathews, *Brian West's Short, Tragic Life is Ended*, WASH. POST, Dec. 23, 1982, at A-5; Sheila Taub, *Withholding Treatment from Defective Newborns*, 10 L. MED & HEALTH CARE 4 (1982); *Probe of Infant's Care Stirs Dispute in Ohio*, AM. MED. NEWS, Aug. 13, 1982, at 3.

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# Patients Who Lack Decisionmaking Capacity

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## Determination of Incapacity

In general, a person's choices regarding care ought to override the assessments of others about what best serves that person. Certain people, however, are incapable of making choices that reflect and promote their personal goals and values. Some patients—on account of age, incapacity, or inexperience—have an insufficiently developed set of goals and values. Some lack sufficient capabilities for understanding, communication and reasoning; among patients facing life-threatening decisions, these faculties are frequently compromised. The principles for determining incapacity<sup>1</sup> and for making decisions on behalf of incapacitated patients that were developed by the Commission in its report on informed consent<sup>2</sup> therefore have special relevance to decisions to forego life-sustaining therapy.

**Elements of the Determination.** Determining whether a patient lacks capacity to make a particular health care decision requires assessing the patient's capability to understand information relevant to the decision, to communicate with care givers about it, and to reason about relevant alternatives against a background of reasonably stable personal values and life goals.<sup>3</sup> The ultimate objective of such an assessment is to

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<sup>1</sup> The term "incapacitated" is used in this Report to refer to patients who lack decisional capacity, rather than referring to general illness or disability. "Incapacity" as used here is roughly equivalent to the conventional legal usage of the term "incompetent."

<sup>2</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE Decisions*, U.S. Government Printing Office, Washington (1982) at 169-88.

<sup>3</sup> *Id.* at 56-68.

diminish two types of errors: mistakenly preventing persons who ought to be considered competent from directing the course of their own treatment, and failing to protect incapacitated persons from the harmful effects of their decisions. Health care professionals usually play a substantial role in making these assessments; their conclusions are often not reviewed by officials outside health care institutions.<sup>4</sup>

Each determination of decisional incapacity focuses on a patient's actual functioning in a particular decisionmaking situation rather than simply on an individual's age or diagnosis. This approach is particularly germane for fairly mature children<sup>5</sup> and for mildly retarded or demented persons. What is relevant is whether a person is in fact capable of making a

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<sup>4</sup> Determining the patient's incapacity, designating and informing a surrogate, and helping the surrogate to decide may require time that is not available in an emergency. In general, because of its grave nature and consequences, a decision to forego life-saving treatment should be made under conditions that permit consultation, reflection, and reasoned decision. In an emergency, ordinarily treatment ought to be given if no decision has previously been made to forego treatment. *See generally* Alan Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 *Wis. L. Rev.* 413,436,476.

<sup>5</sup> Lois A. Weithorn and Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 *CHILD DEV.* 1589 (1982). *See also* Thomas Grisso, *JUVENILES' WAIVER OF RIGHTS—LEGAL AND PSYCHOLOGICAL COMPETENCE*, Plenum Press, New York (1981); Gary B. Melton, Gerald P. Koocher, and Michael J. Saks, eds., *CHILDREN'S COMPETENCE TO CONSENT*, Plenum Press, New York (1983). Law has traditionally viewed people under a specified age—long set at 21 years and more recently at 18—as incompetent to make decisions about any contractual matters, including their own health care; this reverses the usual presumption of competency accorded adults. Some exceptions have been created for "emancipated" or "mature" minors, in recognition that sometimes children have adequate capacity to make decisions and social policy ought to find such decisions sufficient. The ever-expanding scope of these exceptions calls into question the underlying presumption; it may be more reasonable to ask—of any person at any age—"is *this* person capable of making *this* decision?" *See* A. M. Capron, *The Competence of Children as Self-Deciders in Biomedical Interventions*, in Willard Gaylin and Ruth Macklin, eds., *WHO SPEAKS FOR THE CHILD*, Plenum Press, New York (1982) at 57.

The Commission endorses this general trend, recognizing that there is an age, below about 14 years old, at which the traditional presumption of incompetence remains sensible. The presumption, however, is merely a starting point for inquiry. *See* *MAKING HEALTH CARE DECISIONS*, *supra* note 2, at 170, n.6, and Sanford L. Leikin, *Minors' Assent or Dissent to Medical Treatment*, in *id.*, *VOLUME THREE: APPENDICES (STUDIES ON THE FOUNDATIONS OF INFORMED CONSENT)*, at 175.

particular decision despite his or her youth, retardation, or dementia. Even when ultimate decisional authority is not left with a patient, reasonable efforts often should be made to give the person relevant information about the situation and the available options and to solicit and accommodate his or her preferences.

The Commission recommends that determinations of incapacity be made only when people lack the ability to make decisions that promote their well-being in conformity with their own values and preferences.<sup>6</sup> Rarely—infants and unconscious patients are the main exceptions—is incapacity absolute. Even people with impaired capacity usually still possess some ability to comprehend, to communicate, and to form and express a preference. The fact that a patient makes a highly idiosyncratic decision or has a medical or mental condition<sup>7</sup> similar to others who have been unable to make decisions that advance their own well-being may alert health care professionals to the possibility of decisional incapacity, but does not conclusively resolve the matter. "Decisionmaking incapacity" is not a medical or a psychiatric diagnostic category; it rests on a judgment of the type that an informed layperson might make—that a patient lacks sufficient ability to understand a situation and to make a choice in light of that understanding.<sup>8</sup> Indeed, when judges are called upon to make legal determinations of patients' competence, they consider the situation not as medical experts but as laypeople examining the data provided by health care personnel<sup>9</sup> and by others who know

<sup>6</sup> MAKING HEALTH CARE DECISIONS, *supra* note 2, at 172-73.

<sup>7</sup> In fact, a diagnosis of a major psychiatric illness only rarely in itself decides the question of the patient's capacity to make a particular treatment decision. There is no necessary correspondence between mental illness and the presence or absence of decisional capacity either in fact or in law. *See Rogers v. Okin*, 634 F.2d 650, 657-59 (1st Cir. 1980).

<sup>8</sup> *See also* Mark Perl and Earl E. Shelp, *Psychiatric Consultation Making Moral Dilemmas in Medicine*, 307 *NEW ENG. J. MED.* 618 (1982).

<sup>9</sup> The "mental status examination" is perhaps the best example of how professional expertise can be enlisted in making assessments of incapacity. Such an evaluation is intended, among other things, to elicit the patient's orientation to person, place, time, and situation, the patient's mood and affect, and the content of thought and perception, with an eye to any delusions and hallucinations; to assess intellectual capacity, that is, the patient's ability to comprehend abstract ideas and to make a reasoned judgment based on that ability; to review past history for evidence of any psychiatric disturbance that might affect the patient's current judgment; and to test the patient's recent and remote memory and logical sequencing.

In testimony before the Commission, Dr. Paul Hardy, a neurologist, cited the Earle Spring case as an example of need for careful

the individual well, and possibly from personal observation of the patient.

Finally, in any assessment of capacity, due care should be paid to the reasons for a particular patient's impaired capacity—not because the reasons are the determinant of whether the patient's judgment is to be honored, but because identification of the causes of incapacity may assist in their remedy or removal.<sup>10</sup> The Commission urges that those responsible for assessing capacity not be content with providing an answer to the question of whether or not a particular patient is incapacitated. Rather they should, to the extent feasible, attempt to remove barriers to decisional capacity.

**Procedural Policies.** A decision that a patient is incapacitated can be of great importance, both in the Commission's ethical analysis and in the function of law. Courts have generally held that, whereas competent patients may forego any treatment, incompetent patients' wishes can be overridden in order to protect their lives and well-being." Since the

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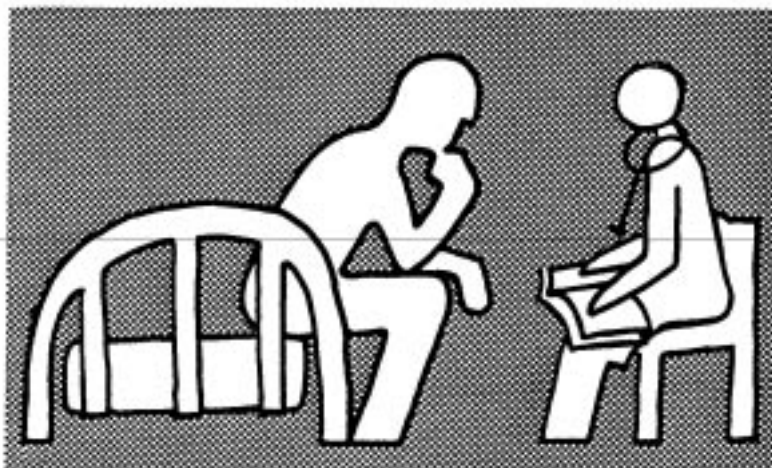
attention to underlying medical conditions bearing on determinations of competence. (Earle Spring's son petitioned a Massachusetts probate court for permission to stop dialysis treatments for his 79-year-old father who had been adjudged incompetent.)

If there is a...major travesty about the Earle Spring case, it lies in the utter confusion on the part of the judicial community and the medical community on how to go about determining competency...There was some conflicting testimony as to whether he was indeed competent or not, and there was even confusion over the exact medical condition and diagnosis....[one psychiatrist] never once recognized that Mr. Spring was clearly aphasic and made certain determinations about Mr. Spring's competency based upon Mr. Spring's speech patterns...I think the field of neuropsychiatry and behavioral neurology will be able to help considerably in the months and years ahead to characterize and define whether an individual is competent or not.

Testimony of Paul Hardy, transcript of 10th meeting of the President's Commission (June 4, 1981) at 137-38; *In re Spring*, 405 N.E.2d 115 (Mass.1980).

<sup>10</sup> See Paul S. Appelbaum and Loren H. Roth, *Clinical Issues in the Assessment of Competency*, 138 AM. J. PSYCHIATRY 1462 (1981); Loren H. Roth *et al.*, *The Dilemma of Denial in the Assessment of Competency to Refuse Treatment*, 139 AM. J. PSYCHIATRY 910 (1982); Albert R. Jonsen, Mark Siegler, and William J. Winslade, *CLINICAL ETHICS*, Macmillan Pub. Co., New York (1982) at 56-66.

<sup>11</sup> *Compare Satz v. Perlmutter*, 379 So.2d 359 (Fla. 1980); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (1978); *In re Osborne* 294 A.2d 372 (D.C. App. 1972), *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. 1978); *with John F. Kennedy Hosp. v. Heston*, 279 A.2d 670 (N.J. 1971); and *Application of President and Directors of Georgetown College, Inc.*, 331 F.2d 1000, *rehearing denied*, 331 F.2d 1010 (D.C. 1964). The court's authority to intervene arises largely from the



threshold issue of capacity is not only so weighty but often so complex,<sup>12</sup> it is of prime importance that assessments of incapacity be made carefully and adequately.

Health care professionals should therefore be familiar with the reason that a careful determination is important as well as with the procedures necessary to achieve it. Furthermore, health care institutions need to have clear policies as to who is responsible for assessing incapacity and by what standards. Institutions should ensure that those who assess capacity know the kinds of inquiries to make, the data to collect, and the records to keep. Finally, provisions also need to be made for reviewing determinations of incapacity both within the institution and, when necessary, through a judicial proceeding.

The first questions about a patient's decisionmaking capacity will usually be raised by attending health care personnel or by family members. Although formal legal procedures exist for adjudicating incompetency, a determination that a patient lacks the capacity to make some or all medical decisions independently is customarily made extra-judicially; only rarely is it reviewed in court. The legal status of such nonjudicial determinations is therefore uncertain, though this common practice is endorsed in the routine admonition to physicians to secure informed consent from the patient's next-of-kin,<sup>13</sup> in institutional regulations,<sup>14</sup> and even in court cases.<sup>15</sup>

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common-law doctrine of *powers patriae*, which recognizes that the state, through probate, juvenile, chancery, and other courts, must act as guardian for those people whose interests cannot otherwise be defended.

<sup>12</sup> See, e.g., *State Dept. of Human Services v. Northern*, 563 S.W.2d 197 (Tenn.1978); *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App.1978).

<sup>13</sup> See, e.g., *Consents*, 2 HOSPITAL LAW MANUAL, Aspen Systems, Rockville, Md. (1975) paragraph 4-12, at 58; Joseph H. King, Jr., *THE*

Some commentators, however, advocate requiring formal, judicial proceedings for all treatment decisions and especially for decisions to forego life-sustaining treatment on an incompetent patient.<sup>16</sup> Ideally, the courts are better equipped to protect the interests of incompetent patients; unfortunately, judicial proceedings, besides consuming time and resources, seem frequently to diffuse responsibility rather than increasing the acuity with which patients' interests are scrutinized.<sup>17</sup>

The Commission therefore believes that determinations of incapacity are best made without routine recourse to the courts. The Commission recommends that—except where state law clearly requires judicial intervention or where a real dispute persists after intrainstitutional review—determinations of decisional incapacity be made by the attending physician and regulated and reviewed at the institutional level, and that those who make and apply the law be encouraged to recognize the validity of such determinations. This recognition will require institutions to adopt procedures that merit such deference; in turn, it should reinforce for all participants in the decisionmaking process the importance of reaching a sound determination in each case.

### Surrogate Decisionmaking

**Identification of a Surrogate.** When a patient lacks the capacity to make a decision, a surrogate decisionmaker should be designated. Ordinarily this will be the patient's next of kin,<sup>18</sup>

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LAW OF MEDICAL MALPRACTICE IN A NUTSHELL, West Publishing Co., St. Paul, Minn. (1977) at 140; Note, 14 CIN. L. REV. 161, 170-72 (1940). The practice of obtaining consent from family members "is so well known in society at large that any individual who finds the prospect particularly odious has ample warning to make other arrangements better suited to protecting his own ends or interests." A. M. Capron, *Informed Consent in Catastrophic Disease Treatment and Research*, 123 U. PA. L. REV. 340, 424-25 (1974).

<sup>14</sup> Joint Commission on Accreditation of Hospitals, ACCREDITATION MANUAL FOR LONG TERM CARE FACILITIES, Chicago (1980) at 54.

<sup>15</sup> See, e.g., *In re Dinnerstein* 380 N.E.2d 134 (Mass. App. Ct. 1978); *In re Nemser*, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966).

<sup>16</sup> John R. Robertson, *THE RIGHTS OF THE CRITICALLY ILL*, Bantam Books, New York (1983) at 33; Charles H. Baron, *Assuring "Detached but Passionate Investigation and Decision" The Role of Guardians Ad Litem in Saikewicz type Cases*. 4 AM. J.L. & MED. 111 (1978); see also Testimony of Jonathan Brant, transcript of 10th meeting of the President's Commission (June 4, 1981), at 27-35.

<sup>17</sup> Robert A. Burt, *TAKING CARE OF STRANGERS*, The Free Press, New York (1979).

<sup>18</sup> In some cases when a guardian is needed, courts have gone to remarkable lengths to identify and appoint even distant family members. See, e.g., *Application of Long Island Jewish-Hillside Medical Center*, 342 N.Y.S.2d 356 (Sup. Ct. 1973).

although may be a close friend or another relative if the responsible health care professional judges that this other person is in fact the best advocate for the patient's interests.<sup>19</sup>

The Commission's broad use of the term "family" reflects a recognition of the fact that often those with most knowledge and concern for a patient are not relatives by blood or marriage.<sup>20</sup> Although more than one person may fall within this category, it will be necessary to designate one person as the principal decisionmaker for the incapacitated patient. One possibility is to define presumptive priority<sup>21</sup>—for example, that a person living with his or her spouse will speak for that spouse, that adult children will speak for elderly, widowed parents, etc. Although such presumptions may be helpful in some cases, the Commission believes that the health care practitioner is responsible for determining who should act as the patient's surrogate. No neat formulas will capture the complexities involved in determining who among a patient's friends and relatives knows the patient best and is most capable of making decisions in the patient's place. The responsibility is therefore on the practitioner either to assign this role of spokesperson (subject to appropriate institutional review) or to seek judicial appointment of a guardian.

The Commission believes that, for several reasons, a family member ought usually to be designated as surrogate to make health care decisions for an incapacitated patient in

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<sup>19</sup> On occasion courts have substituted friends as decisionmakers for incompetent patients, even over the protest of available family members. See, e.g., George F. Will, *A Trip Toward Death*, **NEWSWEEK** 72 (Aug. 31, 1982) (an account of a California couple's attempt to gain custody, instead of the natural parents, of an institutionalized teenager with Down Syndrome), and the case involving Sharon Siebert, see note 29. Chapter Seven *infra*.

<sup>20</sup> We have had situations where the only family member was a daughter on the West Coast who had not seen her father for the last 20 years.

He had lived with a drinking buddy of his for the last 20 years. Do we ignore this friend of his whose actions show that he cared also about him? Do we rely on the daughter who has no relationship in terms of interest in this patient? Often there are no family members at all, yet there may be friends and associates who knew the patient well. Do we ignore them because they do not constitute the traditional concept of family?

Testimony of David Spackman, J.D., transcript of 10th meeting of the President's Commission (June 4, 1981) at 83.

<sup>21</sup> See, e.g., Uniform Probate Code § 5-410.

consultation with the physician and other health care professionals<sup>22</sup>:

- (1) The family is generally most concerned about the good of the patient.
- (2) The family will also usually be most knowledgeable about the patient's goals, preferences, and values.
- (3) The family deserves recognition as an important social unit that ought to be treated, within limits, as a responsible decisionmaker in matters that intimately affect its members.
- (4) Especially in a society in which many other traditional forms of community have eroded, participation in a family is often an important dimension of personal fulfillment.
- (5) Since a protected sphere of privacy and autonomy is required for the flourishing of this interpersonal union, institutions and the state should be reluctant to intrude, particularly regarding matters that are personal and on which there is a wide range of opinion in society.

The presumption that a family spokesperson is the appropriate surrogate may be challenged for any of a number of reasons: decisional incapacity of family members, unresolvable disagreement among competent adult members of the family about the correct decision, evidence of physical or psychological abuse or neglect of the patient by the family, an indication that the family's interests conflict substantially with the patient's, or evidence that the family intends to disregard the patient's stable values, preferences, or specific earlier instructions about treatment.<sup>23</sup> Even if all family members are disqualified from being the principal decisionmaker, for one or

<sup>22</sup> See Richard A. McCormick and Robert M. Veatch, *The Preservation of Life and Self-Determination*, 41 THEOLOGICAL STUDIES 390 (June 1980).

<sup>23</sup> Although the majority of court cases brought on behalf of incompetent patients have involved closely related family members, one court noted the problems that might arise when defining the "family" for such purposes. In the combined appeal of *Storar* and *Eichner*, the majority criticized the "dissent which has abstractly endorsed the right of third parties, at least family members, to adopt a course of 'passive euthanasia' with respect to fatally ill incompetents.... Presumably this right could only be exercised by family members, thus imposing a 'restriction' which itself is open-ended, reaching to the limits of the family tree." *In re Storar*, 420 N.E.2d 64, 67 n.2 (N.Y. 1981), *rev'g In re Storar*, 433 N.Y.S.2d 388 (App. Div. 1980) and *modifying Eichner v. Dillon*, 426 N.Y.S.2d 527 (App. Div. 1980). Usually families appearing before courts have been unanimous in their agreement that treatment should be foregone. *But see, In re Nemser*, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966) (disagreement over amputation for 80-year-old mother, with physician son opposing

more of these reasons, it may still be appropriate to consult with the family in the decisionmaking process.

When an incapacitated patient has no family but does have a court-appointed guardian, special issues arise. Although the reasons for having an existing guardian act as the surrogate for medical decisions are weaker when the guardian is a stranger,<sup>24</sup> such a guardian should be the surrogate in the absence of disqualifying factors.<sup>25</sup> Since the guardian is likely to have been making a number of other decisions for the patient, he or she may have acquired a knowledge of the patient's beliefs, concerns, and values. In addition, the guardian has the sanction of court authority, which may ameliorate practitioners' concerns about civil liability. The decisions of court-appointed guardians about matters of importance to an incompetent person are usually subject to review and prior approval or disapproval by the court. Even when such oversight is not required, physicians should have greater leeway to seek to have the decisions of nonfamily guardians overridden than they do for the decisions of family surrogates, whose judgment should be accorded greater discretion.

If no family or legal guardian is initially available, a suitable surrogate decisionmaker should be designated to ensure a clear assignment of authority for decisionmaking and of responsibility for the exercise of this authority. Unless a suitable surrogate decisionmaker is identified, treatment decisions may lack continuity or may rest on an unclear foundation, making it difficult if not impossible to ensure that the process by which decisions are made is ethically and legally sound.

Although the concept of designating a surrogate for an individual who has no family is clearly sound, in practice there often are no appropriate individuals or agencies available to serve as surrogates. In the context of making decisions about life-sustaining treatment, this is likely to be an especially prevalent problem because of the large number of elderly patients with no family or friends available. One attorney, testifying before the Commission, commented that

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treatment and lawyer son in favor). *See also* Rhonda J. V. Montgomery, *Impact of Institutional Care Policies on Family Integration*, 22 *THE GERONTOLOGIST* 54 (1982).

<sup>24</sup> If the guardian had been nominated by the patient prior to his or her incapacitation, he or she would almost always be included in the definition of family used here.

<sup>25</sup> Allen E. Buchanan. *Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Soikewicz-type Cases*, 5 *AM. J.L. & MED.* 97, 111 (1979). If an incapacitated patient has both a competent family and a legal guardian, they should function together as principal decisionmakers to the extent permitted by local law, and family members should know that they can challenge the guardian in court.

the undeniable tragic fact of the matter is that many, many people, into the thousands, do not have a brother or sister, a mother, a parent, a daughter, or son who can be appointed guardian. There isn't anybody. A lot of them are in institutions, and with the deinstitutionalization process, a lot are now in the community. And there isn't a person to appoint. And we have run out of volunteers.<sup>26</sup>

In some states, public guardianship agencies have been established, but they are underfunded and understaffed and quickly become overburdened with responsibility.<sup>27</sup> Proposals have also been made to establish private, nonprofit social service corporations to provide guardianship services, though they would ordinarily have to rely on public funding unless limited to patients with substantial estates.<sup>28</sup> Regardless of the source of payment, the estimated cost is very high.<sup>29</sup>

In addition, the logistics of having a guardian appointed are quite cumbersome. The head of a corporate guardianship endeavor described the legal process by which guardians have traditionally been appointed as "woefully medieval and oftentimes not worthy of the description of a legal hearing."<sup>30</sup> Another witness stated that in one large American city, it can often take up to eight months to have a guardian appointed, other than for emergency treatment.<sup>31</sup>

Whether or not the selection of a surrogate decisionmaker requires judicial proceedings is an issue that has not been faced squarely by many courts. The New Jersey Supreme Court upheld the appointment of Karen Quinlan's father as her guardian, thus confirming the notion that a close relative is an

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<sup>26</sup> Testimony of Paul Rogers, transcript of 10th meeting of the President's Commission (June 4, 1981) at 106.

<sup>27</sup> John J. Regan, *Protective Services for the Elderly: Commitment, Guardianship, and Alternatives*, 13 *WM. & MARY L. REV.* 569, 609-12 (1972); Rogers, *supra* note 26, at 107; Maureen Morrissey, *Guardians Ad Litem: An Educational Program in Virginia*, 22 *THE GERONTOLOGIST* 301 (1982).

<sup>28</sup> Testimony of Frank Repenseck, Director, Dade County Guardianship Program, transcript of 8th meeting of the President's Commission (April 9, 1981) at 187-204; Rogers, *supra* note 26, at 107.

<sup>29</sup> The estimated cost given to the Commission for a proposed "corporate" guardianship service in Massachusetts was \$3100 per patient per year at 1981 prices. Rogers, *supra* note 26, at 109.

<sup>30</sup> *Id.*, at 104. See also George J. Alexander, *Premature Probate: A Different Perspective on Guardianship for the Elderly*, 31 *STAN. L. REV.* 1003 (1979).

<sup>31</sup> Testimony of Dr. Marianne Prout, transcript of 10th meeting of the President's Commission (June 4, 1981) at 12. This witness testified that a temporary guardian can be appointed in an emergency within a few hours, though even that delay is often detrimental to patient care.

appropriate surrogate, but it did not explicitly pass on the issue of whether or not the surrogate must be court-designated.<sup>32</sup> By contrast the Massachusetts Supreme Judicial Court, in a series of cases, has insisted that a court-appointed guardian generally be named as surrogate for a patient who lacks decisional capacity (subject to direct judicial oversight on appropriate matters), at least when the patient has no family members who are willing and available to participate in the decisionmaking process.<sup>33</sup>

Although all states have statutory provisions allowing the appointment of guardians, none of the statutes deal with whether a person who makes a decision to forego life-sustaining treatment on behalf of another must first obtain sanction from a court to act as decisionmaker. When family members are available and the patient is terminally ill, no court has required judicial appointment of a family member to act as surrogate, although the issue has not yet been presented in this way. In *Dinnerstein*,<sup>34</sup> the Appeals Court of Massachusetts held that the court need not review an order against resuscitation for a "hopeless" patient with loving family. Other judicial cases involving life-sustaining treatment have usually been brought to court on an application for the appointment of a guardian, or on an application of an individual to be appointed guardian for the express purpose of making a decision to forego treatment.<sup>35</sup> In other words, the question of whether a judicially appointed guardian is necessary in all such cases has been sidestepped, and courts have instead considered whether a particular individual is suited to be a guardian and/or whether treatment can be discontinued.

In the Commission's view, the cumbersomeness and costs of legal guardianship strongly militate against its use and ought to be taken into account by lawmakers before they require that decisions about life-sustaining treatment be made by judicially appointed guardians. Yet where the law or the patient's situation clearly requires a judicially appointed guardian, the Commission recommends that provision be made for the establishment of adequate guardianship services. In light of the gap in the law as to when and whether guardians are necessary, the Commission recommends that health care institutions should have policies for the designation of a

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<sup>32</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

<sup>33</sup> See *Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601, 607-09 (1982); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977). See also pp. 153-57 *infra*.

<sup>34</sup> *In re Dinnerstein*, 380 N.E.2d 134 (Mass. App. Ct. 1978).

<sup>35</sup> See, e.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976); *State Department of Human Services v. Northern*, 563 S.W.2d 197 (Tenn. Ct. App. 1978).

surrogate and should be responsible both for providing surrogates for patients who have no close family and for appropriate referral of disputed cases to court.

**Substantive Principles of Surrogate Decisionmaking.** The procedures for decisionmaking on behalf of incapacitated patients—whether they are established by common practice, courts, or legislatures and whether they require formal adjudication or defer to physician judgment—do nothing more than designate the centers for responsibility and the processes to be followed. Knowing what issues to take into account or what weight to give potentially conflicting interests is still necessary for the surrogate who is trying to make morally justified decisions.

The two values that guide decisionmaking for competent patients—promoting patient welfare and respecting patient self-determination—should also guide decisionmaking for incapacitated patients, though their implementation must differ. These values are reflected, roughly speaking, in the two standards that have traditionally guided decisionmaking for the incapacitated: "substituted judgment" and "best interests." Although these standards are now used in health care situations, they have their origins in a different context—namely, the resolution of family disputes and decisions about the control of the property of legal incompetents. These doctrines were developed to instruct guardians about the boundaries of their powers and to provide a standard for guidance of courts that must review decisions proposed or made by a guardian.<sup>36</sup>

Despite the long legal history of both these standards, they provide only hazy guidance for decisionmaking even in their original contexts, not to mention in the often far more complex, urgent, and personal setting of health care. Although a number of recent cases involving decisions about health care for incapacitated patients have given courts the opportunity to clarify their meanings, increased confusion has actually resulted from some of these attempts to add precision to the doctrines.

**Substituted judgment.** The substituted judgment standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose.<sup>37</sup> As a result, the patient's own definition of "well-being" is respected; indeed, the patient's interest in "self-

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<sup>36</sup> See generally A.M. Capron, *The Authority of Others to Decide about Biomedical Interventions with Incompetents*, in Gaylin and Macklin, *supra* note 5, at 115,119-133; Lawrence A. Frolik, *Plenary Guardianship: An Analysis, a Critique, and a Proposal for Reform*, 23 *ARIZ. L. REV.* 599 (1981).

<sup>37</sup> For example, the substituted judgment doctrine permits a surrogate to make a gift of some of an incompetent's assets to a relative to whom the incompetent person had previously made gifts. The court

determination" is preserved to a certain extent, given the fundamental reality that the patient is incapable of making a valid contemporaneous choice.

A surrogate's decision is limited, however, by two general external constraints. First, the surrogate is circumscribed by the same limitations that society legitimately imposes on patients who are capable of deciding for themselves, such as not compromising public health (as in refusing a mandatory vaccination) or not taking steps contrary to the criminal law (for example, through intentional maiming). Second, there are certain decisions that a patient might be permitted to make because of the strong protection afforded self-determination but that are outside the discretion of a substitute decisionmaker. The line is drawn at actions whose potential adverse effects on well-being, as that concept is commonly understood, are so great that they can be permitted only when sufficiently directly chosen by a competent patient. For example, people may choose for themselves not to have a life-sustaining blood transfusion, but a similar decision by a surrogate would require no direct confirmation of the patient's goals and values than a generally expressed disinclination to receive transfusions. Thus even the substituted judgment standard—which is considered "subjective"—is constrained by limitations arising from the inescapable uncertainty of the evidence as to patients' competent preferences and from the significance and irreversibility of the particular medical decisions.

The substituted judgment standard can be used only if a patient was once capable of developing views relevant to the matter at hand; further, there must be reliable evidence of those views. From an ethical perspective—and probably from the perspective of evidentiary adequacy in court as well—the best proof is the patient's prior expression of views about the current medical situation, particularly when abstract statements have been substantiated by choices by the person in similar situations.<sup>38</sup> For example, a person who has repeatedly

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will approve such a gift to the extent that it does not endanger funds needed for the incompetent's support—even if the incompetent person would have been willing to be more generous.

<sup>38</sup> For example, the New Jersey Supreme Court refused to give weight to statements Karen Ann Quinlan was reported to have made about her "distaste for continuance of life by extraordinary medical procedures, under circumstances not unlike those of the present case." Despite the fact that "she was said to have firmly evinced her wish," the court would not consider them because "they were remote and impersonal, [and] lacked significant probative weight." *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 653, cert. denied, 429 U.S. 922 (1976). In contrast, the New York Court of Appeals accepted the prior competent statements, made in the context of a discussion of the moral implications of the *Quinlan* case and in associated classroom teaching, of a religious brother whose medical condition paralleled Quin-

been willing to undergo painful treatments in order to live long enough to see his or her children grow up is likely to want to do so again as long as that goal might be realized. While decisions may be based on a patient's general values, goals, and desires, courts are more likely to honor written statements (such as a "living will") than oral ones because they make it plainer that the person actually expressed the views in question and that the statements were specifically intended to direct what should be done for the individual in certain situations.

In some cases, although a patient lacks the capacity to make a contemporaneous decision about foregoing treatment and may even have been declared legally incompetent, he or she may still express a view about treatment, and surrogates should evaluate the relevance of such statements when making a substituted judgement.<sup>39</sup>

**Best interests.** Because many people have not given serious thought to how they would want to be treated under particular circumstances, or at least have failed to tell others their thoughts, surrogates often lack guidance for making a substituted judgment. Furthermore, some patients have never been competent; thus, their subjective wishes, real or hypothetical, are impossible to discern with any certainty.<sup>40</sup> In these situations, surrogate decisionmakers will be unable to make a valid substituted judgment; instead, they must try to make a choice for the patient that seeks to implement what is in that

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lan's. Brother Fox had said that "he would not want any of this 'extraordinary business' done for him under those circumstances." *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 68 (1981).

<sup>39</sup> This endeavor is especially difficult when the person expresses inconsistent or contradictory views or holds views that fluctuate over time. *See State Dept. of Human Services v. Northern*, 563 S.W.2d 197 (Tenn. Ct. App. 1978), involving an elderly woman suffering from gangrene who refused to consent to the amputation of her gangrenous feet, a procedure her physicians believed necessary to save her life. Despite the fact that she was, as described by the court, "an intelligent, lucid, communicative and articulate individual," she did not "accept the fact of the serious condition of her feet and [was] unwilling to discuss the seriousness of such condition or its fatal potentiality." Furthermore, the woman "had no wish to die." *Id.* at 205. Thus, the inconsistency of her views was that she both wanted to continue to live and to retain her feet, a position that was most untenable in light of the medical evidence. The court determined that this evidenced incapacity regarding the treatment decision and ordered the amputation.

<sup>40</sup> Allen E. Buchanan, *The Limits of Proxy Decision Making for Incompetents*, 29 U.C.L.A. L. REV. 393 (1981); John A. Robertson, *Legal Criteria for Orders Not to Resuscitate: A Response to Justice Liacos*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, AUPHA Press, Ann Arbor, Mich. (1982) at 159-63. *See also, In re Storar*, 52 N.Y.2D 363, 420 N.E.2d 64 (1981).

person's best interests by reference to more objective, societally shared criteria." Thus the best interests standard does not rest on the value of self-determination but solely on protection of patients' welfare.<sup>42</sup>

In assessing whether a procedure or course of treatment would be in a patient's best interests, the surrogate must take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained.<sup>43</sup> An accurate assessment will encompass consideration of the satisfaction of present desires, the opportunities for future satisfactions, and the possibility of developing or regaining the capacity for self-determination.

The impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates.<sup>44</sup>

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<sup>41</sup> The best interests doctrine has received most attention in law in cases involving questions of the custody and care of children, see generally 2 C.J.S. Adoption of Persons §§ 90-91 (1972), and in cases involving the expenditure of trust funds, *see generally* 76 AM. JUR. 2D, Trusts § 288 (1975), neither of which are likely to be accurate guides to understanding how the standard ought to operate in instances of surrogate health care decisionmaking for adults who lack decision-making capacity.

For a discussion of the best interests standard, see Joel Feinberg, RIGHTS, JUSTICE, AND THE BOUNDS OF LIBERTY, Princeton Univ. Press, Princeton, N.J. (1980); Ruth Macklin, Return to the Best Interests of the *Child*, in Gaylin and Macklin, *supra* note 5, at 265; Capron, *supra* note 36; Joseph Goldstein, Anna Freud, and Albert J. Solnit, BEYOND THE BEST INTERESTS OF THE CHILD, The Free Press, New York (1979).

<sup>42</sup> This does not mean the surrogate must choose the means that an individual physician believes is most likely to benefit the patient maximally but only that the surrogate must have reason to believe that the patient will be maximally benefitted. When multiple therapies have different risks, collateral effects, and degrees of success, the surrogate should try to weigh these reasonably and the surrogate's decision should be honored as long as a significant proportion of physicians would agree, whether or not this particular physician does. However, the best interests standard would preclude the surrogate from choosing a therapy that is professionally unacceptable, even if the surrogate might choose that treatment for him or herself.

<sup>43</sup> The phrase "quality of life" has been used in differing ways; sometimes it refers to the value that the continuation of life has for the patient, and other times to the value that others find in the continuation of the patient's life, perhaps in terms of their estimates of the patient's actual or potential productivity or social contribution. In applying the best interest principle, the Commission is concerned with the value of the patient's life for the patient.

<sup>44</sup> In the context of a decision about the forcible administration of antipsychotic medication, the Massachusetts Supreme Court counted the

To avoid abuse, however, especially stringent standards of evidence should be required to support a claim that the average, reasonable person in the patient's position would disregard personal interests (for example, in prolonging life or avoiding suffering) in order to avoid creating emotional or financial burdens for their family or other people to whom they were close.<sup>45</sup>

***The recommended standard.*** The Commission believes that, when possible, decisionmaking for incapacitated patients should be guided by the principle of substituted judgment, which promotes the underlying values of self-determination and well-being better than the best interests standard does. When a patient's likely decision is unknown, however, a surrogate decisionmaker should use the best interests standard and choose a course that will promote the patient's well-being as it would probably be conceived by a reasonable person in the patient's circumstances. On certain points, of course, no consensus may exist about what most people would prefer, and surrogates retain discretion to choose among a range of acceptable choices.

### **Advance Directives**

An "advance directive" lets people anticipate that they may be unable to participate in future decisions about their own health care—an "instruction directive" specifies the types of care a person wants (or does not want) to receive; a "proxy directive" specifies the surrogate a person wants to make such decisions if the person is ever unable to do so<sup>46</sup>; and the two forms may be combined. Honoring such a directive shows respect for self-determination in that it fulfills two of the three values that underlie self-determination. First, following a directive, particularly one that gives specific instructions about

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"impact upon the ward's family" as one of six factors to be considered in reaching a substituted judgment:

An individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment, would likely have on his family. Such a factor is likewise to be considered in determining the probable wishes of one who is incapable of formulating or expressing them himself. In any choice between proposed treatments which entail grossly different expenditures of time or money by the incompetent's family, it would be appropriate to consider whether a factor in the incompetent's decision would have been the desire to minimize the burden on his family.

In *re* Richard Roe III, 421 N.E.2d 40, 58 (Mass. 1981).

<sup>46</sup> *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

<sup>48</sup> This Report uses "proxy" to mean a surrogate whose appointment rests on the designation of the patient while competent.

type of acceptable and unacceptable interventions, fulfills the instrumental role of self-determination by promoting the patient's subjective, individual evaluation of well-being. Second, honoring the directive shows respect for the patient as a person.

An advance directive does not, however, provide self-determination in the sense of active moral agency by the patient on his or her own behalf. The discussion between patient and health care professional leading up to a directive would involve active participation and shared decisionmaking, but at the point of actual decision the patient is incapable of participating. Consequently, although self-determination is involved when a patient establishes a way to project his or her wishes into a time of anticipated incapacity, it is a sense of self-determination lacking in one important attribute: active, contemporaneous personal choice. Hence a decision not to follow an advance directive may sometimes be justified even when it would not be acceptable to disregard a competent patient's contemporaneous choice. Such a decision would most often rest on a finding that the patient did not adequately envision and consider the particular situation within which the actual medical decision must be made.

Advance directives are not confined to decisions to forego life-sustaining treatment but may be drafted for use in any health care situation in which people anticipate they will lack capacity to make decisions for themselves. However, the best-known type of directive—formulated pursuant to a "natural death" act—does deal with decisions to forego life-sustaining treatment. Beginning with the passage in 1976 of the California Natural Death Act, 14 states and the District of Columbia have enacted statutory authorization for the formulation of advance directives to forego life-sustaining treatment (see Figure 1).<sup>47</sup> In addition, 42 states have enacted "durable power of attorney" statutes; though developed in the context of law concerning property, these statutes may be used to provide a legal authority for an advance directive (see Figure 1).<sup>48</sup>

Despite a number of unresolved issues about how advance directives should be drafted, given legal effect, and used in clinical practice, the Commission recommends that advance directives should expressly be endowed with legal effect under

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<sup>47</sup> Appendix D, pp. 309-87 *infra*. One of these states, Virginia, has a statute awaiting the Governor's signature as of March 17, 1983. See also Michael Garland, *Politics, Legislation and Natural Death*, 6 *HASTINGS* CTR. REP. 5 (Oct. 1976); Richard A. McCormick and Andre Hellegers, *Legislation and the Living Will*, 136 *AMERICA* 210 (1977); Barry Keene, *The Natural Death Act: A Well-Baby Check-up on Its First Birthday*, 315 *ANNALS N.Y. ACAD. SCI.* 376 (1978).

<sup>48</sup> Appendix E, pp. 389-437 *infra*. In one additional state, Louisiana, all powers of attorney are durable unless otherwise specified.

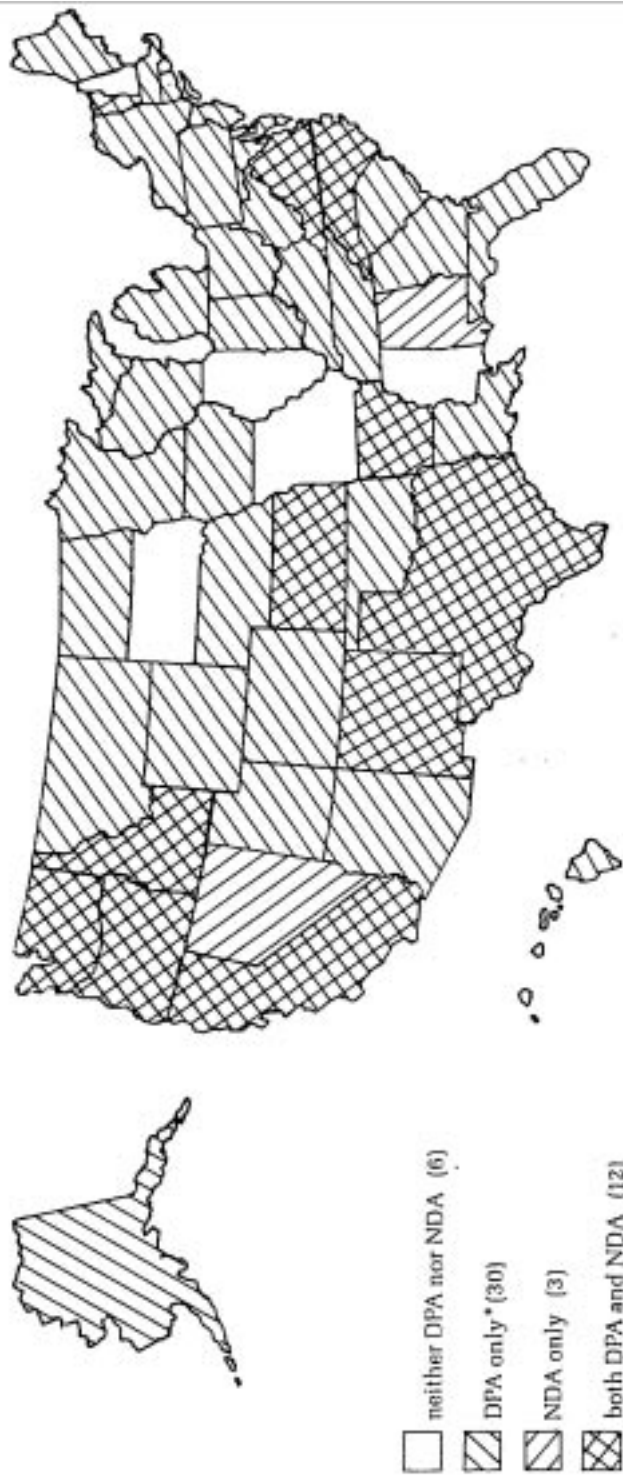


Figure 1: "Natural Death" Acts (NDA) and Durable Power of Attorney (DPA) Acts

state law. For such documents to assist decisionmaking, however, people must be encouraged to develop them for their individual use, and health care professionals should be encouraged to respect and abide by advance directives whenever reasonably possible, even without specific legislative authority.

**Existing Alternative Documents.** Several forms of advance directives are currently used. "Living wills" were initially developed as documents without any binding legal effects; they are ordinarily instruction directives. The intent behind the original "natural death" act was simply to give legal recognition to living wills drafted according to certain established requirements. They are primarily instruction directives, although their terms are poorly enough defined that the physician and surrogate who will carry them out will have to make substantial interpretations. "Durable power of attorney" statutes are primarily proxy directives, although by limiting or describing the circumstances in which they are to operate they also contain elements of instruction directives. Furthermore, durable powers of attorney may incorporate extensive personal instructions.

**Living wills.** People's concerns about the loss of ability to direct care at the end of their lives have led a number of commentators as well as religious, educational, and professional groups to promulgate documents, usually referred to as living wills,<sup>49</sup> by which individuals can indicate their preference not to be given "heroic" or "extraordinary" treatments. There have been many versions proposed, varying widely in their specificity. Some explicitly detailed directives have been drafted by physicians—outlining a litany of treatments to be foregone or disabilities they would not wish to suffer in their final days.<sup>50</sup> The model living wills proposed by educational groups have somewhat more general language<sup>51</sup>; they typically mention "life-sustaining procedures which would serve only to artificially prolong the dying process." One New York group has distributed millions of living wills.<sup>52</sup> The columnist who

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<sup>49</sup> *Questions and Answers About the Living Wills* (pamphlet), CONCERN FOR DYING, New York (n.d.).

<sup>50</sup> Walter Modell, A "Will" to Live (Sounding Board), 290 NEW ENG. J. MED. 907 (1974); *Last Rights* (Letters), 295 NEW ENG. J. MED. 1139 (1976); See also Sissela Bok, *Personal Directions for Care at the End of Life*, 295 NEW ENG. J. MED. 367 (1976).

<sup>51</sup> Among the groups that have promulgated living wills are the Society for the Right to Die, the Euthanasia Education Council, the American Protestant Hospital Association, the American Catholic Hospital Association, and the American Public Health Association.

<sup>52</sup> See note 49 *supra*.

writes "Dear Abby" reports receiving tens of thousands of requests for copies each time she deals with the subject.<sup>53</sup> Despite their popularity, their legal force and effect is uncertain.<sup>54</sup> The absence of explicit statutory authorization in most jurisdictions raises a number of important issues that patients and their lawyers or other advisors should keep in mind when drafting living wills.

First, it is uncertain whether health care personnel are required to carry out the terms of a living will; conversely, those who, in good faith, act in accordance with living wills are not assured immunity from civil or criminal prosecution. No penalties are provided for the destruction, concealment, forgery or other misuse of living wills, which leaves them somewhat vulnerable to abuse. The question of whether a refusal of life-sustaining therapy constitutes suicide is unresolved, as are the insurance implications of a patient's having died as a result of a physician's withholding treatment pursuant to a living will.

Yet even in states that have not enacted legislation to recognize and implement advance directives, living wills may still have some legal effect.<sup>55</sup> For example, should a practitioner be threatened with civil liability or criminal prosecution for having acted in accord with such a document, it should at least serve as evidence of a patient's wishes and assessment of benefit when he or she was competent.<sup>56</sup> Indeed, no practitioner has been successfully subjected to civil liability or criminal prosecution for having followed the provisions in a living will,

<sup>53</sup> Letter from Abigail van Buren to Joanne Lynn (Sept. 10, 1981). Ann Landers reports similar public enthusiasm. Letter from Ann Landers to Joanne Lynn (Sept. 16, 1981).

<sup>54</sup> For a discussion of the legal effects of living wills, see Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 *IND. L. J.* 539, 552 (1969); Michael T. Sullivan, *The Eying Person—His Plight and His Right*, 8 *NEW ENG. L. REV.* 197, 215 (1973); Comment, *Antidysthansia Contracts: A Proposal for Legalizing Death With Dignity*, 5 *PAC. L.J.* 738, 739-40 (1974); Note, *The 'Living Will'? The Right to Death With Dignity?*, 26 *CASE W. RES. L. REV.* 485, 509-526 (1976); Note, *Informed Consent and the Dying Patient*, 83 *YALE L.J.* 1632, 1663-64 (1974); Note, *The Right to Die*, 10 *CAL. W.L. REV.* 613, 625 (1974).

<sup>55</sup> See Note, *Living Wills—Need for Legal Recognition*, 78 *W. VA. L. REV.* 370 (1976); See also, *In re Storar*, 52 *N.Y.2d* 363, 420 *N.E.2d* 64 (1981) (on reliance on oral advance directives with burden of proof being clear and convincing evidence).

<sup>56</sup> See Kutner, *supra* note 54; Note, *The "Living Will": The Right to Death with Dignity?*, *supra* note 54; David J. Sharpe and Robert F. Hargest, *Lifesaving Treatment for Unwilling Patients*, 36 *FORDHAM L. REV.* 695, 702 (1968).

nor do there appear to be any cases brought for having acted against one.<sup>57</sup>

**Natural death acts.** To overcome the uncertain legal status of living wills,<sup>58</sup> 13 states and the District of Columbia have followed the lead set by California in 1976 and enacted statutes that formally establish the requirements for a "directive to physicians."<sup>59</sup> The California statute was labeled a "natural death" act and this term is now used generically to refer to other state statutes. Although well-intended, these acts raise a great many new problems without solving many of the old ones.

No natural death act yet deals with all the issues raised when living wills are used without specific statutory sanction. For instance, the acts differ considerably in their treatment of penalties for failing to act in accord with a properly executed directive or to transfer the patient to a physician who will follow the directive.<sup>60</sup> In some jurisdictions, the statutes consider these failures to be unprofessional conduct and therefore grounds for professional discipline, including the suspension of a license to practice medicine.<sup>61</sup> Other statutes fail to address the issue; presumably, however, existing remedies such as injunctions or suits for breach of contract or for battery are available to patients or their heirs,<sup>62</sup> although

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<sup>57</sup> A UPI study, reported in *The Right to Die*, 12 TRIAL (Jan. 1976), stated that no living will had been tested in the courts. None since has come to the Commission's attention.

<sup>58</sup> See Note, *Living Wills—Need for Legal Recognition*, 78 W. VA. L. REV. 370, 377 (1976); Note, *The "Living Will": The Right to Death With Dignity?*, *supra* note 54, at 525-26.

<sup>59</sup> See note 47 *supra*.

<sup>60</sup> Like most provisions of the statutes, the requirement that the physician who refuses to comply must effectuate a transfer to another physician has not been tested. Such a transfer might at times be very difficult and a "good faith" effort might be the appropriate standard rather than the actual transfer.

<sup>61</sup> The California statute stipulates that a physician's failure to effectuate a binding, though not a merely advisory, directive, or to transfer the patient to another physician who will effectuate the directive of the qualified patient, shall constitute unprofessional conduct. See Appendix D, pp. 324-29 *infra*. The Texas statute weakens this penalty by stipulating that such a failure *may* constitute unprofessional conduct. See Appendix D, pp. 368-73 *infra*. The statutes of Kansas and the District of Columbia, which do not contain the binding/advisory distinction, provide that the failure to properly transfer a patient when the physician cannot comply with a valid advance directive shall constitute unprofessional conduct. See Appendix D, pp. 345-49 335-40 *infra*. The statutes of the remaining states make no explicit provision for penalties for physicians who do not comply with valid advance directives or transfer patients to physicians who will effectuate the directives. See Table D1, pp. 310-12 *infra*.

<sup>62</sup> See Michigan House Bill No. 4492 (March 26, 1981), Appendix E, pp.

there do not appear to be any instances of such penalties being sought.

Some of the statutes attempt to provide patients with adequate opportunity to reconsider their decision by imposing a waiting period between the time when a patient decides that further treatment is unwanted and the time when the directive becomes effective. Under the California statute, for example, a directive is binding only if it is signed by a "qualified patient," technically defined as someone who has been diagnosed as having a "terminal condition." This is defined as an incurable condition that means death is "imminent" regardless of the "life-sustaining procedures" used.<sup>63</sup> A patient must wait 14 days after being told of the diagnosis before he or she can sign a directive, which would require a miraculous cure, a misdiagnosis, or a very loose interpretation of the word "imminent" in order for the directive to be of any use to a patient. The statute requires that when a directive is signed, the patient must be fully competent and not overwhelmed by disease or by the effects of treatment, but a study of California physicians one year after the new law was enacted found that only about half the patients diagnosed as terminally ill even remain conscious for 14 days.<sup>64</sup> There is an inherent tension between ensuring that dying patients have a means of expressing their wishes about treatment termination before they are overcome by

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431-37 *infra*, which provides for the appointment of an agent for medical decisionmaking and presents an approach to physician penalties that is worth considering. Section 12(2) states:

A physician or other health care professional acting under the direction of a physician who fails to observe a refusal of medical treatment or a request for continued medical treatment by an agent shall be legally liable in the same manner and degree as would have been the case if the appointor had been capable of making the decision and had refused or requested the treatment in his or her own right under similar circumstances.

*See also* Bruce L. Miller, *Michigan Medical Treatment Decision Act*, in Cynthia B. Wong and Judith P. Swazey, *DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT*, G.K. Hall Med. Pub., Boston (1981) at 161.

<sup>63</sup> Cal. Health & Safety Code §§ 7187(e), 7191(b) (Deering Supp. 1982), Appendix D, pp. 324-29 *infra*.

<sup>64</sup> Note, *The California Natural Death Act: An Empirical Study of Physicians' Practices*, 31 STAN. L. REV. 913, 928 (1979). Only two of the statutes passed since California's have followed that state's lead on these provisions. Although they differ in details, both Oregon and Texas treat only those directives executed after the patient has been informed that he or she has a terminal illness as "conclusively presumptive" of the patient's desires regarding the withholding or withdrawal of life-sustaining procedures. *See* Appendix D, pp. 362-68, 368-73 *infra*.

incompetence and ensuring that people do not make binding choices about treatment on the basis of hypothetical rather than real facts about their illness and dying process. If a waiting period is deemed necessary to resolve this tension the time should be defined in a way that does not substantially undercut the objective of encouraging advance directives by people who are at risk of becoming incapacitated.

Although the California statute was inspired in part by the situation of Karen Quinlan, whose father had to pursue judicial relief for a year in order to authorize the removal of her respirator, it would not apply in a case like hers.

The only patients covered by this statute are those who are on the edge of death *despite the doctors' efforts*. The very people for whom the greatest concern is expressed about a prolonged and undignified dying process are unaffected by the statute because their deaths are not imminent.<sup>65</sup>

The class of persons thus defined by many of the statutes,<sup>66</sup> if it indeed contains any members, at most constitutes a small percentage of those incapacitated individuals for whom decisions about life-sustaining treatment must be made. Although some statutes have not explicitly adopted the requirement that treatments may be withheld or withdrawn only if death is imminent whether or not they are used,<sup>67</sup> this requirement is still found in one of the most recently passed natural death acts.<sup>68</sup> Such a limitation greatly reduces an act's potential.

Some of the patients for whom decisions to forego life-sustaining treatment need to be made are residents of nursing homes rather than hospitals. Concerned that they might be under undue pressure to sign a directive, the California legislature provided additional safeguards for the voluntariness of their directives by requiring that a patient advocate or ombudsman serve as a witness.<sup>69</sup> The Commission believes that health care providers should make reasonable efforts to involve disinterested parties, not only as witnesses to the

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<sup>65</sup> A.M. Capron, *The Development of Law on Human Death*, 315 ANNALS N.Y. ACAD. SCI. 45,55 (1978).

<sup>66</sup> See state statutes for Alabama, California, Delaware, the District of Columbia, Idaho, Kansas, New Mexico, Oregon, Texas, Vermont, and Washington in Appendix D, pp. 318-49, 353-57, 362-77, 382-87 *infra*.

<sup>67</sup> See Table D1 pp. 310-12 *infra*.

<sup>68</sup> Del. Code Ann. tit. 16, § 2501(e) (1982), Appendix D, pp. 330-35 *infra*.

<sup>69</sup> The California statute, Appendix D, pp. 324-29 *infra*, refers to a patient advocate or ombudsman "as may be designated by the State Department of Aging for this purpose pursuant to any other applicable provision of law." A companion statute providing for such a service was not approved by the legislature, however, precluding residents of California nursing homes effectively from making valid directives. See Capron, *supra* note 65, at 56.

signing of a directive under a natural death act, but also as counselors to patients who request such a directive to ensure that they are acting as voluntarily and competently as possible. Yet statutory requirements of this sort may have the effect of precluding use of advance directives by long-term care residents, even though some residents of these facilities might be as capable as any other persons of using the procedure in a free and knowing fashion.

Paradoxically, natural death acts may restrict patients' ability to have their wishes about life-sustaining treatment respected. If health care providers view these as the exclusive means for making and implementing a decision to forego treatment and, worse, if they believe that such a decision cannot be made by a surrogate on behalf of another but only in accordance with an advance directive properly executed by a patient, some dying patients may be subject to treatment that is neither desired nor beneficial. In fact, although 6.5% of the physicians surveyed in California reported that during the first year after passage of the act there they withheld or withdrew procedures they previously would have administered, 10% of the physicians reported that they provided treatment they formerly would have withheld.<sup>70</sup>

In addition, there is the danger that people will infer that a patient who has not executed a directive in accordance with the natural death act does not desire life-sustaining treatment to be ended under any circumstances.<sup>71</sup> Yet the person may fail to sign a directive because of ignorance of its existence, inattention to its significance, uncertainty about how to execute one, or failure to foresee the kind of medical circumstances that in fact develop.<sup>72</sup> Unfortunately, even the explicit disclaimer contained in many of these laws — that the act is not intended to impair or supersede any preexisting common-law legal rights or responsibilities that patients and practitioners may have with respect to the withholding or withdrawing of

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<sup>70</sup> Note, *supra* note 64, at 938-39.

<sup>71</sup> McCormick and Hellegers, *supra* note 47. McCormick has since withdrawn his opposition to "living will" legislation, despite continuing concern with overtreatment of those who have not signed.

Our experience of recent rulings by the...Courts on the need for legislative direction on these questions, and the fact that an overwhelming number of physicians, attorneys and legislation continue to believe an individual's statement has no legitimacy without a statutory enactment, force us to revise our previous opposition to this legislation.

John J. Paris and Richard A. McCormick, *Living-Will Legislation, Reconsidered*, 145 AMERICA 86,86-87 (1981).

<sup>72</sup> Leon R. Kass, *Ethical Dilemmas in the Care of the Ill:II. What is the Patient's Good?*, 244 J.A.M.A. 1946,1948 (1980).

life-sustaining procedures— does not in itself correct this difficulty.

First, the declarations about the right of competent patients to refuse "life-sustaining procedures" take on a rather pale appearance since such procedures are defined by the statutes as those that cannot stop an imminent death. (In other words, competent patients may refuse futile treatments.) Second, it is hard to place great reliance on preexisting common law rights, since had the common law established such rights there would have been no real need for the statutes. Thus, if health care providers are to treat patients appropriately in states that have adopted natural death acts, they will need the encouragement of their attorneys— backed by sensible judicial interpretation of the statutes— to read the acts as authorizing a new, additional means for patients to exercise "informed consent" regarding life-saving treatment, but not as a means that limits decisionmaking of patients who have not executed binding directives pursuant to the act.

The greatest value of the natural death acts is the impetus they provide for discussions between patients and practitioners about decisions to forego life-sustaining treatment.<sup>73</sup> This educational effect might be obtained, however, without making the documents binding by statute and without enforcement and punishment provisions.

***Durable power of attorney statutes.*** Of the existing natural death acts, only Delaware's explicitly provides for the appointment of an agent for medical decisionmaking if the patient becomes incapacitated.<sup>74</sup> In view of the Commission's conclusion that both instruction and proxy directives are important for medical decisionmaking that respects patients' wishes, this deficiency in the other statutes constitutes a serious shortcoming. Proxy directives allow patients to control decisionmaking in a far broader range of cases than the instruction directives authorized by most existing natural death acts.

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<sup>73</sup> A California Medical Association study of the effects of the California Natural Death Act, conducted one year after it went into effect, emphasized that "the Act has been a positive force in encouraging patients and their families to discuss the subject of terminal illness." Murray Klutch, *Survey Result After One Year's Experience With the National Death Act*, 128 WEST. J. MED. 329, 330 (1978).

<sup>74</sup> Del. Code Ann. tit. 16, § 2502(b) (1982). In the 1981 legislative session in Michigan, House Bill No. 4492 contained provisions designed to authorize the appointment of an agent for medical decisionmaking. See Appendix D, pp. 330-35 *infra*.

Nonetheless, authority to appoint a proxy to act after a person becomes incompetent does exist in the 42 states that have laws authorizing durable powers of attorney.<sup>75</sup> A "power of attorney" is a document by which one person (the "principal") confers upon another person (the "agent") the legally recognized authority to perform certain acts on the principal's behalf. For instance, a person who moves to a new city and who leaves behind an automobile for someone else to sell can execute a power of attorney to permit an agent to complete the necessary legal documents in connection with the sale. In this case the power of attorney is a limited one; it gives the agent authority to perform only a specific act—the transfer of title to a particular piece of property. Powers of attorney may also be general, conferring authority on the agent to act on behalf of the principal in all matters. Such actions by agents are as legally binding on principals as if the latter had performed the acts themselves.

A power of attorney—general or limited—may be employed in making decisions not only about property but about personal matters as well, and in this role powers of attorney might be used to delegate authority to others to make health care decisions. A power of attorney, therefore, can be an advance proxy directive. Using it, a person can nominate another to make health care decisions if he or she becomes unable to make those decisions.

One barrier to this use of a power of attorney, however, is that the usual power of attorney becomes inoperative at precisely the point it is needed; a common-law power of attorney automatically terminates when the principal becomes incapacitated.<sup>76</sup> To circumvent this barrier, many states have enacted statutes creating a power of attorney that is "durable"<sup>w</sup>—which means that an agent's authority to act continues after his or her principal is incapacitated. As a result, durable power of attorney acts offer a simple, flexible, and powerful device for making health care decisions on behalf of incapacitated patients.<sup>77</sup>

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<sup>75</sup> See Appendix E, pp. 389-437 *infra*.

<sup>76</sup> See RESTATEMENT (SECOND) OF AGENCY, American Law Institute Publishers, St. Paul, Minn. (1957) § 122.

<sup>77</sup> Virtually all the durable power of attorney statutes enacted in approximately 40 states have been modeled on three acts: (1) Virginia Code Sections 11-9.1 to .2 (1950), (2) Model Special Power of Attorney for Small Property Interests Act (Uniform Law Commissioners, 1964), and (3) Uniform Probate Code Section 5-501 to 502 (1969). In 1979, the National Conference of Commissioners on Uniform State Law promulgated a Uniform Durable Power of Attorney Act, which has been enacted in four states as of February 1983. See Appendix E, pp. 391-92 *infra* and note 78 *infra*.

The provisions of the Uniform Durable Power of Attorney Act are

Although not expressly enacted for the problems of incompetent patients' health care decisionmaking, the language of these statutes can accommodate the appointment of a surrogate for that purpose and nothing in the statutes explicitly precludes such a use.<sup>78</sup> The flexibility of the statutes allows directives to be drafted that are sensitive both to the different needs of patients in appointing proxy decisionmakers and to the range of situations in which decisions may have to be made.

The Commission therefore encourages the use of existing durable power of attorney statutes to facilitate decisionmaking for incapacitated persons, but it also recognizes the possibility for abuse inherent in the statutes. These statutes do not have rigorous procedures because they were enacted primarily to avoid the expense of full guardianship or conservatorship proceedings when dealing with small property interests.<sup>79</sup> Adapting them to the context of health care may require that greater procedural safeguards be provided: precisely which safeguards are needed might best be determined after more experience has been acquired. Existing durable power of attorney statutes need to be studied, therefore, as they are applied to decisionmaking for incapacitated patients facing health care decisions.

**Proposed Statutes.** Various concerned groups have proposed statutes that might improve upon natural death acts, by being more generally applicable and authorizing proxy designation, as well as upon durable power of attorney statutes, by providing protections and procedures appropriate to health care decisionmaking.

The Society for the Right to Die has proposed a "Medical Treatment Decision Act," which is similar to the existing natural death acts.<sup>80</sup> The proposal shares the narrowness of

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typical. Its basic provisions provide for the appointment of an attorney whose authority continues notwithstanding the principal's subsequent disability or incapacity (Sections 1 and 2). Other provisions protect those who engage in transactions with an attorney in fact (a proxy) by ensuring that, in the absence of the proxy knowing of the principal's death and provided the proxy acts in good faith, the authority to act is not revoked by the principal's death (Sections 4 and

5).  
<sup>78</sup> Four states — California, Kansas, Massachusetts, and Wisconsin — have adopted the Uniform Durable Power of Attorney Act, which creates a strong presumption for conservator of person but does not establish that power. See Appendix E, pp. 391-92 *infra*.

<sup>79</sup> National Conference of Commissioners on Uniform State Laws, **HANDBOOK AND PROCEEDINGS OF THE ANNUAL CONFERENCE MEETING 1964** (1964) at 273-74.

<sup>80</sup> Yale Law School Legislative Services Project, *Medical Treatment Decision Act*, SOCIETY FOR THE RIGHT TO DIE, New York (1981), reprinted in Appendix D, pp. 313-17 *infra*.

application of most such acts and makes no explicit provision for designating a proxy for medical decisionmaking.

The National Conference of Commissioners on Uniform State Laws has drafted a "Model Health Care Consent Act."<sup>81</sup> Despite its comprehensive title, this act does not have consent as a central concern; more correctly it is a "substitute authority to decide" act. It provides for the appointment of a health care representative to make decisions should a patient be incompetent. Although its intent to provide for proxy directives is laudable, the proposal does not resolve certain central issues. In particular, it does not specify which standard should guide a health care representative (best interests or substituted judgment). The act is also imprecise in the determination of capacity to consent. Procedures governing revocation of the appointment of a health care representative and redelegation of authority are uncertain and liable to abuse.

A national educational group called Concern for Dying has had its Legal Advisory Committee draft a "Uniform Right to Refuse Treatment Act."<sup>82</sup> The Act enunciates competent adults' right to refuse treatment and provides a mechanism by which competent people can both state how they wish to be treated in the event of incompetence and name another person to enforce those wishes. In terms of its treatment of such central issues as the capacity to consent and standard by which a proxy decisionmaker is to act, the Uniform Right to Refuse Treatment Act is carefully crafted and in conformity with the Commission's conclusions. Greater opportunity for review of determinations of incompetency and of proxy's decisions may be needed, however, to protect patients' self-determination and welfare.

Another proposed statute was developed by a committee of concerned citizens in Michigan. First submitted to the state legislature in 1979, their bill would have established the authority of a competent person to designate a proxy specifically for health care decisionmaking.<sup>83</sup> Although Michigan had a durable power of attorney statute, it was not used for health care, perhaps because many people did not know of its availability and it seemed to require a lawyer's drafting services. The proposed proxy decisionmaking bill is simple and direct, yet includes significant procedural safeguards.

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<sup>81</sup> *Model Health Care Consent Act* (draft), National Conference of Commissioners on Uniform State Laws, Chicago (1982), *reprinted in* Appendix E, pp. 423-28 *infra*.

<sup>82</sup> *Uniform Right to Refuse Treatment Act* (draft), Concern for Dying, New York (May 1982), *reprinted in* Appendix E, pp. 428-31 *infra*.

<sup>83</sup> Michigan House Bill 4492 (March 26, 1981), *reprinted in* Appendix E pp. 431-37 *infra*: see also Arnold S. Relman, *Michigan's Sensible "Living Will,"* 300 *NEW ENG. J. MED.* 1270 (1979).

**General Considerations in Formulating Legislation.** The Commission believes that advance directives are, in general, useful as a means of appropriate decisionmaking about life-sustaining treatment for incapacitated patients. The education of the general public and of health care professionals should be a concern to legislators, as the statutes are ineffective if unknown or misunderstood. Many of the natural death and durable power of attorney statutes are less helpful than they might be. In the drafting or the amending of legislation to authorize advance directives, a number of issues need attention.<sup>84</sup>

**Requisites for a valid directive.** Some way should be established to verify that the person writing a directive was legally competent to do so at the time. A statute might require evidence that the person has the capacity to understand the choice embodied in the directive when it is executed. The statute should clearly state whether the witnesses that are required attest to the principal's capacity or merely ensure that signatures are not fraudulent. Since such witnesses are likely to be laypeople, the standard of decisionmaking capacity they apply will rest on common sense, not psychological expertise. Furthermore, the standard they are asked to attest to may be as low as that used in wills, unless specified differently.

The principal and the prospective proxy should recognize the seriousness of the step being taken, but this will be difficult to guarantee by statute. One way to increase the likelihood that due regard is given to the subject matter would be to provide that before a directive is executed, the principal (and proxy, where one is involved) must have had a discussion with a health care professional about a directive's potential consequences, in light of the principal's values and goals. This would also help ensure that any instructions reflect a process of active self-determination on the part of the patient.

**Legal effect of directives.** A statute should ensure that people acting pursuant to a valid directive are not subject to civil or criminal liability for any action that would be acceptable if performed on the valid consent of a competent patient. Since directives—particularly those including instructions—may contain unavoidable ambiguities, some recognition of the need for interpretation will be needed to provide adequate reassurance for health care professionals and proxies. Some of the existing statutes speak of protection for actions taken in "good faith."<sup>85</sup> which provides sensible

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<sup>84</sup> These considerations were developed at greater length in MAKING HEALTH CARE DECISIONS, *supra* note 2, at 155-66.

<sup>85</sup> Statutes of Ala., Del., Ks., N.M., Ore., Wash., in Appendices D and E, pp. 309, 389 *infra*; *Medical Treatment Decision Act*, Appendix D, pp. 313-17 *infra*; *Uniform Right to Refuse Treatment Act*, Appendix E, pp. 428-31 *infra*.

protection. Some standard of reasonable interpretation of the directive may need to be imposed, however, on an attending physician's reading of the document, lest "good faith" offer too wide a scope for discretion. Such a standard might best be developed in case law and scholarly commentary rather than in the statute itself.

The wisdom or necessity of penalties for noncompliance (fines, for example, or suspension or revocation of professional licenses<sup>86</sup>) depends upon the problem a statute is attempting to remedy. If health care professionals are unwilling to share responsibility with patients and, in particular, tend to overtreat patients whose physical or mental condition leaves them unable to resist, then—unless they are made legally binding—advance directives are unlikely to protect patients who want to limit their treatment. On the other hand, if health care professionals are simply unsure of what patients want, or if they are willing to share decisionmaking responsibility but are apprehensive about their legal liability if they follow the instructions of a person whose decisionmaking capacity is in doubt, then the threat of penalties would be unnecessary and potentially counterproductive by fostering an adversarial relationship between patient and provider. The evidence available at present does not clearly support substantial penalties.<sup>87</sup>

***Proxy's characteristics and authority.*** Several special questions arise in the context of health care concerning who may act as a proxy and what the proxy may do. A proxy should have the decisionmaking capacity needed for a particular health care situation. The criteria for determining presence of adequate capacity in a proxy are the same as for patients themselves.<sup>88</sup>

Statutes might limit who may serve as proxy so as to avoid the appointment of anyone likely to act upon interests that are adverse to a patient's. In some natural death statutes, the criteria for witnesses explicitly exclude anyone financially involved (as debtor, creditor, or heir) with the patient.<sup>89</sup> If a similar restriction were applied to proxies, this might eliminate virtually everyone who cares about the patient, however. Special restrictions on who may be a proxy may be warranted for patients in long-term care and psychiatric institutions, though the appropriate form of such conditions is uncertain.

In certain circumstances a proxy may be temporarily or permanently unable or unwilling to serve as a substitute

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<sup>86</sup> See state statutes for California, the District of Columbia, Kansas, Oregon, and Texas, Appendix D, pp. 324-29, 335-40, 345-49, 362-73 *infra*.

<sup>87</sup> There are no cases known to the Commission of penalties being imposed under any of the natural death acts that provide for them.

<sup>88</sup> See pp. 121-26 *supra*.

<sup>89</sup> See, e.g., the statute for California, Appendix D, pp. 324-29 *infra*.

decisionmaker. When that occurs, alternate proxies could be limited to people who were named by the principal in an original or amended directive; or, alternately, a proxy could be allowed to delegate his or her authority to another person of the proxy's choosing.<sup>90</sup> This issue might be affected by whether either the original or a substitute proxy was a close relative of the patient, as opposed to a stranger.

Since the proxy stands in the shoes of the patient and is expected to engage in a comparable decisionmaking process, logically the proxy should have access to the patient's medical record. Yet it may sometimes be advisable to allow the proxy's access to be limited to the information needed for the health care decision at hand, in order to respect the patient's privacy.

Any directive issued by a competent person, and especially an instruction directive, can use the Commission's preferred standard for surrogate decisionmaking—substituted judgment.<sup>91</sup> The interpretation of such a directive should ordinarily lie with the surrogate decisionmaker, particularly in the case of a proxy designated by the patient. Provision may have to be made for an administrative mechanism to decide situations in which a health care professional challenges a proxy's decision on the ground that it is based on neither a reasonable interpretation of the patient's instructions nor on the patient's best interests.

**Administrative aspects.** Several procedural concerns probably need to be addressed in any statute for advance health care directives. A statute needs to specify how a directive becomes effective. Some of the natural death acts, as already mentioned, require that a directive be executed after the patient has been informed of a diagnosis, so that the person's instructions are arrived at in the context of the actual, rather than the hypothetical, choices to be made.<sup>92</sup> Some statutes also provide that the directive be renewed every few years so that the signatory can reconsider the instructions or designation in light of changed circumstances or opinions.<sup>93</sup>

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<sup>90</sup> For example, the *Model Health Care Consent Act*, Appendix E, pp. 423-28 *infra*, provides for a limited delegation of power by some individuals, authorized to consent to health care for another. The only proxies who may delegate their decisional authority are family members. Nonfamily health care representatives, who may be appointed according to the terms of the Act, are not authorized to delegate their decisional authority. All delegations must be in writing, and unless the writing so specifies, no further delegation of decisional authority is permitted. Any delegated authority terminates six months after the effective date of the writing.

<sup>91</sup> See pp. 132-34 *supra*.

<sup>92</sup> See Table D1, pp. 310-12 *infra*.

<sup>93</sup> *Id.*

The trigger for a valid directive becoming operative also needs to be specified. A statute may leave that question to the document itself, to be specified by the person executing the directive, or it may provide that a particular event or condition brings the document into play. In either case, the triggering event will require both a standard for action and a specification of who will determine that the standard is met. For example, a directive may become operative when a physician makes a particular prognosis ("terminal illness") or determines that a patient lacks decisional capacity regarding a particular health care choice.

Provision must be made for the process and standard by which a document can be revoked. The value of self-determination suggests that as long as the principal remains competent, he or she should unquestionably have the power to revoke a directive. But what about an incompetent (incapacitated) person? The natural death acts have uniformly provided that any revocation by a principal negates a directive.<sup>95</sup> In the context of foregoing life-sustaining treatment, that result may be sensible, since it would generally seem wrong to cease such treatment based upon a proxy's orders when a patient, no matter how confused, asks that treatment be continued.<sup>95</sup> In other circumstances, however, allowing revocations by an incompetent patient could seriously disrupt a course of treatment authorized by a proxy. When the proxy intends to override the principal's contemporaneous instructions because the incompetent principal is contradicting earlier competent instructions and/or acting contrary to his or her best interests, the question of whether to follow the proxy or the principal may have to be resolved by an independent review.

In general, when disputes arise about such things as the choice made by a proxy or an attempted revocation by an apparently incapacitated principal, a review process will be an important safeguard for the patient's interests. In some circumstances the review mechanism need only judge whether the decisionmaking process was adequate. In other circumstances it may be advisable to review the health care decision itself and the application of the appropriate decisionmaking standard. In the absence of a special provision in the statute,

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■ Appendix D, pp. 309-87 *infra*.

<sup>95</sup> An exception might be the patient who knows that foregoing a treatment is likely to bring about a period of incompetence prior to death, during which the patient might ask for the treatment. If such a patient wants to bind all parties concerned—health care professionals, family, and patient—in a promise to act in accord with the preferences expressed by the patient while competent, such a request might be honored. See Gail Povar, *Case #11*, in James F. Childress, *WHO SHOULD DECIDE? PATERNALISM AND HEALTH CARE*, Oxford Univ. Press, New York (1982) at 224-25.

questions of this sort should lead to intrainstitutional review and, as needed, to judicial proceedings.<sup>96</sup>

**Conclusions.** The Commission commends the use of advance directives. Health care professionals should be familiar with their state's legal mechanisms for implementing advance directives on life-sustaining treatment and encourage patients to use these resources. In particular, practitioners can alert patients to the existence of durable power of attorney devices (in states where they exist) and urge them to discuss their desires about treatment with a proxy decisionmaker. In states without applicable legislation, practitioners can still inform their patients of the value of making their wishes known, whether through a living will or more individual instructions regarding the use of life-sustaining procedures under various circumstances.

Institutions concerned with patient and practitioner education have an important role to play in encouraging patients to become familiar with and use advance directives, and in familiarizing practitioners with the ethical and practical desirability of their patients using these mechanisms. Finally, legislators should be encouraged to draft flexible and clear statutes that give appropriate legal authority to those who write and rely upon advance directives. Such legislation needs to balance the provisions aimed at restricting likely abuses and those intended to allow flexibility and individuality for patients and proxies.

### **Procedures for Review of Decisionmaking**

The responsibility for ensuring that decisionmaking practices are of high quality falls first to the attending physician. No one else is regularly in as good a position to enhance and assess decisionmaking capacity, to inform the patient, to learn the patient's priorities, to designate an appropriate surrogate decisionmaker, and to know when other assistance is needed. Furthermore, helping patients consider how their health affects their lives is a traditional responsibility of physicians. However, the skills necessary are varied and the situations complex. To assign primary responsibility to physicians does not mean that there will be no need to involve others. On the contrary, physicians ordinarily need the assistance of family members, nurses, therapists, and others to help inform and communicate with a patient. And when decisions are serious and errors are irremediable—as is often the case in foregoing life-sustaining treatment—there is additional need for review and appeal, both as to general practices and in specific cases.

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<sup>96</sup> See pp. 153-70 *infra*.

**Judicial Review.** The Commission concludes that ordinarily a patient's surrogate — whether designated through judicial proceedings or informally — should have the legal authority to make decisions on behalf of an incapacitated patient.<sup>97</sup> Decisions made by such surrogates and physicians are now rarely subjected to court review. Only in unusual cases, for example when there is a conflict among next-of-kin<sup>98</sup> or when the surrogate chooses a highly unusual course of treatment or nontreatment,<sup>99</sup> health care providers refuse to honor a surrogate's decision to forego treatment. When this occurs, there are currently two alternatives: either the physician's recommended treatment will be continued and the surrogate will be effectively disenfranchised, or the surrogate or a provider will seek judicial resolution of the dispute.

Increasingly, health care providers have felt compelled to seek judicial review of surrogates' decisions to forego life-sustaining treatment. Some providers have sought review because they have disagreed with the surrogate's decision,<sup>100</sup> but others have done so even when they were comfortable with the decision but feared criminal or civil liability for foregoing treatment,<sup>101</sup> especially when it seemed uncertain that the individual acting as surrogate was properly authorized to do so.<sup>102</sup>

Since only a handful of jurisdictions have had occasion to address the issue (and since legislative guidance is also sparse), it is uncertain whether judicial proceedings must always be initiated in order to withhold or withdraw life-sustaining treatment from incompetent patients. Given that treatments necessary to keep unconscious patients alive for long periods of time had been used for a number of years prior

<sup>97</sup> *But see, In re Roe*, 421 N.E.2d 40 (Mass. 1981) (decision of court-appointed surrogate to administer neuroleptic medications to ward must be reviewed and approved by court).

<sup>98</sup> *See, e.g., In re Nemser*, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966).

<sup>99</sup> *See, e.g., Custody of a Minor*, 393 N.E.2d 836 (Mass. 1979); *In re Hoffbauer*, 47 N.Y.2d 648, 419 N.Y.S.2d 936, 393 N.E.2d 1009 (1979).

<sup>100</sup> *See, In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 68-69 (1981); *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334 (Del. 1980); *In re Quinlan*, 70 N.J.10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

<sup>101</sup> *See, e.g., Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334 (Del. 1980); *In re Quinlan*, 70 N.J. 10, 355A.2d 647, *cert. denied*, 429 U.S. 922 (1976); *Eichner v. Dillon*, 426 N.Y.S.2d 527 (App. Div. 1980), *modified by, In re Storar* 420 N.E.2d 64 (N.Y. 1981).

<sup>102</sup> *See, e.g., In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976). Judges have been involved in other cases when the patient was already a ward of the state or lacked family members or friends to serve as a surrogate. *See, e.g., Superintendent of Belcher-town State School v. Saikewicz*. 370 N.E.2d 417 (Mass. 1977); *Custody of a Minor*, 393 N.E.2d 836 (Mass. 1979).

to *Quinlan*, it is remarkable that this first legal case raising most of the issues concerning decisionmaking for patients lacking capacity did not arise until 1975.<sup>103</sup> Clearly, decisions about this sort of care were being made routinely without formal court review. Indeed, the Supreme Court of New Jersey in *Quinlan* recited at some length the testimony of a physician witness indicating that problems such as these had long existed and ordinarily had been handled without the involvement of people or social institutions other than the patient's family, physicians, and possibly hospital administrators. The witness endorsed this practice, which he termed "judicious neglect":

Don't treat this patient anymore, it does not serve either the patient, the family or society in any meaningful way to continue treatment with this patient.

...No physician that I know personally is going to try and resuscitate a man riddled with cancer and in agony and he stops breathing. They are not going to put him on a respirator...I think that would be the height of misuse of technology.<sup>104</sup>

Thus, one of the things the *Quinlan* case did was to bring these issues into the open for public debate and, in some cases, for a more public resolution through the judicial process.

In its report on informed consent, the Commission endorsed the general approach to decisionmaking for incapacitated patients advocated by the New Jersey Supreme Court in *Quinlan*.<sup>105</sup> This approach involves leaving decisional authority in the hands of an incompetent patient's guardian, in consultation with a hospital "ethics committee."<sup>106</sup> In strong language,

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<sup>103</sup> Of course, the *Quinlan* case did not arise in legal vacuum. The New Jersey court used precedents concerning such issues as religious beliefs, state interests, the right of privacy, and the standards of the medical profession in crafting its opinion. *In re Quinlan*, 70 N.J.10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

<sup>104</sup> 355 A.2d at 657, quoting an expert witness at trial, Dr. Julius Korein. The court in *Saikewicz* referred to similar practices:

The force and impact of [the medical profession's interest in the maintenance of its ethical integrity] is lessened by the prevailing medical ethical standards...[which] does not, without exception, demand that all efforts toward life prolongation be made in all circumstances. Rather...the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment.

Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d ¶17, 426 (Mass.1977).

<sup>105</sup> See, *New Jersey Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients*, reprinted in Appendix G, pp. 463-66 *infra*.

<sup>106</sup> Prior to the *Quinlan* case, the most well-known use of such

the court specifically eschewed judicial review of such decisions:

We consider that a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome.<sup>107</sup>

Two other courts have similarly discouraged routine court review.<sup>108</sup>

By contrast, the Supreme Judicial Court of Massachusetts, in a succession of cases, has explicitly rejected the decision-making method advocated by the New Jersey Supreme Court and instead established judicial review of decisions made by physicians, in conjunction with family members or legal guardians, as the rule rather than the exception. Instead of

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committees was in Seattle, where community representatives helped select among candidates for dialysis, at a time when the treatment was novel and not widely available. Shana Alexander, *They Decide Who Lives, Who Dies: Medical Miracles and a Moral Burden of a Small Town*, 53 LIFE 102 (Nov. 8, 1962). Originally, "social worth" criteria provided a basis for the committee's selection process. "The patient's 'marital status,' 'net worth,' 'occupation,' and 'past performance and future potential' were the types of social worth criteria that the committee members avowedly considered...The specific, often unarticulated indicators that were used reflected the middle-class American value system shared by the selection panel." Renee C. Fox and Judith P. Swazey, *THE COURAGE TO FAIL*, Univ. of Chicago Press, Chicago (1974) at 246. The committee eventually abandoned its "social worth" criteria in favor of professionally evaluated psychological assessments—"evidence of its members' profound disquiet at having to 'play God.'" *Id.* at 268.

The court assumed that such committees exist and quoted with approval a law review article by a physician that stated that "many hospitals have established an Ethics Committee composed of physicians, social workers, attorneys, and theologians,...which serves to review individual circumstances of ethical dilemmas and which has provided much in the way of assistance and safeguards for patients and their medical caretakers." *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 668, cert. denied 429 U.S. 922 (1976) (quoting Karen Teel, *The Physician's Dilemma: A Doctor's View: What The Law Should Be*, 27 BAYLOR L. REV. 6, 8-9 (1975)). See also *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334, 1338 (Del. 1980).

<sup>107</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 669, cert. denied, 429 U.S. 922 (1976).

<sup>108</sup> See, *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 74 (1981) ("Neither the common law nor existing statutes require persons generally to seek prior court assessment of conduct which may subject them to civil and criminal liability"); *Severns v. Wilmington Medical Center, Inc.* 421 A.2d 1334 (Del. 1980).

regarding judicial review as a "'gratuitous encroachment' on the domain of medical expertise," this court

take[s] a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent...Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility ...and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.<sup>109</sup>

The court suggested that although courts are not bound by recommendations of ethics committees, they may consider the deliberations of such groups, as well as taking testimony from medical experts.<sup>110</sup>

The models of decisionmaking procedures for incompetent patients derived from the opinions of the Massachusetts and New Jersey courts are quite different. The norm in Massachusetts—judicial decisionmaking with medical expertise not playing a decisive role<sup>111</sup>—is the exception in New Jersey,

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<sup>109</sup> Superintendent of Belchertown State school v. Saikewicz, 370 N.E.2d 417,434-35 (Mass.1977).

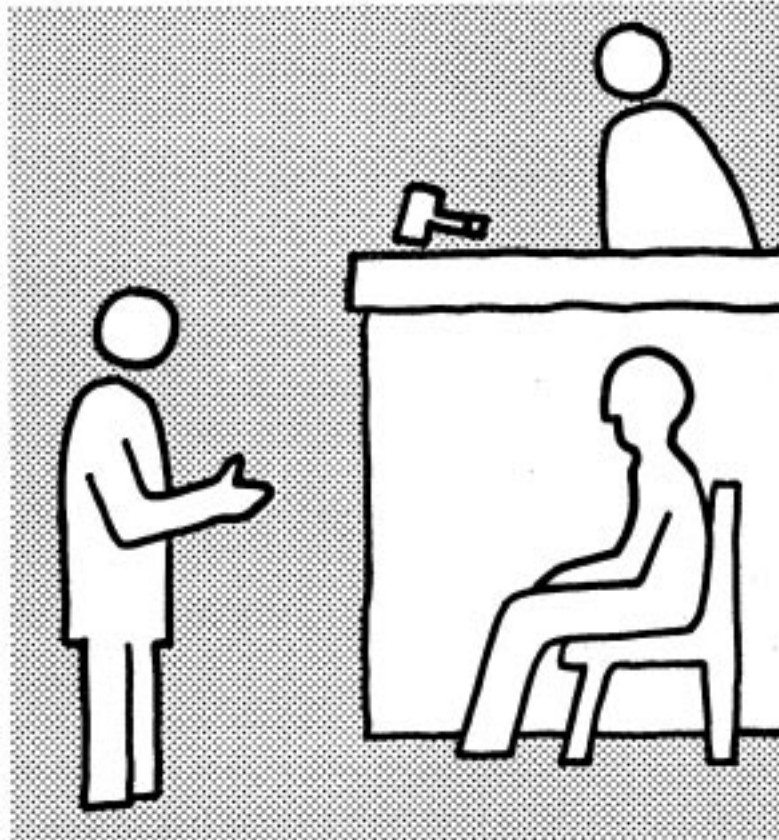
<sup>110</sup> *Id.* at 434.

<sup>111</sup> The Massachusetts Supreme Judicial Court and the Court of Appeals have both provided additional guidance about the full scope of *Saikewicz*. Prior judicial approval of all decisions to forego life-sustaining treatment is not always necessary, even in Massachusetts. The Supreme Court mentioned in *Spring* that "We are not called upon to decide what combination of circumstances makes prior court approval necessary or desirable, even on the facts of the case before us," which certainly suggests that at least some cases do not require such approval. *In re Spring*, 405 N.E.2d 115,121 (Mass.1980).

In *Dinnerstein*, 380 N.E. 2d 134 (Mass. App. 1978), the Court of Appeals held that judicial permission was not necessary to enter a do not resuscitate order in the medical record of an irreversibly terminally ill 67-year-old and severely demented person, and distinguished the need for judicial approval of withholding treatment in *Saikewicz* on the ground that Saikewicz's proposed treatment was reasonably expected to bring about a substantial remission of symptoms. By contrast, in the event of a cardiac arrest, Dinnerstein's situation would still be hopeless.

*Custody of a Minor*, 385 Mass. 697, 434 N.E.2d 601 (1982), also involved a hopelessly ill patient—a several month-old child with a life expectancy of no more than a year or two. In that case, the Massachusetts Supreme Judicial Court also permitted the entry of a DNR order but held, contrary to *Dinnerstein*, that court approval was necessary, because Mrs. Dinnerstein had a "loving family with whom

where decisionmaking by medical practitioners in conjunction with family members is routine, with resort to judicial review only in unusual, undefined circumstances.



The regular reliance on advance judicial review advocated in the Massachusetts decisions has sparked a debate about the relative costs and benefits of having courts rule on decisionmaking by surrogates for incapacitated patients<sup>102</sup> A prominent defender of court involvement claims that "decisions [on behalf of incompetent patients] which are made on the same set of facts will differ from day to day and from doctor to doctor [because] few doctors have worked out principles of

physicians may consult." *Id.* at 608. But the minor here was a baby, abandoned and under the supervision of a public welfare agency. Thus, the Massachusetts court would seem to hold that, when treatment is likely to yield only brief extension of life and a caring family is available, court approval is not necessary.

<sup>108</sup> See, e.g., H. Richard Beresford, *The Role of Judges in Life/Death Decisions for the Neurologically Impaired*, 4 ANNALS NEUROL. 463, 464 (1978); Lee J. Dunn, Jr., *The Eichner/Storar Decision: A Year's Perspective*, 10 L., MED. & HEALTH CARE 117 (1982).

decisionmaking that will survive even the most rudimentary criticism."<sup>113</sup>

Certain aspects of the judicial process do commend it for use in place of such variable decisionmaking. First, the judicial process is a public one. Judges' actions are subject to scrutiny by the public, the press, and legal scholars. Second, judicial decisionmaking is (ideally, at least) principled— with like cases decided alike and pains taken to develop reasoned bases for decisions. Third, the judicial process seeks impartiality by applying rules of evidence and by using disinterested decisionmakers. Finally, the adversarial nature of the process seeks to render a full and fair hearing by encouraging proponents of opposing positions to bring evidence and to present arguments before a neutral judge.<sup>114</sup>

On the other hand, judicial review in such cases is costly in terms of time and expense<sup>115</sup>; it can disrupt the process of providing care for the patient, since medical decisionmaking is evolutionary rather than static; it can create unnecessary strains in the relationship between the surrogate decisionmaker and others, such as the health care providers, who may be forced into the role of formal adversaries in the litigation; and it exposes ordinarily quite private matters to the scrutiny of the courtroom and sometimes even to the glare of the public communications media.<sup>116</sup>

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<sup>113</sup> Charles H. Baron, *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 AM. J.L. & MED. 337,349 (1979).

<sup>114</sup> At times, courts may not be able to maintain a claim of disinterestedness. Rather, there is a risk that judges will have to rely on their personal preferences in an area without well-established law. See Leslie S. Rothenberg, *The Empty Search for an Imprimatur, or Delphic Oracles are in Short Supply*, 10 L., MED. & HEALTH CARE 115 (1982). See also John J. Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 L., MED. & HEALTH CARE 120, 122 (1982). Paris comments on a judge who saves the life of an adult Jehovah's Witness by ordering transfusions because the judge felt he could not bear being responsible for the death, but who did not take as seriously that person's belief that thereby she lost everlasting life.

<sup>115</sup> The Brother Fox case (*Eichner v. Dillon*) continued long past the patient's death, which occurred despite vigorous treatment. Nevertheless, his medical care during the legal battle cost \$87,000 and the legal costs before his death were \$20,000. Paris, *supra* note 114. A similar committee was mandated in *Eichner v. Dillon*, but this was overturned by the appeal to the state's highest court, which felt that such a mechanism required legislation. *Eichner v. Dillon*, 426 N.Y.S.2d 517, 550 (App. Div. 1980) *modified in, In re Storar*, 420 N.E.2d 64, 74 (N.Y. 1981).

<sup>116</sup> See also, *In re Application of Lydia Hall Hospital*, No. 23730 (Sup. Ct. Nassau Cty., N. Y., Oct. 22, 1982). In this case, the family of Peter Cinque, a patient who gave explicit, competent, and informed advance directives to discontinue life-sustaining treatment, has threatened the hospital that went to court seeking to overturn his directive.

These costs may be justifiable if wiser decisions are made and patients are provided with additional protection from harm. Frequently, however, the process of judicial review in these cases is merely a formality. Judges may feel that they are unable to add much to the decisions already worked out among those most intimately involved, particularly in cases that are brought simply to obtain judicial sanction for a course of conduct on which all are agreed.<sup>117</sup> Rather than examining questions that courts are accustomed to addressing, such as whether the particular surrogate should be disqualified because of a conflict of interest, the question typically addressed is whether the particular treatment chosen is the right one. Since an answer to this question would normally require substantial understanding of the patient's evolving medical condition and options, which the courts lack, they may simply defer to the recommendation of the treating physicians.

The Commission nevertheless believes there are enough possibilities for error in the process of decisionmaking for incapacitated persons by families and practitioners that this process should sometimes be reviewed, even though routine judicial oversight is neither necessary nor appropriate. The task of ensuring good decisionmaking about life-sustaining treatment will thus fall to the institutions that provide care for incapacitated dying patients. This responsibility can properly be seen as an extension of the well-recognized institutional responsibility to ensure that the well-being of such patients is promoted in other respects.

#### **Intra-institutional Review and the Role of Ethics Committees**

*Current structures and functions.* The procedures that institutions establish to promote effective decisionmaking for incapacitated individuals can serve a number of specific functions.

- They can review the case to confirm the responsible physician's diagnosis and prognosis of a patient's medical condition.
- They can provide a forum for discussing broader social and ethical concerns raised by a particular case; such bodies may also have an educational role, especially by teaching all professional staff how to identify, frame, and resolve ethical problems.
- They can be a means for formulating policy and guidelines regarding such decisions.
- Finally, they can review decisions made by others (such as physicians and surrogates) about the treat-

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<sup>117</sup>See Rothenberg, *supra* note 114.

ment of specific patients or make such decisions themselves.

This diversity of approaches is exhibited in the current variety of institutional bodies. One philosopher described his hospital's "Ethics Consultation Service" on which he served as having begun as an informal group of interested persons.<sup>118</sup> "Ethical conferences" that can be convened at any time by any physician or nurse who desires to discuss a possible withholding of life-sustaining treatment have been established in one European hospital.<sup>119</sup> A large community hospital in Washington, D.C., has experimented with regularly scheduled meetings within hospital units, at which patient care situations (including ethical issues) are discussed by hospital staff.<sup>120</sup> Other institutions have experimented with ad hoc groups constituted to be especially responsive to the needs of a particular patient.<sup>121</sup>

The institutional body most often mentioned in decision-making contexts is the ethics committee,<sup>122</sup> which is sometimes a continuing committee integrated into the institution's administrative structure and other times independent of it. The prominence of ethics committees as an institutional response to problems with decisionmaking is partly attributable to the important role assigned to them by the New Jersey Supreme Court in the *Quinlan* case.<sup>123</sup> Yet a national survey done for the Commission found that less than 1% of all hospitals — and just 4.3% of the hospitals with over 200 beds — have such committees. Because many of the same concerns are likely to arise in connection with any form of intrainstitutional review, the

<sup>118</sup> Benjamin Freedman, *One Philosopher's Experience on an Ethics Committee*, 11 **HASTINGS** **CTR. REP.** 20 [April 1981].

<sup>119</sup> Gerhard Stalder, *Ethical Committees in a Pediatric Hospital*, 136 **EUR. J. PED.** 119, 121 (1981).

<sup>120</sup> Information included in material obtained from Greater Southeast Community Hospital, Washington, D.C., especially its description of its "Collaborative Practice Committees" (June 1980).

<sup>121</sup> See Mitchell T. Rabkin, Gerald Gillerman, and Nancy Rice, *Orders Not to Resuscitate*, 295 **NEW ENG. J. MED.** 364, 365 (1976). See generally Kathi Esqueda, *Hospital Ethics Committees: Four Case Studies*, 7 **THE HOSPITAL MEDICAL STAFF** 26, 30 (Nov. 1978); Carol Levine, *Hospital Ethics Committees: A Guarded Prognosis*, 7 **HASTINGS** **CTR. REP.** 25, 27 (June 1977); Ronald Sullivan, *Hospitals Turn to Philosophers on Life Issues*, **N.Y. TIMES**, Mar. 19, 1982, at A-1.

<sup>122</sup> This report uses "ethics committees" to mean those committees that have the potential to become involved in decisionmaking in particular patient's cases.

<sup>123</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

<sup>124</sup> See Stuart Youngner et al., *A National Survey of Hospital Ethics Committees*, Appendix F, pp. 443-57 *infra*. In a 1978 survey of Catholic hospitals, 27% responded that they had established medical-moral committees, though it is not clear that they could be involved in

Commission decided to consider the kinds of structures and functions that institutions have already given these committees.

The first issue of concern is the appropriate function of ethics committees.<sup>125</sup> They might be merely prognosis review committees, a role the New Jersey Supreme Court suggested in *Quinlan* when it assigned to the ethics committee the task of agreeing or disagreeing with the responsible attending physicians' determination "that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state."<sup>126</sup> This essentially medical function has confused subsequent discussions of ethics committees, since there is little (if anything) distinctly "ethical" about the judgment the court asked the committee to make. "Ethics committees" established solely to confirm prognoses might better be called "prognosis review committees."<sup>127</sup>

Some health care institutions have primarily consultative ethics committees. In this capacity, they are available to discuss the broader ethical and social concerns of interested parties, especially as they bear on the decision to be made in a particular case, and to provide advice on request. Some

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particular cases. Letter from J. Stuart Showalter, The Catholic Health Association of the United States, to JoanneLynn (Nov. 17, 1982).

<sup>125</sup> See generally Harold L. Hirsch and Richard E. Donovan, *The Right to Die: Medico-Legal Implications of In re Quinlan*, 30 **RUTGERS L. REV.** 267, 273-286 (1977); Levine, *supra* note 121; Robert M. Veatch, *Hospital Ethics Committees: Is There a Role?*, 7 **HASTINGS CTR. REP.** 22 (June 1977).

<sup>126</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 671, *cert. denied*, 429 U.S. 922 (1976).

<sup>127</sup> The committees described in the guidelines that were subsequently promulgated by the responsible New Jersey State agencies were indeed labeled "prognosis committees." *Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients*, reprinted in 74 **J. MED. SOC. N.J.** 35 (April 1977) and in Appendix G, pp. 463-66 *infra*. Alfonso A. Navarez, *Jersey Adopts Plan on Patients in Coma*, N.Y. TIMES, Jan. 26, 1977, at A-1.

New Jersey, however, understandably remains confused over the proper role of such a committee. At the Morris View Nursing Home, for example, where Karen Quinlan is currently a patient, an ethics committee was formed when the nursing home knew she would be coming there. It consists of a physician, an attorney, two clergymen, a social worker, and the chairman, who is also Chairman of the Morris County Welfare Board, which manages the nursing home. This committee apparently sees itself not as a "prognosis committee" but as a committee to deal with "ethical issues."

George J. Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, in Doudera and Peters, *supra* note 40, at 20.40 n.34.

advocates of ethics committees as primarily consultative bodies have been adamant that such groups should not themselves make decisions. As one philosopher involved in a consultative ethics committee put it: "The job of the group is to provide a forum in which professionals can discuss their views regarding a particular case. The one overriding theme of our meetings has been: 'we make no decision.'"<sup>128</sup> Even ethics committees that see their purpose as primarily consultative differ regarding the groups they counsel and support. The Commission's study found that well over half the committees in existence aided physicians in this way, while only slightly more than one-quarter counseled and supported patients and families.<sup>129</sup>

Ethics committees may have an important educational role. The Commission's study revealed that heads of ethics committees felt the groups were generally less effective in educating professionals about issues relevant to life-support decisions than about other areas.<sup>130</sup> Nevertheless, experts testifying before the Commission emphasized several educational roles that the more well established ethics committees play.<sup>131</sup> First, in ethics committees with a diverse membership of physicians, nurses, other professionals, and laypeople, discussions allow the various members to share perspectives and views, which can lead to better decisions regarding the treatment of the incapacitated. Of particular importance here is the way ethics committees can expose the actual decisionmakers in a hospital setting to various ethical and social considerations.<sup>132</sup>

Second, over a period of years ethics committees may provide a setting for people within medical institutions to become knowledgeable and comfortable about relating ethical principles to specific decisions. Third, presenting a number of issues through actual cases that receive institutional attention is likely to underscore the seriousness of the issues involved, the possibility of better and worse resolutions, and the obligations of all to address the issues responsibly. Finally, ethics committees may serve as a focus for community discussion and education, which is likely to stimulate thought beyond issues of incompetence to a consideration of more general bioethical issues.

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<sup>128</sup> Freedman, *supra* note 118, at 20-21.

<sup>129</sup> Table F3, p. 451 *infra*.

<sup>130</sup> Appendix F, pp. 447-48 *infra*.

<sup>131</sup> Testimony of Dr. Ronald Cranford, transcript of 21st meeting of the President's Commission (June 10, 1982) at 18,39.

<sup>132</sup> Cynthia B. Cohen, *Interdisciplinary Consultation on the Care of the Critically Ill and Dying: The Role of One Hospital Ethics Committee*, 10 CRIT. CARE MED. 776 (1982).

The Commission's study revealed that one stated purpose of almost half the ethics committees is to set ethical and social policy for the care of critically ill persons.<sup>133</sup> Although some institutions have combined this function with case management review and advice,<sup>134</sup> questions have been raised about the appropriateness of assigning two such apparently dissimilar tasks to the same group.<sup>135</sup>

Another function of ethics committees is to review certain decisions made by the family of an incapacitated person and his or her practitioner. In its review, the committee would seek to ensure that the interests of all parties, especially those of the incapacitated person, have been adequately represented, and that the decision reached lies within the range of permissible alternatives. The Commission believes that this review function—which more than half the ethics committees classified both as a stated purpose and as their actual role<sup>136</sup>—deserves serious consideration as a way for institutions to discharge their responsibilities to promote the well-being of incapacitated patients. When ethics committees serve as reviewers, they do not supplant the principal decisionmakers for incapacitated persons (that is, families and practitioners) but they do provide for efficient review without regularly incurring the liabilities of judicial review. (They can however, ensure that appropriate cases go to court.)

Finally, ethics committees might be actual decisionmakers.<sup>137</sup> The Commission's study revealed that fewer than 20% of the committees classified the making of final decisions about life support as a stated purpose, while slightly more than 30% classified this as an actual function.<sup>138</sup> As discussed earlier, the Commission believes that health professionals and the surrogate for an incapacitated person should be the primary decisionmakers. Regularly assigning to ethics committees the task of making decisions regarding life-sustaining treatment could undermine the recognition of obligations by those who should be principally responsible. It should be avoided, therefore, though in unusual circumstances a decision might be sought from, and appropriately given by, a committee.

The resolution of many issues concerning the structure and composition of ethics committees depends upon the functions

<sup>133</sup> Table F3, p. 451 *infra*. One report of a committee considers only terminally ill patients. Cohen, *supra* note 132.

<sup>134</sup> Esqueda, *supra* note 121, at 27.

<sup>135</sup> Levine, *supra* note 121, at 27.

<sup>136</sup> Table F3 p. 451 *infra*.

<sup>137</sup> Usually committees are seen as having a role in care of only current patients. Abigail Kuzma recommends that such committees screen and counsel applicants for admission to hospice. Note, *Hospice: The Legal Ramifications of a Place to Die*, 56 *IND. L.J.* 673, 699 (1980-1981).

<sup>138</sup> Table F3, p. 451 *infra*.

assigned to such committees, and rests on the kind of information that can be obtained only with actual experience. Nevertheless, there are some general questions that need to be addressed in deciding whether ethics committees are an appropriate way for institutions to discharge their responsibilities.

**Unresolved issues.** Ironically, the very fact that ethics committees will probably be less formal and burdensome than judicial review in any particular case may cause their total impact on the health care system to be excessively burdensome. This could occur if the apparent accessibility of ethics committees was to lead to routine review of an ever larger number and wider range of medical decisions than would previously have had judicial review. If the existing process of decisionmaking, which is largely private and unreviewed, has been appropriate and has resulted in decisions that are in the aggregate as "good" as those arrived at by an ethics committee, then creating committees will complicate the total process, not improve it. Review might well be of no greater quality if, as sometimes occurs, removing responsibility from a single individual, such as the attending physician, to a larger group tends to diffuse it so that no one person feels personally responsible for the choices being made.<sup>139</sup> Concerns have also been raised that ethics committees will simply act either as rubber stamps for decisions made by others or as debating forums.<sup>140</sup>

Another issue that needs to be clarified is who has the right and responsibility to establish and appoint members to the ethics committees in health care institutions. This is a matter that should be of concern to such organizations as the American Hospital Association and the Joint Commission on the Accreditation of Hospitals. Although the exact nature of the committees may vary with the nature of the institutions in

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<sup>139</sup> George J. Annas, *In re Quinlan: Legal Comfort for Doctors*, 6 **HASTINGS CTR. REP.** 29, 30-31 (June 1976).

<sup>140</sup> *Id.* See also:

Treatment guidelines are useful only insofar as they serve to clarify the prognosis and likely outcomes of various treatments so that the guardian or next of kin can make an informed decision....As long as such guidelines serve as a means of generating information for competent patients, guardians, or next of kin to make the best decision they can, the guidelines are useful. But if they serve to validate the status quo of removing such decisions from the responsible parties and reserving it to the physician or staff they overstep their own proper role and work against the patient.

Thomas A. Shannon, *The Withdrawal of Treatment: The Costs and Benefits of Guidelines*, in Thomas A. Shannon, **BIOETHICS**, Paulist Press, Ramsey, N.J. (rev. ed. 1981) at 219.

which they function, they must have a firm institutional footing.<sup>141</sup> Since more than one ethics committee may be established in large, multispecialty hospitals (perhaps with a division of committees according to their different functions or different patient populations), clear guidelines should be formulated for determining which cases are to be reviewed by each group. Institutions have experimented with different methods of selecting ethics committee members, including selection by the hospital's director on nomination from a committee of staff representatives or by a small interested group who initiated interest in the ethics committee.<sup>142</sup> The desirability of possible selection methods needs to be assessed.

In thinking about the appropriateness of ethics committees, consideration should be given to whether their composition reflects their function. A committee serving exclusively as a prognosis review group might justifiably be staffed exclusively by physicians, whereas such a group would be less appropriate as a forum for consideration of ethical issues. The Commission's study found that physicians and clergy are especially well represented on existing ethics committees; administrators, nurses, and attorneys are moderately well represented; few committees include social workers and laypeople.<sup>143</sup> The Commission believes that institutions should consider seriously the advantages of a diverse membership. First, having individuals from many different specialties, as well as those without professional specialization, can minimize the tendency to take the committee's task as essentially technical. Second, diversity can prevent ethics committees from becoming uncritically accepting of, or adverse to, the view of any one professional or social group.<sup>144</sup> Finally, since one of the central functions of ethics committees may be to advise patients, families, and practitioners who are trying to make informed decisions, many different perspectives should be available to those who seek the committee's guidance.

The question of how frequently ethics committees should meet and what form their deliberations should take also depends upon their designated functions. The capacity to deliberate on short notice, which is necessary to achieve reasonably prompt review, is more likely to be possible if it is recognized that not every member of the committee need be present at every meeting. Subcommittees with areas of special interest may well develop; if so, a meeting of the members of such smaller groups may suffice. Regarding the form of their

<sup>141</sup> Testimony of John A. Robertson, transcript of 21st meeting of the President's Commission (June 10, 1982) at 177.

<sup>142</sup> Esqueda, *supra* note 121, at 27-28.

<sup>143</sup> Table F4, p. 452 *infra*.

<sup>144</sup> Cohen, *supra* note 132, at 778.

deliberations, the members of Morris View Nursing Home's ethics committee (which was established primarily in response to the *Quinlan* decision) found that they achieved a consensus decision, even though no formal procedures had been devised for reaching such an agreement.<sup>145</sup> Other ethics committees have specifically repudiated the attempt to achieve a consensus.<sup>146</sup> The appropriate form of decision may vary with the issue being considered, the function of the ethics committee, and the nature of the larger institution. There is little reason to think that a single opinion based on a majority vote would always be appropriate, although it may be for some situations, such as the decision to refer a case to court.

The issue of who can convene and attend meetings must be resolved. The Commission's study discovered that in all committees, the responsible physician could request a meeting, while in slightly more than half the patient's family was permitted to make such a request.<sup>147</sup> Should all members of ethics committees be able to request a meeting? One committee decided that its members could not do this, in order to avoid the accusation that the group was meddling without authority.<sup>148</sup> If ethics committees are to serve in a review capacity, however, it may be desirable for members to have the authority to request a meeting. There may be some categories of life support cases that should always be reviewed. For example, the Commission proposes that virtually all such decisions for seriously ill newborns be reviewed.<sup>149</sup> Certain decisions for persons who have no natural surrogate might be another category. Concerning attendance, the Commission's study revealed that although all the existing ethics committees permitted the responsible physician to attend their meetings, other people, such as the patient's clergy and family, were far less frequently allowed to attend.<sup>150</sup>

The way to publicize the committee's existence to health care professionals and patients needs to be considered. In one hospital with a well-established and active ethics committee, only 9 of 120 outpatients surveyed knew of its existence, though 76% answered that such committees were needed.<sup>151</sup> Clearly, for a committee to be used when needed, all involved must know both of its existence and of the expectation that it will be called upon.

The use of ethics committees raises serious privacy problems. Patients (and their families) could be unhappy about

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<sup>145</sup> Esqueda, *supra* note 121, at 26, 27.

<sup>146</sup> Freedman, *supra* note 118, at 21.

<sup>147</sup> Table F4, p. 452 *infra*.

<sup>148</sup> Freedman, *supra* note 118, at 21.

<sup>149</sup> See p. 227 *infra*.

<sup>150</sup> Table F4, p. 452 *infra*.

<sup>151</sup> Letter from Stuart Youngner to Joanne Lynn (Jan. 25, 1983).

their medical records being conveyed to ethics committee members without their consent, especially when neither the patients nor their families may themselves be entitled to request or attend a meeting of the committee. Privacy considerations also apply to the keeping of records of committee deliberations and to the use that may be made of any cases discussed. In order to have some basis on which to assess the efficacy of a committee's deliberations over time, some record of the deliberations may be needed. One committee in fact prepares a written summary of its meetings.<sup>152</sup> Yet if records are kept, their use must be restricted. The well-established, active committee just mentioned, for example, prohibits the use as teaching material of specific cases discussed by the committee.<sup>153</sup> Questions regarding the use of committee records as evidence in litigation must also be resolved.

Another legal issue of some concern is the liability of surrogates and practitioners, members of ethics committees, and the institutions in which the committees function. Questions have been raised about the distorting effects of entirely freeing from criminal and civil liability those who must make decisions on behalf of incapacitated persons.<sup>154</sup> Although they should be protected while acting with due care and diligence, primary decisionmakers and those who review their decisions should not be entirely relieved of legal responsibility. The appropriate standard of liability should be determined not simply by worries about ensuring that individuals will serve as members of ethics committees, but also by a concern that their deliberations not be unduly circumscribed by concerns about prosecution.<sup>155</sup> Perhaps a "good faith" standard and exclusion from criminal conspiracy liability would suffice.

Finally, if a major advantage of institutional ethics committees is that they will provide an alternative to court review in most cases, careful attention must be paid to the acceptability of the committees within existing legal structures. In a few states, the courts have held that only the judiciary has the legitimate authority and disinterested stance to make decisions for incapacitated patients.<sup>156</sup> If this rule were to prevail, ethics committees could become at best a helpful step in the review process leading to judicial judgment, and at worst simply another source of delay.

The Commission believes that ethics committees and other institutional responses can be more rapid and sensitive than

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<sup>152</sup> Freedman, *supra* note 118, at 21.

<sup>153</sup> *Id.* at 22.

<sup>154</sup> Annas, *supra* note 139, at 30-31.

<sup>155</sup> A first model statute to regulate the authority and responsibilities of hospital ethics committees has been drafted; *see* Appendix F, pp. 439-42 *infra*.

<sup>156</sup> See notes 109 and 111 *supra*.

judicial review: they are closer to the treatment setting, their deliberations are informal and typically private (and are usually regarded by their participants as falling within the general rules of medical confidentiality), and they are able to reconvene easily or delegate decisions to a separate group of members. Yet before recommending that this approach be more widely adopted—much less that it become a uniform requirement imposed by the Federal government or by hospital accreditation bodies—the Commission believes that the questions raised here about the advantages and disadvantages of such committees must be answered.

The experience with Institutional Review Boards (IRBs) is instructive. Over the past 15 years, IRBs have been developed as a way to review in advance research that exposes human subjects to risk for the benefit of science and society.<sup>157</sup> Formerly, ethical considerations involved in selecting and securing the voluntary informed consent of human subjects had been left largely to the conscience of individual physician-investigators, guided by the norms of the profession and by the prospect of liability or discipline for inappropriate conduct. Although initially somewhat controversial, IRBs are now generally accepted in the biomedical community and are usually thought to be effective in protecting human subjects, in improving public confidence in the research process, and in provoking self-scrutiny on the part of biomedical investigators.<sup>158</sup>

Nevertheless, as the Commission noted in its Second Biennial Report,<sup>159</sup> which deals with human research regulations, surprisingly little is known about the actual operations of such committees, beyond anecdotal accounts and several studies conducted nearly a decade ago. When IRBs were being instituted as a result of Federal guidelines and regulations, no studies were done of their relative efficacy compared with

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<sup>157</sup> See, e.g., John A. Robertson, *The Law of Institutional Review Boards*, 20 U.C.L.A. L. REV. 485 (1979); Robert J. Levine, *ETHICS AND REGULATION OF CLINICAL RESEARCH*, Urban & Schwarzenberg, Baltimore, Md. (1981).

<sup>158</sup> "And you and I have colleagues that did research that you, I, and they would call outrageous in the 1950s, who now say, God, how did I ever do that? You know how I did stuff like that? I just never had to talk to anybody about it. And that was the missing ingredient." Testimony of Dr. Norman Fost, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 148.

<sup>159</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research, *IMPLEMENTING HUMAN RESEARCH REGULATIONS* U.S. Government Printing Office, Washington (1983). See also National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *REPORT AND RECOMMENDATIONS: INSTITUTIONAL REVIEW BOARDS*, U.S. Government Printing Office, Washington (1978).

groups of different composition or with entirely different mechanisms for prospective or retrospective review. Without questioning the general sense that IRBs have been helpful, the Commission believes that any increase in the use of institutional ethics committees to safeguard the interests of incompetent patients should be accompanied by more rigorous study than IRBs initially received.

Whatever the precise nature of the policies formulated, the Commission believes that institutions should recognize and evaluate the problems posed by the need to make decisions for incapacitated persons and should ensure that the decisions made promote their well-being. To provide a basis for evaluating the different forms of decisionmaking, it is especially important that institutions be explicit about the practices they adopt, and that they report their successes and failures.<sup>160</sup>

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<sup>160</sup> This need to report on practices is especially important in light of a concern common among ethics committee members that they are unaware of the existence of other such committees. Communication among committees and in the literature has an important role to play in improving the efficacy of such committees. Esparada, *supra* note 121, at 26, 30.

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## Patients with Permanent Loss of Consciousness

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The general public probably first became aware of the issues addressed in this chapter following the tragedy that began for a New Jersey family on April 15, 1975. On that day, Karen Ann, the 21-year-old daughter of Joseph and Julia Quinlan, lapsed into a coma from which she has never recovered.<sup>1</sup> In the years since, as her situation ceased being solely a private, family concern and—because of legal proceedings<sup>2</sup>—became front-page news, people across the country have confronted such difficult questions as:

- what is the relationship of permanent unconsciousness to life and death?

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<sup>1</sup> Sometime after she ceased breathing for unknown reasons, Karen Quinlan was brought, unconscious, to a hospital emergency room. After her condition stabilized, feeding required a nasogastric tube and breathing required a respirator. She never experienced irreversible cessation of all brain functions (that is, death) but rather retained function of the brain stem and was diagnosed as being in a "persistent vegetative state," a condition that has not changed. Joseph Quinlan and Julia Quinlan, with Phyllis Battelle, *KAREN ANN: THE QUINLANS TELL THEIR STORY*, Doubleday & Co., Garden City, N.Y. (1977).

<sup>2</sup> Karen Quinlan's father sought court appointment as guardian of her person for the express purpose of authorizing the removal of her respirator, whether or not she died as a consequence. He was opposed not only by Karen's physicians but by the local prosecutor and the state attorney general. The New Jersey Supreme Court, however, granted his request. Her physicians gradually discontinued the respirator during May of 1976 and she was able to breathe on her own; at this writing she is alive, cared for in a New Jersey nursing home. *In re Quinlan*, 70 N.J. 10, 355 A. 2d 647, *cert. denied* 429 U.S. 922, (1976); *IN THE MATTER OF KAREN QUINLAN* (2 vol.), Univ. Publications of America, Frederick, Md. (1977).

- how reliable is the medical prognosis of permanence of unconsciousness?
- what life-extending care should be considered unnecessary in the context of patients with little or no chance of regaining cognitive functions?

Uncertainties regarding the care of long-term unconscious patients have been raised with increasing frequency,<sup>3</sup> though the number of such patients whose care has become the subject of judicial scrutiny still represents only a fraction of the total number of permanently unconscious patients.

The Commission's involvement with the issues raised by this group of patients began with its Congressionally mandated study of the "definition" of death." In an empirical investigation conducted as part of that study, the Commission found that although two-thirds of the patients who are supported by an artificial respirator during a coma of at least six hours

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<sup>3</sup> See, e.g., Lawrence K. Altman, *Princess Death: U.S. Physicians Raise Questions*, N.Y. TIMES, Sept. 21, 1982, at C-1; Glenn Collins, *When Life is a Matter for Debate*, N.Y. TIMES, Aug. 16, 1982, at B-12.

In addition to the well-known *Quinlan* case, there have been several other court reviews of the case of comatose patients. *Dockery v. Dockery*, 559 S.W. 2d 952 (Tenn. App. 1977) (appeal of chancery court order, which appointed husband as guardian for purposes of authorizing removal of respirator from comatose wife, mooted by wife's death); *In re Piotrowicz*, No. 1948 (Essex Cty., Mass. Probate Ct., Dec. 23, 1977) (husband appointed guardian of 56-year-old comatose wife for purposes of authorizing withdrawal of respirator); *In re Nichols*, No. A99511, Orange Cty. Calif. Super. Ct. (March 21, 1979) discussed in Note, *Comatose Conservatee—Restrictions of Legal Capacity—Substance or Procedure?*, 7 WASH ST. U. L. REV. 205 (1980); *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (Ohio Com. Pl. 1980) (family sought directive to disconnect life support); *In re Storar* 52 N.Y.2d 363, 420 N.E.2d 64 (1981), *modifying* *Eichner v. Dillon*, 426 N.Y.S.2d 527 (App. Div. 1980) (in which a comatose Catholic priest, Brother Joseph Fox, was allowed to have treatment stopped because he had given strong advance directives); *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334 (Del. 1980) (comatose woman with substantial advance deliberation allowed to stop all treatment); *In re Lydia Hall Hospital*, No. 23730182 (Special Term, Part II, Sup. Ct., Nassau County, N.Y., Oct. 22, 1982) (Peter Cinque, while competent, asked to cease dialysis and then became comatose after a resuscitation effort and court ordered discontinuation of treatment on family request); *In re Cruse*, No. J914419 and *In re Guardianship of Cruse* No. P645318 (Sup. Ct., Los Angeles, Cal., Feb. 15, 1979) (3-year-old child in coma, life-support discontinuance authorized); *In re Young*, No. A100863 (Sup. Ct., Orange County, Cal., Sept. 11, 1979) (removal of respirator allowed for comatose automobile accident victim).

<sup>4</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, **DEFINING DEATH**, U.S. Government Printing Office, Washington (1981).

duration are dead within a month, about 6% remained indefinitely in a "persistent vegetative state."<sup>5</sup> The Commission was especially interested in this group for two reasons. First, for many years the leading set of clinical criteria for the determination of "brain death" were those published in 1968 under the title "A Definition of Irreversible Coma."<sup>6</sup> Using this term as synonymous with death unfortunately served to perpetuate a confusion in the medical field between the state of being permanently unconscious, as are patients in a persistent vegetative state, and that of being dead.<sup>7</sup> Second, and more importantly, once it is acknowledged that permanently unconscious patients are not dead, difficult questions are raised about the type and extent of care that should be provided for them.

Since permanently unconscious patients raise issues at least as difficult as those considered in *Defining Death*, the Commission resolved to give this group special attention in the present study. Two major issues are presented: Who are these patients exactly? And what issues arise during their care that are different from those of other incompetent patients? The first section of this chapter addresses the theoretical concerns in making a diagnosis of permanent loss of consciousness and identifies the major groups of patients in this state, though the Commission leaves to the appropriate biomedical experts the task of providing working guidelines for making the medical diagnosis. After establishing that some patients' unconsciousness can be reliably predicted to be permanent, the chapter attempts to clarify what should be considered permissible care of these patients. The second section evaluates the considerations that would justify continued treatment of these patients. Next, current treatment practices are described and the Commission's analysis is used to distinguish unacceptable practices from desirable ones. The final section presents the Commission's recommendations for decisionmaking processes that encourage both justifiable assignment of authority to decide and ethically defensible decisions.

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<sup>5</sup> About 12%, typically those whose coma was due to drug intoxication, made a good to moderate recovery, and about an equal number were left with severe disability, though they regained consciousness. *Id.* at 94.

<sup>6</sup> Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 *J.A.M.A.* 377 (1968).

<sup>7</sup> See Julius Korein, *Terminology, Definitions and Usage*, 315 *ANNALS N. Y. ACAD. SCI.* 6 (1978); testimonies of Dr. Lawrence Pitts, Dr. Robert Kaiser, and Mr. Leslie Rothenberg, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 348-65; testimony of Dr. David Levy, transcript of 15th meeting of the President's Commission (Dec. 12, 1981) at 275-82.

## Identifying Patients

Unconsciousness. No one can ever have more than inferential evidence of consciousness in another person. A detailed analysis of the nature of consciousness is not needed, however, when considering the class of patients in whom all possible components of mental life are absent—all thought, feeling, sensation, desire, emotion, and awareness of self or environment.<sup>8</sup> Retaining even a slight ability to experience the environment (such as from an ordinary dose of sedative drugs, severe retardation, or the destruction of most of the cerebral cortex) is different from having no such ability, and the discussion in this chapter is limited to the latter group of patients.

Most of what makes someone a distinctive individual is lost when the person is unconscious,<sup>9</sup> especially if he or she will always remain so. Personality, memory, purposive action,

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<sup>8</sup> A determination of unconsciousness will therefore generally be based upon evidence that the person lacks any responsiveness to the internal or external environment (excepting unmodulated reflex responses), does not engage in purposive action, and manifests no other signs of mental activity.

<sup>9</sup> Two other terms could have been used: "coma" and "vegetative state." But "coma" has often been used imprecisely and both terms might connote only a subset of the relevant group. Sometimes coma is graded to reflect all possible degrees of impaired consciousness. See, e.g., Graham Teasdale and Bryan Jennett, *Assessment of Coma and Impaired Consciousness—A Practical Scale*, 1 LANCET 81 (1974); Bruce D. Snyder *et al.*, *Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Others have insisted upon a more restrictive definition that includes absence of eye opening. "Coma is complete unresponsiveness with eyes closed." Fred Plum, *Consciousness and Its Disturbances: Introduction*, in Paul B. Beeson, Walsh McDermott, and James B. Wyngaarden, eds., *CECIL TEXTBOOK OF MEDICINE*, W.B. Saunders Co., Philadelphia (15th ed. 1979) at 640. The first usage is overly inclusive for the present discussion, as it includes responsive and sentient individuals; the second definition is overly restrictive as it excludes unconscious patients whose eyes open, like those in a "vegetative state," a large subgroup of patients with permanent unconsciousness.

The term "vegetative state" (or, more anatomically, "apallic syndrome") denotes unconsciousness with persistent brain-stem functions that maintain subsistence functions and often wakefulness. It includes patients with the appearance of wakefulness but conversely excludes those who are more deeply comatose with closed eyes. See David H. Ingvar *et al.*, *Survival after Severe Cerebral Anoxia with Destruction of the Cerebral Cortex: The Apallic Syndrome*, 35 ANNALS N.Y. ACAD. SCI. 184 (1978). The term needed for the discussion in this Report was selected to include deep coma and vegetative state but to exclude patients with partial impairments of consciousness. "Permanent loss of consciousness" accomplishes this.

social interaction, sentience, thought, and even emotional states are gone.<sup>10</sup> Only vegetative functions and reflexes persist. If food is supplied, the digestive system functions and uncontrolled evacuation occurs; the kidneys produce urine; the heart, lungs, and blood vessels continue to move air and blood; and nutrients are distributed in the body.

Exceedingly careful neurologic examination is essential in order for a diagnosis of complete unconsciousness to be made. Application of noxious stimuli to the nerve endings of an unconscious patient leads to simple, unregulated reflex responses at both the spinal and the brain stem levels. Reflexes may allow some eye movement, grimacing, swallowing, and pupillary adjustment to light. If the reticular activating system in the brain stem is intact, the eyes can open and close in regular daily cycles. The reflex activity can be unsettling to family and other observers, but the components of behavior that produce this appearance are "accompanied by an apparent total lack of cognitive function."<sup>11</sup> In order to have awareness, a person must have an integrated functioning of the brain stem's activating system with the higher "thinking" functions from the thalamus and cerebral hemispheres.<sup>12</sup> Many patients whose brain dysfunctions cause unconsciousness nevertheless have a fairly intact brain stem and, if provided extensive nursing care, are able to remain alive without respirator support for many years.

<sup>10</sup> Some hold that such a patient ought not to be considered a "person." See Joseph Fletcher, *Indicators of Humanhood*, 2 HASTINGS CTR. REP. 1, 3 (Nov. 1972); Lawrence C. Becker, *Human Being: The Boundaries of the Concept*, 4 PHIL. & PUB. AFFAIRS 334 (Summer 1975); John Lachs, *Humane Treatment and the Treatment of Humans*, 294 NEW ENG. J. MED. 838 (1976). Rather than attempt to define "person," the Commission has concentrated on delineating the obligations to provide care to patients who have permanently lost consciousness, since it had earlier concluded that such patients are living human beings. DEFINING DEATH, *supra* note 4, at 7, 38-41.

<sup>11</sup> Fred Plum and Jerome B. Posner, THE DIAGNOSIS OF STUPOR AND COMA, F.A. Davis Co., Philadelphia (3rd ed. 1980) at 6.

<sup>12</sup> Medical science has been unable to detect or postulate neurologic damage to the brain that would result in a functioning cerebrum capable of consciousness but able to perform absolutely no purposeful actions. At the least, to have consciousness a person must have some functioning cerebrum connected to adequate activating structures in the midbrain. Neurological findings indicate that having that much of a functioning central nervous system entails having at least the ability to blink voluntarily or move the eyes deliberately, and usually much more. Patients with the rare neurologic syndrome termed "locked-in state" retain only the ability to control movements of the eyes or eyelids. See, e.g., Martin H. Feldman, *Physiological Observations in a Chronic Case of "Locked-in Syndrome,"* 21 NEUROLOGY 459 (1971); Plum and Posner, *supra* note 11, at 6.24.

**Permanence.** The other essential property of this category of patients is that their unconsciousness is permanent,<sup>13</sup> which means "lasting...indefinitely without change; opposed to temporary."<sup>14</sup> Three sources of uncertainty should be acknowledged about any judgment that a particular patient's unconscious state is permanent.

The first uncertainty affects any scientific proposition about as-yet-unobserved cases. No matter how extensive the past evidence is for an empirical generalization, it may yet be falsified by future experience. Certainty in prognosis is always a matter of degree, typically based upon the quantity and quality of the evidence from which a prediction is made.

Second, this empirical qualification is especially serious in predictions about unconsciousness because the evidence relevant to a prognosis of permanence is still quite limited. The overall number of such patients is small,<sup>15</sup> and most cases have

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<sup>13</sup> The term "permanent" could have been replaced by "persistent," "irreversible," or "judged to be permanent." "Persistent" was rejected because it can apply to situations that are not permanent. Ordinarily a situation is persistent when it lasts a long time, but not necessarily forever. However, repeated evaluations over a period of persistence is often essential to a reliable prognostication of permanence.

"Irreversible" not only conveys permanence but also focuses upon the prognostication of therapeutic possibilities, which might be a beneficial additional nuance. However, using "irreversible" to refer to this class of patients is virtually precluded by its inappropriate use in the phrase "irreversible coma" to describe neurologically dead bodies maintained on artificial circulatory and respiratory support. See notes 6 and 7, *supra*.

The phrase "judged to be permanent" would highlight the irreducible element of probabilistic judgment that is part of the diagnosis of permanent unconsciousness. However, since such judgment is an essential part of every scientific prognostication, it is redundant and unnecessarily awkward. See, e.g., Alvan R. Feinstein, CLINICAL JUDGMENT, Robert Kreiger Pub. Co., Huntington, N. Y. (1967); Mark Siegler, *Pascal's Wager and the Hanging of Crepe*, 292 NEW ENG. J. MED. 853 (1975).

<sup>14</sup> COMPACT EDITION OF THE OXFORD ENGLISH DICTIONARY, Oxford University Press, New York (1971) at 710.

<sup>15</sup> The only prevalence survey available estimates that Japan has about 2000 permanently unconscious patients in long-term care, which, if the prevalence were the same (and if differing definitions of terms did not cause substantial error), would imply less than 5000 at any one time in the United States. S. Sato *et al.*, *Epidemiological Survey of Vegetative State Patients in Tokuhu District in Japan*, 8 *NEUROLOGIA MEDICO-CHIRURGIA* (Tokyo) 141 (1978). See also, Peter Perl, *Silent Epidemic: Modern Medicine Saves Victims of Crash but Creates Dilemma: Coma*, WASH. POST, March 18, 1982, at A-1; William D. Kalsbeek *et al.*, *National Head Injury and Spinal Cord Injury Survey: Major Findings*, 53 J. NEUROSURG. 19 (Supp. 1980); DEFINING DEATH, *supra* note 4, at 92-95. Dr. Ake Grenvik reports between 500

not been carefully studied or adequately reported. Furthermore, the number of variables affecting prognosis (for example, the cause of unconsciousness, the patient's age and other diseases, the length of time the patient has been unconscious, and the kinds of therapy applied) is large and imperfectly understood.

Finally, any prediction that a patient will not regain consciousness before dying, regardless of the treatment undertaken, contains an implicit assumption about future medical breakthroughs. Since some such patients can be maintained alive for extended periods of time (often years rather than days, weeks, or months),<sup>16</sup> this assumption about treatment innovations can be a long-range one. At the moment, however, it introduces only a very small uncertainty, since the possibility of repairing the neurologic injuries that destroy consciousness is exceedingly remote.

Given these three qualifications on the meaning and basis of any judgment regarding permanence, such a judgment is always a matter of probability about whether a particular patient will remain unconscious until he or she dies despite any treatment that might be undertaken. Nevertheless, the Commission was assured that physicians with experience in this area can reliably determine that some patients' loss of consciousness is permanent.<sup>17</sup>

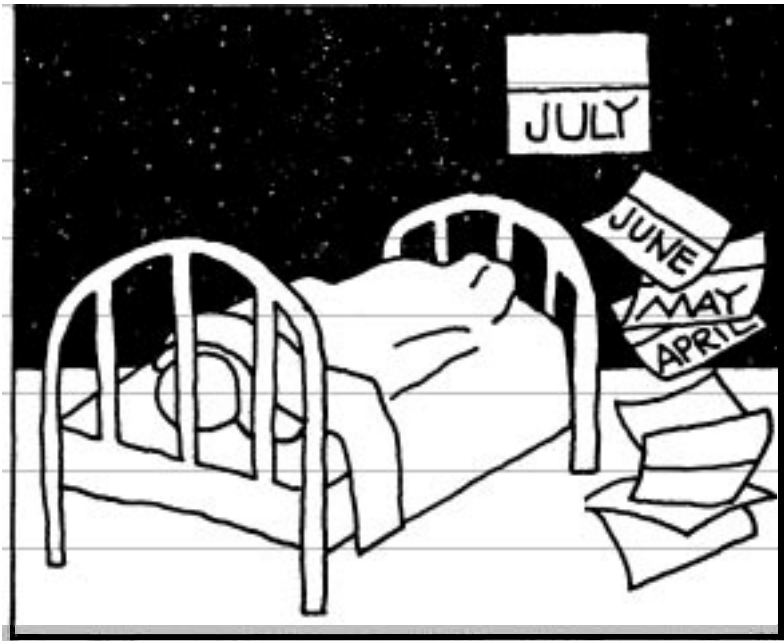
**Disease Categories.** Only a few fairly uncommon diseases cause permanent loss of consciousness. The pathophysiology of an unconscious state that becomes permanent entails severe disruption of the coordinated functioning of the cerebral hemispheres and the midbrain but with retention of sufficient brain-stem activity to sustain vegetative functions. Most commonly, this occurs when the cerebral hemispheres are

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and 1000 patients at Presbyterian-University Hospital in Pittsburgh have had life-sustaining treatment withdrawn because of permanent loss of the important cortical layers of the brain. Letter to Joanne Lynn, Dec. 14, 1981.

<sup>16</sup>The longest case of coma on record is that of Elaine Esposito, who never recovered consciousness after receiving general anesthesia for surgery on August 6, 1941. She died 37 years and 111 days later. Norris McWhirter, ed., **THE GUINNESS BOOK OF WORLD RECORDS**, Bantam Books, New York (1981) at 42. See also the description of a woman injured at age 27 who neither regained consciousness nor left the hospital during the remaining 18 years of her life. Robert E. Field and Raymond J. Romanus, *A Decerebrate Patient: Eighteen Years of Care*, 151 **ILL. MED. J.** 121 (1977).

<sup>17</sup>Letter from Dr. Fred Plum, Neurologist-in-Chief, New York Hospital-Cornell Medical Center, New York, Dec. 22, 1981, reprinted in Appendix G, pp. 459-60 *infra*. See also, *Predicting Outcome After Severe Brain Damage* (Editorial), 1 **LANCET** 523 (1973); *Eichner v. Dillon*, 426 N.Y.S.2d 517, 527-529, modified in, *In re Storar*, 420 N.E.2d 64 (1981).



profoundly injured but the brain stem is nearly entirely spared. Diagnosis in these cases typically involves extensive physical examination, special radiographic and other imaging procedures, and circulation studies of the brain.

Although many individuals with such an injury survive only briefly, some stay alive for an indefinite period and die of some other illness, often contracted while they are unconscious. Nearly all such long-term survivors are in the diagnostic category of "persistent vegetative state" (PVS).<sup>18</sup> This syndrome usually arises from head injury (as from fights, gunshots, or automobile accidents), intracranial hypoxia (as from cardiac arrest, asphyxiation, or hypotensive shock), or intracranial hypoglycemia (as from insulin overdose). If a patient who is initially comatose from a head injury fails to become responsive and aware within a few weeks, the prognosis for any recovery becomes extremely remote. The absence of all responsiveness, vocalization, or purposive

<sup>18</sup> Bryan Jennett and Fred Plum, *The Persistent Vegetative State: A Syndrome in Search of a Name*, 1 LANCET 734 (1972); K. Higashi *et al.*, *Epidemiological Studies on Patients with a Persistent Vegetative State*, 40 J. NEUROL. NEUROSURG. & PSYCHIATRY 876 (1977); Plum and Posner, *supra* note 11, at 338-40.

action one month after the trauma makes a lack of recovery virtually certain, despite vigorous therapy.<sup>19</sup> The incidence of head injuries leading to permanent coma or vegetative state is unclear, as there is no central registry, but preliminary evidence seems to point to at least a few cases each year at each large referral hospital.<sup>20</sup>

As with head injury, hypoxic and hypoglycemic damage to the brain often initially causes loss of function in areas of the brain that might recover with time and treatment. However, probably 12% of patients with nontraumatic coma develop reliably diagnosed PVS.<sup>21</sup> Two patients recovered consciousness after a year of PVS from hypoxia.<sup>22</sup> Recovery of consciousness is very unlikely, however, for patients with hypoxia who remain comatose or in PVS for more than one month.<sup>23</sup> Certainly, extended observation is appropriate before

<sup>19</sup> Testimony of Dr. Lawrence Pitts, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 348-64; Bryan Jennett *et al.*, *Severe Head Injuries in Three Countries*, 40 J. NEUROL., NEUROSURG., & PSYCHIATRY 291 (1977).

<sup>20</sup> Bryan Jennett *et al.*, *Prognosis of Patients with Severe Head Injury*, 4 NEUROSURGERY 283 (1979); Thomas W. Langfitt, *Measuring the Outcome from Head Injuries*, 48 J. NEUROSURG. (1978); **DEFINING DEATH**, *supra* note 4, at 89-107.

<sup>21</sup> See David Bates *et al.*, *A Prospective Study of Nontraumatic Coma: Methods and Results in 310 Patients*, 2 ANNALS NEUROL. 211 (1977); David E. Levy *et al.*, *Prognosis in Nontraumatic Coma*, 94 ANNALS INT. MED. 293 (1981); Higashi, *supra* note 18; **DEFINING DEATH**, *supra* note 4, at 92-95.

<sup>22</sup> In one case, cognitive abilities became normal, although the patient suffered from emotional instability and paralysis of three limbs and remained completely dependent upon others for the rest of his life. Gary A. Rosenberg, Stephen F. Johnson, and Richard P. Brenner, *Recovery of Cognition after Prolonged Vegetative State*, 2 ANN. NEUROL. 167 (August 1977). The other case has recovered only to a locked-in status, with all communication by eyeblink. Lewis Cope, *Doctors Think Mack "in vegetative state,"* MINNEAPOLIS TRIBUNE, March 20, 1980, at A-1; David Peterson, *Shooting Case Turns into Vigil*, MINNEAPOLIS TRIBUNE, March 7, 1980, at A-1; telephone interviews with Ronald Cranford, M.D., consultant neurologist on this case, Ilmnepin County Hospital, Minneapolis, Minn., March 8, 1982, and Dec. 2, 1982.

<sup>23</sup> *Outcome of Non-Traumatic Coma* (Editorial), 2 LANCET 507 (1981); J.A. Bell and H.J.F. Hodgson, *Coma after Cardiac Arrest*, 97 BRAIN 361 (1974); Fred Plum and John J. Caronna, *Can One Predict Outcome of Medical Coma?*, *Outcome of Severe Damage to the Central Nervous System*, CIBA Foundation Symposium #34, Elsevier-North Holland, Amsterdam, (1975) at 121; Bruce D. Snyder, Manuel Ramirez-Lassepas, and D.M. Lippert, *Neurologic Status and Prognosis after Cardiopulmonary Arrest: I. A Retrospective Study*, 27 NEUROLOGY 807 (1977); Bruce D. Snyder, *et al.*, *Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Jorgensen and Malchow-Moller contend that recovery of consciousness before death

making a diagnosis of permanent unconsciousness, at least for hypoxic injuries in otherwise healthy young people.<sup>24</sup>

In addition to those with PVS, four other groups of patients might be diagnosed to be permanently unconscious. First are those who are unresponsive after brain injury or hypoxia and who do not recover sufficient brain-stem function to stabilize in a vegetative state before dying. Most of these die within a few weeks after the brain damage. Although the number of patients in this category is uncertain, it is probably large; more than half the individuals for whom cardiac resuscitation is initially successful die without recovering consciousness, mostly in the first few days.<sup>25</sup>

Second, the end-stage victims of such degenerative neurologic conditions as Jakob-Creutzfeldt disease and severe Alzheimer's disease are permanently unconscious. Only in their final stages do these illnesses become so severe as to bring on complete unconsciousness, and the life span thereafter is only a few weeks or months, depending in part on the extensiveness of support given. Again, the incidence of this source of irreversible unconsciousness is unknown.

A third group of permanently unconscious patients who are in a coma rather than in persistent vegetative state are those who have intracranial mass lesions from neoplasms or vascular masses. If the lesion is correctable, some of these unconscious patients might have restoration of some con-

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can be reliably predicted from careful attention to the time course of EEG and brain stem reflex activity in the first 10 to 36 hours. E.O. Jorgensen and A. Malchow-Moller, *Natural History of Global and Critical Brain Ischaemia: Part III: Cerebral Prognostic Signs After Cardiopulmonary Resuscitation. Cerebral Recovery Course and Rate during the First Year after Global and Critical Ischaemia Monitored and Predicted by EEG and Neurological Signs*, 9 RESUSCITATION 175 (1981). Snyder *et al.* state that "Reliable predictions of survival and outcome can often be based up on LOC [level of consciousness] within 2 days after CPA [cardiopulmonary arrest]." Bruce D. Snyder *et al.*, *Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Evoked potentials may add to the reliability of these early prognostications. Richard Paul Greenberg and Donald Paul Becker, *Clinical Applications and Results of Evoked Potential Data in Patients with Severe Head Injury*, 26 SURG. FORUM 484 (1975).

<sup>24</sup> This caution might be especially appropriate in children. *See, e.g.*, "The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods compared with adults." Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Guidelines for the Determination of Death*, 246 J.A.M.A. 2184, 2186 (1981).

<sup>25</sup> *See, e.g.*, Snyder, Rarnirez-Lassepas, and Lippert., *supra* note 22; Bell and Hodgson, *supra* note 22; DEFINING DEATH, *supra* note 4, at 92-95.

consciousness. However those for whom there is no effective therapy will be unconscious until they die. Such states usually last only for a few days or weeks, and their frequency is unknown.

The fourth source of permanent unconsciousness is congenital hypoplasia of the central nervous system (anencephaly). Various degrees of hypoplasia and dysplasia are possible and some engender brief vegetative life without development of any mentation or cognition. Usually such conditions are apparent because of abnormalities of the cranium at birth. Sometimes the infant is fairly normal, however, and only the failure to achieve the usual developmental landmarks or the appearance of other medical complications leads to detection. Most babies whose anencephaly precludes development of any consciousness die within a few days of birth, and none survive for more than a few months. This condition afflicts one of every 850 births, for an annual incidence of 4000 in the United States.<sup>26</sup>

### Reasons for Continued Treatment

Physicians arrive at prognoses of permanent unconsciousness only after patients have received vigorous medical attention, careful observation, and complete diagnostic studies, usually over a prolonged period. During this time when improvement is thought to be possible, it is appropriate for therapies to be intensive and aggressive, both to reverse unconsciousness and to overcome any other problems. Once it is clear that the loss of consciousness is permanent, however, the goals of continued therapy need to be examined.

**The Interests of the Patient.** The primary basis for medical treatment of patients is the prospect that each individual's interests (specifically, the interest in well-being) will be promoted. Thus, treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and

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<sup>26</sup> See Gayle C. Windham and Larry D. Edmonds, *Current Trends in the Incidence of Neural Tube Defects*, 70 *PEDIATRICS* 333(1982); Lewis B. Holmes, *The Health Problem: Neural Tube Defects*, in National Center for Health Care Technology. **MATERNAL SERUM ALPHA FETOPROTEIN ISSUES IN PRENATAL SCREENING AND DIAGNOSIS OF NEURAL TUBE DEFECTS**, U.S. Government Printing Office, Washington (1980). The annual number of live births used to calculate incidence is from U.S. Department of Health and Human Services, *Health United States 1981*, U.S. Government Printing Office, Washington (1981).

pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.<sup>27</sup>

Any value to the patient from continued care and maintenance under such circumstances would seem to reside in the very small probability that the prognosis of permanence is incorrect.<sup>28</sup> Although therapy might appear to be in the patient's interest because it preserves the remote chance of recovery of consciousness, there are two substantial objections to providing vigorous therapy for permanently unconscious patients.

First, the few patients who have recovered consciousness after a prolonged period of unconsciousness were severely disabled.<sup>29</sup> The degree of permanent damage varied but commonly included inability to speak or see, permanent distortion of the limbs, and paralysis. Being returned to such a state would be regarded as of very limited benefit by most patients; it may even be considered harmful if a particular

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<sup>27</sup> One recent court case points out the conceptual and practical conundrums that arise in defining the interests of a person devoid of all mental life or conscious experience. The suit was brought on behalf of such a plaintiff, seeking damages for loss of enjoyment of life as a result of loss of customary activities. One of the questions for the court was whether it must be shown that the plaintiff is conscious of the fact that he has lost any enjoyment of life. The court answered that, under the disability law, conscious awareness of injuries need not be shown. *Flannery v. U.S.*, 51 U.S.L.W. 2293, 2293 (W. Va. Sup. Ct., 1982).

However, other legal questions are even more vexing:

Someone who has died cannot be said to have "rights" in the usual sense; although a person may have a right to determine how her body is dealt with after death, even that is a troublesome concept....To be sure, Karen Quinlan was not "dead" in most of the increasingly multiple senses of that term, but the task of giving content to the notion that she had rights, in the face of the recognition that she could make no decisions about how to exercise any such rights, remains a difficult one.

Laurence H. Tribe, *AMERICAN CONSTITUTIONAL LAW*, Foundation Press, Mineola, N.Y. (1978) at 936, n 11.

<sup>28</sup> There is a small, finite chance that she [Karen Quinlan] could recover, so keeping her alive for that reason might be a benefit to her, for it at least leaves open the possibility of recovery. This is not to say that Karen Quinlan has a very great chance of recovery, but even a small possibility suggests that it may be in her interests to continue to be alive.

John A. Robertson, *The Courts and Non-treatment Criteria*, in Cynthia B. Wong and Judith P. Swazey, eds., *DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT*, K. Hall Med. Pub., Boston (1981) at 105.

<sup>29</sup> See note 22 *supra*. See also Martin Lasden, *Coming Out of Coma*, N.Y. TIMES, June 27, 1982 (Magazine) at 29.

patient would have refused treatments expected to produce this outcome. Thus, even the extremely small likelihood of "recovery" cannot be equated with returning to a normal or relatively well functioning state. Second, long-term treatment commonly imposes severe financial and emotional burdens on a patient's family, people whose welfare most patients, before they lost consciousness, placed a high value on. For both these reasons, then, continued treatment beyond a minimal level will often not serve the interests of permanently unconscious patients optimally.

**The Interests of Others.** The other possible sources of an interest in continued care for a permanently unconscious patient are the patient's family, health care professionals, and the public. A family possessing hope, however slim, for a patient's recovery shares that individual's interest in the continuation of treatment, namely, the possibility that the prognosis of permanent unconsciousness will prove wrong. Also, families may find personal meaning in attending to an unconscious patient, and they have a substantial interest in that patient's being treated respectfully.<sup>30</sup>

Health care professionals undertake specific and often explicit obligations to render care. People trust these professionals to act in patients' best interests. This expectation plays a complex and crucial part in the professionals' ability to provide care. Failure to provide some minimal level of care, even to a permanently unconscious patient, might undermine that trust and with it the health care professions' general capacity to provide effective care. Furthermore, the self-identity of physicians, nurses, and other personnel is bound in significant ways to the life-saving efforts they make; to fail to do so is felt by some to violate their professional creed.<sup>31</sup>

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<sup>30</sup>Testimony of Earl Appleby, transcript of 25th meeting of the President's Commission (Oct. 9, 1982) at 383-85.

<sup>31</sup>When, some six weeks after the New Jersey Supreme Court opinion authorizing the discontinuance of the respirator for Karen Quinlan, the family asked her attending physician, Dr. Robert J. Morse, why the respirator care was still being continued, Dr. Morse explained, "I have tried to explain to you, I am following medical protocol." When asked how long he would keep her on the respirator if she could not successfully be weaned, Dr. Morse replied, "For as long as it takes. Forever." Quinlan and Quinlan, *supra* note 1, at 287.

Dr. Marshall Brumer, Abe Perlmutter's physician when Perlmutter requested the Florida courts to authorize removal of his life-supporting ventilator, told the Commission: "[The Court-ordered removal of the respirator] was an execution, as the day, location, time, and mode of death were all chosen by the court." When asked how he would have treated a respirator-dependent Karen Quinlan, Dr. Brumer replied. "My opinion of the Karen Ann Quinlan case is that I would support

Consequently, health care providers may have an interest in continued treatment of these patients.<sup>32</sup>

Finally, society has a significant interest in protecting and promoting the high value of human life.<sup>33</sup> Although continued

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her with whatever technologies are available." **Testimony of Dr. Marshall Brumer**, transcript of 8th meeting of the President's Commission (April 19, 1981) at 16.

<sup>32</sup> The New Jersey Supreme Court recognized this interest, in a case involving a blood transfusion for a 23-year-old Jehovah's Witness who had been rendered incompetent and in need of blood as a result of an accident: "The medical and nursing professions are consecrated to preserving life. That is their professional creed. To them, a failure to use a simple established procedure in the circumstances of this case would be malpractice." *John F. Kennedy Memorial Hospital v. Heston*, 279 A.2d 670, 673 (1971).

More recently, however, the Massachusetts Supreme Judicial Court denied that an independent interest of health professionals exists that would go against what patients want or will find beneficial:

Recognition of the right to refuse necessary treatment in appropriate circumstances is consistent with existing medical mores; such a doctrine does not threaten either the integrity of the medical profession, the proper role of hospitals in caring for such patients or the State's interests in protecting the same. It is not necessary to deny a right of self-determination to a patient in order to recognize the interests of doctors, hospitals, and medical personnel in attendance on the patient. Also, if the doctrines of informed consent and right of privacy have as their foundations the right to bodily integrity and control of one's own fate, then those rights are superior to the institutional considerations.

*Superintendent of Belchertown School v. Saikewicz*, 370 N.E.2d 417, 426 (1977) (citation and footnote omitted).

<sup>33</sup> Two unusual circumstances present additional considerations for the interests of others. First, occasionally a permanently unconscious woman is pregnant. If the pregnancy can be continued to the stage of viability for the infant, the interests of the child and the family would usually provide adequate justification for vigorous life-support and therapy until delivery. *See WASH. POST*, March 2, 1982, at A-2, noting the case of a 23-year-old Oregon woman who gave birth to a 7 lb. 13 oz. child after being comatose and on life-support systems for four months. *But see Pettit v. Chester County Hospital*, No. 322, August Term 1982 (Court of Common Pleas, Chester County, Pa.); Mark Butler, *Judge Rules Comatose Woman Can Have Abortion*, *PHIL. INQUIRER*, Aug. 26, 1982, at A-1. *See generally* William P. Dillon *et al.*, *Life Support and Maternal Brain Death During Pregnancy*, 248 J.A.M.A. 1089 (1982).

Second, permanently unconscious patients may be desirable subjects for research. When the research offers prospect of even distant benefit to the subject, it might be approved in the usual way. When the research is not intended to benefit the subject, it would probably be very difficult to secure legally effective consent from a surrogate. *See* President's Commission, *PROTECTING HUMAN SUBJECTS*,

life may be of little value to the permanently unconscious patient, the provision of care is one way of symbolizing and reinforcing the value of human life so long as any chance of recovery remains.<sup>34</sup> Moreover, the public may want permanently unconscious patients to receive treatment lest reduced levels of care have deleterious effects on the vigor with which other, less seriously compromised patients are treated. Furthermore the public has reason to support appropriate research on the pathophysiology and treatment of this condition so that decisions always rely upon the most complete and recent data possible.

There are, on the other hand, considerations for each of these parties — the family, health care professionals, and society — that argue against continued treatment of permanently unconscious patients. As mentioned, long-term treatment commonly imposes substantial financial burdens on a patient's family and on society<sup>35</sup> and often creates substantial psychological stresses for family members and providers.<sup>36</sup> Health

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U.S. Government Printing Office, Washington (1981) at 74-76; Task Force on Research on Senile Dementia, Vijaya Melnick, ed., *Guidelines for Research on Senile Dementia of the Alzheimer's Type*, submitted to National Institutes on Aging (Nov. 1982). Since it would be so easy to overuse these patients in research, great caution is probably appropriate before considering any weakening of the protection involved in the requirement for valid consent.

<sup>34</sup> At least one court has specifically denied a state interest in preserving such a patient's life: "Such a patient has no health and, in the true sense, no life for the state to protect." *Eichner v. Dillon*, 426 N.Y.S.2d 517,543 (1980) *modified in, In re Storar*, 420 N.E.2d 64 (1981).

<sup>35</sup> In 1968 Henry Beecher estimated it would cost \$25,000 to \$30,000 per year for hospital care for each permanently unconscious patient. Henry K. Beecher, *Ethical Problems Created by the Hopelessly Unconscious Patient*, 278 NEW ENG. J. MED. 1425 (1968). While these costs are mitigated by providing care in a skilled nursing facility, inflation must also be taken into account. Even skilled nursing facilities can now cost over \$25,000 per year. Telephone survey of Washington, D.C., area nursing homes (Dec. 1982).

Reported cases provide striking cost estimates. A comatose Tennessee woman who was maintained on a respirator because her death without it might lead to a murder prosecution was costing \$1000 per day. David Meyers, *The California Natural Death Act: A Critical Appraisal*, 52 CAL. ST. BAR J. 326 (1977). Four months of care for a comatose child cost about \$40,000. *In re Benjamin Cruse*. Nos. J914419 and P6 45318 (Los Angeles Superior Ct., Feb. 15, 1979). The first two years of care for an adolescent with persistent vegetative state cost \$280,000. Ronald E. Cranford and Harmon L. Smith, *Some Critical Distinctions between Brain Death and Persistent Vegetative State*, 6 ETHICS IN SCI. & MED. 199, 203 (1979). See also note 115, Chapter Four *supra*.

<sup>36</sup> The disruption of family life, together with the emotional drain on families which elect to care for these patients at home, can be very significant. Moreover, sensational but unverified

care professionals must devote scarce time and resources to treatment that is nearly certain to be futile. Any alternate useful allocation of the resources and personnel is likely to benefit other patients much more substantially.

In sum, the interests of the permanently unconscious patient in continued treatment are very limited compared with other patients. These attenuated interests in continuing treatment must be weighed against the reasons to choose nontreatment in order to arrive at sound public policy on the care of the permanently unconscious.

### Managing Patients' Care

**Current Practice.** Scant information is available on how patients with permanent unconsciousness are most commonly managed. In testimony before the Commission, a neurosurgeon who is doing research on head trauma stated that once he is certain of this diagnosis, he orders "no new therapy."<sup>37</sup> Such patients often succumb to complications of their debilitated state, such as infections, which are more often lethal when antibiotics are not provided. Other cases, such as Karen Quinlan or Minneapolis police officer David Mack,<sup>38</sup> involved the removal of respirator support at some risk of precipitating death. In 1982 the American Medical Association's Judicial Council stated:

Where a terminally ill patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued.<sup>39</sup>

Every few months there are new accounts of court cases involving unconscious patients,<sup>40</sup> which usually arise when a hospital or physician refuses to stop a life-sustaining therapy that family members feel should be halted. Although no data have been published on this issue, it is probably unusual for a family and physician to disagree. The family's wishes about the care of a permanently unconscious patient are probably

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reports from the lay literature regarding miraculous recovery in patients with irreversible brain damage are often unsettling to the families and a source of false hope and further emotional turmoil.

Cranford and Smith, *supra* note 35, at 206.

<sup>37</sup> Pitts, *supra* note 19 at 352.

<sup>38</sup> Sergeant David Mack is the second case in note 22 *supra*.

<sup>39</sup> Judicial Council of the American Medical Association, CURRENT OPINIONS, American Medical Association, Chicago (1982) at 9-10, reprinted in Appendix C, pp. 299-300 *infra*.

<sup>40</sup> See, e.g., James Barron, *Diabetic Dies After L.I. Judge Stops His Life-Sustaining Care*, N. Y. TIMES, Oct. 22, 1982 at A-1; *He's in Coma so Mother Acts in Divorce Case*, PHILA. BULLETIN, Sept. 18, 1981, at A-1.

determinative in most situations when the family has a strong preference.<sup>41</sup> The supportive care that is usually given is probably less than fully intensive care: permanently unconscious patients are unlikely to be admitted to an intensive care unit or to be resuscitated if cardiac arrest occurs. Most of these patients, however, are probably given such measures as basic hygiene and artificial nutrition.

In March 1981, the Los Angeles County Bar Association and the Los Angeles County Medical Association published a set of guidelines on the care of patients in irreversible coma. The two groups have tried to give the outlines of a standard of acceptable care regarding withdrawal of artificial life-sustaining equipment from such patients:



Cardiopulmonary life-support systems may be discontinued if all of the following conditions are present:

- a. The medical record contains a written diagnosis of irreversible coma, confirmed by a physician who by training or experience is qualified to assist in making such decisions. The medical record must include adequate medical evidence to support the diagnosis;
- b. The medical record indicates that there has been no expressed intention on the part of the patient that life-support systems be initiated or maintained in such circumstances; and
- c. The medical record indicates that the patient's family or guardian or conservator, concurs in the decision to discontinue such support.<sup>42</sup>

<sup>41</sup> See, e.g., a survey of 30 physicians in Napa, California, in October 1979, which found that 18 of the 20 physicians who responded would discontinue the respirator on a patient with permanent vegetative state if the next-of-kin agrees. If the permanently unconscious patient can breathe without artificial support, 23 of 29 physicians would stop antibiotics for pneumonia on parental request and 14 of 28 would stop nasogastric tube feedings. David Meyers, *MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING*, Lawyers Cooperative Publishing Co., Rochester, N.Y., (1981) at 167-168.

<sup>42</sup> Joint Ad Hoc Committee on Biomedical Ethics of the Los Angeles County Medical and Bar Associations, *Guidelines for Discontinuance*

This document represents an effort that is both unusual and laudable, although the actual standards are probably representative of unwritten policy in many other locations.<sup>43</sup>

Not only is it unclear what care is most commonly provided, but it is also not known what facilities provide care. The institution, usually a large acute-care hospital, that is caring for a patient when he or she becomes permanently unconscious is likely to continue care if the person is not expected to live more than a few weeks.<sup>44</sup> Patients who are expected to live longer will probably be transferred, whenever possible, from acute care hospitals to long-term care facilities such as rehabilitation hospitals and skilled nursing facilities. The type of institution providing care is likely to affect the care options that are available and encouraged.<sup>45</sup>

**Unacceptable Practices.** Some courses of care are unacceptable because they would fail to respect a patient's living body or would constitute an irresponsible stewardship of a community's resources. Errors of either sort could justifiably be proscribed by laws or regulations as well as by professional standards and policies. Errors of the first sort occur when a patient who is permanently unconscious is treated in ways that deaden the sensitivities or shock the conscience of the public, of professionals, or of the family involved, that violate the secure expectations that people reasonably have about the way they will be treated if they are ever unconscious, or that degrade the trust and confidence required for health professionals' effective performance. Direct or violent killing, abusive actions, or public viewing of a patient should certainly be considered morally reprehensible.

An irresponsible stewardship of society's resources can occur when a permanently unconscious patient is given care that precludes the treatment of others who would be helped far more than the unconscious patient. This could occur, for

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*of Cardiopulmonary Life-Support Systems Under Specified Circumstances* (Adopted by the Medical Assoc. March 2, 1981, and by the Bar Assoc. March 11, 1981), reprinted in Appendix G, pp. 461-62 *infra*.

<sup>43</sup> Other policies have been written. The North Carolina natural death act has provisions allowing discontinuation of life support for certain comatose patients. See Appendix D, pp. 357-62 *infra*. Also, the New Jersey professional associations in medicine, osteopathy, and hospital care produced guidelines to implement the *Quinlon* decision (note 2 *supra*). See Appendix G, pp. 463-66 *infra*. Other guidelines for decisions about the case of permanently unconscious patients have been published. In 1976, the Swiss Academy of Medical Sciences published guidelines that allow discontinuation of "special life-extending measures." *Swiss guidelines on Core of Dying*, 7 HASTINGS CTR. REPORT 30. 31 (June 1977).

<sup>44</sup> See Matt Clark and Marsha Zabarsky, *Hope for Como Victims*, NEWSWEEK 59 (Oct. 12, 1981).

<sup>45</sup> See pp. 106-18 *supra*.

example, were another specific patient to receive less beneficial therapy because a scarce support system is being used with a permanently unconscious patient. Whenever there is reason to believe this is happening, the patient with a remediable illness or even a chance of regaining consciousness should be put on the support system even if it precipitates the death of the permanently unconscious patient. Such an allocation upholds the highest traditions of the medical profession and should be considered to be within current standards of medical practice.

A second failure of responsible stewardship occurs when resources are expended so lavishly in the care of patients who will never regain consciousness that other important social goals are thwarted. This misallocation is usually less grave than that involving particular cases because the connection between the costs of care of the unconscious patient and any harm to others is more attenuated. For the moment, at least, total expenditures on permanently unconscious patients do not appear to be causing substantial identifiable harms to others. Nevertheless, since it is ethically acceptable to limit the provision of treatment, especially when it can at best offer a very small benefit to the patient,<sup>46</sup> policymakers in public and private health care payment programs may legitimately consider means of limiting, or even proscribing, these expenditures. Such limitations should not make a false distinction between the treatment of unconscious patients and other, perhaps greater, types of wasteful treatment or discriminate among unconscious patients based upon whether the reimbursement program is public or private.

**Desirable Practices.** Beyond these unacceptable practices, various possible treatment plans remain, ranging from aggressive measures to assure the longest possible life span to hygiene measures and dignified care for the body. As indicated, vigorous treatment to reverse or prevent all life-threatening illnesses and complications might be justified by the very small possibility of error in prognosis or by the desire to conform with a family's wishes.<sup>47</sup> The attenuated nature of these interests, at least compared with the obligation to benefit most other patients, argues that unlimited vigorous treatment of permanently unconscious patients may properly be discouraged, though it should not be proscribed.

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<sup>46</sup> See pp. 95-100 *supra*.

<sup>47</sup> The concern may also be felt that to deny therapy to these patients diagnosed permanently unconscious might lead to a reduction of vigor in treating patients with a slightly better potential for return to a sentient condition. This concern seems unpersuasive since there has been no discernible diminution in the quality of care of other patients despite several widely publicized cases in which vigorous care for permanently unconscious patients was rejected.

Less aggressive care, which would still be respectful and humane but would use fewer human and financial resources, can be an alternative plan. The kinds of treatment decisions involved relate to the support or nonsupport of vegetative functions and the complications of severe disability.

- Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions<sup>48</sup>--nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such increasingly burdensome interventions is sustaining the body to allow for a remote possibility of recovery. The sensitivities of the family and of care giving professionals ought to determine whether such interventions are made.<sup>49</sup>
- Unconscious patients lack control over elimination. Measures to control bowel movements and provide proper hygiene are appropriate both to preserve the dignity of the patient and to lessen the burden of the care giver, though they rarely alter a person's life span. Similarly, catheterization of the bladder to keep the patient more presentable is justifiable, though it increases the risks of infection. Surgical procedures to provide urinary drainage in instances in which simple catheterization is insufficient are more difficult to justify, however. The expense of care thereafter and the resource use in the initial procedure are substantial, while the benefit to the patient is very small. The same considerations would make it very hard to justify dialysis for a permanently unconscious patient who develops kidney failure.

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<sup>48</sup> Some patients retain reflex swallowing that allows oral feeding. However, at best this is very tedious for care givers and has a high risk of aspiration (with resultant pneumonia) for the patient.

<sup>49</sup> Where all remedial attempts have failed to bring the patient out of chronic coma, but where the patient is able to spontaneously maintain respiration and circulation, it would seem to be a matter between physician and family as to whether or not other, more mundane, care would continue....[If] the family feels the emotional or financial drain too great and the physicians in attendance indicate no reasonable possibility of any recovery, then it can be anticipated that the courts, when presented with the petitions for appointment of a conservator with power to refuse consent to further treatment of any kind, including I.V. drip, antibiotic administration, or for that matter even maintenance in a hospital or other medical institution, can be expected to grant such requests.

Meyers, *supra*, note 41, at 171-72.

- The awkward posture and lack of motion of unconscious patients often lead to pressure sores, and skin lesions are a major complication. Treatment and prevention of these problems is standard nursing care and should be provided. After a prolonged period of paralysis, joints become fixed, and limbs and fingers become irreversibly flexed. If vigorous intervention is maintained for a few months, the patient's body can become fairly rigid in a position that is most accommodating to hygiene and skin care, which is an acceptable goal of simplifying nursing care. Deciding whether to maintain physical therapy for this purpose would depend upon the patient's projected life span and the financial and other costs of making the service available.

Some permanently unconscious patients will have normal airways to the lungs; as part of respirator care earlier in their illness, others will have had a tracheostomy (which provides a hole through the base of the neck into the trachea). Justifying continuation of such costly and intrusive care as a respirator is exceedingly difficult.<sup>50</sup>

- Most of these patients periodically aspirate food or saliva into their lungs, which, combined with inactivity, often leads to pneumonia. Some physicians treat all such pneumonias with antibiotics; others leave them untreated; still others do whatever the family prefers. Though the administration of antibiotics for susceptible infections should not be so automatic a response by care givers and families that it is beyond critical scrutiny in each case, either treating or not treating pneumonia in permanently unconscious pa-

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<sup>50</sup> Weaning a permanently unconscious patient from a respirator when death is an acceptable outcome might well be done rather differently than for patients for whom survival is of paramount importance. Ake Grenvik, *Terminal Weaning: Discontinuance of Life-Supporting Therapy in the Terminally Ill Patient* (Editorial), 11 *CRIT. CARE MED.* (forthcoming, May 1983).

Pointing out the futility of respirator care, Dennis Horan states:

A physician is authorized under the standards of medical practice to discontinue a form of therapy which in his medical judgment is useless...If the treating physicians have determined that continued use of a respirator is useless, then they may decide to discontinue it without fear of civil or criminal liability. By useless is meant that the continued use of the therapy cannot and does not improve the prognosis for recovery.

Dennis Horan, *Euthanasia and Brain Death: Ethical and Legal Considerations*, 315 *ANNALS N.Y.ACAD. SCI.* 363, 367 (1978).

tients remains morally acceptable, since at this time the additional expense of lengthened survival does not seem prohibitive.

### The Decisionmaking Process

Recommending a single management scheme would be neither possible nor desirable because of the great variations in the situations of permanently unconscious patients, the nature of the institutions and persons providing care, and the desires of the families involved. First, the values and beliefs of health care professionals and the policies of the institution may place limits on the treatment options made available, even when all providers try to avoid idiosyncratic thinking or unreasonable rigidity; transfer to other care givers may not be a possibility. Second, decisions are often constrained by legal uncertainty about the effects particular courses of treatment might have for the rights and liabilities of the parties involved.<sup>51</sup> Third, the people who love and care about the patient should have a voice in decisions. Certain options that are morally, medically, and legally valid might be quite unacceptable to them.<sup>52</sup> Finally, realistic possibilities may be curtailed by the unavailability of funds and resources.

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<sup>51</sup> One case went to court for this reason alone:

The attending physicians testified that in their opinion the proper course of action to follow would be to turn off the respirator and let Benjamin die. They also testified that this was the standard of medical conduct in the community and was in conformity with generally accepted medical practice. They further testified that the reason they refused to do this when the parent asked them to was because of the uncertain state of law. That is, the doctors were afraid of any resulting civil and criminal liability that might follow their actions.

*In re Benjamin Cruse*. Nos. J914419 and P645318 Slip op. at 5 (Los Angeles County Super. Ct. Feb. 15, 1979).

<sup>52</sup> Joseph and Julia Quinlan have written:

We understand that conceivably *all* treatment of Karen Ann is extraordinary. That means the antibiotics and the food and the respirator. However, we personally have moral problems with our conscience, with regard to the food and the antibiotics. We have problems with it now, and we realize we would have more problems with it ten years from now.

Quinlan and Quinlan, *supra* note 1, at 282 (emphasis in original).

Others have, however, recognized that distinguishing feeding as more obligatory to provide for these patients is psychologically rather than ethically based. Donald G. McCarthy, *Care of Persons in the Final Stage of Terminal Illness or Irreversibly Comatose*, in Donald G. McCarthy and Albert S. Moraczewski, eds., in *MORAL RESPONSIBILITY IN PROLONGING LIFE DECISIONS*, Pope John Center, St. Louis, Mo. (1981) at 196.

Although a single scheme is not feasible, procedures for deciding among possible alternatives can still be endorsed. Sometimes, though infrequently, a patient will have indicated his or her preferences before losing consciousness.<sup>53</sup> A reasonably specific advance directive to withhold care should be honored those responsible for a permanently unconscious patient.<sup>54</sup> A directive requesting continued treatment should guide those responsible but it cannot supersede their obligation to decide on management of the patient's care in light of all the circumstances, some of which may not have been foreseen by the patient when the directive was given.

When there are several treatment options that are acceptable to all interested parties and there is no advance directive from the patient, the option actually followed should generally be the one selected by the family.<sup>55</sup> When no alternative is acceptable to all concerned, an attempt to reach an acceptable compromise is preferable to forcing a confrontation. If substitu-

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<sup>53</sup> Formalization and standardization of action for patients in prolonged noncognitive states would invade the area of personal belief in a way that would harm freedom of choice. While the patient can no longer express a choice, families and physicians can. If well-documented statements from the patient, either verbal or in the form of a so-called living will, are available, the position so stated can be taken into consideration. My belief is that the end result of such reasoning together will, in most instances, provide an acceptable solution to a tragic problem.

Stuart A. Schneck, *Brain Death and Prolonged States of Impaired Responsiveness*, 58 DENVER L.J.609, 621-22 (1981).

Living wills, whether or not drafted under natural death acts, (*see* pp.139-45 *supra*) are unlikely to apply to this situation. The permanently unconscious patient is probably not terminally ill within the meaning of the statutes, and the measures at issue are not highly intrusive and artificial, both of which are common requirements of living wills. *But see* N.C. Gen. Stat. SS 90-322 (Cum. Supp. 1979) Appendix D, pp. 357-62 *infra*. It may be instructive, however, that many people feel that there is a large and growing consensus that life as a permanently unconscious patient is more horrible than death. *See* *Eichner v. Dillon*, 426 N.Y.S. 2d 517, *modified in, In re Storar*, 420 N.E. 2d 64 (1981).

<sup>54</sup> In *Eichner*, the New York State Superior Court and Court of Appeals relied on Brother Fox's statements in discussions of morals and high school teaching that he would not want to be kept alive in Karen Quinlan's situation. *See In re Storar*, 420 N.E.2d 64, 71-71 (1981).

<sup>55</sup> In one District of Columbia case, the court specifically declined to require formal guardianship or petition to the court. *Parker v. U.S.*, 406 A2d 1275, 1282 (D.C. Ct. App., 1979).

tion of another provider, institution, or funding would achieve accord and is possible, such a course should be followed.<sup>56</sup> Where institutional ethics committees exist, their assistance should be sought since the advice of a group of concerned but disinterested people may foster understanding and agreement.<sup>57</sup>

If disagreement between at least two of these parties — the health care professionals, the family members, and the institution — persists after institutional review, recourse to the courts for the appointment of a guardian may be both appropriate and unavoidable.<sup>58</sup> Any physician involved in such a proceeding is under a strong moral obligation to assist in educating the lawyers and the court about the complexities of the situation. Courts ought to avoid deciding among treatment options, however, because explicit judicial decisions may prematurely rigidify the options available and paralyze the exercise of judgment by the parties directly involved. Rather, the court should appoint a responsible surrogate who is charged with collecting and considering the relevant information and making a decision, which might then be reported to the court.

In general, the courts have followed this course. The New Jersey Supreme Court, for example, held that the constitutional right of privacy of an unconscious patient in a situation like that of Karen Quinlan is broad enough to encompass a right to refuse the application of a mechanical respirator and that her father, as guardian, could make such a choice on her behalf.<sup>59</sup>

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<sup>56</sup> "You see, if the Quinlans had changed the doctor before they brought this case to court, it might never have come to court." Koichi Bai, *Around the Quinlan Case-Interview with Judge R. Muir*, 1 *INT'L J. MED.* 45,55 (Summer 1979).

<sup>57</sup> See pp. 161-65 *supra*.

<sup>58</sup> It may be best to require, where any doubt or disagreement of any kind or degree exists on the part of the physician or the family as to the appropriate course of action, recourse to the courts for conservatorship powers. ...Where no such doubt or disagreement exists between family or physician and where the hopeless diagnosis has been confirmed by an independent consultant after all clinical trials have failed, it would seem unnecessary to involve the courts in any way in decisions to terminate any or all life-support systems.

Meyers, *supra* note 41, at 171-72.

<sup>59</sup> Unfortunately, the court went beyond appointment of the guardian and seemed occasionally to step into the role of guardian itself, giving an opinion on what Karen Ann Quinlan would want were she capable of expressing herself. The court clearly recognized that Karen Quinlan's situation differed from other cases where courts have been asked to rule on the propriety of medical treatments. The court's decision in large measure turned on to the nature of the patient's condition, the degree of invasiveness of the medical care, and the minimal hope for recovery.

A number of other cases of permanently unconscious patients have come before the courts in the seven years since the *Quinlan* decision, and guardians have uniformly been allowed to consent to withdrawal of treatment for patients whose status is comparable to hers.<sup>60</sup> Most of these civil cases relied

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The nature of Karen's care and the realistic chances of her recovery are quite unlike those of the patients discussed in many of the cases where treatments were ordered. In many of those cases the medical procedure required (usually a transfusion) constituted a minimal bodily invasion and the chances of recovery and return to functioning life were very good. We think that the State's interests contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims.

*In re Quinlan*, 70 N.J. 10, A.2d 647, 664, cert. denied 429 U.S. 922 (1976).

The court was careful to note that in the future such decisions must continue to be made on the basis of reliable prognoses to ensure that there is no reasonable possibility of return to a cognitive, sapient slate. For this reason it assigned the task of confirming the prognosis to an "ethics committee." *Id.* at 67. See, New Jersey Guidelines for *Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients*, reprinted in Appendix G, pp. 463-66 *infra*.

<sup>60</sup> See note 3, *supra*. In one Ohio case, the court specified certain requirements to assure the diagnosis and to notify the county coroner and prosecutor. *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

In the case of *Mary Severns*, the Delaware Supreme Court, after hearing evidence that Mrs. Severns, now permanently unconscious, would not have wanted to have treatment continued and that her husband and family were in accord, ruled that treatment could be foregone. Yet the court reserved a final decision until after an evidentiary hearing before a chancery court to confirm the medical facts (which had only been presented as stipulations from unnamed physicians). *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334, 1349-50 (Del. 1980). The resulting chancery court order was quite broad, explicitly extending to authorizing refusal of resuscitation, feeding tubes, and antibiotics. *In re Severns*, No. C.M. 3722 (Ct. of Ch., New Castle County, Del., Dec. 31, 1980).

In the *Brother Fox* case the intermediate court ruling would have required confirmation of the prognosis of terminal illness and "irreversible, permanent or chronic vegetative coma," with "extremely remote" prospects of recovery by the majority vote of a three-member committee. This would be followed by court review, including appointment of a guardian *ad litem* and notification of the Attorney General and appropriate District Attorney. *Eichner v. Dillon*, 426 N.Y.S.2d 527, 550 (1980). The court of appeals overruled the procedural aspects of the case, holding that court review is optional: "[A] mandatory procedure of successive approval by physicians, hospital personnel, relatives and the courts...should come from the Legislature." *In re Storar*, 420 N.E.2d 64, 74 (1981).

largely upon a constitutional claim of privacy on behalf of the unconscious patient against which the state had no substantial contravening interests.<sup>61</sup> In one criminal case, the court decided that responsibility for the permanently unconscious patient's death rested with the robber whose battery caused the unconsciousness, not the physicians who, without prior court sanction, removed a respirator.<sup>62</sup>

In sum, the Commission finds good decisionmaking regarding patients who have permanently lost consciousness to be possible without changes in law or other public policy. The medical profession should continue to carry its weighty obligation to establish diagnoses well and to help families understand these tragic situations. Health care institutions need to provide good policies to govern decisionmaking, including appropriate sources of consultation and advice. Family and friends of the permanently unconscious patient bear not only the protracted tragedy of their loss but also the substantial responsibility of collaborating in decisionmaking. When families can direct the care of an unconscious family member, practices and policies should encourage them to do so and should restrict the degree to which outsiders may intervene in these matters. Courts and legislatures should not encourage routine resort to the judicial system for the actual decisionmaking. Instead, courts ought to ensure that appropriate surrogates are designated and that surrogates are allowed an appropriate range of discretion.

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<sup>61</sup> *But see*, In re Storar, 420 N.E.2d 64 (1981).

<sup>62</sup> Parker v. U.S., 406 A.2d 1275 (D.C. Ct. App., 1979).

### Origin and Scope of the Issue

**New Medical Capabilities.** Remarkable advances in neonatal care now make it possible to sustain the lives of many newborn infants who only one or two decades ago would have died in the first days or weeks after birth. Between 1970 and 1980, the death rate in the first 28 days of life (the neonatal period) was almost halved, the greatest proportional decrease in any decade since national birth statistics were first gathered in 1915.<sup>1</sup> Improvement among the smallest infants—those at greatest risk of death and illness—has been especially dramatic: for newborns weighing 1000-1500 grams, the mortality rate has dropped from 50% to 20% since 1961; fully half the live-born infants weighing less than 1000 grams (2.2 pounds) now survive, compared with less than 10% just 20 years ago.<sup>2</sup> And

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<sup>1</sup> Between 1970 and 1980 neonatal mortality in the U.S. declined by 24%; in comparison, the rate dropped by only 57% in the four decades between 1930 and 1970. Myron E. Wegman, *Annual Summary of Vital Statistics--1980*, 68 PEDIATRICS 755, 759 (1981). Most of the decline is attributed to improved survival rates at specific birth weights, rather than to a change in the proportion of high-risk infants born. Kwang-Sun Lee *et al.*, *Neonatal Mortality; An Analysis of the Recent Improvement in the United States*, 70 AM. J. PUB. HEALTH 15 (1980). See also pp. 199-201 *infra*.

<sup>2</sup> Peter P. Budetti and Peggy McManus, *Assessing the Effectiveness of Neonatal Intensive Care*, 20 MED. CARE 1027 (1982). The weight of newborns is frequently reported in grams; one pound is equivalent to 454 grams. The median birthweight in the United States in 1978 was 3350 grams (7 lbs., 6 oz.) Samuel S. Kessel, Judith P. Rooks and Irving M. Kushner, *A Child's Beginning*, in Select Panel for the Promotion of Child Health, 4 BETTER HEALTH FOR OUR CHILDREN: A NATIONAL STRATEGY, Dept. of Health and Human Services, U.S. Government Printing Office, Washington (1981) at 212.

marked improvements have also been reported in the survival rate of infants with certain congenital defects.<sup>3</sup> ■ . ,

Not all seriously ill newborns fare well, however. Some infants with low birth weight or severe defects cannot survive for long, despite the most aggressive efforts to save them; others suffer severe impairments either as a component of their conditions or as a result of treatments. Thus medicine's increased ability to forestall death in seriously ill newborns has magnified the already difficult task of physicians and parents who must attempt to assess which infants will benefit from various medical interventions, and which will not. Not only does this test the limits of medical certainty in diagnosis and prognosis, it also raises profound ethical issues.

Debates about the ethics of foregoing life-sustaining treatment for newborns began to appear in professional journals in the early 1970s.<sup>4</sup> Ethicists, lawyers, and parents joined in the dialogue. More recently, some of the controversies have been front-page news in the popular press.<sup>6</sup> Attention is often focused on two situations—a mentally retarded baby who requires life-saving surgery to correct a lethal physical defect,<sup>5</sup> and an infant with spina bifida who is expected to suffer some degree of physical and/or mental impairment even

<sup>3</sup> See, e.g., Kevin Turley, Constantine Mavroudis, and Paul A. Ebert, *Repair of Congenital Cardiac Lesions During the First Week of Life*, 66 CIRCULATION 214 (Supp. I 1982); Eduardo Arciniegas et al., *Results of the Mustard Operation for Dextro-transposition of the Great Arteries*, 81 J. THORAC. CARDIOVASC. SURG. 580 (1981); Ronald D. Greenwood and Alexander S. Nadau, *The Clinical Course of Cardiac Disease in Down's Syndrome*, 58 PEDIATRICS 893 (1976).

<sup>4</sup> See e.g., Raymond S. Duff and A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (1973).

<sup>5</sup> See e.g., Richard A. McCormick, *To Save or Let Die*, 229 J.A.M.A. 172 (1974); James M. Gustafson, *Mongolism, Parental Desires, and the Right to Life*, 292 PERSPECTIVES IN BIO. AND MED. 529 (Summer 1973); John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975); Albert R. Jonsen et al., *Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIATRICS 756 (1975); John J. Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 L. MED. AND HEALTH CARE 120 (1982); Paul Bridge and Marlys Bridge, *The Brief Life and Death of Christopher Bridge*, 11 HASTINGS CTR. REP. 17 (Dec. 1981).

<sup>6</sup> See, e.g., Matt Clark, Mariana Gasnell, and Dan Shapiro, *When Doctors Play God*, NEWSWEEK 48 (Aug. 31, 1981); W. Stewart Pinkerton, *Practice of Neglecting Badly Deformed Babies Stirs Troubled Debate*, WALL ST. J., July 21, 1982, at A-1; Walter Sullivan, *Life or Death Choices on Birth Defects*, N.Y. TIMES, June 19, 1981, at B-7.

<sup>7</sup> Perhaps the most well known of these cases is one that occurred at Johns Hopkins Hospital, where a newborn Down syndrome baby with surgically correctable duodenal atresia was left untreated and unfed; he died 15 days later. Gustafson, *supra* note 5; Andre Hellegers,

if operated upon immediately but who will suffer more severe impairment or die if surgery is withheld or postponed.<sup>8</sup> Yet actual life-and-death decisions in neonatal intensive care units (NICUs) encompass a much wider range of medical and social circumstances. In fact, these two situations account for only a small fraction of the difficult cases in decisionmaking about seriously ill newborns.<sup>9</sup>

In this chapter the Commission attempts to dispel the confusion that arises about the treatment of seriously ill newborns and to suggest both the range of ethically and legally acceptable decisions and who should make them. As with the other subjects in this Report, the discussion is not intended as a prescription for the outcome regarding particular decisions that must be made in the case of individual newborns; rather, it provides a framework for those—including policymakers in health care institutions and in the legal system—who are responsible for the decisionmaking process.

**The Infant at Risk.** Decisions about whether life-sustaining treatment is warranted for newborns arise most frequently in two general categories: infants of low birth weight and infants with life-threatening congenital abnormalities.

**Low birth weight infants.** Birth weight is a very strong predictor illness and death in the neonatal period; in general, the lower the birth weight, the higher the mortality rate.<sup>10</sup>

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*Problems in Bioethics: The Johns Hopkins Case*, 8 *OBSTET. & GYNECOL. NEWS* 40 (June 15, 1974); *Who Should Survive?* (film), produced by Joseph P. Kennedy, Jr., Foundation, Washington, D.C.

8 Robert Reid, *MY CHILDREN, MY CHILDREN: THE WORLDWIDE BATTLE AGAINST A MAJOR CRIPPLER OF CHILDREN*, Harcourt Brace Jovanovich, New York (1977); Charles A. Swinyard, ed., *DECISION MAKING AND THE DEFECTIVE NEWBORN*, Charles C. Thomas, Springfield, Ill. (1978).

9 The law and ethics relative to the care of newborns are unexplored territory....The problem with ethics and law in neonatology is that lawyers and philosophers have been looking at the peaks and have very little awareness of the crevices into which one can easily fall....The legal and philosophical discussions relative to neonatology are almost exclusively devoted to these two kinds of cases [Down syndrome and spina bifida]....Because there is no mention of the prominent problem, the legal analysis of neonatology misses the point. The dominant problem in the newborn nursery is prematurity.

Albert R. Jonsen, *Ethics, Law, and the Treatment of Seriously Ill Newborns*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, AUPHA Press, Ann Arbor, Mich. (1982) at 236-37.

<sup>10</sup> Lula O. Lubchenco, *THE HIGH RISK INFANT*, W. B. Saunders Co., Philadelphia (1976) at 100; K. Lee, *The Very Low Birthweight: Principal Predictor of Neonatal Mortality in Industrialized Popula-*

About 230,000 infants born in the United States each year—7% of all live births—weigh 2500 grams or less, which is classified as low birth weight (LBW).<sup>11</sup> One study of LBW infants born at several major medical centers between 1974 and 1976 found that these small newborns were 40 times more likely than infants of normal weight to die in the neonatal period and five times more likely to die between one month and one year of age.<sup>12</sup> Mortality among LBW infants ranges from about 10% for those weighing 2000-2500 grams to nearly 100% for those under 750 grams. Very low birth weight infants—those who weigh less than 1500 grams—face an especially high risk of death; although they constitute only 1% of all newborns, they account for almost half of all infant deaths.<sup>13</sup> LBW infants are also at increased risk for serious congenital defects and impairments.<sup>14</sup>

Most LBW infants are premature, although some are small despite a normal gestation period. Within each LBW category, the prognosis improves with increased gestational age.<sup>15</sup> The most common complication of prematurity is hyaline membrane disease, a consequence of immature lung development, which is associated with 50-70% of deaths among premature infants.<sup>16</sup> Affected infants must be placed on mechanical ventilators to counteract the insufficient oxygen supply associated with this condition; like the disorder, this treatment can cause substantial morbidity and mortality.<sup>17</sup>

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*tions*, 97 J. PEDIATRICS 759 (1980); Lasalle D. Leffall, Jr., and Joan Maxwell, *Reducing Infant Mortality by Preventing Premature Births*, WASH. POST, Dec. 5, 1982, at C-8.

<sup>11</sup> Office of Technology Assessment, U.S. Congress, *THE COSTS AND EFFECTIVENESS OF NEONATAL INTENSIVE CARE (Case Study #10)* U.S. Government Printing Office, Washington (1981) at 11 (hereinafter cited as *COSTS OF NEONATAL CARE*).

<sup>12</sup> Sam Shapiro *et al.*, *Relevance of Correlates of Infant Deaths for Significant Morbidity at 1 Year of Age*, 136 AM. J. OBSTET. GYNECOL. 363 (1980).

<sup>13</sup> *COST OF NEONATAL CARE*, *supra* note 11, at 11.

<sup>14</sup> Shapiro, *supra* note 12.

<sup>15</sup> Lubchenco, *supra* note 10, at 103-04.

<sup>16</sup> Gordon B. Avery, ed., *NEONATOLOGY*, J.B. Lippincott Co., Philadelphia (2nd ed. 1981) at 376.

<sup>17</sup> The respiratory distress syndrome (RDS) caused by hyaline membrane disease causes such complications as: respiratory failure; brief episodes without breathing (apnea); pulmonary hemorrhage; and cerebral (intraventricular) bleeding. These are serious—sometimes life-threatening—conditions. Serious intraventricular hemorrhage, for example, usually results in permanent brain damage. In addition, the mechanical ventilation often necessary to treat infants with RDS can cause morbidity. Some infants will require long-term tracheostomy, in which a tube is inserted in the neck to create an adequate airway. These infants cannot make sounds and require continuous special nursing care. Therapeutic doses of oxygen used to treat RDS can also

Feeding also presents special problems for these tiny newborns. Not only is the gastrointestinal tract unable to absorb certain foodstuffs yet, but these infants often lack the sucking and swallowing reflexes necessary for oral feeding. The amount of feeding through intravenous lines is limited both by the number of potential sites and the capacity of the immature kidneys to handle the added volume. Excess fluid intake can severely compromise an overworked heart, while an insufficient amount of fluid limits growth and denies these infants such essential nutrients as calcium. Having too little calcium can retard bone growth and increase the likelihood of bone fractures. Extremely premature infants are also very susceptible to infections (from an immature immune system), internal hemorrhage (from a deficiency of coagulation factors), anemia, and a host of other disorders.

Low birth weight is associated with several maternal risk factors. Women who have LBW infants are more likely than other mothers to be poor, nonwhite, single, poorly educated, or under 18 or over 35.<sup>18</sup> Inadequate prenatal health care is also strongly associated with low birth weight and infant mortality.<sup>19</sup>

***Infants with congenital abnormalities.*** About 4% of the approximately 3.3 million infants born in this country each year have one or more readily detectable congenital abnormalities.<sup>20</sup> These infants are often born at term, rather than

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lead to retrolental fibroplasia, a cause of blindness. And the mechanical ventilation can cause permanent and sometimes progressive lung damage.

<sup>18</sup> See Victor Eisner *et al.*, *The Risk of Low Birthweight*, 69 AM. J. PUB. HEALTH 887 (1979); BETTER HEALTH FOR OUR CHILDREN: A NATIONAL STRATEGY *supra* note 2, at 212.

<sup>19</sup> Eisner, *supra* note 18; D.M. Kessner *et al.*, *Infant Death: An Analysis by Maternal Risk and Health Care* 1 CONTRASTS IN HEALTH STATUS, Institute of Medicine, Washington (1973); A.B. Dott and A.T. Fort, *The Effect of Maternal Demographic Factors on Infant Mortality Rates: Summary of the Findings of the Louisiana Infant Mortality Study. Part I.*, 123 AM. J. OBSTET. GYNECOL., 847 (1975). In 1977 about one-fourth of all mothers did not receive prenatal care during the first trimester, a critical period in the development of the fetus. Moreover, those who do not receive prenatal care tend to be the women who otherwise are at the greatest risk of having a low birth weight infant. Better Health for Our Children, *supra* note 2. A combination of factors, including availability of physicians, financing, and education, contribute to high-risk mothers not receiving the care that could prevent premature births. The Commission's Report, SECURING ACCESS TO HEALTH CARE, U.S. Government Printing Office, Washington (1983), explores these issues. at 60-62, 78.

<sup>20</sup> This term refers to morphologic abnormalities of internal or external organs arising before birth that have actual or potential clinical significance. James B. Wyngaarden and Lloyd H. Smith, Jr., CECIL TEXTBOOK OF MEDICINE, W.B. Saunders Co., Philadelphia (1982) at 22.

prematurely. These abnormalities have been traced to inheritance of defective genes (as in phenylketonuria or Marfan syndrome), chromosomal abnormalities (as in Down Syndrome), and environmental factors, including *in utero* viral infection or chemical exposure (one well-known instance being children born with limb abnormalities because their mothers had taken thalidomide). Although many causes of birth defects have been identified, the majority of congenital abnormalities are of unknown etiology and probably result from a complex interaction of genetic and environmental factors.<sup>21</sup>

Two types of congenital abnormalities have been especially prominent in discussions of the ethics of neonatal care: neural tube defects (NTDs), and permanent handicaps combined with surgically correctable, life-threatening lesions. Defects involving the neural tube, which is the embryonic precursor of the brain and spinal cord, are among the most common serious birth defects of unknown etiology, affecting approximately two of every 1000 babies born in the United States.<sup>22</sup> One type of NTD is anencephaly, a condition in which the brain is entirely or substantially absent. Anencephalic infants usually die within a few hours or days.<sup>23</sup> Another type of NTD, meningomyelocele (spina bifida) involves abnormal development of the brain or spinal cord. Spina bifida causes physical and/or mental impairments that range widely in severity and frequently involve many organ systems. Vigorous surgical, medical, and rehabilitative therapies have improved the prognosis for many children with spina bifida. Some individuals with this condition have normal intelligence and can lead independent lives.

Public attention has recently been focused on the second group of cases—infants who have both a correctable life-threatening defect and a permanent, irremediable handicap that is not life-threatening, such as mental retardation.<sup>24</sup> One well-known example is Down Syndrome, which occurs once in about every 700 live births.<sup>25</sup> Individuals with Down Syndrome are mentally retarded, although the precise extent of retardation cannot be determined in early infancy.<sup>26</sup> Babies with this

<sup>21</sup> Barbara R. Migeon, *Genetic Problems Affecting Infants*, in Y. Edward Hsia *et al.*, eds., *COUNSELING IN GENETICS*, Alan R. Liss, Inc., New York (1979) at 114-15.

<sup>22</sup> Aubrey Milunsky and Elliot Alpert, *Maternal Serum AFP Screening*, 298 *NEW ENG. J. MED.* 738 (1978).

<sup>23</sup> One NTD that precludes development of consciousness, anencephaly, is discussed in Chapter Five *supra*.

<sup>24</sup> See notes 5 and 7 *supra*.

<sup>25</sup> William L. Nyhan and Nadia O. Sakati, *GENETIC AND MALFORMATION SYNDROMES IN CLINICAL MEDICINE*, Year Book Med. Pub., Inc., Chicago (1976) at 21. See also William L. Nyhan and Edward Edelson, *THE HEREDITY FACTOR*, Grosset & Dunlap, New York (1976) at 128-9.

<sup>26</sup> Although IQs from about 18-92 have been reported, most Down

syndrome often have other congenital defects, particularly cardiac abnormalities. Most Down Syndrome infants do not require any unusual medical care at birth, but a minority have a complication that would be fatal unless surgically corrected during the first year of life. The two most common problems are gastrointestinal blockage and congenital heart defects. Children with an obstruction at the outlet of the stomach, for example cannot be fed; untreated, they would develop a fatal pneumonia or starve to death. Surgical repair of this defect, however, is typically successful.

### Response of the Health Care System

**Neonatal intensive care.** The history of special care for unhealthy newborns began just over a century ago when Dr. E. Tarnier installed in his Paris clinic what he called "warming chambers" for premature infants.<sup>27</sup> The modern, high-technology neonatal intensive care units that are widespread today—here are at least 7500 NICU beds in approximately 600 hospitals across the country—were first established in the 1960s.<sup>28</sup> The proposal to have neonatology be a subspecialty of pediatrics was made in 1960<sup>29</sup>; since the first neonatology certification examinations by the American Board of Pediatrics (in 1975), over 1000 neonatologists have been certified.<sup>30</sup>

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Syndrome children have an IQ between 30 and 55; quite a few score less than 30 and only in rare cases does the IQ exceed 70. ("Normal" IQ is from 80-120.) Hans Zellweger and Victor Ionasescu, *Genetics of Mental Retardation*, in Charles H. Carter, ed., *MEDICAL ASPECTS OF MENTAL RETARDATION*, Charles C. Thomas, Springfield, Ill. (2nd ed. 1978) at 160. The higher scores occur in a small percentage of the cases in which all of the person's cells do not carry the chromosomal aberration, a condition known as mosaicism. Karol Fisher, Richard Koch, and George N. Donnell, *Comparison of Mental Development in Individuals with Mosaic and Trisomy 21 Down's Syndrome*, 58 *PEDIATRICS* 744 (1976).

<sup>28</sup> While these new devices proved useful in clinics, they also caught the public's imagination when their use was demonstrated in international expositions over the years. At the Berlin exposition in 1896 they were dubbed "child hatcheries" (kinderbrutanstalt). Incubator-baby exhibits were popular in America as late as 1939 (the New York World's Fair). William A. Silverman, *Incubator Baby Side Shows*, 64 *PEDIATRICS* 127 (Aug. 1979).

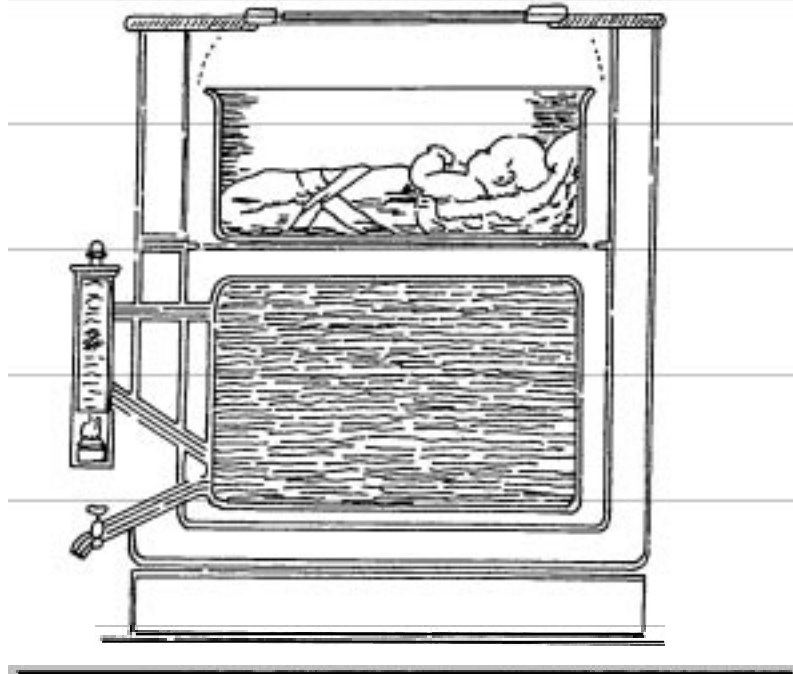
<sup>29</sup> *COST OF NEONATAL CARE*, *supra* note 11, at 7 and 15. During the 1970s, nearly every state passed legislation mandating that private insurance cover neonatal intensive care, which probably helped ensure that NICUs would become available. David T. Deal, *Bioethical Implications of Health Care Insurance for Newborns: A Comparative Analysis of Fifty States' Law*, unpublished manuscript (April 1978).

<sup>29</sup> Edward R. Schlesinger, *Neonatal Intensive Care: Planning for Services and Outcomes Following Care*, 82 *J. PEDIATRICS* 916 (1973).

<sup>30</sup> Information provided by personal communication with Anne Justus, American Board of Pediatrics (Jan. 1983).

Figure 2: Tarnier-Martin Couveuse (1880).

Source: William A. Silverman, Incubator Baby Side Shows, 64 *PEDIATRICS*, 211 (1979). Copyright American Academy of Pediatrics 1979.



An estimated 6% of live-born infants go to a neonatal intensive care unit, where the length of stay averages 8-18 days.<sup>31</sup> The cost of such high-technology care is estimated at \$8000 for an average case; in 1978, \$1.5 billion was spent on NICU care.<sup>32</sup>

The introduction of NICUs has coincided with a dramatic decrease in mortality during the first month of life. Most of this improvement is due to better survival rates for LBW infants rather than to a change in the proportion of high-risk births.<sup>33</sup> Although the effectiveness of NICUs has not been determined directly by clinical trials, the improvements in birth-weight-specific mortality together with other relevant data suggest

<sup>31</sup> COST OF NEONATAL CARE, *supra* note 11, at 15.

<sup>32</sup> *Id.* at 19.

<sup>33</sup> For a summary of data on the effectiveness of NICUs, see Budetti and McManus, *supra* note 2; Nigel Paneth *et al.*, *Newborn Intensive Care and Neonatal Mortality in Low-Birth-Weight Infants*, 307 *NEW ENG. J. MED.* 149 (1982).

that NICUs have played an important role in those reductions.<sup>34</sup>

Although NICU treatment saves many seriously ill newborns, can be both a painful experience for the infant and an anguishing one for parents and care givers. Watching the suffering of an infant the size of an adult's hand—connected to awesome machinery and offered only distant prospects of somewhat normal survival—inevitably takes an emotional toll.<sup>35</sup> Some NICUs assign certain staff members to support and counsel parents and to arrange support programs for the NICU staff.<sup>36</sup>

**Post-hospital needs.** The societal commitment to save the lives of seriously ill newborns is dramatically illustrated by the high technology of the NICU. The resources and energy expended and the emotional strains endured attest to the high value placed on providing some of society's most vulnerable members with the opportunity to live and thrive. But the needs of these children do not end with their discharge from the hospitals; many survivors have long-term diseases or handicaps.<sup>37</sup>

The potential that the NICU has fought to preserve for these children can only be realized if support is sufficient after they leave the hospital. Their families must often travel a financially and emotionally perilous path to realize that potential.<sup>38</sup> Physically handicapped youngsters, for example,

<sup>34</sup> See, e.g., John C. Sinclair *et al.*, *Evaluation of Neonatal-Intensive Care Programs*, 305 *NEW ENG. J. MED.* 489 (1981).

<sup>35</sup> See, e.g., Robert and Peggy Stinson, *On the Death of a Baby*, *ATLANTIC MONTHLY* (July 1979), reprinted with commentary in 7 *J. MED. ETHICS* 5 (1981). A longer treatment of this case was published since: Robert and Peggy Stinson, *THE LONG DYING OF BABY ANDREW*, Little, Brown, Boston (1983). The Stinsons describe their emotional ordeal as they watched a series of hopeless "treatments" result in increased pain and suffering for their dying premature infant.

<sup>36</sup> The Commission heard testimony from Carole Kennon, for example, on her role as a social worker with the NICU at Children's Hospital National Medical Center. Transcript of 16th meeting of the President's Commission (Jan.9,1982) at 9.

<sup>37</sup> For example, low birth weight infants are more likely to experience visual, hearing, respiratory, and neurological problems and other morbidity as they grow. **COSTS OF NEONATAL CARE**, *supra* note 11, at 34-38.

<sup>38</sup> Even when families have good insurance coverage, the costs can be significant. A small copayment for each procedure can result in large out-of-pocket payments and some costs (such as some special child care and education, transportation to major medical centers for treatment, and the loss of a wage earner to child care responsibilities) are not included in insurance coverage. Altogether, the expenses can total thousands or even tens of thousands of dollars. See, e.g., Anne Norman, *The High Cost of Saving Ultra-Premies* (Letter), 3 *SCIENCE* 82 22 (Oct.1982); public funding has eased this burden in many cases and

need long-term training for ambulation and independence; the development of mentally retarded children can be greatly enhanced by intensive stimulation, particularly when begun at a very young age.<sup>39</sup> Studies show that appropriate early intervention is cost-effective, yet it is sometimes difficult to obtain or pay for these services.<sup>40</sup>

Handicapped children and their families may also need counseling to help them respond productively to their difficulties, including the stress placed on the marriage and on family life.<sup>41</sup> In addition to professional assistance, parents and

allowed families to obtain services. Private charitable organizations also play a crucial role in raising funds and providing services for the handicapped. In expanding the opportunities for the disabled, public and charitable programs often ultimately reduce societal costs. George R. Dunlop, *Remedies as Ills*, 64 BULL. AM. COLL. SURGEONS 2 (Dec. 1979).

<sup>39</sup> Jane E. Brody, *Personal Health*, N. Y. TIMES, Dec. 22, 1982, at C-8; Norris G. Haring and Alice H. Hayden, *Effectiveness and Cost-Efficiency of Early Intervention with Handicapped Children*, Hearing before Subcomm. on the Handicapped, Comm. on Labor and Human Resources, U.S. Senate (April 30, 1981) at 115; Inter-Act (The National Committee for Services to Very Young Children with Special Needs and Their Families), EARLY INTERVENTION FOR CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES: FINDINGS AND RECOMMENDATIONS, WESTAR Series Paper #11 (June 1981).

<sup>40</sup> Federal laws have affirmed the rights of the handicapped and resulted in Federal funds for educational programs and research. A significant portion of Federal funding for service and education is distributed to localities in several different block grants (*e.g.*, maternal-child health, preventive programs, etc.). Under this program, states have the option of allocating some or all of the funds either for services to the handicapped or to other programs in the block grant category. *See generally* Hearing before Subcomm. on the Handicapped, *supra* note 39.

Although a few states mandate comprehensive services, in most jurisdictions the handicapped compete with other social service groups for scarce discretionary funds. Even within the handicapped community there is competition since the type of services needed varies enormously depending on the type and severity of the disability.

<sup>41</sup> Albert J. Solnit and Mary H. Stark, *Mourning and the Birth of a Defective Child*, 16 THE PSYCHOANALYTIC STUDY OF THE CHILD (journal) 523 (1961); Elizabeth D'Arcy, *Congenital Defects: Mothers' Reactions to First Information*, 3 BRIT. MED. J. 796 (1968); Dennis Drotar *et al.*, *The Adaptation of Parents to the Birth of an Infant with Congenital Malformation: A Hypothetical Model*, 56 PEDIATRICS 710 (1975); N. Johns, *Family Reactions to the Birth of a Child with a Congenital Anomaly*, 5 MED. J. AUST. 277 (1971); John H. Kennell and Marshall H. Klaus, *Caring for Parents of an Infant Who Dies*, in Marshall H. Klaus and John H. Kennell, eds., MATERNAL-INFANT BONDING C.V. Mosby, St. Louis (1976) at 202; D. Gary Benfield *et al.*, *Grief Response of Parents*

siblings often benefit greatly from support groups whose members share similar experiences and helpful suggestions.

### Current Decisionmaking Practices

**Physicians' Views.** A major stimulus to the ethical and legal debate on foregoing life-sustaining treatment for newborns was provided by a 1973 medical journal article that described how and why nontreatment had been chosen for 43 of the 299 babies who died in a 30-month period in the intensive care nursery of Yale-New Haven Hospital.<sup>42</sup> The decision against treatment followed deliberations in which "parents and physicians... concluded that prognosis for meaningful life was extremely poor or hopeless."<sup>43</sup> The authors argued strongly for leaving such decisions to parents and physicians.

Other physicians confirmed that decisions to forego therapy are part of everyday life in the neonatal intensive care unit; with rare exceptions, these choices have been made by parents and physicians without review by courts or any other body.<sup>44</sup> This approach has been endorsed by the American Medical Association, whose Judicial Council holds that "the decision whether to exert maximal efforts to sustain life [of seriously deformed newborns] should be the choice of the parents."<sup>45</sup>

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*to Neonatal Death and Parent Participation in Deciding Care*, 62 PEDIATRICS 171 (1978); Catherine LaRoche *et al.*, *Grief Reactions to Perinatal Death: An Exploratory Study*, 23 PSYCHOSOMATICS 510 (1982).

<sup>42</sup> Duff and Campbell, *supra* note 4.

<sup>43</sup> *Id.* at 890.

<sup>44</sup> Well, we at Children's Hospital have to make the decision to forego life-sustaining therapy in about 40 to 45 cases per year. And I want to impress upon you we get some of the sickest infants in the area, that it is not really a well premature infant. And if it sounds like a lot of cases it is, because we get the sickest ones....We are talking about a total population of admission rates to the intensive care unit of approximately 400 infants. Of those 400 infants, about a third of them die, so we are talking about perhaps a hundred-and-some-odd deaths, and out of those perhaps about half we make the decision to stop. It is not that those infants might not—and particularly with some of the intraventricular bleeds, they might go on to die on their own a week later or two weeks later or three weeks later.

Testimony of Dr. Anne Fletcher, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 8, 26; Dr. Robert E. Cooke, Statement before *Hearing on Medical Ethics: The Right to Survival*, Subcomm. on Health, Comm. on Labor and Public Welfare, U.S. Senate (1974) at 26.

<sup>45</sup> Judicial Council of the American Medical Association, CURRENT OPINIONS, American Medical Association, Chicago, (1982) at 9, *reprinted in* Appendix C, pp. 299-300 *infra*.

Surveys of physicians show that most would follow parental wishes to stop treatment for at least some abnormal infants. When California pediatricians were polled in 1975 about how they would treat a Down Syndrome baby with a life-threatening intestinal obstruction (assuming parental agreement and immunity from existing laws), 17% said they would do "everything humanly possible" to save the baby's life, while 61% would give ordinary medical care but "nothing heroic" (meaning the baby would die without the operation to remove the obstruction).<sup>46</sup> In a national study in 1977, pediatricians and pediatric surgeons were asked whether they would acquiesce in a parental decision not to treat a Down Syndrome infant having congenital heart disease.<sup>47</sup> Even though immunity from the law was not mentioned, 85% of the pediatric surgeons responding and 65% of the pediatricians said they would follow the parents' wishes. A third study found that 51% of the pediatricians surveyed in Massachusetts would not recommend surgery for a Down Syndrome infant with intestinal blockage.<sup>48</sup>

Data from these interviews and surveys risk revealing only what people think they would or should do, rather than what those who have been faced with such a choice actually do. A recent Connecticut Department of Health Services study of actual decisionmaking practices for newborns—which included reviews of all deaths in an NICU for six months and of death certificates for 20 newborns, as well as interviews with families and professionals—revealed that "actual practices are remarkably consistent throughout the state."<sup>49</sup> Only two cases were found in which treatment was continued over parental objections and only two in which there was any suspicion that the child's interests were not being advanced. It found that teams of providers "consult continually about the patient's condition" before "decisions become recommendations to parents for the treatment of their infants."<sup>50</sup>

Shortcomings of the Present System. Despite reports of occasional cases in which seriously erroneous decisions about

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<sup>46</sup> *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, 6 HASTINGS CTR. REP. 2 (April 1976).

<sup>47</sup> Anthony Shaw, Judson G. Randolph, and Barbara Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (Supp. 1977).

<sup>48</sup> David Todres et al., *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977).

<sup>49</sup> Thayer Baldwin, Jr., *Infant Death: Life and Death in Newborn Special Care Units*, Bureau of Health System Regulation, Connecticut State Dept. of Health Services, mimeo. (March 1982) at 5.

<sup>50</sup> *Id.*

the treatment of newborns were carried out, such events appear to be very rare.<sup>51</sup> Nonetheless, a number of shortcomings in current decisionmaking about seriously ill newborns are apparent:

- appropriate information may not be communicated to all those involved in the decision;
- professionals as well as parents do not at times understand the bases of a decision to treat or not to treat; and
- actions can be taken without the informed approval of parents or other surrogates.

**Communication.** Given the complexity of the situation it is hardly surprising that communication problems arise in decisionmaking about life-support for critically ill infants. As the Connecticut study found, however, the problems are much more than technical ones:

All parties interviewed felt that our society and the providers have not done enough to communicate information necessary for decisionmaking to the parents. Providers may choose not to discuss some considerations because of their concern about the capacity of distraught parents to comprehend and absorb complex and technical information; however, the most frequently cited insufficiency derives from preconceptions held by the physicians and parents about the quality of life of handicapped individuals.<sup>52</sup>

Unfortunately, the circumstances in which many of these decisions have to be made compound the barriers to communication: the family may not live close to the tertiary care institution where the infant is being treated; often the family's life is highly disrupted, especially when there are other children and when the birth was a complicated one and the

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<sup>51</sup> Of the more than three million babies born each year in the United States, tens of thousands are born prematurely or with congenital anomalies and many of them would die quickly if not treated. Yet it is rare for treatment not to be provided when it is predicted to provide a means of remedying the medical problem: the cases when approval for such treatment is denied are few enough to be newsworthy. While very disturbing, they may be inevitable in a society that treasures personal and familial autonomy. Greater control by state officials, in the name of protecting the helpless, would actually be warranted only if it clearly saved more lives. Furthermore, such steps would raise problems of governmental intrusion into private matters in many cases where no better decision could be made. See pp. 219-23 *infra*.

<sup>52</sup> Baldwin, *supra* note 49, at 6. One couple, troubled by the experiences they had with their severely ill son, called for better ways to make decisions about treatment. "We regard any decision making by concerned physician and parents behind closed doors of the pediatric unit as a haphazard approach." Bridge and Bridge, *supra* note 5, at 19.

mother remains hospitalized; and there are so many interrelated decisions about care that have to be made on a continuous basis that it is hard to convey all the relevant facts and probabilities to anyone not constantly involved in the situation. For these and other reasons, the teams of nurses, physicians, and other specialists in NICUs develop patterns for dealing with—and categorizing—patients.<sup>53</sup> Although pressure from parents to communicate more information is not necessarily resisted, especially if the NICU team is comfortable with the way the parents are using the information, team members can seldom take the time to understand the background of the family or see the situation from the parent's perspective.

**Understanding.** It is not only parents who have a hard time with the decisions to be made. On interviews conducted for a study of the treatment of critically ill patients, some physicians said they would be unable to comply with a parental request to withdraw life-sustaining treatment yet were unable to give any reason for their position.

Those who indicated that they would treat such infants [anencephalics] were asked "to explain why. Few of them could offer an explicit rationale. In general, it appeared that those who would treat such a child did so because the idea of withdrawing therapy was simply unthinkable. Very few doctors seemed to have given such matters enough consideration to have worked out a philosophical position toward them."

Some decisions are even made by default.

Each time we discussed it [whether or not to resuscitate a child with severe problems] we were unable to make a decision so that when the child stopped breathing we did resuscitate because we hadn't decided not to.<sup>55</sup>

**Approval.** Physicians sometimes believe they must make the decisions because the parents will feel guilty over anything less than an optimal outcome for the baby.<sup>56</sup> Taking responsi-

<sup>53</sup> "Babies are not just babies. A particular baby fits into a loose typology that is part of the staffs way of seeing things." Robert Bogdan, Mary Alice Brown, and Susan Bannerman Foster, *Be Honest but Not Cruel: Staff/Parent Communication on a Neonatal Unit*, 41 HUMAN ORGANIZATION 6, 7 (1982).

<sup>54</sup> Diana Crane, *THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS*, Russell Sage Foundation, New York (1975) at 76.

<sup>55</sup> *Id.* at 81.

<sup>56</sup> And at the end of this, I feel it is important, and I think we as a team feel it is important, that we make a recommendation of what is to be done. That is not to say that we don't feel the parents have a decision to make, but it is a decision with us and not a decision on their own. And we usually have felt it is our duty to make a decision, and then have them agree with us,

bility for the decision is sometimes difficult to separate psychologically from being responsible for the medical condition.<sup>57</sup> Providers may try to shield parents from this guilt. If this removes parents' control of decisionmaking, however, the child loses the protection of its surrogates. Moreover, as one parent told the Commission:

I am very uncomfortable with the doctor assuming that if there are two equal things, he will decide and take the responsibility. I think when you become a parent, and I am an adopted parent, so I feel that responsibility even more - - had assumed there would be hard decisions to make, and some of them were harder than I had anticipated. But nonetheless, I felt that was a responsibility I took for myself. And I don't want to turn it over to somebody who is going to spare me that.<sup>58</sup>

Some physicians have trouble simultaneously allowing parents to retain control of decisionmaking and sharing the burdens of responsibility.

Unfortunately, manipulations of the situation are occasionally made for the benefit of the health care professionals instead of the parents.

Consultation with the family is used in part as a method of insuring that they will accept the decision and not take legal action against the physician later. It is not considered appropriate for the family to make the final decision.<sup>59</sup>

Additionally, parents may be excluded from the decisions entirely or presented with a narrower range of "choices" than is appropriate.<sup>60</sup>

**The Legal Framework.** Even when these shortcomings are overcome, conscientious health care teams still face serious problems such as parents who are incapable or unwilling to participate in decisionmaking or who make what seem to the team to be decisions that are substantially harmful to the child.

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rather than to have them feel they made the decision completely on their own.

Fletcher, *supra* note 44, at 17.

<sup>57</sup> Bogdan, Brown, and Foster, *supra* note 53; Fletcher, *supra* note 44, at 8.

<sup>58</sup> Testimony of Minna Nathanson, transcript of 17th meeting of the President's Commission (Feb. 12, 1982) at 153.

<sup>59</sup> Crane, *supra* note 54, at 74.

<sup>60</sup> See Stinson and Stinson, *supra* note 35, and Bridge and Bridge, *supra* note 5.

Although health care professionals and institutions are reluctant to become enmeshed in legal proceedings,<sup>61</sup> in certain cases they may feel they have no choice but to enter that arena, with all the new uncertainties and difficulties that will create for their treatment of the infant in question.

The paucity of directly relevant cases makes characterization of the law in this area somewhat problematic, but certain points stand out. First, there is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants.<sup>62</sup> Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents.<sup>63</sup> Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervene parental decisions before they become opera-

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<sup>61</sup> In a national survey, pediatricians and pediatric surgeons who were asked to rank the importance of possible decisionmakers placed courts at a distant fourth behind parents, doctors, and hospitals ethic committees. Shaw, Randolph, and Manard, *supra* note 47, at 591.

<sup>62</sup> The common-law antecedents of this presumption are largely to be found in a notion of paternal (and later parental) supremacy in family matters and in the corollary that children had few, if any, rights as persons, being regarded in law as chattels. These antecedents are now largely discredited and rejected, and have been supplanted by a tempered right of parental autonomy. This right has gradually developed under a constitutional aegis in this century, guided largely by principles of religious freedom and due process until the 1960s. *See, e.g., Meyer v. Nebraska*, 262 U.S. 390 (1923) (right to raise child); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (parents' rights to control education of their children). *Cf. Prince v. Mass.*, 321 U.S. 158 (1944) (parental authority to have child religious literature circumscribed). More recently the theory began to be influenced by, if not assimilated to, the developing constitutional right of privacy. *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (parents' right to direct religious upbringing of children). *See pp. 31-32* (discussion of right of privacy).

<sup>63</sup> Familial privacy has received increasing protection from law throughout this century. In the earlier stages of legal development, the source of this protection was sometimes found in the constitutional right of religious freedom; it has gradually evolved into a more secular protection generally referred to as the right of privacy. The substantive core includes the authority of parents to establish family values, to set goals for the family and for its individual members, and to make decisions affecting the welfare of family members free from interference by agencies of the state. For example, although the law requires that children go to school, parents can generally choose the school. Parents must provide adequate food and shelter, but they need not conform to the opinions of others as to the best food or the most appealing shelter. The society as a whole benefits from promoting diversity, and privacy law has played an increasing role in protecting diverse life-styles and values.

tive to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.<sup>64</sup>

Plainly, these two legal doctrines—respect for parental discretion and protection of children against harm—pull in opposite directions and it is often difficult to know how to reconcile them in a particular case. These difficulties may partially account for the dispute over what constitutes "neglect and abuse." The meaning of these terms has varied over time and has rarely been the subject of careful legislative definition in statutes.<sup>65</sup> Yet although the standards remain vague even in the medical arena, as long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervised.<sup>66</sup> The courts have exercised their authority to appoint a guardian for a child when the parents are not capable of participating in decisionmaking or when they have made decisions that evidence substantial lack of concern for the child's interests.<sup>67</sup> Although societal

<sup>64</sup> See, e.g., *Model Child Protection Act* (1983), reprinted in Appendix H, pp. 478-93 *infra*.

<sup>65</sup> Note, *State Intrusion into Family Affairs*, 26 *STAN. L. REV.* 1383 (1974); Judith Areen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Abuse and Neglect Cases*, 63 *GEO. L.J.* 887, 891 (1975); Michael Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 *STAN. L. REV.* 985 (1975).

<sup>66</sup> Generally, when the medical treatment at issue for a minor child is for a disease or condition that is not severe or life-threatening, courts will accede to parental wishes not to treat even when physicians disagree. The courts have been particularly reluctant to order treatment when it is possible to delay the decision until the child reaches the age of majority. See, e.g., *In re Seiferth*, 309 N.Y. 80, 127 N.E.2d 820 (1955) (surgery not ordered for 14-year-old boy with cleft palate), *In re Green*, 220 Pa. Super. Ct. 191, 286 A.2d 681 (1971) (surgery to correct spinal curvature). Likewise, even when the consequences of foregoing treatment may be grave, courts have refused to order treatment where parents have had well-grounded concerns that the risks outweigh the possible benefits. *In re Tuttendario*, 21 Pa. Dist. 561 (1912) (treatment for rickets may have been more dangerous than the disease); *In re Hudson*, 13 Wash.2d 673, 126 P.2d 765 (1942) (surgery for greatly enlarged and useless arm with "gross possibility of fatality"). *But see*, *In re Sampson*, 29 N.Y.2d 900, 279 N.E.2d 918, 328 N.Y.S.2d 686 (1972) (over parental objection, court ordered surgery for 15-year-old boy with neurofibromatosis whom the court described as grotesque and repulsive), criticized in Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, in Willard Gaylin and Ruth Macklin, eds., *WHO SPEAKS FOR THE CHILD*, Plenum Press, New York (1982) at 153, 180-84.

<sup>67</sup> By far, most of the cases involving judicial inquiry into parents' medical choices for their children have occurred in situations in which parents have opted for unconventional "medical" care for their children (such as laetrile for the treatment of cancer; see, e.g., *Custody of a Minor*, 393 N.E.2d 836 (Mass. 1979)). When there has been a

involvement usually occurs under the auspices of governmental instrumentalities— such as child welfare agencies and courts— the American legal system ordinarily relies upon the private initiative of individuals, rather than continuing governmental supervision, to bring the matter to the attention of legal authorities.<sup>68</sup>

### An Ethical Basis for Decisionmaking

Since newborns are unable to make decisions, they will always need a surrogate to decide for them.<sup>69</sup> In nearly all cases, parents are best situated to collaborate with practitioners in making decisions about an infant's care,<sup>70</sup> and the range of choices practitioners offer should normally reflect the

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medically accepted treatment likely to be of help to the child whose life is in danger the courts have ordered treatment over parental objection. *See, e.g., In re Pogue*, No. M-18-74 (Super. Ct. D.C. Nov. 1, 1974) (blood transfusion ordered for otherwise healthy baby over objection of Jehovah's Witness parents); *Raleigh Fitkin-Paul Morgan Mem. Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964) (transfusion needed at birth); *Hoener v. Bertinato*, 67 N.J. Super. 517, 171 A.2d 140 (Juv. & Dom. Rel. Ct. 1961). When the only treatments available have been novel or of great risk the courts have acquiesced in parental decisions to forego treatment. *In re Green*, 12 CRIME & DELINQUENCY 377 (Child Div., Milwaukee County Ct. Wis. 1966) (court would not order child to have controversial treatment for sickle-cell anemia for which mother had not consented).

■ "Indeed, a significant number of care and protection petitions are initiated by hospitals or members of their staffs, since they are often the only persons outside the family in a position to detect signs of abuse, neglect, or abandonment." Cited in *Custody of a Minor*, 434 N.E.2d 601,607 (Mass.1982).

<sup>69</sup> *See* pp. 126-31 *supra*, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS*, U.S. Government Printing Office, Washington (1982) at 181-88, for a general discussion of the designation and role of surrogates.

<sup>70</sup> There are any number of explanations for this societal allocation of authority: respect for the family and a desire to foster the diversity which it brings; the fitness of giving the power to decide to the same people who created the child and have the duty to support and protect him; the belief that a child cannot be much harmed by parental choices which fall within the range permitted by society and a willingness to bear the risks of harm this allocation entails or a belief that in most cases "harm" would be hard for society to distill and measure anyway; or simply the conclusion that the administrative costs of giving authority to anyone but the parents outweigh the risks for children and for society unless the parents are shown to be unable to exercise their authority adequately.

A. M. Capron, *Legal Considerations Affecting Clinical Pharmacological Studies in Children*, 21 *CLINICAL RESEARCH* 141.146 (1972).

parents' preferences regarding treatment (see Table 1, p. 218). Parents are usually present, concerned, willing to become informed, and cognizant of the values of the culture in which the child will be raised. They can be expected to try to make decisions that advance the newborn's best interests. Health care professionals and institutions, and society generally, bear responsibility to ensure that decisionmaking practices are adequate.

**Parental Autonomy and Countervailing Considerations.**

Families are very important units in society. Not only do they provide the setting in which children are raised, but the interdependence of family members is an important support and means of expression for adults as well. Americans have traditionally been reluctant to intrude upon the functioning of families, both because doing so would be difficult and because it would destroy some of the value of the family, which seems to need privacy and discretion to maintain its significance." Parents and a child's physician may choose, for example, to correct a disfiguring birthmark or not, to have a generalist or a specialist attend to an injury, or to accept or reject hospitalization for many illnesses. Public policy should resist state intrusion into family decisionmaking unless serious issues are at stake and the intrusion is likely to achieve better outcomes without undue liabilities.

When parental decisionmaking seems not to take account of a child's best interest, however, the stage is set for public intervention. This issue has usually arisen in cases in which the parent's values differ from those common in society. For example, parents are free to inculcate in their children a religious belief that precludes the acceptance of transfused blood. But when a transfusion is necessary for the success of surgery that would be life-saving or without which a child would suffer substantial, irreversible harm, parents' prerogatives must yield to the child's interest in life or in leading a reasonably healthy life.<sup>72</sup> Parents are not, as the Supreme Court has stated, entitled to make martyrs of their children.<sup>73</sup>

The growth of neonatal intensive care has posed problems for parental decisionmaking in addition to those arising from

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<sup>71</sup> Margaret O'Brien Steinfels, *Children's Rights, Parental Rights, Family Privacy, and Family Autonomy*, in Gaylin and Macklin, *supra* note 66, at 223.

<sup>72</sup> Although some of the earlier cases were rooted in religious claims, others — including a companion case to *Pierce* — were rooted in liberty interests. See *Pierce v. Hill Military Academy*, 268 U.S. 510 (1925). Since the enunciation of a constitutional right of privacy in *Griswold v. Connecticut*, 381 U.S. 479 (1965), and its subsequent growth, claims of parental autonomy now seem more appropriate to be couched in those terms.

<sup>73</sup> *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

unusual beliefs. Parents may be reeling emotionally from the shock of having a seriously ill child instead of the normal, healthy infant they had imagined. Assuming they have had no previous experience with the condition in question, they are likely to be poorly informed about long-term prospects for the child, be subject to pressing financial exigencies, and be worried about effects on siblings and the family as a whole. Furthermore, the infant's condition may require rather urgent response, often while the mother is still recovering from delivery.

Yet, with suitable assistance, most parents can overcome these difficulties and make decisions on the child's behalf in an appropriate fashion. In order to make good decisions, parents must be told the relevant information, including as accurate an appraisal of prognosis as possible. The medical information they receive, including its uncertainties, should be up-to-date.<sup>74</sup> Their consideration of the situation may be helped by the opportunity to talk with other parents who have faced such decisions, with consultant medical specialists, and perhaps with religious advisors.<sup>75</sup> When reasonably possible, procedures should be used to sustain the infant's life long enough to avoid undue haste in decisionmaking.<sup>76</sup>

If parents continue to insist on a course of action that presents a substantial risk of seriously jeopardizing the infant's best interests, prompt intrainstitutional review should occur. When a decision consistent with the child's interests is still not reached, the health care provider should seek to have a court appoint a surrogate in place of the parents, on the grounds that the parents are incapacitated to make the decision, unable to agree, unconcerned for the infant's well-being, or acting out of an interest that conflicts with the child's.<sup>77</sup>

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<sup>74</sup> See, e.g., Herman A. Hein, Christina Christopher, and Norma Ferguson, *Rural Perinatology*, 55 *PEDIATRICS* 769 (1975); Herman A. Hein, *Evaluation of a Rural Perinatal Care System*, 66 *PEDIATRICS* 540 (1980).

<sup>75</sup> John C. Fletcher, *COPING WITH GENETIC DISORDERS: A GUIDE FOR CLERGY AND PARENTS*, Harper & Row, New York (1982).

<sup>76</sup> John A. Robertson, *Dilemma in Danville*, 11 *HASTINGS* *CTR. REP.* 5, 6 (Oct. 1981).

<sup>77</sup> There are no reported appellate cases of this type, but a few trial court decisions have overridden parental refusals of treatment of their defective newborn children. See, e.g., *Main Medical Center v. Houle*, No. 74-145 (Cumberland County Super. Ct., Maine, Feb. 14, 1974) (court order to repair meningomyelocele mooted by baby's death); *In re Cicero*, 101 Misc.2d 699, 421 N.Y.S.2d 965 (Sup. Ct. Bronx County, 1979) (parental refusal to treat meningomyelocele overridden). *In re Elin Daniel*, Case No. 81-15577 FJO1 (Miami, Fla., June 23, 1981); *Court-Ordered Surgery on Baby Held Success*, *N.Y. TIMES*, Sept. 18, 1981, at A-9.

Besides information, parents need empathy and understanding; health care professionals face the difficult task of keeping lines of communication open with parents who are often unsure of their own feelings and abilities to cope with this tragedy, uncomfortable in the hospital environment, and burdened by other practical barriers to participating in their child's care. Yet these difficulties should not lead to a hasty judgment that parents are uninterested in a child's welfare or incapable of good decisionmaking.<sup>78</sup> Great efforts must be made to understand parents' values and improve their ability to decide on a course of action. In cases when parents are not present, a suitable surrogate from within the family might well be available (for example, the grandmother of the baby of an adolescent mother), but an infant without family surrogates will always need to have another guardian named.

**Best Interests of the Infant.** In most circumstances, people agree on whether a proposed course of therapy is in a patient's best interests. Even with seriously ill newborns, quite often there is no issue—either a particular therapy plainly offers net benefits or no effective therapy is available. Sometimes, however, the right outcome will be unclear because the child's "best interests" are difficult to assess.

The Commission believes that decisionmaking will be improved if an attempt is made to decide which of three situations applies in a particular case—(1) a treatment is available that would clearly benefit the infant, (2) all treatment is expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain (see Table 1, p. 218). The three situations need to be considered separately, since they demand differing responses.

**Clearly beneficial therapies.** The Commission's inquiries indicate that treatments are rarely withheld when there is a medical consensus that they would provide a net benefit to a child. Parents naturally want to provide necessary medical care in most circumstances, and parents who are hesitant at first about having treatment administered usually come to recognize the desirability of providing treatment after discussions with physicians, nurses, and others. Parents should be able to choose among alternative treatments with similarly

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<sup>78</sup> With some exceptions...the staffs assessment of parents and parents' dispositions toward their babies and the degree to which parents are understanding what is being told to them is often inaccurate. Most assessments of parents are based on limited knowledge, derived mainly from short observations, limited conversations, or secondhand reporting of incidents and information. What is known is episodic, not informed by the context of the perinatal experience in the lives of the parents.

Bogdan, Brown, and Foster, *supra* note 53, at 11.

Table 1:

## Treatment Options for Seriously Ill Newborns—Physician's Assessment in Relation to Parent's Preference

Physician's Assessment of Treatment Options*	Parents Prefer to Accept Treatment**	Parents Prefer to Forego Treatment**
Clearly beneficial	Provide treatment	Provide treatment during review processtt
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do sot	Forego treatment

\* The assessment of the value to the infant of the treatments available will initially be by the attending physician. Both when this assessment is unclear and when the joint decision between parents and physician is to forego treatment, this assessment would be reviewed by intra-institutional mechanisms and possibly thereafter by court.

\*\* The choice made by the infant's parents or other duly authorized surrogate who has adequate decisionmaking capacity and has been adequately informed, based on their assessment of the infant's best interests.

t See p. 220 *infra*.

tt See pp. 218-19 *infra*.

beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved.

Many therapies undertaken to save the lives of seriously ill newborns will leave the survivors with permanent handicaps, either from the underlying defect (such as heart surgery not affecting the retardation of a Down Syndrome infant) or from the therapy itself (as when mechanical ventilation for a premature baby results in blindness or a scarred trachea). One of the most troubling and persistent issues in this entire area is whether, or to what extent, the expectation of such handicaps should be considered in deciding to treat or not to treat a seriously ill newborn. The Commission has concluded that a very restrictive standard is appropriate: such permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant. Though inevitably somewhat subjective and imprecise in actual application, the concept of "benefit" excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment. Rather, net benefit is absent only if

the burdens imposed on the patient by the disability or its treatment would lead a competent decisionmaker to choose to forego the treatment. As in all surrogate decisionmaking, the surrogate is obligated to try to evaluate benefits and burdens from the infant's own perspective.<sup>79</sup> The Commission believes that the handicaps of Down Syndrome, for example, are not in themselves of this magnitude and do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.

This is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants\*; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

**Clearly futile therapies.** When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably futile endeavors is ethically and legally justifiable. Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period. The moment of death for these infants might be delayed for a short time — perhaps as long as a few weeks — by vigorous therapy.<sup>81</sup> Of course, the prolongation of life — and hope against

<sup>79</sup>The importance of adopting the viewpoint of the incompetent patient, see pp. 131-36 *supra*, is especially well illustrated regarding newborns. For many adults, life with severe physical or mental handicap would seem so burdensome as to offer no benefits. However, this assessment arises largely from the adults' existing hopes and aspirations that would be forever unfulfilled. From the perspective of an infant who can be helped to develop realistic goals and satisfactions, such frustrations need not occur. In fact, many, severely handicapped persons are quite successful in finding and creating meaningful lives despite various limitations. Adopting the infant's point of view requires valuing these successes equally with a more conventional ideal. See, e.g., Karen M. Metzler, *Human and Handicapped*, in Samuel Gorovitz *et al.*, eds., *MORAL PROBLEMS IN MEDICINE*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1976) at 358.

<sup>80</sup>For a discussion of discrimination against handicapped, see Institute of Medicine. *HEALTH CARE IN THE CONTEXT OF CIVIL RIGHTS*, National Academy of Sciences, Washington (1981). Cf. Helge H. Mansson, *Justifying the Final Solution*, 3 *OMEGA* 79 (May 1972).

<sup>81</sup>People differ in their assessment of when a potential prolongation of life is to be taken as meaningful. The analysis in this section applies to babies whose lives will end in infancy and are likely to be measured in hours or days, not years.

Medicine may *never* have all the solutions to all the problems

hope— may be enough to lead some parents to want to try a therapy believed by physicians to be futile. As long as this choice does not cause substantial suffering for the child, providers should accept it, although individual health care professionals who find it personally offensive to engage in futile treatment may arrange to withdraw from the case.<sup>82</sup>

Just as with older patients, even when cure or saving of life are out of reach, obligations to comfort and respect a dying person remain. Thus infants whose lives are destined to be brief are owed whatever relief from suffering and enhancement of life can be provided, including feeding, medication for pain, and sedation, as appropriate. Moreover, it may be possible for parents to hold and comfort the child once the elaborate means of life-support are withdrawn, which can be very important to all concerned in symbolic and existential as well as physical terms.

*Ambiguous cases.* Although for most seriously ill infants there will be either a clearly beneficial option or no beneficial therapeutic options at all, hard questions are raised by the smaller number for whom it is very difficult to assess whether the treatments available offer prospects of benefit—for example, a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator-dependent premature infant whose long-term prognosis becomes bleaker with each passing day.

Much of the difficulty in these cases arises from factual uncertainty. For the many infants born prematurely, and sometimes for those with serious congenital defects, the only certainty is that without intensive care they are unlikely to survive; very little is known about how each individual will fare with treatment. Neonatology is too new a field to allow accurate predictions of which babies will survive and of the complications, handicaps, and potentials that the survivors might have.<sup>83</sup>

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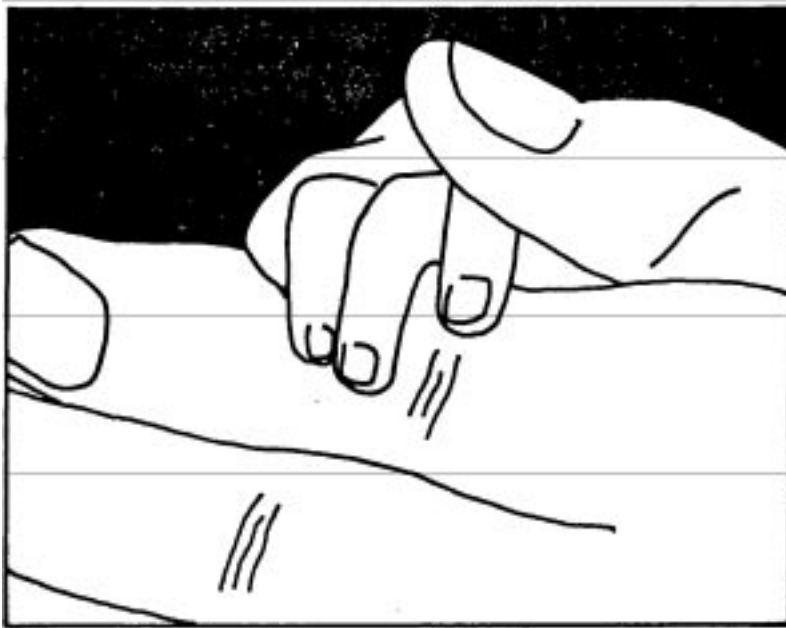
that occur at birth. I personally foresee no medical solution to a cephalodymus or an anencephalic child. The first is a one-headed twin; the second, a child with virtually no functioning brain at all. In these cases the prognosis is an early and merciful death by natural causes. There are no so-called "heroic measures" possible and intervention would merely prolong the patient's process of dying. Some of nature's errors are extraordinary and frightening...but nature also has the kindness to take them away. For such infants, neither medicine nor law can be of any help. And neither medicine nor law should prolong these infants' process of dying.

Dr. C. Everett Koop, *Statement before Hearing on Handicapped Newborns, Subcomm. on Select Education Comm, on Education and Labor, U.S. House of Representatives* (Sept. 16, 1982).

<sup>82</sup> See pp. 91-94 *supra*.

<sup>83</sup> Uncertainty about the course is partly the consequence of the

The longer some of these babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals can be on whether further treatment is warranted or futile. Frequently, however, the prospect of long-term survival and the quality of that survival remain unclear for days, weeks, and months, during which time the infants may have an unpredictable and fluctuating course of advances and setbacks.



One way to avoid confronting anew the difficulties involved in evaluating each case is to adopt objective criteria to distinguish newborns who will receive life-sustaining treatment from those who will not. Such criteria would be justified if there were evidence that their adoption would lead to decisions more often being made correctly.

Strict treatment criteria proposed in the 1970s by a British physician for deciding which newborns with spina bifida<sup>84</sup>

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rapidly expanding ability to save newborns who until recently could not have survived. Neonatal intensive care is a rapidly developing field and long-term follow-up on much of the most modern treatment is not yet available. Limited experience also compromises the ability to assess the effects—especially long-term physical and psychological effects—of medicine's effort to create a womb-like environment for the premature infant. See Albert R. Jonsen, *Justice and the Defective Newborn*, in Earl E. Shelp, ed., *JUSTICE AND HEALTH CARE*, D. Reidel Pub. Co., Boston (1981) at 95.

<sup>84</sup> John Lorber, *Early Results of Selective Treatment of Spina Bifida*

should receive treatment rested upon the location of the lesion (which influences degree of paralysis), the presence of hydrocephalus (fluid in the brain, which influences degree of retardation), and the likelihood of an infection. Some critics of this proposal argued with it on scientific grounds, such as objecting that long-term effects of spina bifida cannot be predicted with sufficient accuracy at birth.<sup>85</sup> Other critics, however, claimed this whole approach to ambiguous cases exhibited the "technical criteria fallacy."<sup>86</sup> They contended that an infant's future life—and hence the treatment decisions based on it—involves value considerations that are ignored when physicians focus solely on medical prognosis.<sup>87</sup>

The decision [to treat or not] must also include evaluation of the meaning of existence with varying impairments. Great variation exists about these essentially evaluative elements among parents, physicians, and policy makers. It must be an open question whether these variations in evaluation are among the relevant factors to consider in making a treatment decision. When Lorber uses the phrase "contraindications to active therapy," he is medicalizing what are really value choices.<sup>88</sup>

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*Cystica*, 4 BRIT. MED. J. 201 (1973); John Lorber, *Results of Treatment of Myelomeningocele*, 13 DEV. MED. & CHILD NEUROL. 279 (1971). See also Terrence F. Ackerman, *Meningomyelocele and Parental Commitment: A Policy Proposal Regarding Selection for Treatment*, 5 MAN & MED. 291 (1980).

<sup>85</sup> John M. Freeman, *The Shortsighted Treatment of Myelomeningocele: A Long-Term Case Report*, 53 PEDIATRICS 311 (1974); Robert Reid, *Spina Bifida: The Fate of the Untreated*, 7 HASTINGS CTR. REP. 16 (Aug. 1977).

<sup>86</sup> Robert M. Veatch, *The Technical Criteria Fallacy*, 7 HASTINGS CTR. REP. 15, 16 (Aug. 1977).

<sup>87</sup> Courts, for example, sometimes automatically assume the priority of the value of a longer life. In the case of Kerri Ann McNulty, a Massachusetts probate judge ruled that corrective surgery had to be done on a month-old infant diagnosed as having congenital rubella, cataracts on both eyes, deafness, congenital heart failure, respiratory problems, and probable severe retardation. After reviewing the medical testimony, the court explicitly eschewed "quality of life" considerations, stating: "I am persuaded that the proposed cardiac surgery is not merely a life prolonging measure, but indeed is for the purpose of saving the life of this child, *regardless of the quality of that life.*" In the Matter of Kerri Ann McNulty, No. 1960 (Probate Ct., Essex Co., Mass., Feb. 15, 1978).

<sup>88</sup> Veatch, *supra* note 86, at 15. But see Stuart F. Spicker and John R. Raye, *The Bearing of Prognosis on the Ethics of Medicine: Congenital Anomalies, the Social Context and the Law*, in Stuart F. Spicker, Joseph M. Healy, Jr., and H. Tristram Engelhardt, Jr., eds., *THE LAW-MEDICINE RELATION: A PHILOSOPHICAL EXPLORATION*, D. Reidel Pub. Co., Boston (1981) at 189, 202-05, 212.

The Commission agrees that such criteria necessarily include value considerations. Supposedly objective criteria such as birth weight limits or checklists for severity of spina bifida have not been shown to improve the quality of decision-making in ambiguous and complex cases. Instead, their use seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers.<sup>89</sup>

Furthermore, any set of standards, when honestly applied, leaves some difficult or uncertain cases. When a child's best interests are ambiguous, a decision based upon them will require prudent and discerning judgment. Defining the category of cases in a way that appropriately protects and encourages the exercise of parental judgment will sometimes be difficult. The procedures the Commission puts forward in the remainder of this chapter are intended to assist in differentiating between the infants whose interests are in fact uncertain and for whom surrogates' decisions (whether for or against therapy) should be honored, and those infants who would clearly benefit from a certain course of action, which, if not chosen by the parents and providers, ought to be authorized by persons acting for the state as *parens patriae*.

### Policy Evaluation and Recommendations

The few systematic studies of decisionmaking about seriously ill newborns support the contentions of care professionals before the Commission and elsewhere that such decisionmaking usually adheres to the precepts outlined in this chapter.<sup>90</sup> As shown previously, however, problems of two kinds do occur: (1) parents receive outdated or incomplete information from their physicians and this limits their capacity to act as surrogate decisionmakers,<sup>91</sup> and (2) in what appears

<sup>89</sup> Many have noted that diffusion of responsibility often acts to make no one feel responsible. See, e.g., R. B. Zachary, *Commentary: On the Death of a Baby*, 7 *JMED.ETHICS* 5, 11 (1981).

<sup>90</sup> See notes 46-49 *supra*.

<sup>91</sup> Hein, *supra* note 74.

When they [parents] begin to hear both points of view—sometimes it's only that there are excellent adoptive homes for such kids—that's often never raised—that changes the decision. Sometimes they just need to learn more about Down's. Parents have such horrible fantasies about it; it's mongolism and it's something monstrous, they think. This wider process is often nothing more exotic than bringing facts into the discussion.

Testimony of Dr. Norman Fost, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 161.

to be a limited number of cases, inappropriate decisions are made without triggering a careful reevaluation.<sup>92</sup>

**Improving Initial Decisions.** The Commission believes that professional associations and health care institutions should help ensure that the best information is available and is used when decisions about life-sustaining treatment are made.<sup>93</sup> This is especially important in the cases of neonates because of both rapidly expanding medical capabilities and other efforts to maximize the potential of the disabled. Physicians should seek, and institutions might require, specialist consultations in such cases.

Where problems arise in communication between parents and nurses or physicians, institutions should provide responsive means to improve the communication and resolve the impasse. A high priority for care givers in this area should be the development of personal and team skills in communication and the enhancement of surrogates' capacities for effective decisionmaking.

**Ensuring Appropriate Review.** Although personal morality and compassion, high standards of professional ethics, and current laws and regulations ensure that the vast majority of decisions about seriously ill infants are made correctly and that incorrect decisions are redressed, occasionally actions are

<sup>92</sup> Robertson, *supra* note 76. Perhaps the best-known case, and the only one in which there is an appellate court decision, is the one that has come to be known as the Infant Doe case, in which parents elected to forego treatment of their newborn child who had Down syndrome, tracheoesophageal atresia, and possibly additional anomalies. The course of nontreatment was one "medically recommended" way in which to proceed, according to the opinion of the trial court in an action brought by child welfare authorities on the complaint of some party other than either the physicians or the parents of the child. The trial court eventually sustained the parents' decision not to treat, *In re Infant Doe*, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. April 12, 1982). *writ of mandamus dismissed sub nom. State ex rel. Infant Doe v. Baker*, No. 482 S 140 (Indiana Supreme Ct., May 27, 1982) (case mooted by child's death). Assessing this case is made difficult by the privacy concerns involved in judicial proceedings. See Steven R. Valentine, *Briefs Ordered Sealed in "Infant Doe" Appeal Case*, **RIGHT TO LIFE NEWS**, Nov. 24, 1982, at 8.

<sup>93</sup> You were asking if it is possible to do it [counsel parents of seriously ill newborns] without a team...I can't imagine doing it without a team, frankly, because there are so many different parts of each parent that need attending to in a decision that is the most excruciating one they will ever make, and no one professional discipline can do all of that.

Testimony of Carole Kennon, Social Worker, transcript of 16th meeting of the President's Commission (Jan 9, 1982) at 31. See also Hein, *supra* note 74.

taken without the consent of an infant's surrogate or tragically erroneous decisions are made by both physicians and surrogates. Judicial proceedings provide a possible means to handle these situations, although the Commission does not find them to be the best—nor even a very available and convenient—method.

Actions taken without a surrogate's consent are not readily susceptible to redress through the courts, since the parents are not likely to be in a position to evaluate—or even to detect—what is happening in their child's care if they are excluded from decisionmaking; furthermore, civil proceedings would be cumbersome, costly, and slow.<sup>94</sup> In many institutions, people concerned about erroneous decisions by both physicians and surrogates intervene only by complaining to public officials that child abuse or criminal homicide has occurred or may be about to occur. This very serious accusation usually requires that the complainant believes the evidence is sufficient to warrant legal action.

Furthermore, the adversarial atmosphere generated by this approach is unlikely to lead to infants receiving the most suitable care. The same problem arises with the regulations issued by the Department of Health and Human Services in the wake of the *Infant Doe* case<sup>95</sup> to prevent handicapped infants

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<sup>94</sup> I think we have...a real contrast in time-frame analysis between the medical and legal profession....When we talk about quick court decisions we are talking about 12 days. When I talk about quick, it means running down the stairs rather than taking an elevator....You have to understand when physicians want an answer they want it in 10 minutes. When lawyers produce an answer, they congratulate themselves for producing it in 10 days.

Testimony of Dr. Marianne Prout, transcript of 10th meeting of the President's Commission (June 4, 1981) at 35-36; Arnold Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 *L. a MED.* 233 (1978).

In addition to being ill-equipped to respond quickly enough to life-threatening situations, courts have been criticized for being unable to respond to the dynamic nature of decisionmaking necessary for medical treatment choices. Compare the statement of I. David Todres in Cynthia B. Wong and Judith P. Swazey, eds., *DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT*, G.K. Hall Med. Pub., Boston (1981) at 122-23 with *Maine Medical Center v. Houle* No. 74-145 (Super. Ct. Cumberland County, Me., Feb. 14, 1974) reprinted in Robert F. Weir, ed., *ETHICAL ISSUES IN DEATH AND DYING*, Columbia Univ. Press, New York (1977) at 185. *In re Teague*, No. 104-212-81886 (Cir. Ct. Baltimore, Md., filed Dec. 4, 1974) (child born with spina bifida died before action could be taken on the case.). See p. 159 *supra*.

<sup>95</sup> Office of the Secretary, Department of Health and Human Services, *Nondiscrimination on the Basis of Handicap*, 48 Federal Register 9630 (1983) (interim final rule modifying 45 C.F.R. § 84.61). See also Office

from being "discriminatorily denied food or other medical care."<sup>96</sup> Instead of adding further uncertainty to an already complex situation,<sup>97</sup> the Federal government would do better to encourage hospitals to improve their procedures for overseeing

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for Civil Rights, Department of Health and Human Services, *Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice to Health Care Providers*, 47 Federal Register 26,017 (1982)(notice issued May 18, 1982, applying 45 C.F.R. Part 84 to health services for handicapped children), *reprinted in* Appendix H, pp. 467-68 *infra*.

Under the March 1983 notice, a warning must be posted in relevant places in hospitals that it is unlawful to exclude any "otherwise qualified handicapped individual" from the benefits of any Federally assisted program. A toll-free 24-hour "hotline" number is provided for anyone who knows of any handicapped infant who is being denied food or "customary medical care." Under the earlier notice, the Department reminded the nearly 7000 hospitals that receive Federal aid that existing HHS regulations apply § 504 of the Rehabilitation Act of 1973 to health services and treat Down Syndrome as a handicap within the meaning of § 504. Prior to 1982, § 504 had only been used once in the context of newborns with congenital anomalies. *See* Protection and Advocacy Agency of Hawaii v. Kapiolani Children's Hospital, Health and Human Services Doc. No. 09-79-3158 (1980), *cited in* Nancy Lee Jones, *Application of Section 504 of the Rehabilitation Act of 1973 to Handicapped Infants*, Congressional Research Service, Library of Congress, Washington (July 9, 1982).

<sup>96</sup> *Discrimination Against the Handicapped*, *supra* note 95, at 9630.

<sup>97</sup> Questions remain, for example, concerning such difficult matters as decisions regarding very low birth weight babies on the edge of viability, decisions for those with multiple serious congenital anomalies, and decisions for infants who are dying. Witnesses testifying before the Commission expressed concern that virtually every operative phrase of the DHHS directive needs amplification and would be subject to varieties of interpretation.

There are two problems with Section 504: (1) it is not clear if or why a handicap can *never* be a justification for withholding treatment; and (2) the phrase "medically contraindicated" is ambiguous...the wording of this exemption is so vague that it is unintelligible. What is meant by a medical contraindication to treatment?...The language of Section 504 does not tell us *whether* it is permissible to withhold dialysis from a hydranencephalic child, or *why* it is impermissible to withhold intestinal surgery from a child with Down Syndrome.

Norman Fost, *Putting Hospitals on Notice*, 21 HASTINGSCTR. REP. 5 (Aug. 1982). *See also*, *Life Support Notice Attacked*, AM. MED. NEWS, July 16, 1982 at 17 (response by American Academy of Pediatrics to the Section 504 directive).

Furthermore, the term "handicapped" is in no way limited in application to neonates. The impact of a regulation of this sort on the care of other patients could be substantially in conflict with this Report.

life-and-death decisions, especially regarding seriously ill newborns. Using financial sanctions against institutions to punish an "incorrect" decision in particular cases is likely to be ineffective and to lead to excessively detailed regulations that would involve government reimbursement officials in bedside decisionmaking. Furthermore, imposing such sanctions could unjustly penalize the hospital's other patients and professionals.

The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants; accrediting bodies could appropriately require this. Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. Other cases, such as when the physician and parents disagree, might well also be reviewed. The policy should allow for different types of review and be flexible enough to deal appropriately with the range of cases that could arise. Some cases may require only a medical consultation to confirm a diagnosis of an inevitably fatal condition, for example. In other cases, when the benefits of therapy are less clear, an "ethics committee" or similar body might be designated to review the decisionmaking process.<sup>98</sup> This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases. Cases included in this category should certainly encompass those in which a decision to forego life-sustaining therapy has been proposed because of a physical or mental handicap, as well as cases where a dispute has arisen among care givers and surrogates over the proper course of treatment.

Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate. Such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested "representative of the public" and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.

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<sup>98</sup> See pp. 160-70 *supra*.

Insofar as possible, infants' lives should be sustained long enough to gather the best information and to permit expeditious review. When the parents and physician feel justified in acting without either or both of these conditions, as might happen with a rapidly deteriorating medical status, retrospective review should be undertaken.<sup>99</sup> Unlike turning to the courts for scrutiny of every case involving treatment of a seriously ill newborn, review of this limited category of cases would not seem likely to generate inappropriate social or financial costs.

In light of the lack of comprehensive information about decisionmaking practices and the fact that the Commission's recommendation is largely untried, the Commission encourages institutions, social scientists, and funding agencies to evaluate the effectiveness of such regularized review in order to improve its efficiency and efficacy and to refine the definition of the circumstances in which it is needed.

**Long-Term Implications.** The value society places on promoting the health and welfare of children has ramifications beyond neonatal intensive care units. When the decision is made to give seriously ill newborns life-sustaining treatment, an obligation is created to provide the continuing care that makes a reasonable range of life choices possible. A major conference on critically ill newborns concluded:

The advocates of intensive care must become the advocates for development of humane continuing care and for sufficient funding of programs to support families whose children require special attention at home or in institutions. Neonatology cannot be developed in isolation from the continuing specialized care which, unfortunately, will be needed by some of the survivors of life-threatening neonatal disorders.<sup>100</sup>

Adoption and foster care should be available for parents unable to raise their seriously handicapped child.<sup>101</sup> To aid

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<sup>99</sup> Ensuring a retrospective review removes any incentive for hasty actions to avoid prospective review, a course that could be a disadvantage to at least some newborns. Retrospective review cannot change what happened to a particular child, but it can help ensure a high standard of decisionmaking practices in the institution and can censure seriously erroneous decisionmaking, both internally and by referral to the courts.

<sup>100</sup> Albert R. Jonsen *et al.*, *Critical Issues in Newborn Intensive Care: A Conference Report and a Policy Proposal*, 55 *PEDIATRICS* 756, 764 (1975).

<sup>101</sup> As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than *either assume* full responsibility for the treatment, care, and nurture of such

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parents, support that is responsive to the emotional and financial demands of handicapped persons and their families should be available. As a physician who has been pioneer in the treatment of infants and children recently commented, such support is an essential concomitant to a commitment to sustaining life.

I'm very much involved in making sure that habilitation and rehabilitation of spina bifida individuals is advancing, because that's really the hope. If...I have preserved a thousand children who are going to sit in wheelchairs in nursing homes with normal intelligence...if that's what I've done, I've created a nightmare.<sup>102</sup>

Private organizations have made enormous contributions on behalf of the disabled; yet public funds may ultimately be needed so that these children, once rescued, are not then left to drown in a sea of indifference and unresponsiveness. Public support for effective voluntary organizations and governmental programs is the inescapable extension of society's deep interest in sustaining life in neonatal intensive care units. Furthermore, to the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised.

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children *or honor* the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life.

Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervision for the Child at Risk*, in Gaylin and Macklin, *supra* note 66, at 153.

<sup>102</sup> Dr. David McClone, Interview on *Sunday Morning* (transcript), CBS Network, Aug. 29, 1982, at 25.



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# Resuscitation Decisions for Hospitalized Patients

# 7

## Origin and Scope of Resuscitation Efforts

**Medical Capabilities.** Resuscitation—the ability to rescue people from the brink of death by restoring life-giving heart-beat and breathing<sup>1</sup>—is one of modern medicine's most dramatic achievements.<sup>2</sup> The development of resuscitation techniques has been intimately connected with the refinement of medical instrumentation, the development of hospitals, and advances in anesthesia, surgery, and medical research generally.<sup>3</sup> Leading figures in the history of medicine have been at the

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<sup>1</sup> Resuscitation is the revival of a living being from apparent death. Initially, medical efforts were aimed at restoring breathing (*e.g.*, in victims of asphyxiation). The concern of this chapter is limited, however, to the capability, developed over the past three decades, to reverse cessation of heartbeat (also termed cardiac arrest). Unless heartbeat is reestablished within minutes, damage to the brain becomes total and irreversible, spontaneous breathing cannot be recovered, and the patient is dead.

<sup>2</sup> Various means of resuscitation have long existed. The oldest account is probably the prophet Elisha's revival of the lifeless son of a Shunamite woman:

And he went up, and lay upon the child, and put his mouth upon his mouth, and his eyes upon his eyes, and his hands upon his hands: and he stretched himself upon the child; and the flesh of the child waxed warm.

<sup>3</sup> Kings 4:31-7 (New English).

<sup>4</sup> See D.K. Brooks, *RESUSCITATION*, William & Wilkins Co., Baltimore, Md. (1967).

forefront of these developments. Vesalius first described ventricular fibrillation<sup>4</sup> with its relationship to interrupted breathing, and he attempted intubation and artificial respiration with a reed inserted into a trachea.<sup>5</sup> In a pioneering 17th century work on circulation, William Harvey is credited with the first recorded direct manipulation of the heart (a pigeon's) as a resuscitation technique.<sup>6</sup> In 18th century Britain, John Hunter experimented with inserting the nozzle of a bellows into the trachea of a dog whose chest had been opened and found that spontaneous breathing could be restored after as much as ten minutes. Hunter was instrumental in establishing "receiving houses" along waterways for revival of nearly drowned sailors.<sup>7</sup> These buildings stocked resuscitation apparatus, including bellows and silver catheters for tracheotomies.<sup>8</sup>

An important round of advances in resuscitation techniques followed the development of anesthesia, first used in surgery in the 1840s.<sup>9</sup> Pioneering physicians using chloroform and ether soon found they had unsheathed a double-edged sword— anesthesia's remarkable ability to suspend consciousness carried a corresponding risk of cardiac arrest. Extensive animal experiments fostered the development of treatments for cardiac arrest during or following surgery. In 1898, French surgeons reported success in briefly restoring the heartbeat of an appendectomy patient when it stopped five days after surgery, an especially notable event because it was the first such attempt on a hospital ward.<sup>10</sup>

<sup>4</sup> Ventricular fibrillation is a certain kind of ineffective heart motion that progresses rapidly to complete cardiac standstill unless treated but that is especially susceptible to correction by resuscitation.

<sup>5</sup> B.B. Milstein, *CARDIAC ARREST AND RESUSCITATION*, Lloyd-Luke Medical Books, London (1963) at 2; F.A. Willius and T.J. Dry, *A HISTORY OF HEART AND CIRCULATION*, W.B. Saunders Co., Philadelphia (1948).

<sup>6</sup> Carl E. Bartecchi, *Cardiopulmonary Resuscitation—An Element of Sophistication in the 18th Century*, 100 *AM. HEART J.* 580 (Oct. 1980).

<sup>7</sup> John Hunter, *Proposals for the Recovery of People Apparatus Drowned*, 66 *PHIL. TRANS.* 412 (1776).

<sup>8</sup> I. McLellan, *Nineteenth Century Resuscitation Apparatus*, 36 *ANESTHESIA* 307 (1981).

<sup>9</sup> Logan Clendening, ed., *SOURCE BOOK OF MEDICAL HISTORY*, Dover Pub., New York (1942) at 355.

Milstein, *supra* note 5, at 8; T. Tuffier and L. Hallion, *De la*

<sup>10</sup> *Conipression rhymie du coeur dans la syncope cardique par embolie*, 24 *BULL. Soc. CHIRURGIE PARIS* 937 (1898).

Resuscitation of heart action became much more likely when pharmacologic and electric rhythm control interventions were developed in the 1940s.<sup>11</sup> It was discovered that adrenaline and procaine could restore heartbeat, and in 1947 the first instance of electric defibrillation of a heart was reported—a patient's heartbeat was restored after 70 minutes of ventricular fibrillation.<sup>12</sup>

In 1960, research demonstrated that circulation could be maintained in a patient without heartbeat by external cardiac massage.<sup>13</sup> Until this time, cardiac arrest had been treated by thoracotomy (surgically opening the chest) and direct massage. Emergency cardiac resuscitation<sup>14</sup> was first used mainly in recovery rooms, accompanied by the monitoring of electrocardiograms and arterial pressure. The procedure was fairly straightforward and was soon used in all parts of a hospital.<sup>15</sup>

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<sup>11</sup> H.D. Adams and L.V. Hand, *Twenty Minute Cardiac Arrest with Complete Recovery*, 118 J.A.M.A. 133 (1942); C.S. Beck, *Resuscitation for Cardiac Standstill and Ventricular Fibrillation Occurring During Operation*, 54 AM. J. SURG. 273 (1941).

<sup>12</sup> C.S. Beck, W.H. Pritchard, and H. Feil, *Ventricular Fibrillation of Long Duration Abolished by Electric Shock*, 135 J.A.M.A. 985 (1947). Electricity must have been thought useful in 1814, though specific cases are not reported. In the *Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons*, published in May 1814 in THE CHEAP MAGAZINE (see Figure 3, page 237), are these lines:

The electric fluid, nature's purest fire,  
The soul-reviving vigor can inspire,  
Breathe through the frame a vivifying strife,  
And wake the torpid powers to sudden life.

Leonard Scherlis, *Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons*, 9 CRIT. CARE MED. 430, 431 (1981).

<sup>13</sup> W.B. Kouwenhoven, J.R. Jude, and G.G. Knickerbocker, *Closed-chest Cardiac Massage*. 173 J.A.M.A. 1064 (1960). See generally Judith P. Swazey and Renee C. Fox, *The Clinical Moratorium: A Case Study of Mitral alve Surgery* in Paul A. Freund, EXPERIMENTATION WITH HUMAN SUBJECTS, George Braziller, New York (1969) at 315; Lael Wertenbaker, TO MEND THE HEART, Viking Press, New York (1980).

<sup>14</sup> See American Heart Association and National Academy of Sciences/National Research Council, *Standards and Guidelines for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 244 J.A.M.A. 453 (1980).

<sup>15</sup> This chapter focuses on resuscitation in hospitals, a setting that much more often allows for advance deliberation about undertaking resuscitation than does cardiac arrest at home or work. However, it did become clear in the 1960s that the lay public could be taught to perform emergency cardiopulmonary resuscitation with an acceptably low injury rate. Since then, training courses with practice manikins have been developed for groups such as lifeguards, police, firefighters, and ambulance personnel. For a treatment of the distinct but related issues concerning bystander-initiated resuscitation, see George J.

Over 15 years, cardiopulmonary resuscitation (CPR) using external compression has become routine in general hospital wards and emergency rooms and has given impetus to the newly developed specialized coronary and intensive care units.

Resuscitation after a cardiac arrest involves a series of steps directed toward sustaining adequate circulation of oxygenated blood to vital organs while heartbeat is restored.

Efforts typically involve the use of cardiac massage or chest compression and the delivery of oxygen under compression through an endo-tracheal tube into the lungs. An electrocardiogram is connected to guide the resuscitation team.... Various plastic tubes are usually inserted intravenously to supply medications or stimulants directly to the heart. Such medications can also be supplied by direct injection into the heart.... A defibrillator may be used, applying electric shock to the heart to induce contractions. A pacemaker... may be fed through a large blood vessel directly to; the heart's surface.... These procedures, to be effective, must be initiated with a minimum of delay.... Many of the procedures are obviously highly intrusive, and some are violent in nature. The defibrillator, for example, causes violent (and painful) muscle contractions which... may cause fracture of vertebrae or other bones.<sup>16</sup>

Though initially developed for otherwise healthy persons whose heartbeat and breathing failed following surgery or near-drowning, resuscitation procedures are now used with virtually everyone who has a cardiac arrest in a hospital. The initial success rate for in-hospital resuscitation is about one in three for all victims and two in three for patients hospitalized with irregularities of heart rhythm. Among patients who are successfully resuscitated, about one in three recovers enough to be discharged from the hospital eventually.<sup>17</sup> Especially

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Annas, *CPR: The Beat Goes On*, 12 HASTINGS CTR. REP. 24 (Aug. 1982); Mickey S. Eisenberg, Lawrence Bergner, and Alfred Hallstrom, *Cardiac Resuscitation in the Community*, 241 J.A.M.A. 1905 (1976). Robert G. Thompson, Alfred P. Hallstrom, and Leonard A. Cobb, *Bystander-Initiated Cardiopulmonary Resuscitation in the Management of Ventricular Fibrillation*, 90 ANNALS INT. MED. 737 (1979).

Sometimes "resuscitation" is used to cover a number of dramatic, emergency, life-sustaining interventions, including, for example, blood volume replacement. In this Report resuscitation is used only to refer to those efforts undertaken to restore heartbeat.

<sup>16</sup> *In re Dinnerstein*, 380 N.E.2d 134, 135-36 (Mass. App. 1978).

<sup>17</sup> W.A. Tweed *et al.*, *Evaluation of Hospital-based Cardiac Resuscitation, 1973-1977*, 122 CAL. MED. ASSOC. J. 301 (1980). This rate is improved when fewer patients have resuscitation: at one center, a 56% successful resuscitation rate was reported when resuscitation was

when used on the general hospital population, long-term success is fairly rare. In the past decade, health care providers have begun to express concern that resuscitation is being used too frequently and sometimes on patients it harms rather than benefits.<sup>18</sup>

**Special Characteristics of CPR.** Cardiopulmonary resuscitation of hospitalized patients has certain special features that must be taken into account in both individual and institutional decisionmaking:

- Cardiac arrest occurs at some point in the dying process of every person, whatever the underlying cause of death. Hence the decision whether or not to attempt resuscitation is potentially relevant for all patients.
- Without a heartbeat, a person will die within a very few minutes (that is, heartbeat and breathing will both irreversibly cease).
- Once a patient's heart has stopped, any delay in resuscitation greatly reduces the efficacy of the effort. Hence a decision about whether to resuscitate ought to be made in advance.
- Although resuscitation grants a small number of patients both survival and recovery, attempts at it

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tried on only 30% of all in-hospital deaths. DeBard collected all cases in the literature and found 39% initial success and 17% discharge to home. Mark DeBard, *Cardiopulmonary Resuscitation: Analysis of Six Years' Experience and Review of the Literature*, 10 *ANNALS EMERG. MED.* 408 (1981). In contrast, Hershey and Fisher found only 3% success in a general hospital population where virtually all deaths were attended by resuscitation efforts. Charles O. Hershey and Linda Fisher, *Why Outcome of Cardiopulmonary Resuscitation in General Wards is Poor*, 1 *LANCET* 31 (1982). One careful prospective study found 4.9% long-term survivors of resuscitation efforts after cardiac arrest. Bernard Messert and Charles Quagliari, *Cardiopulmonary Resuscitation Perspectives and Problems*, 1 *LANCET* 410, 411 (1976). One in 20 patients who have survived resuscitation has severe brain damage and about one in 4 has some serious and permanent injury. Clark Chipman *et al.*, *Criteria for Cessation of CPR in the Emergency Department*, 10 *ANNALS EMERG. MED.* 11,14 (1981).

■ John Castagna, Herbert Shubin, and Max Harry Weil, *Cardiac Arrest in the Critically Ill Patient*, 2 *HEART AND LUNG* 847 (1973); I. Fiisgen and J.D. Summa, *How Much Sense Is There to Resuscitate an Aged Person?*, 24 *GERONTOLOGY* 37 (1978); Thomas L. Petty, *Mechanical Last "Rights,"* 142 *ARCH. INT. MED.* 1442 (1982); (Editorial) *Cardiac Resuscitation in Hospital: More Restraint Needed?*, 1 *LANCET* 27 (1982); *Orders Not to Attempt Cardiac Resuscitation*, National Institutes of Health Clinical Center. Policy and Communications Bull. No. 82-4 (July 12, 1982).

usually fail; even when they reestablish heartbeat, they can cause substantial morbidity.<sup>19</sup>

- Clinical signs during resuscitation efforts do not reliably predict functional recovery of a patient.<sup>20</sup> Thus it is difficult to apply the sorts of adjustment and reconsideration that other interventions receive to a decision to resuscitate. Usually, the full range of efforts has to be applied until it is clear whether heartbeat can be restored.
- The conjectural nature of advance deliberations about whether or not to resuscitate may make the discussions difficult for the patient, family, and health care professionals.

**Policies on Orders Not to Resuscitate.** Pioneering policies on "No Code" orders ("code" being the shorthand term for the emergency summoning of a "resuscitation team" by the announcement of "Code Blue" over a hospital's public address system) or "DNR orders" (for "Do Not Resuscitate") were published by several hospitals in 1976.<sup>21</sup> The policies followed the recognition by professional organizations that non-resuscitation was appropriate when well-being would not be served by an attempt to reverse cardiac arrest. For example, the 1974 version of the "Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)" of the American Heart Association and the National Academy of Sciences states, "Cardiopulmonary resuscitation is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected."<sup>22</sup>

A growing number of hospitals are now developing such policies,<sup>23</sup> while those with policies are already updating them,

<sup>19</sup> See, e.g., E. L. Nagel, *Complications of CPR*, 9 CRIT. CARE MED. 424 (1981).

<sup>20</sup> Chipman, *supra* note 17, at 14-16.

<sup>21</sup> Mitchell T. Rabkin, Gerald Gillerman, and Nancy R. Rice, *Orders Not to Resuscitate*, 295 NEW ENG. J. MED. 364 (1976); Optimum Care for Hopelessly Ill Patients: A Report of the Critical Care Committee of the Massachusetts General Hospital, 295 NEW ENG. J. MED. 362 (1976); M. Kirchner, *How to Go in Prolonging Life: One Hospital's System*, MED. ECON. (July 12, 1976); See also Francis P. Arena, Martin Perkin and Alan Turnbull, *Initial Experience with a "code-no code" Resuscitation System in Cancer Patients*, 8 CRIT. CARE MED. 733 (1980).

<sup>22</sup> National Conference Steering Committee, *Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 227 J.A.M.A. 837,864 (1974).

<sup>23</sup> The prevalence of written policies nationwide is not known. The Commission's experience, in organizing hearings and from letters it received, indicates that many hospitals are drafting policies, but that it is not uncommon, especially for community hospitals, not to have a written policy.

**Figure 3: An 1814 Popularization of Resuscitation Procedures**

Source: Leonard Scherlis, M.D., *Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons*, 9 CRIT.CARE MED. 430 (1981).



especially to streamline procedures and to clarify that resuscitation is sometimes against good practice.<sup>24</sup> Three state medical societies—in Alabama, Minnesota, and New York—have promulgated brief guidelines to help establish the approved standard of care regarding DNR orders.<sup>25</sup> A Citizen's Committee in Los Angeles wrote guidelines for the county-run hospitals.<sup>26</sup> A 1982 survey of hospitals in San Francisco County and City found that policies had been written by all acute care hospitals but two—the ones run by the Veterans Administration and the Army.<sup>27</sup> The San Francisco Medical Society and the Bar Association of San Francisco collaborated to produce,

<sup>24</sup> See, e.g., *Guidelines: Orders Not to Resuscitate*, Beth Israel Hospital, Boston, Mass., March 31, 1981, reprinted in Appendix I, pp. 501-05 *infra*.

<sup>25</sup> Reprinted in Appendix I, pp. 497-500 *infra*.

<sup>26</sup> Reprinted in Appendix I, pp. 510-11 *infra*.

<sup>27</sup> Medical-Legal Interprofessional Committee, No Code Subcommittee, *Survey of No Code Guidelines in San Francisco Bay Area Hospitals (1982)*.

with explanatory commentary, a model for developing each hospital's No-Code policy.<sup>28</sup> Representatives of the district attorney's office and the county coroner's office were involved in its development.

**Legal Status.** As would be expected with a practice so recently established, the writing of orders against resuscitation has received little attention in court. Even so, the few cases and opinions are surprisingly diverse, giving no clear direction as to a legal consensus. In the *Dinnerstein* Case, the intermediate appeals court of Massachusetts held that an order not to resuscitate a "patient in the terminal stages of an unremitting, incurable terminal illness" was appropriate and "peculiarly within the competence of the medical profession...in light of the patient's history and condition and the wishes of her family."<sup>29</sup> Yet news accounts in 1982 stated that a criminal investigation of a hospital in Queens was begun because the New York Attorney General's Office disapproved DNR orders being written for elderly, incompetent patients.<sup>30</sup>

<sup>28</sup> Reprinted in Appendix I, pp. 494-97 *infra*.

<sup>29</sup> Shirley Dinnerstein was a 67-year old nursing home resident who suffered from Alzheimer's disease, a type of senile dementia. When her family and physician sought an action for declaratory relief to determine the legal status of a no-code order, she had progressed to the point where she was "in an essentially vegetative state," immobile, speechless, catheterized, and fed by a nasogastric tube. *In re Dinnerstein*, 380 N.E.2d 134, 135 (Mass. App. 1978). The *Dinnerstein* case came in the wake of the Massachusetts Supreme Court decision in *Saikewicz*, which some commentators had interpreted to require Probate Court approval of any decision to forego life-sustaining treatment of incompetent, terminally ill patients. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

*But see*, *Hoyt v. St. Mary's Rehabilitation Center*, D.C. File No. 774555, Hennepin County Minnesota District Court (Feb. 13, 1981) (findings of fact and order) slip op. at 3. In this case Jane Hoyt, a friend of 41-year-old Sharon Siebert, sought court review of Siebert's no code order. Mrs. Siebert suffered brain damage and required "total care," including nasogastric feeding. Her father consented to the order, but "understood that it meant Mrs. Siebert would not be placed on long term mechanical life support equipment; he did not understand that it meant that Mrs. Siebert would not be given brief emergency cardiopulmonary resuscitation." The court issued a restraining order to prevent the entering of a no-code order and substituted the friend instead of the father as guardian, noting, "the decision of the guardian was not made after due consideration...nor is there sufficient evidence that he sought to consider what Mrs. Siebert would have wanted had she been able to make the decision for herself." *See also* Jane Hoyt, *No Dr. Blue/Do Not Resuscitate*, 3 *BIOETHICS Q.* 128 (Summer 1981); Ronald E. Cranford and Mary S. Schneider, *Siebert Commentary: Medical-Legal Issues*, 3 *BIOETHICS Q.* 16 (Spring 1981).

<sup>30</sup> David Margolick, *Hospital Is Investigated on Life-Support Policy* N.Y. TIMES, June 20, 1982, at A-34; Ronald Sullivan, *Hospitals Seek*

Not surprisingly, providers are uncertain about their liability under the law, and, in the words of one attorney who wrote to the Commission, "common sense is often subordinated to a hysterical reaction to the possibility of litigation."<sup>31</sup> A physician in a community hospital told the Commission:

Older physicians are afraid of putting "do not resuscitate" down because they are afraid of being sued for making a wrong decision. The younger physicians are anxious to put a "do not resuscitate" down because they are afraid of being sued for making a wrong decision. The nurses will not act without a "do not resuscitate" because they are afraid of being sued.<sup>32</sup>

Even the authority of the courts regarding DNR orders is subject to divided opinion. In April 1982, Massachusetts held that the state's juvenile courts have authority to enter "no code" orders.<sup>33</sup> Three months later, the Attorney General of California wrote that probate courts in that state do not have such authority—contending, indeed, that a "no code" order cannot legally be written for an incompetent ward of the court in California.<sup>34</sup> Improvements in this situation probably depend on clarification of the underlying standard of socially accepted medical practices for decisions to forego resuscitation.<sup>35</sup>

## Ethical Considerations

**The Presumption Favoring Resuscitation.** Resuscitation must be instituted immediately after cardiac arrest to have the best chance of success. Because its omission or delayed application is a grievous error when it should to have been

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*Rules on Withholding Life-Support*, N. Y. TIMES, Nov. 17, 1982, at B-3; *In re Grand Jury Proceedings: People v. Doe*, No. 333 (N.Y. Ct. App. June 18, 1982) (hospital may not assert physician-patient or social worker-client privilege or patients' right of privacy when facing valid grand jury *subpeona duces tecum*.)

<sup>31</sup> Stuart Showalter, Director, Division of Legal Services of the Catholic Health Association of the United States, quoted in a letter from John E. Curley, Jr., President of CHA, to the Commission (March 25, 1982). *See also*, "Few DNR orders are being written for incompetent patients in New York State at present, largely because district attorneys state that they consider such orders to be illegal and subject to criminal prosecution." Personal communication from Joel Glass, attorney with Ackerman, Salwen, and Glass, New York City, to JoanneLynn (Jan.10,1983).

<sup>32</sup> Testimony of Dr. Albert Fine, transcript of 10th meeting of the President's Commission (June4,1981) at 95.

<sup>33</sup> *Custody of a Minor*, 434 N.E.2d 601 (Mass. 1982).

<sup>34</sup> 65 Ops. Cal. Att'y Gen. 4178 (1982), *reprinted in* Appendix I pp. 537-45 *infra*.

<sup>35</sup> *See e.g.*, Note, *No-Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment from the Terminally Ill*, 26 WAYNE L. REV. 139 (1979).

used to attempt to save a life, most hospitals now provide for the rapid assembling of a team of skilled resuscitation professionals at the bedside of any patient whose heart stops.

When there has been no advance deliberation, this presumption in favor of resuscitation is justified. Although the concern a few years ago was about overtreatment, some health care professionals are now worried about unwarranted undertreatment—a weakening of the presumption in favor of resuscitation.<sup>36</sup> Very different presuppositions are involved when a physician feels a need to justify resuscitating as opposed to not resuscitating someone. In either case, however, the risks of an inappropriate decision with grave consequences for a patient are great if the issues are not properly addressed according to well-developed criteria. In order to avoid using resuscitation in circumstances when it would be appropriate to omit it, advance deliberation on the subject is indicated in most cases. As in all decisions in medicine, the basic issue should be what medical interventions, if any, serve a particular patient's interests and preferences best. When a person's interests or preferences cannot be known under the circumstances, a presumption to sustain the patient's life is warranted.

**The Values at Stake.** In considering the relative merits of a decision to resuscitate a patient, concerns arise from each of three value considerations—self-determination, well-being, and equity.<sup>37</sup>

**Self-determination.** Patient self-determination is especially important in decisions for or against resuscitation. Such decisions require that the value of extending life—usually for brief periods and commonly under conditions of substantial disability and suffering—be weighed against that of an earlier death. Different patients will have markedly different needs and concerns at the end of their lives; having a few more hours, days, or even weeks of life under constrained conditions can be much less important to some people than to others. In decisions concerning competent patients, therefore, first importance should be accorded to patient self-determination, and the patient's own decision should be accepted.

This great weight accorded to competent patients' self-determination means that attending physicians have a duty to ascertain patients' preferences,<sup>38</sup> which involves informing

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<sup>36</sup> See, *Doctor Sees Trend Not to Resuscitate*. WASH. POST, June 13, 1982, at A-4.

<sup>37</sup> See pp. 26-27 *supra*.

<sup>38</sup> Although the attending physician bears, the responsibility, often others among the care giving professionals, religious advisors, or family members are in a good or better position to discuss the issues and convey the information. This is to be encouraged, but the physician is still obliged to see that it is done well.

each patient of the possible need for CPR and of the likely consequences (both beneficial and harmful) of either employing or foregoing it if the need arises.<sup>39</sup> When cardiac arrest is considered a significant possibility for a competent patient, a DNR order should be entered in the patient's hospital chart only after the patient has decided that is what he or she wants. When resuscitation is a remote prospect, however, the physician need not raise the issue unless CPR is known to be a subject of particular concern to the patient or to be against the patient's wishes. Some patients in the final stages of a terminal illness would experience needless harm in a detailed discussion of resuscitation procedures and consequences.<sup>40</sup> In such cases, the physician might discuss the situation in more general terms, seeking to elicit the individual's general preferences concerning "vigorous" or "extraordinary" efforts and inviting any further questions he or she may have.<sup>41</sup>

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<sup>39</sup> Contrary to the Commission's conclusions, some have contended that involving the patient is unnecessary:

Consent of the patient is irrelevant because we are dealing with a situation in which there is no course of treatment for which to secure consent. This is different from the case in which there is a medically accepted course of treatment, but the patient does not wish to be subjected to this care.

William G. Ketterer, Senior Attorney, NIH, in a letter to James H. Erickson, Assistant Surgeon General and Joel M. Mangel, Deputy Assistant General Counsel for Public Health (April 8, 1977) at 6.

The Commission finds it necessary for the patient or surrogate to have given valid consent to any plan of treatment, whether involving omissions or actions, and rejects this claim. *See* pp. 66-73 and 126-31 *supra*.

<sup>40</sup> *See, e.g.*, "Such explanations to the patient, on the other hand, are thoughtless to the point of being cruel, unless the patient inquires, which he is extremely unlikely to do." Steven S. Spencer, "Code" or "No Code": A Non Legal Opinion, 300 NEW ENG. J. MED. 138,139 (1979).

*But see* "The physician and family often underestimate the patient's ability to handle this issue and participate in the decision." Steven H. Miles, Ronald E. Cranford, and Alvin L. Schultz, *The Do-Not-Resuscitate Order in a Teaching Hospital*, 96 ANNALS INT. MED. 660,661 (1982).

<sup>41</sup> Sometimes it seems cruel and unnecessary. Other times it is just difficult, in the midst of what is usually a very emotional and difficult time, to get around to the question of whether you want us pumping on your chest when you die....Having taken care of someone for some period of time has usually generated prior tacit, if not overt, understanding between the patient and me on these issues.

Michael Van Scoy-Mosher, *An Oncologist's Case for No-Code Orders*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, AUPHA Press, Ann Arbor, Mich. (1982) at 16; *see also* Ronald A. Carson and

**Well-being.** A second important ethical consideration is whether resuscitation will promote a patient's welfare. A physician's assessment of "benefit" to a patient incorporates both objective facts, based on the physician's evaluation of the patient's physical status before and following resuscitation, and subjective values, in considering whether resuscitation or non-resuscitation best serves the patient's own values and goals. In virtually all cases the attending physician is in a better position to evaluate the former, while a competent patient is best able to determine the relative value of alternative outcomes.

Even though decisions about resuscitation should recognize the importance of patients' self-determination it may sometimes be necessary to question patients' choices on the grounds of protecting well-being. First, a patient may be mistaken about the course of treatment that will actually achieve the end he or she desires. Even a competent patient may initially misunderstand the nature of alternative outcomes or their relationship to his or her values because of the complexity of the alternatives, the psychological barriers to understanding information, and so forth. Dissonance between the physician's and the patient's assessments of benefit point to the need for such steps as further discussion, reexamination of the patient's decisionmaking capacity, and reassessment of the physician's understanding of patient's goals and values; indeed, in some cases patients may even wish to evaluate their values and goals.

Second, decisions may have to be based on "well-being" because "self-determination" is not possible under the circumstances. Many patients for whom a decision not to resuscitate is indicated have inadequate decisional capacity, often due to their underlying illnesses. In these cases, providers and surrogates must assess whether resuscitation—like any other medical intervention—is or is not likely to benefit the patient. Of course, physicians face many of the same difficulties in deciding that patients do, and their attempts to assess "benefit" will not always lead to clear conclusions.

**Equity.** The Commission has concluded previously that "society has an ethical obligation to ensure equitable access to...an adequate level of care without excessive burdens."<sup>42</sup> Should resuscitation always be considered part of the "adequate level"? Resuscitation decisions are currently made with

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Mark Siegler, *Does "Doing Everything" Include Cpr?*, 12 HASTINGS CTR. REP. 27 (Oct. 1982); John J. Paris, *Comfort Measures Only For "DNR" Orders*, 6 CONN. MED. 195 (April 1982).

<sup>42</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *SECURING ACCESS TO HEALTH CARE*, U.S. Government Printing Office, Washington (1983) at 4.

little regard to the costs incurred or to the manner in which costs are distributed, except when competent patients decide to include such considerations as a reflection of their own concern for family well-being or for distributional justice. The Commission heard from a number of people, however, who wondered if providers and others should consider whether the costs of resuscitation are warranted for those patients for whom survival is very unlikely and who would, in any case, suffer overwhelming disabilities and diseases.<sup>43</sup>

To determine whether cardiac resuscitation is a component of care that all hospitalized patients should have access to, the predicted value of this procedure would have to be compared with other medical procedures that generate comparable expenses and burdens. It is the Commission's sense that, at the moment, resuscitation efforts usually provide benefits that justify their cost, and thus resuscitation services generally should continue to be provided when desired by a patient or an appropriate surrogate. When, in a particular case, an attempt to resuscitate would clearly be against the patient's stated wishes or best interests, then the reason for not resuscitating does not arise from concerns for equitable use of societal resources, though it may incidentally help conserve them.

Of course, a more refined analysis of whether particular cases or categories of cases should be excluded under the

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<sup>43</sup> "[W]hether one month's additional cost of acute hospital care should or should not be incurred...is an important and relevant ingredient in the decisionmaking process...[W]e as a society must face the issue not of whether to preserve life but rather for how long." Letter from Joel May, Health Research and Educational Trust of New Jersey, to Joanne Lynn (May 11, 1982). "[T]he prolongation of life in hopeless situations must truly be viewed in the context of family resources and societal resources." Letter from Leo F. Greenawalt, President, Washington State Hospital Association, to Austin Ross, Vice-president, Virginia Mason Hospital, Seattle, WA (June 10, 1982). "Obviously, we must be very careful not to waste precious resources and money when it is to no avail." Letter from Dr. Ake Grenvik, Professor of Anesthesiology and Surgery, Univ. of Pittsburgh, to Joanne Lynn (March 30, 1982).

Proposals have been made that patients with advanced and irreversible diseases and organ system failures, including dementia, should not be offered resuscitation, principally because the expense and the necessary shifting of resources from other important uses are considered so disproportionate to the benefits. *E.g.*, in 1967 BBC-TV reported the following notice in a London hospital: "The following patients are not to be resuscitated: very elderly, over 65, malignant disease. Chronic chest disease. Chronic renal disease." In the controversy that ensued the physician who posted the notice received public support from a number of his colleagues. Louis Lasagna, *Physicians' Behavior Toward the Dying Patient*, in Orville Brim, Jr., *et al.*, eds., *THE DYING PATIENT*, Russell Sage Foundation, New York (1970) at 87.

**Table 2:****Resuscitation (CPR) of Competent Patients—Physician's Assessment in Relation to Patient's Preference**

Physician's Assessment	Patient		Patient
	Favors CPR'	No Preference	Opposes CPR*
CPR Would Benefit Patient	Try CPR	Try CPR	Do not try CPR: review decision**
Benefit of CPR Unclear	Try CPR	Try CPR	Do not try CPR
CPR Would Not Benefit Patient	Try CPR; review decision**	Do not try CPR	Do not try CPR

\* Based on an adequate understanding of the relevant information.

\*\* Such a conflict calls for careful reexamination by both patient and physician. If neither the physician's assessment nor the patient's preference changes, then the competent patient's decision should be honored.

definition of "adequate care" might be attempted. A controversial step would be to attempt to eliminate resuscitations that, while advancing a patient's interests or in accord with a patient's preferences, sustained a very marginal existence at a very high cost.<sup>44</sup>

However, the negative consequences of trying to discern such categories in a workable way provide strong arguments against adopting such policies. Explicitly precluding resuscitation for some categories of patients would almost certainly be insensitive to their values, denigrating to their self-esteem, and distressing to health care professionals.<sup>45</sup> Also, the uncertainties over prognosis with resuscitation for each individual patient would make it very difficult to write clear and workable categories. It is unlikely that the costs incurred by marginally beneficial resuscitation are so substantial that their reduction should be a higher priority than the reduction of other well-documented kinds of wasteful or expensive and marginally beneficial care.<sup>46</sup>

### Guidance for Decisionmaking

**Competent Patients.** When a competent patient's preference about resuscitation and a physician's assessment of its

<sup>44</sup> Resuscitation efforts themselves commonly cost over \$1000 and usually entail substantial derivative costs in caring for the surviving patients who suffer side effects.

<sup>45</sup> See pp. 97-98 *supra*.

<sup>46</sup> See pp. 98-100 *supra*. See also, SECURING ACCESS TO HEALTH CARE, *supra* note 42, at 185-90.

probable benefits coincide, the decision should simply be in accord with that agreement (see Table 2). When a physician is unclear whether resuscitation would benefit a patient but a competent patient has a clear preference on the subject, the moral claim of autonomy supports acting in accord with the patient's preference. Self-determination also supports honoring a previously competent patient's instructions.<sup>47</sup>

Some patients, although apparently competent, do not express a preference for one course over another. Such patients may not have reached a judgment in their own minds (saying, for example, merely, "whatever you think, Doc") or they may simply be unwilling to articulate a view one way or the other. Provided that the patient's unwillingness to declare a view at the moment does not reflect incompetence, the physician should not immediately ask family members to substitute their views for those of the patient, but should instead seek to involve family members in other useful ways (assuming that the patient does not object to their participation), comparable to the roles sometimes played by clergy, nurses, and other professionals. First, the family may be able to facilitate communication between the hospital staff and the patient, making sure that the issues to be addressed have been understood and helping to overcome any barriers to understanding. Second, they may be able to help the patient to make his or her preferences known to the care giving professionals. Ideally, these efforts will lead the patient to express a preference for or against resuscitation.

Of course, it is necessary to have some operative policy while a patient is being encouraged to make a choice, and patients should be informed about what that will be. Until the person expresses a clear preference, the policy in effect should be based on the physician's assessment of benefit to the patient; when it is unclear whether an attempt at CPR would be

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<sup>47</sup>For a discussion of the rationale and procedures for prior directives see pp. 136-53 *supra*. The weight assigned to such written or oral instructions—in other words, the extent to which a presently *incompetent* patient is treating as expressing a *competent* preference through an advance directive—depends on the facts of each case.

If a patient while competent anticipated a later incompetence and medical condition, understood what should be entailed in a decision for or against resuscitation, and made firm and explicit statements regarding the decision, then those directives should be honored provided there is no reason to think that the patient's choice had changed or would have changed. Advance directives can be in the form of written instructions or of statements made to health care professionals, members of a patient's family, or others.

The physician will have to assess whether the patient adequately understood the ramifications of the choice and clearly stated his or her decision.

beneficial, there" should be a presumption in favor of trying resuscitation.

When physicians and patients disagree about resuscitation, further discussion is warranted. Each can explain the basis of his or her position and why the other person's judgment seems unwarranted or mistaken. In some cases, consultation with experts may be helpful to resolve doubts about the facts of the case. Together, such steps often produce agreement.

Although disagreement in no way implies that a patient is incompetent, it will often be appropriate for the physician, and perhaps consultants or an advisory committee, to reexamine this issue if discussion does not lead to agreement between patient and physician—and also for the physician to reexamine his or her own thinking and to talk with advisors about it. The serious consequences of the patient's choice—which may include severe disability if resuscitation is tried or death if it is foregone—demand that this process be carried out with care. Once the adequacy of the patient's decisionmaking capacity is confirmed, then the patient's preference should be honored on grounds of self-determination, especially since the choice touches such important subjective values.

If a physician finds the course of action preferred by a competent patient to be medically or morally unacceptable and is unwilling to participate in carrying out the choice, he or she should help the patient find another physician. Indeed, such a change should be explored even when the physician is prepared to carry out the patient's wishes despite an initial disagreement if the difference of opinion created barriers to a good relationship.

**Incompetent Patients.** Decisionmaking for incompetent patients parallels that for competent ones except that when a physician or surrogate decisionmaker believes that resuscitation is not likely to benefit the patient, there are some additional constraints<sup>48</sup> (see Table 3). Whenever a surrogate and physician disagree, as when only one thinks that resuscitation is warranted, the case should receive careful review, initially through intrainstitutional consultation or ethics committee. Urgent situations, however, or disagreements that are not resolved in this way should go to court. During such proceedings, resuscitation should be attempted if cardiac arrest occurs.

The review entailed will vary. When a physician feels that there is no benefit, a surrogate may either concur after additional consultations or may find another physician, espe-

<sup>48</sup> See Comment, *Medico-Legal Implications of "Orders Not to Resuscitate,"* 31 *CATH. U. L. REV.* 515,535(1982).

<sup>49</sup> See pp. 160-70 *supra*.

**Table 3:****Resuscitation (CPR) of Incompetent Patients—Physician's Assessment in Relation to Surrogate's Preference**

Physician's Assessment	Surrogate		Surrogate Opposes CPR'
	Favors CPR'	No Preference	
CPR Would Benefit Patient	Try CPR	Try CPR	Try CPR until review of decision*'
Benefit of CPR Unclear	Try CPR	Try CPR	Try CPR until review of decision**
CPR Would Not Benefit Patient	Try CPR until review of decision**	Try CPR until review of decision**	Do not try CPR

\* Based on an adequate understanding of the relevant information.

\*\* See pp. 246-48 *infra*.

cially if a consulting physician disagrees with the doctor who initially attended the patient. When a surrogate opposes resuscitation that a physician feels is beneficial, discussing the reasons in an impartial setting may uncover erroneous presuppositions, misunderstandings, or self-interested motives and allow for a resolution that is in the patient's best interests. When a surrogate is ambivalent, confirmation of the expected value of resuscitation by a consultant may be persuasive; continued ambivalence may signal the need for a new surrogate. The hospital will have to be able to ensure that helpful and effective responses are provided for these various situations.

If a patient has no surrogate and orders against resuscitation are contemplated, at least a *de facto* surrogate should be designated. When the physician feels that the decision against resuscitation is quite uncontroversial, a consultation with another physician, professional staff consensus, or agreement from an institutionally designated patient advocate can provide suitable confirmation of the initial judgment. Decisions like these are made commonly and should be within the scope of medical practice rather than requiring judicial proceedings. Decisions that are more complex or uncertain should occasion more formal intrainstitutional review and sometimes judicial appointment of a guardian.

**Judicial Oversight.** As made clear throughout this Report, the Commission believes that decisionmaking about life-sustaining care is rarely improved by resort to courts. Although

physicians might want court adjudication when they believe that a patient's decision against resuscitation is clearly and substantially against his or her interests, courts are unlikely to require people to submit to such an intrusive and painful therapy unless they conclude that the patient is incompetent.<sup>50</sup> Some form of review mechanism within a hospital is generally more appropriate and desirable for such disagreements. The courts are sometimes the appropriate forum for serious, intractable disagreements between a patient's surrogate and physician, however. When intrainstitutional procedures have not led to agreement in such cases, judges may well have to decide between two differing accounts of a patient's interests.

### Institutional Policies

If DNR decisions always took place when there was time for deliberation and data gathering and only a few people were involved, little more would need to be said. However, potential rescuers often have limited personal knowledge of the patient and, once cardiac arrest occurs, there is no time or deliberation. Furthermore, too many people are involved to permit everyone to be brought into the decisionmaking process. In response to the special problems that attend resuscitation attempts,<sup>51</sup> formal and informal policies have been developed to govern decisionmaking and communication of decisions within institutions.<sup>52</sup> The Commission believes that institutional policymakers need to address three basic concerns.

**The Need for Explicit Policies.** Hospitals should have an explicit **policy**<sup>53</sup> on the practice of writing and implementing

<sup>50</sup> See pp. 30-32, 39 *supra*. To stop recourse to the courts from becoming routine, the courts could decline DNR cases involving competent patients unless the circumstances were unusual. Particularly to be discouraged are cases in which physicians or hospitals desire court review of decisions that are actually uncontroversial, simply to shield themselves from liability.

<sup>51</sup> See pp. 235-36 *supra*.

<sup>52</sup> See generally Theodore R. LeBlang, *Does Your Hospital Have a Policy for No-Code Orders? Part 2*, 9 LEG. ASPECTS MED. PRACTICE 5,6-7 (April 1981); No Code Subcommittee of the Medical-Legal Interprofessional Committee, sponsored by the San Francisco Medical Society and the Bar Association of San Francisco, *Final Report*, July 20, 1982, reprinted in Appendix I pp. 494-97 *infra*. Miles, Cranford, and Schultz, *supra* note 40; *No-Code Orders*, 7 L. REP. 1 (March 1982); Aileen McPheil *et al.*, *One Hospital's Experience With a "Do No Resuscitate" Policy*, 125 CANADIAN MED. ASSOC. J. 830 (1980).

<sup>53</sup> Concerns about resuscitation practices are not, however, limited to the hospital settings. "All information available on CPR deals with hospital settings. I am concerned about long term care facilities because the population is different and I feel their age and condition preclude mandatory blanket CPR...The usual policy is to let the nurse

DNR orders.<sup>54</sup> In the absence of an established mechanism, decisionmaking might fail to meet the requirements of informed consent or the responsibility for making and carrying out the decision might be assigned to an inappropriate person.<sup>55</sup> Physicians should be allowed to decide to stop a resuscitation effort in progress, although the authority of inexperienced or untrained individuals to make such a decision should be limited. Moreover, without a deliberate process for reaching decisions about resuscitation, legitimate options may never receive the full consideration of patients, physicians, and other involved parties. Consultations with the nursing staff might well be required.<sup>56</sup>

Hospital policies should require appropriate communication with patients about the resuscitation decision. DNR policies should require that any such order be written in a patient's chart with sufficient documentation of the supporting reasons. Physicians may also need to review the order periodically, though changing a DNR order due to a revised assessment of its likelihood to benefit the patient will probably be rare.

**The Need for Balanced Protection of Patients.** Hospital policies should recognize that DNR orders can be justified by being in accord with a patient's competent choice or by serving the incompetent patient's well-being. Such policies can serve to remind staff that reflex resuscitation efforts applied to all patients not only denies people the ability to control the course of their own lives (a legal wrong) but also sometimes inflicts actual harm on individuals. At the same time, hospital policies on resuscitation should aim to protect the interests of incompetent patients (who are least likely to be able to protect

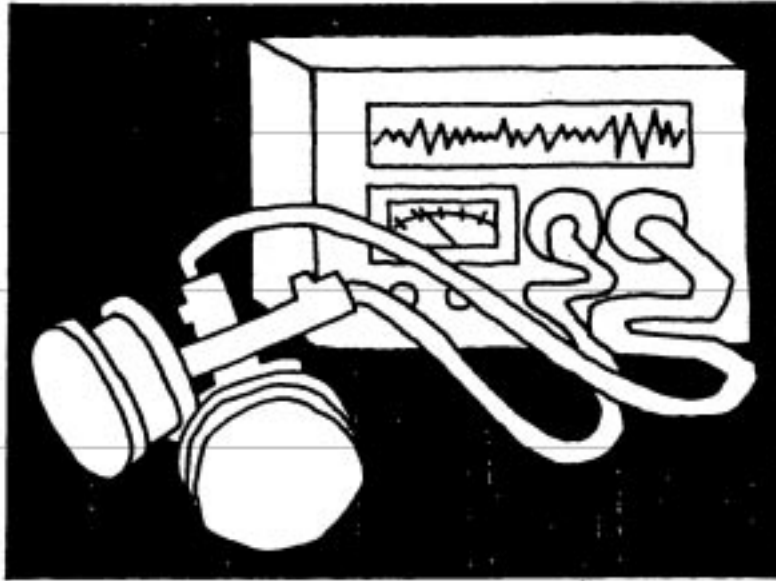
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on the scene make a decision." A nurse quoted in Jane Greenlaw, *Orders Not to Resuscitate: Dilemma for Acute Care as Well as Long-Term Care Facilities*, 10 L. MED. & HEALTH CARE 29 (Feb. 1982).

<sup>54</sup> Since the principles governing decisionmaking about resuscitation are the same as for decisionmaking generally, such a policy might well include other decisions. Indeed, at Northwestern Memorial Hospital near Chicago, the policy covers all orders that preclude "the use of extraordinary or 'heroic' measures to maintain life." Reprinted in Appendix I pp. 511-13 *infra*. The policy at the University of Wisconsin's hospital covers decisionmaking generally. Reprinted in Appendix I pp. 513-17 *infra*.

<sup>55</sup> Mila Aroskar, Josephine M. Flaherty, and James M. Smith, *The Nurse and Orders Not to Resuscitate*, 7 HASTINGS CTR. REP. 27 (Aug. 1977); Leah Curtin, *CPR: Optimal Care vs. Maximal Treatment*, 10 SUPERVISOR NURSE 16 (Aug. 1979).

<sup>56</sup> "The physician must discuss his/her opinion and decision concerning both competence and DNR orders with the nursing staff from the outset and frequently thereafter." *Guidelines: Orders Not to Resuscitate*, Somerville Hospital, Mass., Memorandum #80-7, (Feb. 27, 1980). reprinted in Appendix 1, pp. 507-10 *infra*.



themselves), by favoring resuscitation, for example, when the deliberations about a particular patient have not yet been completed. Indeed, for incompetent patients, the policy should make it clear that the presumption in favor of resuscitation can only be overcome by a finding that resuscitation offers a patient no significant overall benefit or that the patient would clearly not have wished to be resuscitated under the circumstances. Especially in treatment areas such as intensive and cardiac care units, where many patients are at risk for cardiac arrest, policies should try to reduce the number who are resuscitated without appropriate prior deliberation.

By encouraging prior deliberation, the policies can also reduce the need some now see for "partial resuscitation," in which less than a full effort to resuscitate the patient is made because the attending physician never made a clear decision or because it was thought important to placate or comfort family members or hospital staff.<sup>57</sup> Success at resuscitation is rare enough when all efforts are expended, so such limited efforts are usually doomed from the start. Thus, "partial codes" become a kind of dishonest effort that needs to be justified by

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<sup>57</sup> [The use of partial codes] represents a tempting act of rationalization that is neither medically nor ethically sound. At best it is a waste of time and a failure to face reality and hard decisionmaking; at worst, it is an ethical fraud. I doubt that "partial codes" can be justified, but I see them frequently...  
John Goldenring, Letter, 300 *NEW ENG. J. MED.* 1057, 1058 (1979).

reasons stronger than merely the providers' discomfort in discussing DNR decisions.<sup>58</sup>

Any DNR policy should ensure that the order not to resuscitate has no implications for any other treatment decision. Patients with DNR orders on their charts may still be quite appropriate candidates for all other vigorous care, including intensive care.<sup>59</sup> Thus, orders regarding supportive care that is to be provided should be written separately.

Finally, to respond to the conflict that professional staff feel and yet to protect patients' interests in preserving both personal choice and well-being, institutions may wish to provide guidelines for situations in which a patient with a DNR order suffers cardiac arrest as a result of a medical intervention.<sup>60</sup> Although the subject has not been well studied, patients whose cardiac arrest occurs under such circumstances may well have a better chance of successful resuscitation, since the arrest is more likely to have occurred in closely monitored settings and from fairly reversible causes.<sup>61</sup> Policies might

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<sup>57</sup> There are many forms of "codes": slow code, chemical code, partial code. In my opinion, there is a time and a place for a limited code. Recently, I took care of an Hassidic rabbi. Because Hassidic Jews are 'very uncomfortable with DNR orders or anything that might hasten death, such a course of action was not acceptable to him. We decided that it was reasonable to make some effort to resuscitate, but not necessarily all efforts. Setting such a limit on resuscitative efforts was acceptable to the family. In this case we decided that it would not be acceptable to intubate him nor to leave him on a respirator. So, there is a way of giving what I will call a partial code—some attempt at resuscitation, but not applying everything known to man.

Michael Van Scoy-Mosher, *supra* note 41, at 15 (citation omitted). *See also* Marc D. Basson, *Introduction: The Decisive to Resuscitate--Slowly*, in Marc D. Basson, Rachel Lipson, and Doreen Ganos, eds., *TROUBLING PROBLEMS IN MEDICAL ETHICS*, Alan R. Liss, Inc., New York (1981) at 117; Paris, *supra* note 41.

<sup>59</sup> The no-resuscitation status is compatible with maximal and aggressive medical care, and does not imply that current treatment will be withdrawn or that additional therapy will not be initiated. Decisions as to the choice and level of treatment should be based on continued evaluation of clinical information and the patient's condition regardless of a do-not-resuscitate order.

Miles, Cranford, and Schultz, *supra* note 40, at 661. *But see* David Bar-Or, *The Do Not Resuscitate Order* (Letter), *97 ANNALS INT. MED.* 280 (1982); George Spelvin (pseudonym), *Should a 'No-Code' Be a Death Sentence?*, *MED. WORLD NEWS* 64 (April 27, 1981).

<sup>60</sup> *See* pp. 94-95 *supra*.

<sup>61</sup> In one series of 48 cases, two patients whose cardiac arrests resulted directly from biomedical procedures survived resuscitation to go home. Arena, Perlin, and Turnbull, *supra* note 21, at 734. In

require specific discussion of this issue in certain settings or acknowledge that sometimes the DNR order is justifiably overridden.

**The Need for Internal Advice and Review.** Hospital policy should provide for appropriate resolution of disagreements on resuscitation decisions. Intrainstitutional review of decisions that raise persistent disagreements has been shown to be very effective in some institutions, both for clarifying the issues in a case and for achieving compassionate and responsive resolution of the issues.<sup>62</sup>

Hospital staff should not be forced to undertake an action they regard as unethical. All staff should have access to the review mechanism for advice and for clarifying the issues. If that proves unsatisfactory, every effort should be made to have other staff from within the institution care for the patient. Barring that, if the person's medical condition allows it, transfer to another institution may be appropriate. Hospital staff should try, however, to avoid becoming so inflexible that they are unable to respond comfortably to appropriate orders, whether for or against resuscitation. Hospitals have a responsibility in staff education and recruitment to provide sufficient staff resources and flexibility.

Cases should be brought to court when it is necessary to decide whether a patient is competent to make a decision not to be resuscitated or, if not competent, which decision serves the patient's interests. Very few, if any, cases should be brought to court solely to protect the hospital from the unlikely prospect of liability.

## Policy Implications

**Law.** If hospitals ensure that decisionmaking practices are reasonable and that internal review and advice are readily available, decisions concerning resuscitation will seldom need to come before courts. Adequate protection of the interests of incompetent patients should probably be achieved by holding the physician and institutional officials responsible for obtaining appropriate review when a surrogate's decision seems erroneous and for referring to court those disputes that remain unresolved after these internal processes. Also, each state should have some court with clear jurisdiction over these

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particular, policies should encourage consideration of this potential dilemma when especially risky procedures are being discussed with a patient who otherwise would have a DNR order.

<sup>62</sup> Comment, *Medico-Legal Implications of "Orders Not to Resuscitate," supra* note 48, at 518 n.9; Testimony of Dr. Mitchell Rabkin, transcript of 10th meeting of the President's Commission (June 4, 1981) at 65-69.

cases and with power to decide that certain patients' conditions might warrant DNR orders.

In states and localities in which prosecutors have indicated that they do not condone DNR orders and that they might bring criminal charges against physicians or hospitals that use such policies,<sup>63</sup> the public, as well as health care professionals and institutions, should defend the practice and make it clear that nonresuscitation is being used thoughtfully and correctly.

**Federal Involvement.** The Federal government is a significant financier and provider of health care. In its role as funder the government must be careful not to link reimbursement rates to resuscitation status. Such linkage has arisen once in the response of providers to a directive from the California State Health Department. This "Field Instruction Notice" stated: "a terminally ill patient with a 'no code' status and those care needs limited to making the person as comfortable as possible and free of pain, while preserving that person's personal dignity to the extent possible, would not meet the criteria for acute hospitalization." The response of California practitioners to what amounts to an automatic review of the appropriate Medi-Cal reimbursement level (which was very likely to be downgraded from hospital level to skilled nursing facility) was apparently to issue few DNR orders on Medi-Cal patients in the hospital. This was an unfortunate and foreseeable effect of what is, on its face, a quite reasonable Medi-Cal policy and illustrates why such review should use other, more fixed, indices of patients' needs.<sup>64</sup> The existence or nonexistence of a DNR order does not in itself signify whether other care is appropriate or inappropriate; intensive efforts to support a seriously ill patient are not rendered inappropriate simply because attempts to revive the patient would be unwarranted in the event of a cardiac arrest.

As providers of health care, the various Federal agencies should develop policies and practices in accord with those outlined above. For the Veterans Administration (VA), the closest to an official policy statement on DNR orders is found in a Chief Medical Director's letter<sup>65</sup> of November 20, 1979, that focuses on the fact that a "no code" order can violate the conscience of a nurse or other provider who was not a party to

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<sup>63</sup> See notes 30, 31, and 34 *supra*.

<sup>64</sup> *Level of Care Determination on Acute Care Patients, and How it Relates to a Terminal Patient with a "No-Code" status*, memorandum. California Dept. of Health Services, reprinted in Appendix I, pp. 535-36 *infra*.

<sup>65</sup> Letter from James C. Crutcher, VA Chief Medical Director, to Directors, VA Medical and Regional Office Centers, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics Regarding "No Code" and Other Similar Orders (Nov. 20, 1979), reprinted in Appendix I, pp. 518-19 *infra*.

the original decision and who may disagree with it. The response was to leave the decision to the judgment of "the health care provider caring for the patient at the time of cardiopulmonary arrest."<sup>66</sup> To permit that provider to make a sound judgment, the letter encourages adequate documentation in progress notes of "the diagnosis, the prognosis, the patient's wishes (when known), the wishes of the family members and the recommendations of the attending staff (not resident) physician."<sup>67</sup> Some VA hospitals do not follow this policy; sometimes different services within a given hospital follow differing policies; and sometimes a VA hospital follows this policy while a neighboring hospital run by medical school that the VA hospital is closely affiliated with has a policy more in line with the one recommended in this chapter. The Commission recommends that the VA revise its policy in line with the Commission's analysis in this Report or encourage individual hospitals to do so.<sup>68</sup> At the very least the policy should be adjusted to ensure that patients' interests and preferences become its central focus.

Medical treatment facilities operated by the Department of Defense currently address the DNR issue in quite disparate ways. There seems to have been a general reluctance to allow DNR orders, perhaps stemming from such policies as the Army Surgeon General's letter<sup>69</sup> of December 13, 1977, which seems to say that, except when mandated under natural death acts, orders may never be given not to resuscitate a patient. Some individual military hospitals are in the process of writing policies.<sup>70</sup> Some Navy and Army physicians advocate revision of the overall policies to ensure that DNR orders in military facilities are congruent with good ethical practice and law.<sup>71</sup> The Commission endorses such a revision and the introduction of clear policy that encourages correct use of DNR orders and of CPR.

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<sup>66</sup> *Id.* at 519.

<sup>67</sup> *Id.*

<sup>68</sup> Although involving discontinuation of a respirator rather than CPR, the VA was recently sued for refusing to discontinue a life-sustaining treatment. *Foster v. Tourlettotte*, No. CV81-5046 (S.D. Cal. May 27, 1982); Dorothy Townsend, *Court Upholds Man's Plea for Cutoff Life Support*, L. A. TIMES, Oct. 24, 1981, at A-1.

<sup>69</sup> See Appendix I, pp. 520-22 *infra*.

<sup>70</sup> For example, the National Naval Medical Center in Bethesda, Md., has written a policy that is substantially in conformity with the recommendations in this chapter.

<sup>71</sup> See, e.g., Letter from Dr. James G. Zimmerly, J.D., M.P.H., Col, MC, USA, to LTG Berhard T. Mitemeyer, MC, USA, *Termination of Life Support and Entering of No-Code Orders* (April 1, 1982), reprinted in Appendix I, pp. 522-29 *infra*.

The Public Health Service, in its direct provision of health services at the Clinical Center of the National Institute of Health, has adopted a brief and quite acceptable policy.<sup>72</sup> There seems to be no overall policy regarding other aspects of Public Health Service health care delivery, though practices may well be regulated at a local level.

**Hospital Accreditation.** Much of medical practice is governed by independent and private organizations, which, like the government, bear a responsibility to encourage sound decisions regarding resuscitation. Organizations that accredit health care institutions do not now mandate any policy or education on the subject of resuscitation beyond the requirement of the Joint Commission on the Accreditation of Hospitals that special care unit staff know the medical procedures involved and that all orders about patient care be written ones.<sup>73</sup> At the least, in order to be accredited hospitals should be required to have a general policy regarding resuscitation—preferably one that addresses the three basic needs discussed in this chapter.

**Professional Education.** Similarly, physicians and hospital staff should be educated concerning resuscitation decisions. The policymakers and organizations responsible for medical school accreditation, standardized examinations for medical students, physician and nurse licensure, and physician specialty certification should adopt appropriate training and education requirements.

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<sup>72</sup> Policy and Communications Bull. No. 82-4, *Orders Not to Attempt Cardiac Resuscitation*, National Institutes of Health Clinical Center, (July 12, 1982), reprinted in Appendix I, pp. 519-20 *infra*.

<sup>73</sup> Joint Commission on Accreditation of Hospitals, **ACCREDITATION MANUAL FOR HOSPITALS**, Chicago (1981 ed.) at 184.

