chapter 3

Legal Issues

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Chapter 3

Legal Issues*

This chapter discusses the development and current state of case law and statutes related to decisions about the use of life-sustaining technologies for individual patients. It begins with and is centered around the concepts of self-determination, the patient's right of privacy, the patient's right to refuse unwanted medical treatment, and the implications of these concepts for patients with various levels of decisionmaking capacity. Some persons who reviewed the chapter for OTA suggested that it focuses too greatly on these concepts and should give more emphasis to patients' rights to request and receive treatment and the consequent obligation of society to provide it. These ideas are discussed in chapter 2. A related policy issue—access to care—is discussed throughout the report. This chapter emphasizes the concepts of self-determination, the patient's right of privacy, and the patient's right to refuse treatment because of their greater role in the development of case law and statutes related to decisions about life-sustaining technologies for individual patients.

INTRODUCTION

Laws generally define or reflect what society considers to be the limits of morally appropriate and acceptable behavior. In a complex and technologically advanced society, there are continuous challenges to the foundations that underlie the law. When moral norms and standards of behavior are uncertain, or in conflict, the case law and statutes in different jurisdictions may reflect this diversity of opinion. When consensus has been reached, the case law and statutes of most jurisdictions tend to be similar.

Existing case law and statutes that address medical decisionmaking reflect both consensus and divergence. Societal consensus is reflected in the generally accepted legal principle that adult patients who can understand and appreciate the likely consequences of various treatment options (including nontreatment) are entitled to make their own treatment decisions. Adults are legally presumed to be capable of consent or refusal unless a court declares otherwise.

Although these patient-empowering principles stand firmly etched in our case law and statutes, there is tremendous uncertainty and anxiety among health care providers about what their legal obligations to patients are and what their permissible range of action is. One reason for this uncertainty is that some patients are not capable of making treatment decisions for themselves due to temporary or permanent mental impairment. Case law and statutes in different jurisdictions give different answers to the questions of who is to make decisions, and on what basis, for these patients. A second reason for uncertainty is that technological progress has outpaced the legal process, thus raising questions about how existing case law and statutes apply to new technologies.

Yet another reason for uncertainty is that many health care providers are not aware of or do not fully understand the legal principles, case law, and statutes relevant to medical decisionmaking. This situation is not surprising. Although the law concerning patient's rights has evolved over a long period of time, the first court case to draw na-

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[*] This chapter is based on several OTA contract reports: Lisa J. Raines, J.D. "Life-Sustaining Technologies for Elderly People: The Legal Issues" (January 1987); Connie Zuckerman, J. D., "Life-Sustaining Technology and the Elderly: The Legal Issues" (June 1986); and George J. Areas, J.D., M. P.H., and Leonard H Glantz, J.D., "Withholding and Withdrawing of Life-Sustaining Treatment for Elderly Incompetent Patients: A Review of Court Decisions and Legislative Approaches" (December 1985).

tional attention to the legal issues involved in withholding or withdrawing life-sustaining treatment from a comatose or terminally ill patient was decided in 1976–little more than a decade ago. Since then, courts in different States have handed down rulings that are contradictory in cases that seem similar from the point of view of health care providers. Many of the contradictions have been resolved as lower court rulings have been appealed and sometimes overturned by higher courts, and the areas of agreement and consistency among different States are growing. Nevertheless, it is difficult for busy health care providers to keep up with changing case law and statutes. It is also difficult for nonlawyers—and even for lawyers at times—to understand the implications of existing case law and statutes for individual treatment decisions (62).

This chapter describes the legal principles, case law, and statutes related to decisions about the use of life-sustaining medical technologies—particularly as they apply to elderly people. It describes the development of the law and its present state, discusses areas of controversy and criticism, and considers the implications of relevant legal principles for patients and caregivers. The chapter does not discuss statutes or government regulations that pertain to reimbursement for medical care or licensing and certification of health care providers and facilities—both of which are discussed in other chapters of the report.

LEGAL CONCEPTS THAT EMPOWER INDIVIDUAL PATIENTS

The Common Law Right of Self-Determination

American case law has long recognized an individual's right to make certain personal choices. As early as 1891, in *Union Pacific Railway Co. v. Botsford,* the U.S. Supreme Court endorsed the fundamental right of self determination:

> No right is held more sacred or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraints or interference by others, unless by clear and unquestionable authority of law (110).

The right of self determination was first clearly applied to medical decisionmaking in a 1914 opinion by Justice Cardozo in the New York case *Schloendorff v. New York Hospital:*

> Every human being of adult years and sound mind has the right to determine what shall be done with his own body (101).

A strong and explicit restatement of this right appeared in the 1960 Kansas case *Natanson v. Kline:*

> Anglo-American law starts with the premise of thoroughgoing self determination. It follows that each man is considered to be master of his own body and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment (85).

The individual's right of self-determination is now firmly rooted in American case law and statutory law. It is one of the basic concepts underlying a patient's right to be informed about and to consent to or refuse proposed medical treatments.

The Constitutional Right of Privacy

The concept of a constitutional right of personal privacy was first articulated in an 1890 Harvard Law Review article in which Louis Brandeis and Samuel Warren discussed the importance of the "principle of . . . an inviolate personality" (1 14). Later, while serving on the U.S. Supreme Court, Justice Brandeis further championed this notion, when he wrote in a dissenting opinion that has since become the prevailing view:

> The makers of our Constitution recognized the significance of man's spiritual nature, of his feelings, and of his intellect. They knew that only part of the pain, pleasure, and satisfactions of life are to be found in material things. They sought to protect Americans in their beliefs, their thoughts, their emotions and their sensations. They conferred, as against the government, the right to be let alone–the most comprehensive of rights and the right most valued by civilized men (88).

The "right to be let alone, " also called the "right of privacy, " is not explicitly articulated in any of the provisions of the Constitution. It is generally considered to emanate from the penumbra of several of the guarantees of the Bill of Rights, including: the First Amendment right of association, the Fourth Amendment right to be secure against unreasonable searches and seizures, the Fifth Amendment right against self-incrimination, the Ninth Amendment protection of rights not explicitly enumerated in the Constitution, and the Fourteenth Amendment guarantees of liberty.

In recent years, the U.S. Supreme Court has held that the right of privacy protects individuals from governmental intrusion in fundamental and personal medical decisions. This right has been the constitutional basis used by the Court to protect private individual decisions ranging from the use of contraceptives, in Griswold *v. Connecticut,* 1965 (40); to the termination of pregnancy through abortion, in *Roe v.. Wade,* 1973 (96); to the refusal of psychotropic medications by those confined in mental institutions, in Mills v. *Rogers,* 1982 (82).

The Supreme Court has not addressed the question of whether the constitutional right of privacy includes a right to refuse life-sustaining medical treatment. Several State courts have held that it does, however. In 1976, the New Jersey Supreme Court held in *In re Quinlan* that the right of privacy "is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions" (52).

Eighteen months later, in *Superintendent of Belchertown State School v Saikwicz (109),* the Massachusetts Supreme Judicial Court concurred that the right of privacy includes a right to refuse life-sustaining medical treatment. Since the *Saikewicz* case, several other courts have also permitted patients to refuse life-sustaining treatment as an exercise of their right to privacy (see, for example, *In re Colyer,* 1983 [45]).

Neither the constitutional right of privacy nor the common law right of self-determination is absolute. Generally, as discussed later in this chapter, several societal interests have been found to potentially override these rights. It is rare that these state interests are so compelling as to trump the patient decision, however, and in most cases, the right of privacy and the right of self-determination support the ability of patients to make personal medical decisions (118).

INFORMED CONSENT TO TREATMENT

Development of the Doctrine of Informed Consent

Early American common law (and medieval English common law from which our legal traditions are derived) considered any harmful or offensive nonconsensual touching a "battery" for which monetary damages could be sought in a court of law. Physicians' efforts to heal patients through physical contact such as surgery were considered "touching." A physician who did not obtain a patient's consent prior to the touching could be held liable for battery, even if the physician had performed an appropriate procedure and had done so carefully (118).

Although a physician was not permitted to obtain a patient's consent through deceptive methods, he or she was not required to give the patient more than a superficial description of the impending procedure and its likely consequences. The law at first focused narrowly on the fact of a nonconsensual "touching" or intervention, rather than on whether the patient truly understood what was being proposed. Even in the famous 1914 *Scholondorff* case (101), in which Justice Cardozo extolled the right of adults to determine what is done with their own bodies, the court was not concerned about the information that individuals needed to exercise this right (118).

The common law right of self-determination means little, however, if' health care providers have no obligation to disclose information necessary for patients to thoughtfully exercise the right. The patient's need for information is especially acute in the case of new treatments and procedures that not only present more options and benefits but also are more complex and may be associated with greater risk.

In the late 1950s, the physician's legal duty to obtain a patient's consent was broadened to include an obligation to disclose relevant information so that a patient could make an intelligent decision as to whether to give or withhold consent to treatment. If the doctor obtained a patient consent without first adequately explaining the procedure, he or she could avoid liability for battery (since the "touching" was technically consensual) but still be liable for medical malpractice (1 18). (Medical malpractice is a form of negligence defined in the law as conduct that falls below the acceptable professional standards and causes injury to the patient.) If a patient would have withheld consent had he or she known all of the relevant facts, then any injury resulting from the treatment could result in' a judgment of malpractice.

Standards for Informed Consent

The first case to use the phrase "informed consent" publicly was the 1957 California case ***Salgo v. Stanford University Board of Trustees (99)***, but it was the landmark 1960 Kansas case ***Natanson v. Kline (85)*** that fully articulated the notion of a standard of care with regard to disclosure of information. The Kansas court, concerned about imposing too onerous a burden on physicians, limited the duty of physicians to inform to "disclosures which a reasonable medical practitioner would make under the same or similar conditions. " This standard, known as the "professional practice" or "reasonable physician" standard, has been adopted by the majority of States. Under this standard, the extent of appropriate disclosure is viewed as a medical question requiring a physician's expertise to answer. In malpractice litigation, when the professional practice standard is applied, the plaintiff must prove the prevailing standards of medical practice in the community by the testimony of a medical expert. (In Colorado, however, once the plaintiff shows a failure to disclose, it is the physician who must prove that his or her conduct conforms to community standards (see Hamilton v. Hare@ [411).

The professional practice or reasonable physician standard has been criticized for perpetuating the custom of many physicians of disclosing very little information before seeking a patient's consent. The ancient Hippocratic texts told physicians to "perform (duties) calmly, concealing most things from the patient while you are attending to him" (59). Some people believe that this view still infuses medical education and practice (63,64).

Three cases decided in 1972, ***Canterbury v. Spence (24); Cobbs v. Grant, (26);*** and ***Wilkinson v. Vesey*** (115), rejected the professional practice or reasonable physician standard and adopted a "reasonable patient" standard. In ***Canterbury v. Spence,*** the U.S. Court of Appeals for the District of Columbia declared:

> To bind the disclosure obligation to medical usage is to arrogate the decision of revelation to the physician alone. Respect for the patient's right of self determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves (24).

The court outlined a "reasonable patient" (or "materiality") standard requiring the physician to disclose all information that would be considered by a reasonable patient as material to the patient's decision. Materiality was to be judged not from the subjective perspective of a specific patient but rather from the objective perspective of "a reasonable person, in what the physician knows or should know to be the patient's position" (24).

In *Cobbs v. Grant (26),* the California Supreme Court also adopted the reasonable patient standard, noting that the effect of the professional practice rule had been to give physicians absolute discretion in making (or not making) disclosures. In *Wilkinson v. Vesey* (115), the Rhode Island Supreme Court held that "the patient's right to make up his mind should not be delegated to a local medical group, many of whom have no idea as to his informational needs. "

Some commentators consider the reasonable patient standard to be more progressive than the professional practice standard (37)77)) but the reasonable patient standard remains the minority rule. The principal difficulty with this standard is that it provides little guidance to the physician. What a reasonable patient would need to know is not always easy to determine, and physicians who have made judgments on this basis have later found that their decisions do not always coincide with a jury's evaluation. A major reason for this variance is the 20/20 hindsight of juries. A risk of serious injury is likely to appear far more material after the patient has suffered the injury than before. In 1980, in Woolley v. Henderson (117), a Maine court explicitly rejected the reasonable patient approach for this reason. Other courts have rejected the reasonable patient standard on grounds that medical expertise is required to answer questions about the adequacy of disclosure (see, for example, Bly v. *Rhoads*, 1976 [15]). Since 1972, the trend among courts that have considered the issue has been to adopt the professional practice standard (77,90).

Under either the reasonable patient or professional practice standard, it is generally agreed that in order to fulfill the obligation to inform, the physician must at least disclose the diagnosis, the prognosis, the proposed treatment, alternate treatments, the risks and benefits of all options, and the consequences of not intervening at all. The physician should also give the patient an opportunity to ask questions. Generally, the level of disclosure required to avoid malpractice liability is higher in those States adopting the reasonable patient standard than those adopting the professional practice standard.

Exceptions to the Informed Consent Requirement

Exceptions to the informed consent requirement have been recognized for four situations:

1. emergencies when the delay in treatment necessary to obtain a patient consent would result in significant harm to the patient,
2. unanticipated conditions that arise during surgery 'when obtaining consent would expose the patient to the risks of a second surgical procedure,
3 "therapeutic privilege" situations when a physician reasonably believes that the patient mental or physical well-being would be seriously threatened if he or she learned the information, and
4 wavier situations when the patient has clearly expressed a desire not to receive the information.

In the context of this report, it should be noted that exceptions to the consent requirement are frequently required in cases of unanticipated cardiac or respiratory arrest (emergencies). In addition, some people believe that elderly patients are more likely than younger patients to waive a full explanation of their diagnosis, prognosis, treatment options, and potential risks of treatment, This belief is based on evidence that elderly people are somewhat more likely than younger people to be satisfied with the amount of information they receive (90) and that, as a group, they generally have more deferential attitudes toward health care professionals and are more respectful of authority than younger people (65,87).

In practice, waivers of the informed consent requirement are often based on a tacit understanding between the patient and the health care provider rather than on the explicitly stated preference of the patient (61). To ensure that health care providers do not simply assume that elderly or other patients want to waive their right to informed consent, many commentators have suggested that such waivers should be explicitly stated by the patient and should be allowed only in situations where the provider has made clear his or her willingness to discuss the proposed treatment with the patient (6,61,80,90).

Practical Problems in Informed Consent

Disclosing and explaining information so that a patient's consent or refusal is truly informed is a process that requires time, patience, and an ability to communicate on the part of the physician or other health care provider. The fast pace and pressures of modern medical practice, particularly in hospitals, may leave health care providers with little time or inclination to explain complex medical technologies clearly to their patients or to discuss the risks and benefits of alternate treatments. Moreover, some commentators have noted that the educational experience in most medical schools and the process of professional socialization during internship and residency frequently do not prepare physicians to communicate effectively with patients about their illness, its treatment, and the associated risks, benefits, and alternatives (63,64). These problems are exacerbated when health care providers assume, sometimes without evidence, that a patient is not capable of understanding the explanation, or when a patient has a hearing or speech impairment that interferes with communication. Both situations arise more frequently with elderly patients than younger ones.

One study of medical decisionmaking in a hospital and an outpatient clinic (73) concluded that informed consent as it is envisioned in the law—a process in which a physician provides a patient with information and the patient then brings his or her personal preferences and values to bear on the information, makes a decision, and instructs the physician as to how to proceed—is largely absent from clinical practice. That study showed that patients were seldom given information about the risks and benefits of a proposed treatment before a decision about the treatment was made, They were almost never given information about alternate treatments. Some chronically ill patients—notably those on renal dialysis—were well informed about all aspects of their conditions and treatment, and outpatients were better informed than inpatients. However, most patients acquiesced passively in the physicians' treatment decisions without being informed as required by informed consent law.

According to the researchers, the divergence between informed consent as envisioned by the law and the decisionmaking practices observed in this study arises not only from the behavior of physicians but also from the apparent wishes, expectations, and behavior of patients:

> **Our findings suggest that even if doctors were acting in the way anticipated by law, decisionmaking would bear little resemblance to the legal model . . . . We have been struck by the fact that overwhelmingly, even when patients are given information about their treatment and treated as if they had decisional authority, they act in a passive manner. When asked, most patients seemed happy with the amount of information they were getting, and even when they wanted more, it was rarely in order to make decisions about treatment. Even when they said they wanted information to make treatment decisions, they often acted as if they would rather have the doctor decide. For the most part, patients were not very interested in much of what was told to them. Even when they were interested in the information, they still often acted as if the final decision ought to be left to the** doctor (73).

The researchers in this study suggest that the model of medical decisionmaking that underlies the doctrine of informed consent—i.e., that medical decisionmaking involves one or more discrete decision points at which the treatment options are clear and one can be selected—is invalid **in many clinical situations. In actuality, they say:**

> **Much of the decisionmaking that doctors engage in takes place at a preconscious level , . . Quite early in the process the physician reaches a diagnosis and a decision about the preferable treatment. Seldom does the doctor see a series of alternative possibilities. Rather, for each problem there typically exists a medically preferable treatment, not a series of alternatives from which a patient may choose. It does not seem to the doctor to be a decisionmaking process but simply a question of persuading the patient to accept proper treatment. The decision has been made—by the doctor (73).**

The model of medical decisionmaking that underlies the informed consent doctrine may be more relevant for some types of treatments, some treatment settings, and some patient populations than others. The model is most applicable for patients who have a single medical problem for which there are several treatment options (37,73). In contrast, for some critically ill patients receiving multiple treatments in an intensive care unit (ICU), the medical decisionmaking process may be virtually continuous because of the patient's unstable condition and the complex interaction of multiple illnesses and treatments, In such a situation, the model of medical decisionmaking that requires the patient to be informed and to consent to each decision may be almost impossible to apply. Similar situations may arise with some severely debilitated patients who require a series of decisions, each of which can have life -and death implications. Both types of decisionmaking situations arise with the medical treatments, treatment settings, and patient populations discussed in this report.

One practical question about informed consent law is the validity and necessity of written consent forms. Many observers point out that the goals of informed consent law are not fulfilled when a patient simply signs a preprinted form without prior communication between the patient and the health care provider about the risks and benefits of the proposed treatment, about alternate treatments, and about the patient wishes. Yet research and anecdotal evidence indicate that many health care providers act as if getting the patient signature on a consent form constitutes informed consent (37,61,63,73,90).

Legal experts point out that except when consent is needed for patient participation in a research protocol, a written consent form is not legally required (6,61). Moreover, a written consent form may not even constitute legal proof that informed consent has occurred (14,43,61 ,105). According to two observers, patients who have signed such a form may claim that they didn't really give informed consent:

> (Patients may claim), "I was nervous"; "I didn't understand because the doctor used big, technical words"; 'I was in such pain that I would do anything to get rid of it"; "They had already given me a shot so I wasn 't clearheaded"; "The nurse handed me this piece of paper at the last minute and I signed it without even looking at it ." Such claims are likely to carry extra weight in the mind of a jury that is contemplating the plight of an injured older patient (61).

Although signed consent forms may not constitute proof that informed consent was obtained, they generally create a legal presumption that it was, and shift the burden of responsibility to the patient to prove that it was not (61).

Despite questions about the legal necessity and validity of written consent forms, most hospitals, nursing homes, and other health care facilities require such forms, particularly for surgical and other procedures that are considered invasive.[1] A requirement for a signed consent form does not guarantee that any meaningful communication has taken place between the patient and the health care provider and may sometimes delay the initiation of treatment while the form is signed, witnessed, and noted in the patient medical record. In cases where the patient is not decisionally capable, obtaining a signed consent form may require locating a surrogate and having that individual come to the hospital or nursing home to sign the form. For these reasons, some physicians who agree in theory that patients or their surrogates should almost always be involved in treatment decisions and who generally discuss such decisions with patients or their surrogates may regard the process of obtaining written consent as burdensome record keeping and may, therefore, resent formal requirements for informed consent (37).

Recognizing the legitimacy of concerns about written consent forms does not solve the problem of how to ensure that informed consent takes place. Some observers have suggested that changes in medical education and professional socialization during medical internship and residency are the best solution to the problem (37,63). Others suggest that legal suits by patients who have been harmed as a result of medical interventions for which they did not give true informed consent are another method for changing medical practice (37). Finally, changes in hospital and nursing home policies with regard to written v. verbal consent and specific delineation in such policies of the role of the patient or surrogate in the decisionmaking process might also be helpful.

None of these solutions, however, will address problems that arise because, as discussed earlier, the model of medical decisionmaking that underlies the doctrine of informed consent does not reflect the realities of some clinical situations. Further analysis is needed to identify informed consent procedures that are both valid and meaningful in situations where decisionmaking is virtually continuous due to the critical and unstable nature of the patient's condition.

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[1] Many health care facilities do not require a signed consent form for treatments that do not involve surgery and are not considered invasive, for example, nasogastric tube feeding and antibiotic treatment (see ch 8 and ch 9)

THE RIGHT TO REFUSE TREATMENT

The doctrine of informed consent and the case law and statutes that underlie it support the patient's right to refuse treatment (also known as "withholding consent "). In theory, this right is not diminished by the potentially fatal consequences of refusing life-sustaining treatment or by the opposing views of attending health care professionals. (In practice, as discussed throughout this report, physicians and other health care professionals are often very reluctant to withhold or withdraw life-sustaining treatment and sometimes do not recognize or accept a patient decision to refuse such treatment.)

To exercise the right to refuse treatment, a patient must possess the requisite mental capacity to process the disclosed information and to make a voluntary health care decision. Although most adult patients are either clearly capable or clearly incapable of making such a decision, some patients have questionable or fluctuating decisionmaking capacity. (See later section "Assessing Decisionmaking Capacity in Elderly Patients.")

Like consent, refusal of life-sustaining or any other therapy by a patient should be based on an informed choice, made in a voluntary manner (81). The information needed to make an informed choice has been examined above.

A voluntary choice implies an absence of coercion. Patients and physicians may have different values and goals in the context of health care decisions. The physician is expected to infuse the informed consent discussion with all of his or her professional expertise and experience and to provide advice and opinion accordingly; the physician is not a neutral observer but rather a skilled advocate of a particular position. It is the patient, however, who is legally vested with the right to decide whether to undertake the treatment. If, after full disclosure by the physician, the patient weighs the risks and benefits of a proposed procedure against his or her own individual fears, hopes, and beliefs, and decides to refuse the intervention, then this is a decision that the physician is legally required to accept. In general, however, if a patient decision violates the physician's convictions, the physician may withdraw from treating the patient as long as the physician makes reasonable efforts to assist the patient in obtaining appropriate continuing care. (See discussion of the societal interest in protecting the ethical integrity of the medical profession below.)

Societal Interests That May Limit the Patient's Right To Refuse Life-Sustaining Treatment

Strong as it may be, the patient's right to refuse medical treatment is not absolute. The law requires that this right be balanced against the interests of society and, in certain very limited circumstances, give way (77).

Four societal interests have been identified by the courts as potentially worthy of causing the court to override a patient's right to refuse treatment:

1. the preservation of human life,
2. the protection of third parties,
3. the prevention of suicide, and
4. the protection of the ethical integrity of the medical profession.

The societal interest in the preservation of human life is based on the fundamental religious and ethical concept of the value of human life in general and the value of each individual's life. This societal interest has been raised as a competing argument in virtually all court cases concerning refusal of life-sustaining medical treatment.

Although the societal interest in preservation of human life is related to the well-being of individual patients, unless some other individual is adversely affected by a patient's decision, the balancing process applied by the courts has always come out in favor of the patient's decision. The patient objective well-being alone has never been sufficient legal justification to force unwanted medical treatment on a decisionally capable patient (77,118).

In certain cases, there are cognizable third-party interests in the patient decision to refuse treatment. Particularly when the patient has minor children who would suffer financially or emotionally or who would be abandoned because of the patient decision to refuse life-saving or life-sustaining treatment, the state, in its parens patriae role, may feel compelled to override the patient health care decision. This societal interest is obviously more relevant to patients who are parents of young children. Few elderly persons fall into this category.

The societal interest in prevention of suicide is based on the value of human life and the corollary that the individual's life has value even if he or she does not recognize it. This societal interest has been raised most strongly in court cases concerning individuals who are decisionally capable and who wish to refuse life-sustaining treatment. It has also been considered, however, in some cases involving patients who are not decisionally capable (see, for example, In re *Quinlan* [52]). In general, the courts that have considered cases of both kinds have concluded that refusal of life-sustaining medical treatment does not constitute suicide (5,1 18).

Finally, there is the societal interest in the ethical integrity of the medical profession. Some people argue that the traditional role of health care providers, i.e., to use appropriate therapies to cure or ameliorate the effects of disease or injury, could be seriously affected if patients are allowed to refuse life-sustaining treatments; and that health care providers may view themselves as instruments of the patient's death in such circumstances and thereby he demoralized (17). These concerns notwithstanding, established case law explicitly articulates that protecting the ethical integrity of the medical profession does not demand that patients accept whatever treatment physicians propose, particularly if the treatment would be futile or if the patient holds other values (such as bodily integrity or privacy) above the preservation of his or her own life.

Whether health care providers and health care facilities must participate in withholding or withdrawing treatment when such participation violates their own convictions, is a question on which courts have differed. In the 1986 ruling in *Brophhy v.* New *England Sinai Hospital, Inc. (21),* the Massachusetts Supreme Judicial Court ruled that Mr. Brophy's feeding tube could be legally withdrawn but that the hospital he was in could not he compelled to participate in removing the tube and that Mr. Brophy could be transferred to another facility for this purpose. In the 1986 New Jersey case *In re Requena (53),* in contrast, the judge ruled that Mrs. Requena had the right to refuse tube feeding and that the hospital she was in, which had petitioned the court to have her discharged, must allow her to stay without being tube fed.

The case of Elizabeth Bouvia (see box 3-A) illustrates the conflict between the patient's right of self-determination, right of privacy, and right to refuse unwanted treatment, on the one hand, and the societal interests in preservation of human life, prevention of suicide, and protection of the ethical integrity of the medical profession, on the other hand. In the final decision in this case, the California Court of Appeal ruled, as courts have generally ruled, that societal interests are seldom so compelling that they can override the patient fundamental right to refuse unwanted medical treatment (5,111,118).

Practical Problems in Refusing Treatment

The patient's right of self-determination and right to refuse treatment are of little value if they are not supported in practice. Indeed, the treatment setting and the beliefs and personalities of the parties involved may have as much, if not more, impact on a patient ability to refuse treatment than the dictates of legal theory.

Hospitals may be overwhelming and intimidating for some patients. They are often large, complicated institutions. Patients are often subject to a steady stream of providers and procedures, some of which are not explained and some of which are ordinarily provided without the patient's explicit consent—for example, medications. Overall, a patient may have little influence over the daily course of events and may perceive a loss of control.

The primary goal of hospitals is the diagnosis and remedy of acute medical conditions, so that patients can return to their baseline functioning. There is a strong institutional commitment to curing disease and preserving life, and sophisticated equipment and highly trained staff are readily available to achieve these goals. The patient who refuses life-saving or life-sustaining interventions stands directly opposed to this institutional commitment.

Box 3-A.—The Elizabeth Bouvia Case

Elizabeth Bouvia has suffered since birth from severe cerebral palsy. As a result, she is quadriplegic and immobile except for slight movements of her right hand and sufficient facial muscle control to eat if spoonfed. Bouvia experiences constant pain from muscle contractions and arthritis, which is partially relieved by morphine. Despite her disability and pain, however, Bouvia is not suffering from a terminal illness, and death from her condition is not imminent.

In 1983, Bouvia admitted herself to a hospital in Riverside, California, and announced her intent to starve herself to death. When this decision was challenged by the hospital staff, she sought a court order to prevent any health care—including nutrition and hydration—without her consent.

Bouvia contended that insertion of a nasogastric tube against her will would violate her common law right of self-determination and her constitutional right of privacy. Physically unable to take her own life, she claimed that she had a right to determine when and how her life would end and that society has an obligation to honor and to assist her in achieving that right.

The hospital's lawyers asserted that there is no statutory, constitutional, or ethical right to commit suicide, nor to enlist the aid of others in so doing. The hospital's medical and nursing staff believed that honoring Bouvia's wishes would be contrary to medical ethics and would have a devastating effect on the morale of other patients. They were also concerned that possible criminal, civil, or license revocation proceedings might result.

The trial court in *Bouvia* v. *County of Riverside* (18) found that Bouvia was mentally capable of making medical decisions and that her decision was rational and primarily reached because of the nature and extent of her physical condition rather than from unhappiness due to nonmedical life situations. Therefore, the court determined, the ultimate issue was "whether or not a severely handicapped, mentally competent person who is otherwise physically healthy and not terminally ill has the right to end her life with the assistance of society." The court concluded that she did not. While recognizing Bouvia's right to terminate medical intervention, the court held this right had been overcome by the strong interests of society to preserve life and prevent suicide.

After losing her case, Bouvia reportedly went to Mexico to seek her death. When she learned that Mexican health care providers were no more sympathetic than those in Riverside, she returned to California and entered a private facility where she remained without incident for over a year. In late 1985, she was admitted to a hospital in Los Angeles, where a "morphine pump" was installed for pain control. Two months later, she was transferred to another hospital (3).

During this period, Bouvia's ability to take in sufficient nutrients by mouth deteriorated. Although she was eating voluntarily, her weight dropped below 70 pounds. To increase her caloric consumption, a nasogastric feeding tube was inserted against her will. Bouvia sought a court order to terminate the tube feeding. In February 1986, the trial court in *Bouvia* v. *Glenchur* (19) denied her petition. Despite Bouvia's testimony that she had not attempted to starve herself since her trip to Mexico and medical evidence suggesting that her liquid diet was medically reasonable, the court held that Bouvia had no right to refuse nasogastric tube feeding because "in the opinion of the medical staff at defendant hospital, plaintiff's refusal would to a reasonable medical certainty directly result in a life-threatening condition."

Bouvia's attorneys appealed. The California Court of Appeal held in April of 1986 that a patient has the right to refuse "any medical treatment or medical service, even when such treatment is labeled 'furnishing nourishment and hydration,'" and that this right exists "even if its exercise creates a 'life threatening condition.'" The court also stated that the "right to refuse medical treatment is basic and fundamental," and is "recognized as a part of the right of privacy protected by both the [California] State and Federal constitutions . . . . Its exercise requires no one's approval" (20).

In its decision, the appellate court clarified that there is no requirement that patients be terminally ill or "imminently" dying before exercise of the right to refuse treatment. (It is estimated that Bouvia could live for 15 or 20 years on tube feeding.) It affirmed that decisions to forgo medical treatment or life support through mechanical means belong only to the patient.

> It is not a medical decision for her physicians to make. Neither is it a legal question whose soundness

> is to be resolved by lawyers or judges. It is not a conditional right subject to approval by ethics committees or courts of law. It is a moral and philosophical decision that, being a competent adult, is hers alone (20).

The court also firmly rejected arguments that physicians have a right to preserve a patient's life against that patient's wishes. "It is incongruous, if not monstrous," the court wrote, "for medical practitioners to assert their right to preserve a life that someone else must live, or, more accurately, endure, for '15 to 20 years.' We cannot conceive it to be the policy of this State to inflict such an ordeal upon anyone" (20).

Finally, the court found that Bouvia's motives for exercising her right to refuse treatment are immaterial. At the same time, it rejected arguments that she is in fact attempting to commit suicide (20).

The difference between the 1983 and the 1986 cases lies in the premises on which the cases were based. In the first case, Bouvia had sought the right to refuse any nutrition at all. Since she could eat enough to live and chose not to, her refusal of tube feeding was viewed as attempting to commit suicide. In the recent case, she sought the right to avoid artificial feeding while voluntarily taking in whatever nutrients she could tolerate. Since she could no longer voluntarily orally consume adequate amounts of food, tube feeding was viewed as "medical treatment" replacing a faild physical function. On that premise, the appellate court found her right to refuse artificial feeding in the second case to be similar to the right to refuse treatment generally.

The appellate court added that it did not "doubt the sincerity of the hospital and medical personnel's moral and ethical beliefs . . . However, if the right of the patient to self-determination is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors" (20).

Although the trial judge who initially denied Bouvia's request in February 1986 distinguished the Bouvia predicament from other termination-of-treatment cases by noting that Bouvia could live for many more years with the proper nutrients, the appellate court held that such a distinction was inappropriate:

> In so holding, the trial court mistakenly attached undue importance to the amount of time possibly available to petitioner, and failed to give equal weight and consideration to the quality of life; an equal, if not more significant, consideration.
>
> Here, if force-fed, petitioner faces 15 to 20 years of a painful existence, endurable only by the constant administration of morphine. Her condition is irreversible. There is no cure for palsy or arthritis. Petitioner would have to be fed, cleansed, turned, bedded, toileted by others for 15 to 20 years! Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through physical acts of others. Her mind and spirit may be free to take great flights but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation, and dehumanizing aspects created by her helplessness (20).

In the face of the strong institutional commitments to provide treatment, refusing treatment requires courage and personal force on the part of the patient-qualities that may be difficult for a critically or terminally ill or severely debilitated patient to muster. This is especially true when the patient is intimidated or confused by the situation he or she is in. Moreover, when a patient is wholly dependent on physicians, nurses, and other health care providers for all of his or her physical needs (as a patient may be in a hospital), the patient may be reluctant to risk the caregivers' disapproval or rejection by refusing treatment.

Residents of nursing homes face some of the same practical problems in refusing treatment as hospital patients. Specifically, the daily routine and general atmosphere in some facilities engender extreme dependence and a feeling of loss of control. Moreover, many nursing home residents are not cognizant of their rights to receive information about their condition and treatment and to consent to or refuse proposed interventions. Finally, many nursing home residents are disoriented or memory impaired (at least 63 percent according to the findings of the 1985 National Nursing Home Survey [112]). Even if a resident has the full capacity to make decisions, the staff sometimes assumes that he or she does not (4).

An outpatient setting, such as a physician's office, may be less intimidating than a hospital or nursing home for several reasons. There is often more equality in the relationship between patient and physician in an outpatient setting. An outpatient may be in better health than a hospital or nursing home patient, and his or her overall functioning may be better. The encounter between an outpatient and physician is scheduled in advance and at the patient's convenience, rather than occurring without warning as, for example, when the physician stops by the patient's room in a hospital or nursing home. Finally, if an outpatient is dissatisfied with the information and options presented, he or she can simply leave the physician's office and seek the advice and services of another physician.

This apparent ease for the elderly patient in an outpatient setting is deceptive, however. In particular, it may not be quite so easy for the elderly patient to "shop around" for the most accommodating and respectful caregiver. Many elderly people have low incomes. If a physician does not accept Medicaid, or requires the patient to pay a premium above the Medicare reimbursement rate, that physician is, in effect, unavailable for some elderly patients. Moreover, lack of transportation keeps many elderly patients from leaving one caregiver for another who is less accessible geographically. Thus, even outpatients may experience practical problems in finding a physician who will continue to treat them but accept their refusal of a proposed medical intervention.

Legal Liability for Failure To Recognize the Patient's Right To Refuse Treatment

The only reported case in which health care professionals and health care institutions have been held to be potentially liable for damages for failing to recognize a patient right to refuse treatment is Leach v. Shapiro (70):

> In 1980, Edna Leach, a 70-year-old woman with amyotrophic lateral sclerosis ALS), was admitted to an Akron, Ohio, hospital because of breathing difficulty She had a cardiac arrest in the hospital, was placed on a mechanical ventilator and nasogastric tube feeding, and remained in the hospital in a chronic vegetative state *(69).*
>
> After 4 months, her husband asked her physician to remove the ventilator. The physician refused, and the husband, who was her legal guardian, petitioned an Ohio court for an order to discontinue life support. The court granted the petition in December 1980. The mechanical ventilator was removed in January 1981, and Mrs. Leach died (70).
>
> In 1982, Mrs. Leach's estate petitioned the court for punitive damages for the 159 days she was on life support following her husband's request that the ventilator be removed. The trial court that heard the case dismissed it on the grounds that there was no legal basis for a finding of punitive damages in such a case (70).
>
> The appeals court reversed this decision, ruling that the physician and the hospital could be liable for punitive damages if it could be shown that Mrs. Leach's legal guardian did not give explicit informed consent for the treatment and that Mrs. Leach had previously expressed her wish not to be kept alive on machines. The case was sent back to the trial court for determination of these facts (70).

Prior to the trial, the hospital settled out of court with the Leach estate. At the trial, in which the physician remained a defendant, the judge ruled that there was not sufficient evidence to go to a jury, and the case was dismissed (103).

COMPETENCY AND DECISIONMAKING CAPACITY

The law presumes that adults are competent—that is, all adults are considered to be able to exercise the full panoply of rights afforded to them upon reaching the age of majority. This legal presumption of competence is a global protection that grants individuals the freedom to act in numerous spheres of life.

Not all adults have sufficient mental abilities to make and articulate rational decisions, however. If factual evidence that a patient lacks decisionmaking capacity is presented to a court of the appropriate jurisdiction to rebut the presumption of competency, the patient may be declared "incompetent ." Unless there is a formal court challenge to an individual's competency, however, the legal presumption of competency and all the attendant rights it affords remain in effect.

When nonlawyers describe an individual as "competent" in the context of a health care decision, they rarely intend the label to evoke the global legal presumption just described. Instead, they usually mean only that they personally believe the individual has the requisite mental capacity to consent to or refuse a particular medical intervention. Likewise, when nonlawyers describe an individual as "incompetent" in this context, they seldom mean that a court has determined that the individual is incompetent. Rather, they mean that they personally think the individual does not have the requisite mental capacity to consent to or refuse treatment.

In this report, in order to avoid confusion between the two meanings, the words "competent" and "incompetent" are used only in the legal sense. Thus, the word "incompetent" is only used to describe an individual who has been determined by a court to be incompetent. The words "decisionaily capable" and "decisionally incapable" are used to describe an individual's mental capacity as determined formally or informally by any individual or group other than a court. Used in this way, the terms competent and decisionally capable are not always synonymous—adult patients can retain their legal presumption of competence while being clearly not decisionally capable in the opinion of their caregivers or families. Likewise, the terms incompetent and decisionally incapable are not necessarily synonymous—adult patients who have been declared incompetent by a court may be perceived by their caregivers or families to be able to participate in a specific health care decision. (Few health care providers would risk following a treatment decision of a patient who has been adjudicated incompetent, though.) Moreover, in some cases, courts have decided that an individual is not capable of making a specific health care decision but have not declared the individual incompetent.

In the reality of medical practice, if a patient consents to a proposed intervention, it is very unlikely that the patient's competency will be challenged, particularly if family members also agree (33,77). If all agree that a proposed intervention promotes the patient's objective well-being, it is in no one's interest to probe the patient's decisionmaking capacity and undermine the patient presumed competency. People sometimes assume that if "competent," the patient would have chosen the option that promotes his or her objective well-being anyway, In the absence of contrary evidence, no one is likely to challenge this assumption (118).

Thus, refusals of therapeutic or diagnostic procedures that are recommended by a physician trigger most assessments of a patient's decisionmaking capacity (33,9 o). It is generally agreed that when a patient's choice differs from what is thought to be in his or her objective best interest, caregivers should confirm that the patient is decisionally capable. This is not to say that *because* the patient chooses differently than the physician, the patient is decisionally incapable. But when a patient refuses an intervention that would be lifesaving or medically beneficial, it is prudent to make certain that the patient is accurately informed, acting voluntarily, and able to reconcile this decision with his or her personal values and preferences (33,118).

Assessing Decisionmaking Capacity in Elderly Patients

Although American law presumes, absent a ruling by a court to the contrary, that every adult is capable of consent or refusal of any proposed medical treatment, the reality is that health care providers, family members, and others often assume that elderly people are decisionally incapable. Actions that would not be thought to indicate incapacity in a younger person all of a sudden do indicate it in an elderly person (5). This is not a new problem, The sons of Greek dramatist Sophocles brought a proceeding against him to obtain his property and supported their argument that Sophocles was a lunatic on the basis of his preoccupation with writing his play *Oedipus at Colonus.* In his defense, Sophocles read from the play and asked the jury if it seemed the work of an imbecile. The jury reportedly applauded the reading and declared Sophocles to be of sound mind. One modern legal commentator opines that under contemporary statutes, use of this defense could result in the sons' walking out of the courtroom "in control of his property" (9). Indeed, many States retain "advanced age" as sufficient grounds for appointment of a conservator over one's property. Moreover, until 1976 in California and 1978 in Illinois individuals could be found incompetent merely because they were "old and sick" (9).

Some persons of all ages are clearly incapable of making decisions (e.g., persons who are permanently unconscious) but there are many other persons whose ability to make decisions is not clear. Among the elderly, such persons may suffer from the early stages of Alzheimer's disease or another disease that causes dementia. Although they may be currently capable of making decisions about their medical care, this status is often fluctuating or declining. Alternatively, many acute and chronic diseases and conditions can affect mental ability—usually temporarily. Infections, cardiovascular disease, dehydration, and nutritional deficiencies are a few examples. Persons with any of these diseases or conditions may be currently incapable of making decisions, although it is likely that their decisionmaking capacity will be restored. Pain or fatigue associated with acute or chronic disease and many medications can also cause temporary confusion. Those who assess a patient mental abilities need to be aware of these effects and their potential impact on the patient decisionmaking capacity.

Because of the sensitivity of the aged brain to any changes in a person's physical condition, fluctuating cognitive ability may be more common among elderly people than younger people. Persons with fluctuating cognitive ability may appear quite lucid at some times and confused and disoriented at other times. Such patients may be able to make decisions during intervals of lucidity, but if a patient cognitive ability fluctuates, accurate assessment may take more than one visit. Some experts suggest that when assessment of decisionmaking capacity is being conducted in a nonemergency setting, there should be at least two contacts with the patient on different days (7).

There are no uniformly accepted procedures for determining decisionmaking capacity. In fact, in many clinical settings, patients' cognitive deficits that may affect decisionmaking capacity are not routinely identified (31,38,66,79,89,95). When the need to determine a patient decisionmaking capacity arises in the context of a proposed diagnostic procedure or therapeutic intervention, the determination is often made quickly and on an ad hoc basis, frequently without any manifest awareness on the part of the physician or other health care provider that it is being made (73).

In hospitals and sometimes in nursing homes, if a patient refuses a proposed intervention, staff may request an evaluation by a consulting psychiatrist. Whether the psychiatrist has the final word on the patient capacity to make the decision depends on many factors, including the policies of the institution, its sensitivity to the rights of patients, and even the strength of the patient refusal (1 18).

Health care providers ma-y turn to family members or in their absence other available parties (such as clergy or close friends) for help in assessing the patient capacity to make a decision. Those who know the patient best can help to determine whether the patient's articulated refusal is consistent with the preferences and values that he or she has expressed over a lifetime. For example, is the patient refusal of a proposed amputation consistent with the importance he has previously given to such factors as personal appearance or the ability to walk independently? Perhaps the patient has been an athlete who previously told his loved ones that he would never want to lose his leg, even if his life was in jeopardy (118).

If a patient's decision is in accord with his or her previously articulated values, caregivers may be more inclined to accept it even if there is uncertainty about the patient's decisionmaking capacity. In such a situation, labeling the patient "decisionally capable" permits the caregivers to respect the patient decision and is consistent with the "empowering" notion that underlies the concept of legal competency (118). In such cases, however, the caregiver must walk a fine line between respecting the patient's right to make decisions and protecting the patient from a harmful decision. If the patient does not possess the mental capacity to process the information necessary to render consent or refusal, then the caregiver's acceptance of the patient articulated choice, simply because patients generally have the right to make these decisions, may constitute a mockery of the principles that underlie the concept of informed consent. Patients who are decisionally incapable **need to be protected from harmful choices** *(33,118).*

Assessment of Decisionmaking Capacity by Courts

On rare occasions, courts are presented with the question of whether or not a patient is competent to refuse treatment. Usually in the course of seeking a judicial determination, the petitioner is also asking the court to appoint a legal guardian to make the decision for the patient, presumably in favor of accepting the proposed treatment. The petitioner may also be asking the court to decide whether the proposed treatment should be provided.

In most cases where judicial determination of decisionmaking capacity is sought, the court relies strongly on the opinions of the patient's physician, other health care providers, the consulting psychiatrist (if there is one), the family, and occasionally the patient.

As mentioned above, a judicial determination of decisionmaking capacity does not necessarily equate to a formal decision of the patient's legal status as a competent adult. An individual may be considered legally competent, and therefore retain all of the attendant rights (e.g., the right to vote, make a contract, or write a will), but still be declared incapable of making the specific decision in question. Conversely, a court may declare the individual incompetent and appoint a guardian to manage all aspects of his or her life, even though only one type of ability was originally in question.

Recourse to a court to determine a patient decisionmaking capacity is not routine, and many commentators do not believe it should be (7,77,78,91). Health care providers and families tend to avoid seeking court resolution on questions of decisionmaking capacity because such determinations can be costly, time consuming, and emotionally stressful. Judicial hearings are generally open to the public and may lead to publicity that disturbs those who prefer private resolution **of such matters. Moreover, although it is possible in an emergency to get a quick judicial resolution, in the ordinary situation, the wheels of justice grind very slowly. State court systems are usually backlogged, and patients with life-threatening conditions often die before their cases are decided (although some cases have been decided after the patient died).**

There is no evidence that judges have a better analytic ability or ethical framework on which to determine decisionmaking capacity than those who work in health care institutions. Although they may be less biased than those who care for the patient, judges have little experience with these types of cases and, by and large, rest their decisions on the caregivers' recommendations. Thus, little may be gained by bringing these determinations to court. Moreover, there is a small risk that once the assessment of decisionmaking capacity is brought to court, a judge may rule on the patient's legal status as a competent adult. The patient might not only be disempowered in the context of the specific health care decision, but could lose all the fundamental rights that accompany the legal presumption of competence (1 18).

The foregoing discussion is not meant to imply that it is never appropriate to ask courts to rule upon a patient decisionmaking capacity. Courts are the appropriate forums for the determination and protection of individual rights, and some legal experts argue that a court hearing is the most appropriate procedure for determining decisionmaking capacity (11). Others believe that a court hearing is appropriate only in certain cases, for example, when health care providers disagree among themselves or disagree with family members about whether a patient is decisionally capable. Alternatively, there may be patients whose decisionmaking capacity is so questionable that caregivers require a judicial declaration before they are comfortable in accepting the patient decision. In most cases, however, the question of a patient decisionmaking capacity, can be decided in the health care institution, *if* caregivers are sensitive to factors that may affect either the patient capacity or the assessment, including institutional setting and caregiver biases (118). In some institutions, this is a big *if*.

Substantive Criteria for Determining Decisionmaking Capacity

There are few published judicial pronouncements on the substantive criteria for assessing decisionmaking capacity. This situation is primarily attributable to three factors. First, as previously noted, judicial determination of decisionmaking capacity in the context of health care decisions is rare, and courts have therefore had few opportunities to consider the issue. Second, the courts that have ruled in cases involving capacity and medical decisionmaking have, for the most part, been presented with patients who were clearly decisionally incapable. In those cases, the judicial opinion focused not on the ability of the patient to make the decision, but rather on the authority of a third party to make decisions on the patient's behalf. Third, the courts that hear these cases frequently do not issue written opinions.

Legal scholars have identified three approaches to determining decisionmaking capacity: outcome, status, and functional ability. Under the outcome approach, the determination of decisionmaking capacity is based on whether the patient's actual decisions reflect community values and conventional wisdom about appropriate health care. Under the status approach, an individual's decisionmaking capacity is determined on the basis of his or her status in predetermined categories (i.e., consciousness, age, physical or mental diagnosis) without regard to his or her actual decisionmaking capacity. The functional approach focuses on the individual's actual functioning in decisionmaking situations (5,90).

The few courts that have considered criteria for determining decisionmaking capacity have generally adopted the functional approach rather than the outcome or status approach. Commentators have proposed four possible tests to measure a person's decisionmaking capacity using the functional approach:

1. evidencing a choice,
2. evidencing an understanding of relevant information and issues,
3. rationally manipulating the relevant information, and
4. in addition to the above three, appreciating the nature of the situation (7).

Appreciating the nature of the situation is seen as "distinct from factual understanding in that it requires the subject to consider the relevance to his immediate situation of those facts he has understood previously in the abstract" (98). It is regarded as the strictest test.

Two cases illustrate the functional approach to determining decisionmaking capacity. Both cases involved elderly patients who refused life-saving amputation of gangrenous limbs. Applying similar criteria, the courts judged one patient decisionally capable and the other decisionally incapable.

A 1978 Massachusetts case, Lane v. ***Candura (68),*** concerned a 77-year-old widow who initially vacillated and ultimately refused to allow amputation of her gangrenous leg. In the court's opinion, Mrs. Candura possessed "the legally requisite competence of mind and will to make the choice for herself ." The court recognized that the patient was "lucid on some matters and confused on others." The focus of the court inquiry, however, was on whether she made a choice "with full appreciation of the consequences." With that perspective, the court found Candura to be capable of making her "most unfortunate'' but "not . . . uninformed decision" (68). The court stated:

> Senile symptoms, in the abstract, may, of course, justify a finding of incompetence, but the inquiry must be more particular. What is lacking in this case is evidence **that Mrs. Candura's areas of forgetfulness and confusion cause, or relate in any way to, impairment of her ability to understand that in rejecting the amputation she is, in effect, choosing death over life (68).**

The *Candura* court cited for support a 1973 Pennsylvania case, In ***re Yetter*** (57), and a 1978 New Jersey case, In ***re Quackenbush (51),*** in which patients with fluctuating lucidity were declared capable of refusing life-sustaining surgery. For the ***Candura*** court, the key factor in determining decisional capacity was the patient's capability of "appreciating the nature and consequences" of refusing treatment (68).

This focus on the patient's ability to appreciate and understand the nature and consequences of refusing treatment was also important to the court **in a 1978 Tennessee case, *State Department of Human Services v. Northern (107).*** Mary Northern was a 72-year-old patient with gangrenous feet who refused permission for her feet to be amputated. She was considered to be generally lucid and of sound mind. On the one issue of her rotting feet, however, Northern would not recognize the seriousness of her condition or the possibility that she might die without surgery. In fact, the court stated, "she evinces a strong desire to live and an equally strong desire to keep her dead feet" (107).

For the *Northern* court, it was the woman's inability publicly to give evidence of "a comprehension of the facts of her condition" that led the court to hold Northern incapable of making the decision (107). The court stated:

> Capacity means mental ability to make a rational decision, which includes the ability to perceive, appreciate all relevant facts . . . . On the subjects of death and amputation of her feet, her comprehension is blocked, blinded, or dimmed to the extent she is incapable of recognizing facts which would be obvious to a person of normal perception (107).

Thus, the courts in both of these cases chose to emphasize the patient's ability to comprehend and appreciate both the situation and the consequences of refusal of treatment in determining whether the patient has the requisite capacity to refuse treatment.

A variety of tests to determine a patient's decisionmaking capacity have been proposed [see, for example, President's Commission, 1982 [90]; Roth, et al., 1977 [98]; Stanley, 1983 [106]). There is general agreement that the goal is to construct a test that balances patient autonomy or self-determination and the need to protect decisionally incapable patients from harmful decisions. All the proposed tests measure the patient's capacity to make the particular health care decision at issue, not his or her decisionmaking capacity in general. Yet the tests differ in their language and stringency. Some commentators argue that standards of decisionmaking capacity should change depending on aspects of the specific decision, e g., the potential risk to the patient and the certainty of treatment outcome (see, for example, Drane, 1985 [33]). The existence of this variety of tests highlights the fact that determinations of decisionmaking capacity reflect conflicting societal judgments about when patients should be accorded the freedom to decide as they please, and when protection, more than autonomy, is the primary goal (118).

LEGAL ASPECTS OF MEDICAL DECISIONMAKING FOR DECISIONALLY CAPABLE ELDERLY PATIENTS

Elderly people who are clearly capable of making decisions, or who have been assessed to be capable by whatever criteria, have the same rights to make health care decisions as do all other adults. Their age in no way diminishes the recognition and respect that caregivers owe to decisionally capable patients who face proposed medical intervention. Thus, a decisionally capable elderly patient has the right to be informed of the diagnosis, prognosis, proposed intervention, risks of that intervention, availability of other options and their risks, and consequences of not intervening at all. After receiving this information, he or she is legally empowered to either consent to or refuse the intervention, even if that refusal should lead to serious harm or death for the patient.

Several State and Federal courts have affirmed the right of decisionally capable elderly patients to refuse unwanted medical interventions whether such refusal involves withholding or withdrawing the treatment. For example, in the 1980 Florida case ***Satz v. Perlmutter (100),*** the appeals court affirmed a trial court order that permitted a 73-year-old, mentally alert, terminally ill, hospitalized patient to be removed from the mechanical ventilator that sustained his breathing. The court stated:

> We find, and agree with, several cases upholding the right of a competent adult patient to refuse treatment for himself. From this agreement, we reach our conclusion that, because Abe Perlmutter has a right to refuse treatment in the first instance, he has a concomitant right to discontinue it (100).

More recently, in a 1984 California case, ***Bartling v. Superior Court (13),*** the appeals court strongly upheld the right of a decisionally capable, elderly patient to discontinue treatment. Mr. Bartling was a 70-year-old man who suffered from five major medical problems, none of which was imminently life-threatening. During a hospitalization for depression, a routine chest X-ray showed a tumor on his lung. Bartling agreed to a biopsy, during the course of which his lung collapsed. Bartling was placed on a mechanical ventilator, and efforts to wean him from it were unsuccessful.

When both Bartling and his wife requested that the ventilator be removed, his physicians refused to comply, and Bartling was placed in "soft restraints" to prevent him from disconnecting the ventilator tubes. Bartling petitioned the court for damages and for an order to restrain the hospital from administering any medical care without his consent. The hospital, a religiously affiliated institution, argued that it was devoted to the preservation of life and that it would be unethical for hospital physicians "to disconnect life-support systems from patients whom they viewed as having the potential for cognitive, sapient life" (13).

The California Court of Appeal found that Bartling was mentally capable of deciding to have the ventilator disconnected and that he "knew he would die if the ventilator were disconnected but nevertheless preferred death to life sustained by mechanical means" (13), In a clear statement of the right of decisionally capable hospitalized patients, the court stated further:

> If the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors, The right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right which must not be abridged (13).

Nursing home residents who are decisionally capable have a legal right to be informed and to consent to or refuse any medical intervention, regardless of their age or residence in a nursing home. There is one known (but unpublished) judicial opinion that discusses the right of an elderly, decisionally capable nursing home resident to refuse treatment. In this 1984 case, In the Matter ***of Application of Plaza Health and Rehabilitation Center (58),*** a New York court found that the resident, an 85-year-old man, was decisionally capable at the time he began refusing to eat ("he knowingly and willingly made that decision with the full understanding of the consequences, a hastened death") and that the facility, therefore, was neither required nor permitted to surgically force-feed him. The judge stated, "I will not, against his wishes, in effect order this 85- or 86-year-old person to be operated upon and/or to be force-fed in any manner, or to be restrained for the rest of his natural life" (58). Although the judge did not explicitly state on what basis he made this decision, it is clear that this opinion is supported by the resident's common law right of self-determination (118).

OTA is not aware of any judicial decisions that explicitly discuss the rights of the decisionally capable, elderly patient at home. However, a 1986 New Jersey case, ***In re Farrell*** **(48)** concerned a 37-year-old woman with amyotrophic lateral sclerosis (ALS) who was on a mechanical ventilator at home. The Supreme Court of New Jersey found that the woman was decisionally capable and that the ventilator could be removed as she requested. Observers point out that there is no reason to doubt that an elderly patient's right to make informed, voluntary decisions applies when the patient is living at home, just as it does when the patient is in other settings, and that this right could be judicially vindicated if necessary (32,118).

Despite the legal right of decisionally capable elderly patients to make health care decisions and to refuse unwanted treatment, many practical difficulties can interfere with their exercise of this right, as discussed earlier. Especially troublesome is the possibility that some elderly persons who are decisionally capable and who refuse treatment may be assumed to be or said to be decisionally incapable without a careful and unbiased determination of their decisionmaking capacity. It is not known how often such situations occur, but three factors suggest that they may occur more often than is generally recognized: 1) lack of agreed upon procedures and criteria for determining decisionmaking capacity; 2) the fact that determinations of decisionmaking capacity are sometimes made quickly and informally by health care providers who are barely aware that they are making such a determination (73); and 3) the widespread societal myth that elderly people are generally senile and confused (22).

LEGAL ASPECTS OF MEDICAL DECISIONMAKING FOR DECISIONALLY INCAPABLE ELDERLY PATIENTS

For patients who are clearly incapable of making decisions in general, or who have been assessed to be incapable of making a particular decision, several questions arise:

- **Can life-sustaining treatment ever be refused on behalf of a decisionally incapable patient?**
- **If so, who is empowered to make that decision?**
- **What criteria should guide a person who is making a decision on behalf of such a patient?**

Courts that have considered treatment decisions for persons who are decisionally incapable have begun with the premise that such persons' rights are the same as the rights of persons who are decisionally capable. For example, the **court in the 1977 Massachusetts case Superintendent *of Belchertown State School v. Saikewicz*** (109), which involved possible chemotherapy for a 68-year-old congenitally retarded man, explicitly stated:

> The substantive rights of the competent and the incompetent person are the same in regard to the right to decline potentially life-prolonging treatment . . . . The recognition of that right must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both (109).

Since courts have recognized the uniform applicability of the fundamental rights of patients in medical decisionmaking, the challenge has been to develop procedures and substantive criteria for decisionmaking that protect these rights and at the same time protect vulnerable patients from harmful decisions and protect societal interests related to the decisions (s). Case law and statutes provide a variety of procedures to accomplish these goals. Among them are procedures for designating a surrogate decisionmaker (as authorized by durable power of attorney, guardianship, and family consent laws and some living will statutes) and procedures for documenting a patient treatment preferences while the patient is decisionally capable—notably living wills. In addition, several courts have outlined substantive criteria to guide decisionmaking for persons who are decisionally incapable and/or set out procedures for reviewing treatment decisions for such persons. These criteria and procedures vary in different States because of differences in case law and statutes in each State. Thus, no one description covers every jurisdiction.

Criteria and procedures for decisionmaking for persons who are decisionally incapable are extremely important for the technologies and the kinds of patients that are the focus of this report. Although in medical practice in general, most patients are decisionally capable, many patients who are candidates for the five technologies discussed in this report are not decisionally capable at the time treatment decisions must be made, No reliable figures are available on the number of such patients. As discussed in chapters 8 and 9, however, some of the elderly people who are candidates for tube feeding or life-sustaining antibiotic therapy are confused as a result of organic diseases that cause dementia. People with such diseases are sometimes also candidates for resuscitation, mechanical ventilation, and dialysis. Furthermore, many persons who are not demented may be so sick at the time decisions about life-sustaining technologies must be made that they are not able to participate in the decisions. At the extreme are patients who are unconscious at the time of the decision.

Most decisions about life-sustaining treatments for decisionally incapable elderly patients arise in hospitals or nursing homes, but the courts that have considered cases involving such decisions have generally not limited the applicability of their rulings to specific settings. An exception was the 1985 ruling of the New Jersey Supreme Court in the case of Claire Conroy (46), which was held to apply only to nursing home residents (see discussion below).

Designating a Surrogate Decisionmaker

In many jurisdictions, adults are legally authorized to appoint, in advance of incapacity, another person to act as a surrogate or proxy decisionmaker. In the event that the individual subsequently becomes incapable of making health care decisions, the surrogate is empowered to act,

The advance appointment of a surrogate decisionmaker by a patient has several preconditions. The patient must be capable of making decisions at the time the directive is made, must have thought about the need to appoint a surrogate in advance, and must have had someone available and willing to take on that role. For elderly individuals without relatives or close friends, appointing a surrogate may be difficult.

For individuals who have someone to appoint as surrogate, designating this person in advance can minimize confusion and uncertainty in future medical decisions. Selecting a surrogate in advance assures the patient that someone trustworthy and knowledgeable will be acting on his or her behalf if it becomes necessary.

If a patient has not appointed a surrogate before becoming decisionally incapable, health care providers who must make treatment decisions for the patient may turn to the courts to appoint a surrogate. More frequently though, they designate (formally or informally) a family member or friend of the patient to act as the surrogate. Who is designated as a surrogate in either of these situations depends on several factors, including the case law and statutes of the jurisdiction and the availability of family or close friends of the patient.

According to one observer, a surrogate decisionmaker should possess the following qualities:

- he or she should have no conflict of interest or should be able to overcome a potential conflict of interest;
- he or she should have the capacity to participate in the decisionmaking process in an informed and conscientious manner (with the necessary corollary that health care providers must provide the appropriate information); and
- he or she should have the ability to advocate the patient's interests throughout the decisionmaking process (25).

Advance Appointment of a Surrogate Decisionmaker by the Patient

Depending on the State, an individual can appoint a surrogate decisionmaker through either a durable power of attorney or a living will. All States and the District of Columbia have a durable power of attorney statute. These statutes permit individuals (known as "principals") to delegate to another (known as the "proxy," "agent," or "attorney in fact") the legal authority to act on the principal's behalf. Such empowerment is "durable" because, unlike the traditional power of attorney, it does not automatically terminate if the principal subsequently becomes incompetent.

Durable power of attorney statutes were originally intended to permit financial or property transactions in the absence of the principal. Nothing in the language of these statutes precludes or limits the use of a durable power of attorney as a device for delegating medical decisionmaking authority, and no court has ruled that a durable power of attorney cannot be used for this purpose (5). However, some uncertainty remains, except in the 15 States[2] that expressly allow this use (either through statutes or their interpretation) (27,83).

Some States, for example, California and Rhode Island, have a specific form that is used to establish a durable power of attorney for health care. The California form is illustrated in figure 3-1. Most States do not require a specific form, however. A sample form that could be used in any of these States is illustrated in figure 3-2. In some States, a durable power of attorney for health care must be notarized to be valid, and in some States, it must be filed with a specific government office (83).

The process of executing a durable power of attorney may encourage an individual to consider his or her treatment preferences and discuss them

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[2] **Arizona, California, Colorado, Connecticut, Hawaii, Idaho, Iowa Maryland, Nevada, New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, and Virginia (27).**

Figure 3-1 .—California's Form for Creating a Durable Power of Attorney for Health Care

CALIFORNIA
STATUTORY FORM DURABLE POWER OF ATTORNEY FOR HEALTH CARE
(California Civil Code Section 2500)

Warning to Person Executing This Document

This is an important legal document which is authorized by the Keene Health Care Agent Act. Before executing Iii!, document, you should know these important facts:

This document gives the person you designate as your agent (the attorney in fact) the power to make health care decisions for YOU. Your agent must act consistently with your desires as stated in this document or otherwise made known.

Except as you otherwise specify in this document, this document gives your agent the power to consent to your doctor not giving treatment or stopping treatment necessary to keep you alive.

Notwithstanding this document, you have the right to make medical and other health care decisions for yourself so long as you can give informed consent with respect to the *particular* decision. In addition, no treatment may be given to you over your objection at the time and health care necessary to keep You alive may not be stopped or withheld if you object at the time.

This document gives your agent authority to consent, to refuse to consent, or to withdraw consent to any care treatment, service or procedure to maintain, diagnose or treat a physical or mental condition. This power is subject to any statement of your desires and any limitations that You include in this document. You may state in this document any types of treatment that you do not desire. In addition, a court can take away the power of your agent 10 make health care decisions for you if your agent (1) authorizes anything that is illegal, (2) acts contrary to your known desires, or (3) where your desires are **not** known, does anything that is clearly contary to your best interests.

Unless you specify a shorter period in this document, this power will exist for seven years from the date you execute this document and, if you are unable to make health care decisions for yourself at the time when this seven-year period ends, this power will continue to exist until the time when you become able to make health care decisions for yourself.

You have the right to revoke the authority of your agent by notifying your agent or your treating doctor, hospital, or other health care provider orally or in writing of the revocation.

Your agent has the right to examine your medical records and to consent to their disclosure unless you limit this right in this document.

Unless you otherwise specify in this document, this document gives your agent the power after you die to (1) authorize an autopsy, (2) donate your body or parts thereof for transplant or therapeutic or educational or scientific purposes, and (3) direct the disposition of your remains.

This document revokes any prior durable power of attorney for health care.

YOU should carefully read and follow the witnessing procedure described at the end of this form. **This document will** not be valid unless you comply with the witnessing procedure

If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

Your agent may need this document immediately in case of an emergency that requires a decision concerning your health care Either keep this document where it is immediately available to your agent and alternate agents or give each of them an executed copy of this document. You may also want to give your doctor an executed copy of this document.

Do not use this form if you are a conservatee under the Lanterman-Petris-Short Act and YOU want to appoint your conservator as your agent. You can do that only if the appointment document includes a certificate of your attorney.

SOURCE: California Civil Code Sections 2410-2443,

Figure 3-1 .—California's Form for Creating a Durable Power of Attorney for Health Care—Continued

1. Designation of Health Care Agent.

I, ____

(Insert your name and address)

____

do **hereby designate and appoint** ____

____

(**Insert** name **address and** telephone number of one individual only as your agent to make health care decisions for You. None of the following may be designated as your agent: (1) your treating healh care provider, (2) a nonrelative employee of your treating health care provier, (3) an operator of a community care facility, or (4) a nonrelative employee of an operator of a community care facility.)

as my attorney in fact (agent) to make health care decisions for me as authorized in this document. For the purposes of this document, "health care decision" means consent, refusal of consent, or withdrawal of consent to any care treatment, service, or procedure to maintain, diagnose,~ or treat an individual's physical or mental condition.

2. Creation of Durable **Power of Attorney for Health Care**

By this document I intend to create a durable power of attorney for health care under Sections 2430 to 2443, inclusive of the California Civil Code This power of attorney is authorized by the Keene Health Care Agent Act and shall be construed in accordance with the provisions of Sections 2500 to 2506 inclusive of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity.

3. General Statement of Authority Granted.

Subject to any limitations in this document, I hereby grant to my agent full power and authority to make health care decisions for me to the same extent that I could make such decisions for myself if I had the capacity to do so. In exercising this authority, my agent shall make health care decisions that are consistent with my desires as stated in this document or otherwise made known to my agent, including, but not limited to, my desires concerning obtaining or refusing or withdrawing life-prolonging care treatment, services, and procedures.

(If you want to limit the authority of your agent to make health care decisions for You, You can state the limitations in paragraph 4 ["Statement of **Desires, Special Provisions, and Limitations"] below. You can indicate your desires by including a statement** of your desires in the same paragraph.)

4. Statement of Desires, Special Provisions, and Limitations.

(Your agent must make health care decisions that are consistent with your know desires. You can, but are not required to, state your desires in the space provided below. You should consider whether You want to include a statement of your desires concerning life-prolonging care, treatment, services, arid procedures. You can also include a statement of your desires concerning other matters relating to your health care. You can also make your desires known to your agent by discussing your desires with your agent or by some other means. If there are arty types of treatment that you do not want to be used, You should state them in the space below. If You want to limit in any other way the authority given your agent by this document, You should state the limits in the space below. If You do not state any limits, your agent will have **broad powers to make health care decisions** for you, except to the extent that there are limits provided by **law.)**

In exercising the authority under this durable power of attorney for health care my agent shall act consistently with my desires as stated below and is subject to the special provisions and limitations stated below:

(a) Statement of desires concerning life-prolonging care, treatment, services, and procedures:

(b) Additional statement of desires, special provisions, and limitations:

(You may attach additional pages if you need more space to complete your statement. If you attach additional pages, you must date and sign **EACH of the additional pages at** the **same time you date and sign this document.)**

5. Inspection **and Disclosure of Information Relating to My Physical or Mental Health.**

Subject to any limitations in this document, my agent **has the power and authority to** do all of the following:

(a) Request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records.

Figure 3.1 .—California’s Form for Creating a Durable Power of Attorney for Health Care—Continued

(b) Execute on my behalf any releases or other documents that may be required in order to obtain this information.

(c) Consent to the disclosure of this information.

(If you want to limit the authority of your agent to receive and disclose reformation relating to your health, You must state the limitations in paragraph 4 [“Statement of Desires, Special Provisions, and Limitations”] above.)

6. Signing Documents, Waivers, and Releases.

Where necessary to implement the health care decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

(a) Documents titled or purporting to be a “Refusal to Permit Treatment” and “Leaving Hospital Against Medical Ad\ ice. ”

(b) Any necessary wavier or release from liability required by a hospital or physician.

7. **Autopsy; Anatomical Gifts; Disposition of Remains.**

Subject to any limitations m this document, my agent has the power and authority to do all of the following:

(a) Authorize an autopsy under Section 7113 of the Health and Safety Code.

(b) Make a disposition of a part or parts of my body under the Uniform Anatomical Gift Act (Chapter 3.5 [commencing with Section 7150] of Part 1 of Division 7 of the Health and Safety Code).

(c) Direct the disposition of my remains under Section 7100 of the Health and Safety Code.

(If you want to limit the authority of your agent to consent to an autopsy, make an anatomical gift, or direct the disposition of your remains, you must state the limitations in paragraph 4 [“Statement of Desires, Special Provisions, and Limitations”] above.)

8. Duration.

(Unless you specify a shorter period in the **space below,** this power of attorney will exist for seven years from the date YOU execute this document and. You are unable to make health care decisions for yourself at the time when this seven-year period ends, the power will continue to exist until the time when you become able to make health care decisions for yourself.)

This durable power of attorney for health care expires on:

____

(Fall in this space ONLY if you want the **authority of** your agent to end **EARLIER** than the sewn-year period described above.)

9. Designation of Alternate Agents.

(You are not required to designate any alternate agents but you may do so. Any alternate agent YOU designate will be able to make the same health care decisions as the agent you designated m paragraph 1, above, in the event that the agent is unable or ineligible to act as your agent. If the agent *you* designated is your spouse. he or she *becomes* ineligible to act as *your agent* if your marriage IS dissolved.)

If the person designated as my agent in paragraph 1 is not available or becomes ineligible to act as my agent to make a health care decision for me or loses the mental capacity to make health care decisions for me or if I revoke that person’s appointment or authority to act as my agent to make health care decisions for me then I designate and appoint the following persons to serve as my agent to make health care decisions for me as authorized in this document, such persons to serve in the order listed below:

A. First Alternate Agent ____

____

(Insert name, address, and telephone number of first alternate agent)

B. Second Alternate Agent ____

____

(Insert name address, and telephone number of second alternate agent)

10. Nomination of Conservator of Person.

(A conservator of the person may be appointed for you if a court decides that **one should be appointed.** The conservator is responsible for your physical care, which under some circumstances includes making health care decisions for you. You are not required to nominate a conservator but you may do so. The court will **appoint** the person you nominate unless that would be contrary to your best interests. You may, but are not required to, nominate as your conservator the same person you named m paragraph 1 as your health care agent, You can nominate an Individual *as your* conservator by completing the space below)

If a conservator of the person is to be appointed for me, I nominate the following individual to serve as conservator of the person:

____

(Insert name and address of person nominated as conservator of the person)

____

11. Prior Designations Revoked.

I revoke any prior durable power of attorney for health care.

Figure 3-1.-California's Form for Creating a Durable Power of Attorney for Health Care—continued

Date and Signature of Principal
(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY)

I sign my name to this Statutory Form Durable Power of Attorney for Health Care on

______________ at ____
(Date) (City) (State)

____

(This power of attorney will not be valid unless it is signed by two qualified witnesses who are present when you sign or acknowledge your signature. If you have attached any additional pages to this form, you must date and sign each of the additional pages at the same time you date and sign this power of attorney.)

Statement of Witnesses

(This document must be witnessed by two qualified adult witnesses. None of the following may be used as a witness: (1) a person you designate as your agent or alternate agent, (2) a health care provider, (3) an employee of a health care provider, (4) the operator of a community care facility, (5) an employee of an operator of a community care facility. At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

(READ CAREFULLY BEFORE SIGNING. You can sign as a witness only if you personally know the principal or the identity of the principal is proved to you by convincing evidence.)

(To have convincing evidence of the identity of the principal, you must be presented with and reasonably rely on any one or more of the following:

(1) An identification card or driver's license issued by the California Department of Motor Vehicles that is current or has been issued within five years.

(2) A passport issued by the Department of State of the United States that is current or has been issued within five years.

(3) Any of the following documents if the document is current or has been issued within five years and contains a photograph and description of the person named on it, is signed by the person, and bears a serial or other identifying number:

(a) A passport issued by a foreign government that has been stamped by the United States Immigration and Naturalization Service.

(b) A driver's license issued by a state other than California or by a Canadian or Mexican public agency authorized to issue drivers' licenses

(c) An identification card issued by a state other than California.

(d) An identification card issued by any branch of the armed forces of the United States.)

(Other kinds of proof of identity are not allowed.)

I declare under penalty of perjury under the laws of California that the person who signed or acknowledged this document is personally known to me (or proved to me on the basis of convincing evidence) to be the principal, that the principal signed or acknowledged this durable power of attorney in my presence that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney in fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, nor an employee of an operator of a community care facility

(Signature—Witness I)	(Signature—Witness II)
(Print Name)	(Print Name)
(Residence Address)	(Residence Address)
(Date)	(Date)

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare under penalty of perjury under the laws of California, that I am not related to the principal by blood, marriage, or adoption, and, to the best of my knowledge I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature: ______________________ Signature: ______________________

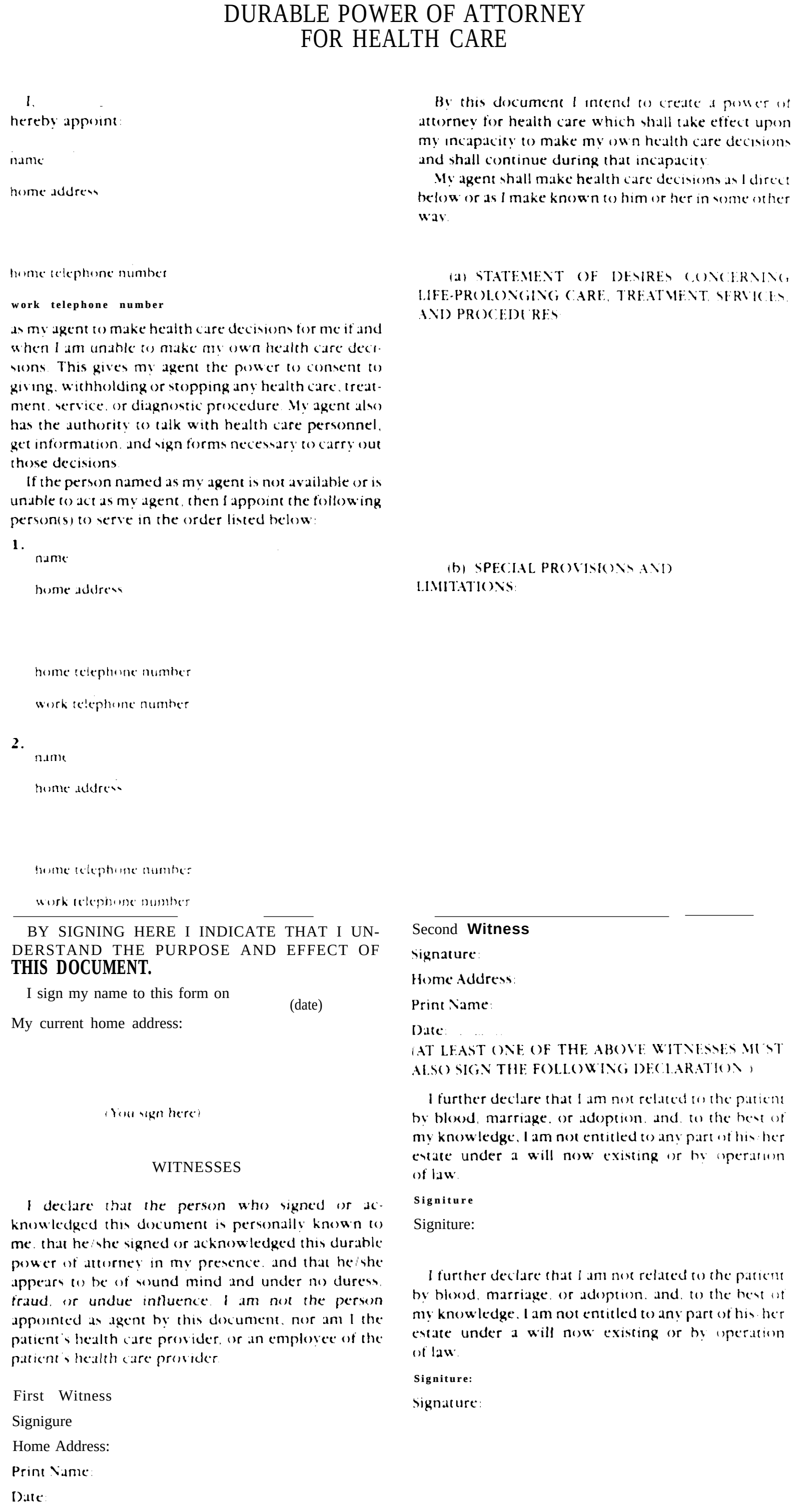
Statement of Patient Advocate or Ombudsman

(If you are a patient in a skilled nursing facility, one of the witnesses must be a patient advocate or ombudsman. The following statement is required only if you are a patient in a skilled nursing facility—a health care facility that provides the following basic services: skilled nursing care and supportive care to patients whose primary need is for availability of skilled nursing care on an extended basis. The patient advocate or ombudsman must sign both parts of the "Statement of Witnesses" above AND must also sign the following statement.)

I further declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by subdivision (f) or Section 2432 of the Civil Code.

Signature: ____

Figure 3-2.—Sample of a General Form for Creating a Durable Power of Attorney for Health Care



DURABLE POWER OF ATTORNEY
FOR HEALTH CARE

I,
hereby appoint:

name

home address

home telephone number

work telephone number

as my agent to make health care decisions for me if and when I am unable to make my own health care decisions. This gives my agent the power to consent to giving, withholding or stopping any health care, treatment, service, or diagnostic procedure. My agent also has the authority to talk with health care personnel, get information, and sign forms necessary to carry out those decisions.

If the person named as my agent is not available or is unable to act as my agent, then I appoint the following person(s) to serve in the order listed below:

1.
name

home address

home telephone number

work telephone number

2.
name

home address

home telephone number

work telephone number

By this document I intend to create a power of attorney for health care which shall take effect upon my incapacity to make my own health care decisions and shall continue during that incapacity.

My agent shall make health care decisions as I direct below or as I make known to him or her in some other way.

(a) STATEMENT OF DESIRES CONCERNING LIFE-PROLONGING CARE, TREATMENT, SERVICES, AND PROCEDURES:

(b) SPECIAL PROVISIONS AND LIMITATIONS:

BY SIGNING HERE I INDICATE THAT I UNDERSTAND THE PURPOSE AND EFFECT OF **THIS DOCUMENT.**

I sign my name to this form on
(date)

My current home address:

(You sign here)

WITNESSES

I declare that the person who signed or acknowledged this document is personally known to me, that he/she signed or acknowledged this durable power of attorney in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as agent by this document, nor am I the patient's health care provider, or an employee of the patient's health care provider.

First Witness
Signigure
Home Address:
Print Name:
Date:

Second **Witness**
Signature:
Home Address:
Print Name:
Date:

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I further declare that I am not related to the patient by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of his/her estate under a will now existing or by operation of law.

Signiture
Signiture:

I further declare that I am not related to the patient by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of his/her estate under a will now existing or by operation of law.

Signiture:
Signature:

SOURCE: Barbara Mishkin, Hogan & Hartson, Washington, DC with the surrogate so that when decisions must be made, they will reflect what the individual would have chosen (118). Anecdotal evidence suggests, however, that some individuals who execute durable powers of attorney do not discuss their treatment preferences with the designated surrogate. Some do not even notify the person they have designated as their surrogate that the durable power of attorney has been executed. In such situations, the designated surrogate may be ill-prepared to make treatment decisions on the principal's behalf (35).

In seven States,' statutes that authorize living wills allow individuals to appoint a surrogate decisionmaker through their living will (27). (Living wills documents in which an individual sets forth his or her wishes concerning life-sustaining treatments in the event that he or she becomes decisionally incapable—are discussed at greater length later in this chapter.) Depending on the State statute, a surrogate appointed through a living will can perform any of several functions: serving as an advocate for the patient's preferences as explicitly documented in the living will, filling in gaps or clearing up confusion about the patient's explicit directives based on prior discussions with the patient, or making decisions when the patient has left no explicit directives.

Two States—Indiana and Iowa-do not directly address surrogate appointments in their living will statutes, but by providing for consultation between the physician and the patient's representative, do inferentially authorize such appointments. Moreover, in States that do not require a specific form for a living will, an individual may be able to include a surrogate appointment. The legal authority of surrogates appointed in this way is uncertain, however (27).

Court-Appointed Surrogate Decisionmaker

Under their parens ***patriae*** powers, States have the authority and obligation to protect individuals who are incapable of protecting their own interests, This power, derived from English common law, gives courts the authority to appoint legal guardians, both for children (who are categorically considered unable to protect themselves) and for adults who are decisionally incapable. Some States require that the adult first be adjudicated incompetent before a guardian will be appointed; other States recognize that adults can be incapacitated in only certain spheres and will therefore appoint guardians for limited purposes. Appointment proceedings are alternatively known as guardianship, conservatorship, or committeeship proceedings, depending on the State (118).

Resort to a court of law for the appointment of a legal guardian to make health care decisions on behalf of a decisionally incapable adult is not common. It is most likely to occur when the decisionally incapable adult has no family or close friends; or the treatment plan is considered controversial, and health care providers and family want prior judicial guidance and assurance about the appropriateness of their actions; or the health care providers and family or close friends disagree about the course of action to be taken on behalf of the patient. Although courts are willing to appoint legal guardians for the specific purpose of making health care decisions and some of the most noteworthy court decisions about the rights of decisionally incapable patients have arisen in this context (including In re ***Quinlan*** **[52]),** a guardianship proceeding can be expensive, time-consuming, and emotionally stressful for the family and for the patient, if he or she is aware of it (83).

Many State guardianship statutes specify a preference for appointing a family member to be the legal guardian. Some States allow people to nominate, while they are decisionally capable, a person to be their court-appointed guardian in the event that they become decisionally incapable in the future and guardianship is required (27).

In some States, it is unclear whether guardians already appointed for general management tasks also have the authority to make health care decisions for their wards. Some States require such a guardian to return to court and seek specific judicial authorization to make health care decisions (118). Under a new law that takes effect in the District of Columbia in July 1987, court-appointed guardians are not allowed to make decisions about life-sustaining treatment for their wards without explicit approval of the court, un-

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[d] **Delaware, Florida, Louisiana,** Virginia, Utah, **Texas, and Wyoming** (27).

less the authority to make such decisions is specifically granted to the guardian when the guardianship is set up (76).

It is often very difficult to find someone to serve as a guardian for persons who do not have a family member or friend to act in this capacity and whose estate is not large enough to pay a lawyer or other individual to act as their guardian. Some States have a public office that serves as the guardian of last resort for such persons. In Arizona, for example, the Public Fiduciary's Office in each county acts as guardian for persons who are adjudicated incompetent and have no other legal guardian. This office is staffed with both lawyers and social workers and is legally empowered to make both financial and treatment decisions for its wards. According to a former public guardian for the State of Arizona, it costs about $500 to establish guardianship through this program and $300 to $500 per year to manage each case (16).

Although the experience with public guardianship has been favorable in Arizona, some public guardianship programs have had problems. In Los Angeles, for example, the public guardian was sued for inappropriate institutionalization of wards, and in other jurisdictions, public guardians have mishandled the funds of wards (102).

Informal Designation of a Surrogate Decisionmaker and Family Consent Laws

In everyday medical practice, few patients who are decisionally incapable have a court-appointed guardian or a surrogate whom they explicitly appointed before they became decisionally incapable. The usual procedure in hospitals, nursing homes, and other health care facilities is for health care providers to turn to the patient next of kin or other close family or friends who know the patient and seem to have his or her best interests in mind. Frequently, one family member indicates to the provider that he or she will act as the family spokesperson. At other times, the provider informally selects one family member to assist with decisionmaking.

Although this practice frequently works well, it is potentially fraught with difficulty if individual family members disagree about who should be the surrogate decisionmaker or about whether a specific treatment should be provided. In such situations, the health care provider or facility may petition a court or urge the family to petition a court for appointment of a legal guardian. More often, the provider may seek to reconcile the wishes of different family members informally, without insisting that one individual be designated as the surrogate. Anecdotal evidence suggests that the latter approach often leads providers to defensive decisionmaking—that is, the provider may opt for treatment decisions that he or she believes are least likely to result in a successful law suit if one family member chooses to sue.

Fifteen States have family consent laws that empower relatives of decisionally incapable patients to make legally binding decisions on behalf of those patients without a formal guardianship proceeding.[1] In some of these States, family members may make such decisions only after a physician has certified that the patient is terminally ill. Case law in five States[2] supports the right of family members to make health care decisions for patients who are terminally ill or irreversibly comatose (83). In most States, however, there is no legal authority for family members to make decisions on behalf of their elderly relatives even though this is a common and widely accepted practice.

The assumptions that underlie the tradition of informally designated family surrogates include the belief that the family is the most concerned about the patient's best interests, and the belief that the family is the most knowledgeable about the patient's values and preferences. In some cases, this is clearly not true. If there is evidence to contradict either of these beliefs, some commentators advise health care providers to seek legal counsel, and perhaps to petition a court for appointment of a legal guardian (118).

The Substantive Basis for the Surrogate Decision

Ideally, two fundamental values—patient well-being and patient self determination—should un-

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[1] Arkansas, Florida, Georgia, Idaho, Iowa, Louisiana, Maine, Maryland, Mississippi, New Mexico, North Carolina, Oregon, Texas, Virginia, and Utah (33).

[2] California, Connecticut, Florida, Georgia, and New Jersey (83).

derlie surrogate decisions for persons who are decisionally incapable (90,118). Various courts and legal scholars have developed standards for decisionmaking that reflect these values in differing degrees.

Best Interest v. Substituted Judgment

The two legal standards that generally guide surrogate decisionmaking are the "best interest standard" and the "substituted judgment standard. " Each standard guides decisionmaking from a different perspective.

If a patient has left no directives, has failed to convey his or her treatment preferences to anyone, or was never capable of making such decisions, the surrogate must rely on the best interest standard. This standard focuses on objective, societally shared criteria. The surrogate makes the decision from the point of view of a hypothetical "reasonable person" and considers such factors as the relief of suffering, the usefulness or futility of the proposed intervention, and the risks, benefits, and burdens of the proposed intervention to the patient. Most scholars agree that benefits and burdens to family and society should be irrelevant to a decision based on the best interest standard even though such considerations might be a factor in a decisionally capable patient's choice (118).

The substituted judgment standard requires the surrogate to use the patient's personal values and preferences as the basis for health care decisions. Under this standard, the surrogate's decision should be the same decision that the patient would make if he or she were able to decide. As the Saikewicz court stated in 1977, this standard requires the surrogate to "don the mental mantle of the incompetent" (109).

The substituted judgment standard is a subjective standard that necessitates that the patient at one time must have been decisionally capable and must have expressed, in some manner, values and preferences that are relevant to the decision to be made. It is generally preferred over the best interest standard when these criteria are met, because it allows the patient's own definition of "wellbeing" to be in control; also, in a certain way, the substituted judgment standard permits a decisionally incapable patient to exercise his or her right to self-determination, although he or she is unable to do so directly (5,91).

Types of Substituted Judgment Cases

There are two types of substituted judgment cases: those in which the patient explicitly stated wishes and preferences prior to becoming incapable, and those in which the patient made no explicit statement, but where the surrogate is able to infer what the patient would have wanted regarding the specific decision because of a close familiarity with the patient, patient's lifestyle, and patient's patterns of behavior. Some States, such as New York, require an explicit statement supported by "clear and convincing" evidence (55); no inferences are permitted in those jurisdictions. Other States, such as Massachusetts, clearly permit inferences, and even extend the use of what they consider the "substituted judgment" standard to situations where the patient was never capable of judgment in the first place. In either case, the most effective way for individuals to ensure that decisions about their treatment will reflect their own values and preferences, should they someday be incapable of making decisions for themselves, is through the use of an advance directive (i.e., a durable power of attorney, a living will, or both) (118).

An example of a substituted judgment case involving an explicit prior statement is that of Brother Fox, an 83-year-old member of the Roman Catholic Society of Mary, who, following routine hernia surgery, was left in a permanent vegetative state on a mechanical ventilator. During a prior bioethical discussion of the Karen Ann Quinlan case, Brother Fox had expressed to his fellow clerics a personal desire not to be maintained by '(extraordinary means" if he were ever in a similar situation. As the court noted, the issue of whether or not someone else can speak for the patient "is not presented in this case because here Brother Fox made the decision for himself before he became incompetent" (55). Since Brother Fox's prior statements of desires were "obviously solemn pronouncements," the court ruled that they must be followed. As the New York court noted, prior declarations can provide '(clear and convincing" evidence of a person's wishes, and in the absence of evidence to the contrary should be considered the best evidence of the declarant's actual preferences (55).

An example of substituted judgment by inference when no explicit prior statement exists is the 1983 Washington State case In *re Colyer* (45). The patient was a 69-year-old woman who had sustained a cardiac arrest. Although she was resuscitated by paramedics, Bertha Colyer suffered massive brain damage. She was placed on a mechanical ventilator and remained in a comatose, unresponsive state. The Washington court said that "her prognosis for any sort of meaningful existence was zero" (45). Colyer's husband, who was her legal guardian, asked the court for permission to remove the ventilator. Although the patient had never explicitly stated her preferences regarding such an act, her husband inferred that this would have been her decision, had she been able to decide. The *Colyer* court commented:

> There is no evidence that Bertha Colyer explicitly expressed her desire to refuse life-sustaining treatment. Nevertheless, her husband and her sisters agreed that Bertha Colyer was a very independent woman, that she disliked going to doctors, and, if able to express her views, that she would have requested the treatment be withdrawn. Given the unanimity of the opinions expressed by Bertha's closest kin, together with the absence of any ill motives, we were satisfied that Bertha's guardian was exercising his best judgment as to Bertha's personal choice when he requested the removal of the life support system (45).

In the 1985 New Jersey case In *re Conroy* (46), the court discussed various ways a surrogate might make a substituted judgment despite the lack of a prior explicit statement. Just as the Colyer court noted such factors as the patient's prior independence, her dislike of doctors, and her family's unanimity about what she would have wanted, so too did the Conroy court outline relevant information. The *Conroy* court stated:

> . . . an intent not to have life-sustaining medical intervention . . . might take the form of reactions the patient voiced regarding medical treatment administered to others . . . It might also be deduced from a person's religious beliefs and the tenets of that religion . . . or from the patient's consistent pattern of conduct with respect to prior decisions about his own medical care (46).

The *Conroy* court, however, recognized that while all relevant evidence should be considered "the probative value of such evidence may vary depending on the remoteness, consistency, and thoughtfulness of the prior statements or actions and the maturity of the person at the time of the statements or acts" (46).

The *Conroy* court set forth three alternate standards for surrogate decisionmaking that depend on the amount of evidence that is available about the patient preferences, and the benefits, burdens, pain, and suffering associated with continued treatment. The three standards are:

1. a subjective test, where it is "clear that the particular patient would have refused the treatment under the circumstances involved";
2. a limited-objective test, which permits treatment to be withdrawn if there is some trustworthy evidence that the patient would have refused, and "the decisionmaker is satisfied that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for the patient"; and
3. a pure-objective test, where there is an absence of trustworthy evidence, but the net burdens of the patient's life with the treatment clearly and markedly outweigh the benefits that the patient derives from life. In addition, the "unavoidable, recurring and severe" pain of the patient's life with treatment is such that administering life-sustaining treatment would be "inhumane" (46).

It must be noted, however, that the *Conroy* court restricted its opinion to cases involving "nursing home residents, suffering from serious and permanent mental and physical impairments, who will probably die within 1 year, even with treatment, and who, though formerly competent, are now incompetent to make decisions about their life-sustaining treatment and are unlikely to regain such competence" (46).

Judicial Review of Surrogate Decisions

Whether a court must review a surrogate's decision to withhold or withdraw life-sustaining treatment on behalf of a decisionally incapable patient varies widely among jurisdictions. Even within the same jurisdiction, some types of cases appear to require more review than others, depending on the treatment setting, the treatment options, and the vulnerability of the class to which the patient belongs. In some jurisdictions, cases have been brought to court precisely because of uncertainty about the appropriateness of nonjudicial resolution. In the context of deciding those cases, courts have outlined procedures for surrogates to follow, some of which require judicial involvement.

Two recent Washington State cases, In re Colyer (45) and In re *Guardianship of Hamlin (49),* resulted in court decisions that established the following procedures for that State. If the family, the treating physician, and the institutional "prognosis committee" all agree that the patient's prognosis is terminal, then the family may assert the personal right of the incompetent to refuse life-sustaining treatment without seeking prior appointment of a guardian or prior judicial review of the decision. In cases where no family is available, a guardian must be appointed by a court. Once a guardian is appointed, there is no need for judicial involvement in the substantive decision to withhold or withdraw life-sustaining treatment, as long as the guardian, treating physicians, and prognosis committee are all in agreement. In either situation, however, any party is permitted to petition for court intervention, and '(if there is a disagreement between parties involved in the decisionmaking process, court intervention would be appropriate" (49).

In the *Quinlan* case (52), the New Jersey court did not expressly address the issue of whether a court-appointed guardian was necessary. The court stated, however, that if the patient family, guardian, and attending physicians agree that there is no reasonable possibility the patient will emerge from a "comatose condition to a cognitive, sapient state, and that the life-support apparatus should be discontinued, " then they should consult with the institution's "ethics committee. " If the ethics committee agrees with the prognosis, then treatment may be withdrawn, judicial review is not necessary, and there is no attendant legal liability for any of the involved parties (52).

With regard to nursing home residents, the New Jersey Supreme Court's decision in the *Conroy* case spelled out special procedures, different from those articulated in the *Quirlan* case, because of '(the special vulnerability of mentally and physically impaired, elderly persons in nursing homes and the potential for abuse with unsupervised, institutional decisionmaking in such homes" (46). The *Conroy* decision delineated the following procedures:

1. There must be a determination that the patient is incapable of making the particular decision, and a guardian must be named. This is required even if the patient has already been declared legally incompetent and already has a general guardian.
2. If, based on one of the three articulated surrogate standards (see previous *Conroy* discussion), the guardian believes life-sustaining treatment should be withheld or withdrawn, then he must contact the State Ombudsman for Institutionalized People.
3 The Ombudsman must investigate the situation and must receive evidence concerning the patient's condition from the patient's physician and from two physicians unaffiliated with the facility, who must confirm the patient's medical condition and prognosis.
4. If the Ombudsman receives sufficient supportive evidence, and concurs in the decision to withdraw or withhold treatment, then such action is permitted (46).

Thus, although judicial involvement was not required, the involvement and oversight of a State agency was required. Decisions handed down June 24, 1987, by the New Jersey Supreme Court in the cases of Hilda Peters and Nancy Jobes appear to substantially reduce the categories of patients for whom these procedures are required, but they remain in effect for some patients.

A series of cases in Massachusetts set out somewhat confusing and unclear criteria for determining when judicial review of surrogate decisions is necessary. The 1977 Massachusetts case *Superintendent of Belchertown State School v. Sai-*

kewicz (109) concerned a 67-year-old, institutionalized, congenitally retarded man who suffered from acute and terminal leukemia. The Massachusetts court explicitly rejected the *Quinlan* procedures and stated that only the court could permit chemotherapy to be withheld from him:

> We take a dim view of any attempt to shift the ultimate decisionmaking responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent (109).

In the 1978 Massachusetts case In re *Dinnerstein (47)*, the patient was a 67-year-old woman with Alzheimer's disease who was in a persistent vegetative state. Her family and physician sought prior judicial approval of a decision not to resuscitate the patient should she suffer a respiratory or cardiac arrest. The court distinguished this case from the *Saikewicz* case, because the latter involved treatment that could prolong life—i.e., treatment that "contemplates, at the very least, a remission of symptoms enabling a return towards a normal, functioning, integrated existence." Since resuscitation does "nothing to cure or relieve the illness which will have brought the patient to the threshhold of death," the court considered a "Do Not Resuscitate" order to be a question for the attending physician, not for a court of law.

Finally, in a 1980 case, *In re Spring* (54), the Massachusetts court attempted to clarify its two earlier opinions. The court articulated a list of factors that might influence the decision about whether prior judicial approval of a surrogate decision is required. The court made no attempt, however, to categorize which combinations of these factors would mandate court review. The factors included the extent of the patient's mental impairments, whether a State institution had custody of the patient, the patient's prognosis with or without the proposed treatment, the risks of treatment, the patient's understanding of these risks, the urgency of the decision, and the clarity of professional opinion as to what would constitute appropriate medical practice in the given situation. The court also noted that while "court approval may serve the useful purpose of resolving a doubtful or disputed question of law or fact, . . . it does not eliminate all risk of liability. "

It is thus evident that the necessity for judicial review of surrogate decisions is highly variable, depending on the jurisdiction, the patient's condition, and the setting of the decision. Different jurisdictions place different values on the roles of physicians, families, state agencies, and courts in decisions to withdraw or withhold life-sustaining treatment from decisionally incapable patients. This again reflects the tension that underlies these decisions–a tension between permitting the preferences of previously capable but now decisionally incapable patients to guide surrogate decisionmaking and protecting decisionally incapable patients from harmful decisions.

Living Wills

A living will is a document that gives directions from an individual about how that person wants decisions about life-sustaining treatments to be made in the event that he or she becomes decisionally incapable in the future. When living wills were first devised in 1969, they had no legal sanctioning, but because they enunciated the patient's specific treatment preferences, they were considered morally persuasive (118). Even without specific legal sanctioning, a living will may be considered as a clear expression of the patient wishes under the substituted judgment standard discussed above (11).

In an attempt to make living wills legally binding and to standardize language, meaning, and usage, many States have enacted legislation establishing formal requirements for living wills, California was the first State to enact such legislation, and the name of its statute, the "Natural Death Act)" has become a generic label for living will statutes (118). As of January 1987, 38 States[6] and the District of Columbia had enacted such legislation (104).

Generally, State living will statutes provide immunity from legal liability for health care pro-

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[6] Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Maine, Maryland, Mississippi, Missouri, Montana, Nevada, New Hampshire, New, Mexico, North Carolina, Oklahoma, Oregon, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming (103).

viders who withhold or withdraw "life-sustaining" or "life-prolonging" treatment from a patient who has a "terminal condition" pursuant to a declaration executed by the patient. Refusal of treatment through a living will is not considered suicide, and health care providers who comply with a patient's living will are protected from prosecution for aiding and abetting suicide, which is a crime in most States (5,111). Apart from these general similarities, however, living will statutes vary significantly from State to State.

Variations in State Living Will Statutes

As discussed earlier, living will statutes in seven States specifically allow the appointment of a surrogate decisionmaker, whereas living will statutes in other States do not address this issue. Living will statutes in different States also vary with respect to the form of the declaration, formalities involved in its execution, the nature of the care that can be withheld or withdrawn, and the nature of the patient's condition warranting nontreatment.

Living will statutes in three States require that a particular form must be used without any changes.7 Most States, however, allow individuals to adapt the basic form to reflect their needs and preferences as long as the State's requirements for a valid living will are followed (83). Utah's living will form (see fig. 3-3) has a specific entry (item 4) that allows an individual to write in any personal instructions that do not contradict the basic intent and requirements of the State act.

All States require that a living will must be signed in the presence of at least two witnesses, but the requirements for who may serve as a witness vary. Because of potential conflicts of interest, living will statutes in some States do not allow relatives, persons who might inherit the individual's estate, or persons who are responsible for the individual's care to act as witnesses (83).

Some States require that living wills be notarized to be valid, and some require that they be filed with a certain State office. In two States, California and Oklahoma, a living will is binding only if the patient signs it *after* he or she is diagnosed as terminally ill (83).

Living wills may be revoked by the individual at any time. In most States, they remain in effect until they are revoked, but in a few States they must be reaffirmed every few years (83).

Living will statutes in most States specify that '(life-sustaining" or "life-prolonging" treatments may be withheld or withdrawn in certain circumstances, but that "comfort care" and procedures that are necessary to alleviate pain may not be withheld or withdrawn. variations in the wording of these provisions in different statutes affect which specific treatments may be withheld or withdrawn. About half the States prohibit withholding or withdrawal of nutritional support and hydration on the basis of a living will (see ch. 8). In addition, the wording of some State living will statutes is unclear with regard to antibiotic therapy (see ch. 9).

Most State living will statutes require that an individual must be "terminally ill" before the living will is implemented, but the definition of "terminally ill" varies in different statutes and is unclear in some. According to one commentator:

> The definition of "terminal illness" (in living will statutes) generally requires diagnosis of an irreversible condition that will lead to death; many States add "with or without the administration of life-sustaining treatment." In many States, death must be "imminent)" but imminent is often not defined (83).

The definition of terminal illness in many State living will statutes excludes persons who are in a persistent noncognitive state (or coma) and persons suffering from severe dementia (5,83).

Lack of uniformity among State living will statutes means that living wills that are valid in one State may not be honored in another State. Only four States–Hawaii, Maine, Maryland, and Montana—specifically recognize living wills from other States (83).

The Uniform Rights of the Terminally 111 Act

In 1985, in order to address the lack of uniformity and to correct some perceived anomalies, com-

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'California, Idaho, and Oregon (83).

Figure 3-3.-Utah's Form for Creating a Living Will

Directive to Physicians and Providers of Medical Services

This directive is made this__________________day of______________________ ____________________..

1. **I,** ____________________________________ **being of sound mind, willfully and voluntarily make known my desire** that my life not be artificial}' prolonged by Life-sustaining procedures except as 1 may otherwise provide **in this directive.**

2. I declare that if at any time 1 should have an injury, disease, or illness, which is certified in writing to be a terminal condition by two physicians who have personally examined me, and in the opinion of those physicians the application of life-sustaining procedures would serve only to unnaturally' prolong the moment of my death and to unnaturally postpone or prolong the dying process, **I** direct that these procedures be withheld or withdrawn and my death be permitted to occur naturally.

3. I expressly intend this directive to be a final expression of my legal right to refuse medical or surgical treatment and to accept the consequences from this refusal which shall remain in effect notwithstanding my future inability to give current medical directions to treating physicians and other providers of medical services.

4.1 understand that the term "life-sustaining procedure" does not include the administration of medication or sustenance, or the performance of any medical procedure deemed necessary to provide comfort care, or to alleviate pain, except to the extent I specify below that any of these procedures be considered life-sustaining:

5. I reserve the right to give current medical directions to physicians and other providers of medical services so long as **I** am able, even though these directions may conflict with the above written directive that life-sustaining procedures be withheld or withdrawn.

6. I understand the full import of this directive and declare that I am emotionally and mentally competent to make this directive.

____

Declarant's Signature

____

City, County and State of Residence

We witnesses certify that each of us is 18 years of age or older and each personally witnessed the declarant sign or direct the signing of this directive; that we are acquainted with declarant and believe him to be of sound mind; that the declarant's desires are as expressed above; that neither of us is a person who signed the above directive on behalf of the declarant; that we are not related to the declarant by blood or marriage nor are we entitled to any portion of declarant's estate according to the laws of intestate succession of this state or under any will or codicil of declarant; that we are not directly financially responsible for declarant's medical care; and that we are not agents of any health care facility in which the declarant may be a patient at the time of signing this directive.

____________________	____________________
Signature of Witness	*Signature of* **Witness**
____________________	____________________
Address of Witness	*Address of Witness*
____________________	____________________

SOURCE: Utah Personal Choice and Living Will Act, Utah Code No. 75-2-1101, 1985 plexities, and impediments in existing State statutes, the National Conference of Commissioners on Uniform State Laws approved a Uniform Rights of the Terminally Ill Act as a model for State legislation (86). The Uniform Act authorizes a person to control decisions about life-sustaining procedures in the event that he or she is in a terminal condition and is unable to participate in treatment decisions. It defines "terminal condition" as "an incurable or irreversible condition that, without the administration of life-sustaining procedures, will, in the opinion of the attending physician, result in death within a relatively short time" (86). "Life-sustaining procedure" is defined as "any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process" (86).

The Uniform Act does not rule out withholding or withdrawing any specific medical procedures, including nutritional support and hydration and antibiotics, on the basis of a living will. It does state, however:

> This (act) does not prohibit any action considered necessary by the attending physician for comfort care or alleviating pain (86).

It does not address the appointment of a surrogate decisionmaker.

Reservations About Living Wills

Many different criticisms and reservations about living wills have been expressed. Some commentators are generally opposed to living wills and present many arguments against them. Others generally support the concept of living wills but express reservations about one or more aspects of their interpretation and use or about the requirements of living will statutes in particular States or the Uniform Rights of the Terminally Ill Act.

Because attitudes about withholding and withdrawing life-sustaining procedures vary greatly, some aspects of living wills, State living will statutes, and the Uniform Act that are considered drawbacks by some individuals are considered positive features by others. People who are generally opposed to withholding or withdrawing life-sustaining treatments, for example, approve of provisions in living will legislation that limit their applicability to situations in which death is imminent and provisions that prohibit withholding or withdrawing nutritional support and hydration. Conversely, people who support the patient's right to refuse any unwanted medical interventions usually disapprove of strict limitations on the situations in which they are applicable (i.e., the definition of terminal illness) or limitations on the types of procedures that maybe withheld or withdrawn on the basis of a living will.

One frequently mentioned reservation about living wills is that individuals may not be able to accurately predict what their treatment preferences will be at an undetermined time in the future. In this context, some commentators point out that treatment options may change in the future. They also point out that it is difficult for anyone to anticipate all aspects of a future situation that might affect his or her treatment preferences. Thus, some commentators argue that individuals who execute a living will when they are healthy because they believe they will not want life-sustaining treatment if they become terminally ill or severely debilitated may change their minds when actually faced with such a situation (11)67). Supporters of living wills point out that the documents can always be revoked by an oral declaration of the patient. Clearly, a comatose or severely demented patient is not capable of revoking his or her living will. Although some people may regard this as a problem, others do not.

No court has yet considered the case of a decisionally incapable patient who has a valid living will but who gives some indication that he or she wishes to receive treatment that would not otherwise be provided because of the living will. According to one analyst:

> Since one of the primary purposes of executing a living will while competent is to have its provisions carried out should one become incompetent prior to the time it becomes operative, its provisions should arguably be controlling at that time. However, it is difficult to imagine a court ordering life-sustaining treatment to be discontinued in the face of any evidence, however meager, that the patient no longer desires this (11.1).

Another frequently mentioned reservation about living wills is whether they are specific enough to direct decisionmaking. Some commentators argue that although a living will may indicate **a** patient general **treatment preferences, it is often too general to provide any meaningful guidance** for specific treatment decisions **(12,34, 94).** For this reason, some people believe that living wills should be regarded as advisory (44). Others believe that living wills are or can be sufficiently specific to direct decisionmaking and that they should be regarded as the patient's decision. In this **context,** people who oppose living wills argue that they fail to give adequate consideration **to** the physician's judgment about appropriate medical care for the patient (44).

A third reservation about living wills is that they only allow individuals to refuse treatment they do not want. Some people believe that living wills should also allow individuals to request "maximum care" or specific treatments they do want to receive in the event that they become decisionally incapable ***(60,67).***

Some commentators favor a durable power of attorney over a living will as a method for individuals to ensure that their treatment preferences are recognized if they become decisionally incapable (108). One reason for this is that under a durable power of attorney, the designated surrogate can request treatment, as well as refuse it. In addition, a durable power of attorney is not limited in its applicability to situations in which the patient is terminally ill. Finally, under a durable power of attorney, the designated surrogate can be informed of the details of a specific treatment decision and any newly developed treatment options that the patient could not have been aware of. Thus, a durable power of attorney meets several criticisms of living wills—i e.) that they do not allow individuals to request treatment, that they are limited to situations in which the patient is terminally ill, that they are not specific enough to direct decisionmaking, and that an individual cannot anticipate what treatments may become available in the future.

One concern of some people who support living wills is whether State living will statutes and the Uniform Act include adequate provisions for enforcement. Many State living will statutes and the Uniform Act require health care providers who are unwilling to comply with a patient's living will to transfer the patient to another health care provider who will comply. In some States, the failure of **a** health care provider to comply with **a** patient's living will or to transfer the patient to another health care provider who will comply constitutes unprofessional conduct, and in a few States, it is a misdemeanor under State law. In many States, however, failure to comply with **a** patient's living will or to transfer the patient to another health care provider who will comply carries no penalty (5,83).

The ***Bartling*** case (13), discussed earlier, illustrates one aspect of the problem of enforcement of a patient's living will. Although Mr. Bartling had executed a valid living will under the California Natural Death Act, it did not become operative because his physicians refused to certify that his condition was terminal within the definition included in the Act (111).

Some commentators argue that the provisions of many State living will statutes and the Uniform Act give physicians too much discretion to determine when and if a patient's living will becomes operative and that they therefore allow physicians to thwart the intentions of patients who have executed valid living wills. Others believe that physician discretion in these matters is necessary and appropriate.

Anecdotal evidence suggests that in some instances, health care providers disregard a patient's living will if one or more members of the patient family disagree with the patient's directives and ask the physician to treat the patient regardless of his or her advance directive. OTA is not aware of any court cases that have addressed such a situation.

A final, practical problem with living wills is that in some circumstances, health care providers may not be aware that an individual has a living will. This is particularly likely to occur in emergency treatment situations, when the patient's personal physician is not involved in a treatment decision for any reason, and for patients who do not have family or friends to notify the health care provider that the patient has a living will.

The Right To Refuse Treatment Act

Because of dissatisfaction with many provisions of State living will statutes, the Legal Advisors

Committee of Concern for Dying proposed the Right To Refuse Treatment Act (5). This model act would provide a method for individuals who are decisionally capable to appoint a surrogate decisionmaker and specify how they wish to be treated if they become decisionally incapable. It would allow individuals to refuse any medical intervention. Moreover, the act provides that the patient's directives should be followed '(even if the continuance of the medical procedure or treatment could prevent or postpone the person's death" (71). Thus, it is not restricted to situations in which the patient is terminally ill. Finally the proposed act provides that failure to comply with a patient's directives shall result in "civil liability and professional disciplinary action, including license revocation or suspension" (71). It has not been enacted in any State but is being considered in 1987 by the Massachusetts legislature.

Future Directions for Living Wills

In spite of the various criticisms and reservations, State living will statutes have provided legitimacy for the idea of advance directives. They outline substance and procedure for patients, surrogates, and physicians to follow, so that these parties can act with some legal guidance and moral comfort, and so that caregivers are more likely to respect the wishes of a previously capable patient. Even the process of debating and enacting such legislation raises public consciousness and encourages more individuals to consider and document their preferences in advance of incapacity (118).

People who strongly oppose withholding and withdrawal of life-sustaining treatment are likely to oppose living wills and living will statutes, regardless of their specific provisions. Other people who support the patient's right to refuse unwanted medical interventions in some or all circumstances may welcome further analysis, debate, and legislative changes that address some of the problems with living wills.

With regard to the question of whether living wills are or can be specific enough to direct decisionmaking, two directions for analysis and debate seem promising. First, advance directives that include both the appointment of a surrogate decisionmaker and explicit documentation of the patient's treatment preferences ideally could result in the surrogate applying and interpreting the patient's preferences in the context of specific treatment situations—including situations the patient did not or could not have specifically anticipated (34,91). Further analysis of the legal and ethical implications and practical difficulties of this approach is needed.

Second, hospitals, nursing homes, and other health care facilities could develop institutional policies to guide physicians and others in the application and interpretation of a patient's living will with respect to a specific proposed intervention, Further analysis of this approach is also needed.

The lack of uniformity of State living will statutes could be addressed through Federal legislation to create a national living will law. Such legislation might include minimum national requirements for executing a valid living will. Because of differences of opinion about living wills, particularly about the nature of the care that can be withheld or withdrawn (i.e., the definition of "life-sustaining treatment") and the nature of the patient's condition warranting nontreatment (i.e., the definition of '(terminally ill"), such legislation could face considerable opposition from people who object to the specific definitions used in the proposed legislation. Alternatively, individual States that do not currently recognize a valid living will from another State could be required to revise their living will statute to do so (62). Both approaches require further analysis.

As indicated in the Right To Refuse Treatment Act, one method for enforcing living wills is to legislate specific penalties for a physician or health care facility that fails to honor a patient's living will. Other methods are also possible. At present, the Joint Commission on Accreditation of Hospitals (JCAH) does not require hospitals or nursing homes to have a policy honoring living wills in order to be certified by JCAH. Nor do Medicare and Medicaid require the hospitals and nursing homes that treat Medicare and Medicaid patients to have a policy honoring living wills. In response to a 1986 JCAH survey, about 80 percent of hospitals and nursing homes said that they recognize patients' living wills, and the remaining 20 percent said they do not (74). Changes in the JCAH, Medicare, and Medicaid requirements to require health care facilities to have institutional policies honoring living wills would probably result in acceptance and implementation of patients' living wills in many of the facilities that do not recognize them now.

Further analysis is needed of the proposal that individuals should be allowed to specify in a living will the treatments they do wish to receive if they become decisionally incapable. The legal and ethical implications of this proposal and the practical problems associated with its implementation have received relatively little attention. Especially problematic are the implications of the proposal with respect to the broader legal and ethical question of whether people should have a right to medical care (see ch. 2).

Finally, although the concept of living wills is more widely recognized now than it was a few years ago, most people have not executed a living will. The number who do so may increase in the future, but few observers believe that most patients will ever have a living will. Innovative methods are needed to encourage people who want to document their treatment preferences to execute a living will. This approach leaves unanswered, however, the questions of how to make treatment decisions for patients who did not document their treatment preferences in advance and how to make such decisions for people who were never decisionally capable and thus could not have executed a valid living will.

Nor does it address the question of how persons who are decisionally capable but who live in States that do not have a living will statute can ensure that their treatment preferences will be recognized in the event that they become decisionally incapable. As of January 1987, 12 States[8] did not have a living will statute. Eleven of these States had living will legislation under consideration in 1986, but the bills did not pass (104). In two States that do not have a living will statute—New York and New Jersey—living wills have been recognized by State courts as a clear and convincing statement of a patient's wishes that may be followed by health care providers without specific judicial authorization (83). The validity of a living will in the other 10 States that do not have a living will statute is uncertain.

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[8]Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, and South Dakota (103).

NONJUDICIAL CONSULTATIVE SOURCES

Several consultative sources are used, to a greater or lesser extent in different facilities and jurisdictions, to facilitate, guide, direct, or monitor decisions about life-sustaining treatments. The legal status of each source with respect to these decisions is unclear, however, except in jurisdictions where specific case law or statutes authorize a role for them in the decisionmaking process.

Institutional Ethics Committees

As noted in chapter 2, institutional ethics committees are multidisciplinary groups established within a hospital or nursing home to address ethical dilemmas that arise within the facility. The percentage of hospitals that have an ethics committee has increased rapidly in the past few years. Now more than 50 percent of hospitals have an ethics committee (29,39). It is not known how many nursing homes have an ethics committee.

Ethics committees may serve any of three different functions in hospitals or nursing homes:

1. Education—Ethics committees often serve as a focal point for multidisciplinary discussion and staff education about ethical dimensions of medical care.
2. Development of policies and guidelines—Ethics committees in many facilities develop and propose institutional guidelines for decisionmaking for incapacitated patients and policies for Do-Not-Resuscitate (DNR) orders, treatment of handicapped newborns, and other difficult decisionmaking situations.
3. Consultation and case review-Ethics committees sometimes serve as a forum for discussing and resolving ethical and other concerns about specific cases; they may advise staff, families, or even patients about difficult treatment decisions; in some facilities they also re -

view treatment decisions and decisionmaking practices to ensure that the interests of all parties, especially decisionally incapable patients, have been **represented (30).**

The degree to which an institutional ethics committee serves each of these functions varies in different hospitals and nursing homes.

Despite widespread endorsement of ethics committees and the rapid growth in their numbers over the past few years, many questions remain about their role in medical decisionmaking vis-a-vis the legal system. One noncontroversial way that some ethics committees relate to the legal system is by providing physicians and other hospital or nursing home staff with information about recent developments in case and statutory law that are relevant to treatment decisions or decisionmaking procedures. Another relatively noncontroversial way that some ethics committees relate to the legal system is by advising health care providers that certain patients may need a legal guardian or that certain treatment decisions may require judicial review (72).

Far more controversial is the question of when, if ever, an ethics committee can function as a substitute for a court in a case that might otherwise require judicial involvement. The concept of ethics committees first received public attention as a result of the 1976 decision of the new Jersey Supreme Court in the ***Quinlan*** case, in which the court ruled that the decision to withdraw life-sustaining treatment could be made without judicial review if the institution's "ethics committee" agreed that there was no possibility that Karen Quinlan would return to '(a cognitive, sapient state" (52). Despite its specific reference to an "ethics committee" and its statement that these committees could serve as "a more appropriate forum" than a court of law for the review of such ethical dilemmas (52), the Quinlan court actually assigned the committee a purely prognostic role—to determine whether there was any chance of Karen Quinlan's recovery (72), In the 1983 case, In ***re Colyer (45),*** the Washington State court delineated a similar role for what it referred to as a "prognosis committee" (2).

State courts have considered at least three cases in which institutional ethics committees were involved in aspects of treatment decisions other than establishing the patient's prognosis (116). In these three cases, the courts reached three different conclusions about the relationship between ethics committees and the courts.

In the ***1977Saikewicz*** case (109), the Massachusetts court indicated that ethics committee determinations may be admitted into a court case as evidence of the physician's good faith and proper standards of medical care (116). In contrast, in the 1984 Georgia case In ***re L.H.R. (50),*** the court ignored the determination of the ethics committee and said that there was no need for ethics committee consultation in this case or other similar cases. The court stated:

> In the case of incompetent adults who are terminally ill, in a chronic vegetative state with no reasonable possibility of regaining cognitive function, we find that the family of the adult or the legal guardian may make the decision to terminate life-support systems without prior judicial approval or consultation of an ethics committee (50).

Finally, in the 1984 Minnesota case In ***re Torres (56),*** the court considered the determination of several ethics committees that had been consulted and used them as evidence that a correct treatment decision had been made (116). In this case, the court said that ethics committees "are uniquely suited to provide guidance to physicians, families, and guardians when ethical **dilemmas arise" (56) and that an ethics committee's determination that life support could be removed would eliminate** the need for a court order.

It has been suggested that ethics committee review and approval of treatment decisions may minimize liability and reduce malpractice suits against the health care providers and facilities involved in such decisions (36)42,93,97). On the one hand, this suggestion might be taken to imply that the decision of an ethics committee would be accepted by a court as correct and would eliminate the need for court review, as in In ***re Torres (56).*** Some observers believe that ethics committees should not substitute for courts in this way because ethics committees' deliberations do not include the legal safeguards inherent in a court proceeding. According to one observer:

> Deferring to committees on the ultimate question of whether treatment should be forgone is . . . inappropriate. Committees operate under no uniform set of rules, and have no formal accountability. To defer to them on the resolution of cases involving foregoing treatment would be to carve out a class of important, life-and-death disputes that are deprived of any access to real court review: the court would merely rubber-stamp the committee *(116).*

On the other hand, ethics committee review and approval of a treatment decision might be expected to minimize liability and reduce malpractice suits because ethics committees provide an institutional forum for discussion of treatment decisions. By involving all interested parties, such committees may decrease the possibility of misunderstanding or dissatisfaction with the final decision and thus reduce the chance that one of the parties will take the case to court (36).

A third possibility is that ethics committee review and approval of a treatment decision might decrease the possibility of a successful law suit against a health care provider or facility because the court would consider the involvement of the ethics committee as evidence of the good intentions of the health care provider in the decision-making process, as in the Saikewicz case (109).

Whether institutional ethics committees actually reduce legal liability or the frequency of malpractice suits against health care providers or facilities involved in decisions about life-sustaining treatments is a question that cannot be answered with available data. Further analysis and research on the relationship between ethics committees and the legal system are needed.

Ombudsmen

“Ombudsman” is a Swedish term for a person who acts as a citizen representative. Under the Older Americans Act, States are required to have a Long-Term Care ombudsman program. The ombudsman serves as an advocate for nursing home residents and is available to oversee and enforce their rights. Ombudsmen investigate complaints, and if necessary, they can initiate judicial proceedings. As discussed earlier, the ***Conroy*** court, sensitive to the potential for abuse in decisions to withhold or withdraw life-sustaining treatment from incompetent nursing home residents, ruled that the State Ombudsman for Institutionalized People must investigate and approve decisions to withhold or withdraw treatment from nursing home residents (46). This decision (as modified by 1987 decisions of the Court) applies only in New Jersey, and courts in other States have not defined a role for the State ombudsman in such decisions.

Professional Societies

Professional societies utilize the combined expertise, experience, and prestige of their members to develop and promote policies that affect the delivery of health care in general and all aspects of medical decisionmaking. In 1986, two professional organizations-the Los Angeles County Medical and Bar Associations–issued a joint policy statement regarding the withholding or withdrawal of life-sustaining medical treatment, for example (75). This collaborative effort between attorneys and physicians was intended to assist physicians faced with the legal and ethical dilemmas of life-support decisions and to educate attorneys and patients as to the issues presented by advanced medical technology.

Of more national prominence was the March 1986 policy statement of the American Medical Association (AMA) that endorsed the right of a patient or the patient’s surrogate, if available, to make decisions about life-sustaining treatment and declared that artificial nutrition and hydration constitute treatment that can be discontinued in appropriate circumstances (l). Although this AMA statement is not binding on anyone, it is a strong statement from a prestigious organization, and it wiIl most likely influence courts and legislators in their future decisions. Policy statements of the American Nurses Association; of national, State, and local hospital, nursing home, home care, and hospice associations; of the professional societies that represent physician specialists in critical care medicine and each of the five technologies discussed in this report; and of societies that represent allied health professionals who provide each of the technologies can also be expected to influence such decisions.

Institutional Policies for Decisionmaking

As discussed throughout this report, hospitals, nursing homes, and other health care facilities have developed institutional policies that define how decisions about life-sustaining treatments are to be made in the facility. Most such policies address decisions about resuscitation and DNR orders, but some facilities have limited treatment policies that apply to decisions about all kinds of life-sustaining treatments.

The relationship between institutional policies for decisionmaking and the legal system is unclear. Whether such policies provide legal protection for health care providers who follow them is not known. Moreover, there is disagreement about whether institutional policies for decisionmaking increase some legal risks for providers or facilities. Other questions also arise. What are the legal implications for facilities that institute a policy honoring living wills in States that do not have a living will statute, for example? An OTA report addressing these questions and other aspects of institutional policies for decisionmaking is in process and will be released in early 1988.

CRIMINAL LIABILITY

Physicians, like all professionals, are required by law to perform their duties according to certain standards of professionalism. If they fall below those standards and thereby harm their patients, they may be liable under civil law—that portion of the law that deals with relationships among individuals and groups. Criminal law—the portion of the law dealing with acts against the state defined in the criminal codes of the States and the United States and punishable by penalties described in the codes—has rarely been used for regulating physicians' conduct when they are engaged in good faith efforts to treat patients (5,118).

The few courts that have confronted the issue of using the criminal law to review whether a physician has properly practiced his or her profession have expressed great distaste for using the law for this purpose (5). In the 1976 Massachusetts case ***Commonwealth v. Edelin (28),*** for example, the court makes clear that only in the most extraordinary cases should the criminal law be used as a way to review the actions of physicians performing "professional tasks" and that the presumptions against criminality are very much in favor of a physician who acts in "good faith."

In considering cases in which prior judicial approval for withholding treatment is being requested, several courts have considered and rejected the possibility of a criminal charge. In the 1980 Massachusetts case ***In re Spring*** (54), for example, the court briefly discussed the concern physicians might have regarding criminal liability and concluded that:

> Action taken without judicial approval might be the subject of either criminal or civil liability. Little need be said about criminal liability: there is precious little precedent, and what there is suggests that the doctor will be protected if he acts on a good faith judgment that is not grievously unreasonable by medical standards (.54).

There is only one reported case involving withholding or withdrawing life-sustaining treatment in which physicians have actually been accused of a crime—the 1983 California case, ***Barber v. Superior Court*** (10). That case concerned a patient, Clarence Herbert, who suffered a cardiac arrest following surgery and was placed on a mechanical ventilator. He had severe brain damage as a result of the cardiac arrest, and his physicians, Neil Barber and Robert Nedjl, informed his family that he was not expected to recover from his comatose condition. The family requested that he be removed from the ventilator. Two days later, when he had not died, the family asked that intravenous nutritional support and hydration be withdrawn. The physicians complied, and Mr. Herbert died in 6 days,

Mr. Herbert's physicians were subsequently charged with murder. The California magistrate who heard the evidence concluded that the physicians did not cause Mr. Herbert's death; that the physicians acted in good faith and exercised sound medical judgment; and that their state of mind did not constitute malice as defined in the California statutes on murder. Therefore, the charges were dismissed. The State appealed this decision to a Superior Court judge, who reinstated the charges, finding that regardless of the physicians good faith and exercise of sound judgment, their actions were unlawful.

The California Court of Appeal overturned the Superior Court ruling and found that charges of murder could not be brought against the doctors. The Court of Appeal commented:

> It appears to us that a murder prosecution is a poor way to design an ethical and moral code for doctors who are faced with decisions concerning the use of costly and extraordinary (life support) equipment (10).

The court concluded that cessation of life-support measures is not an “affirmative act” but is an “omission of further treatment” (10). It recognized that one can commit a crime by omission only if there is a duty to act. The question in the *Barber* case involved determining the physician’s duty to an irreversibly comatose patient. The court concluded that “a physician has no duty to continue treatment, once it has proven to be ineffective” and that in a case in which the physician has made a “hopeless prognosis” based on accepted medical practice, and the patient’s family wishes to discontinue treatment, such cessation of treatment, though intentional and with the knowledge the patient would die, does not constitute an unlawful failure to perform a legal duty (10).

The court recognized that the difficult issues are who is to determine that a patient prognosis is hopeless and who is authorized to direct termination of treatment. It declined to give specific answers beyond indicating that such determinations are ‘(essentially medical” and need to be made based on facts unique to each case (10).

The court did provide a general guideline for decisions about withholding or withdrawing life-sustaining treatment by stating that the benefits of treatment should exceed the burdens. Thus, the court said, the burdens of minimally painful or intrusive treatment may sometimes be disproportionate to the benefits if the prognosis is virtually hopeless. It therefore becomes the physician’s task to make a diagnosis and prognosis based on accepted medical practice. Where possible, the patient should be the ultimate decisionmaker. When the patient is incapable, however, the family members are to make the decision based on what they believe the patient would want if able to express his or her own wishes (10).

Since the *Barber* case was the first instance in which physicians were charged with homicide for withholding or withdrawing medical care, it has caused tremendous concern within the medical community. Given this concern, a number of points must be made. First, the physicians prevailed; the charges against them were dismissed. Although one should not minimize the emotional toll legal proceedings take on the defendants, the reality is that the court supported the physicians actions. Second, the *Barber* case never actually came to trial. All the legal proceedings that took place were designed to determine if the prosecutor could convict these physicians of homicide if he could prove the facts he alleged. The court did not conclude that the prosecution could not prove the facts, but rather that, even if proven, the facts did not support a charge of homicide. Third, the case was primarily concerned with the issue of the cessation of artificial nutrition and hydration, which was (and is) the most controversial area of the law. Even the district attorney was unconcerned about the removal of the ventilator. Fourth, it was family members who requested withdrawal, not the patient. There has never been a criminal action based on a patient’s request to withhold or withdraw treatment. Finally, the court was very supportive of physicians, and expressed its displeasure at the use of the criminal process in this most sensitive area. It is extremely unlikely, after the *Barber* case, that any good faith cessation of medical treatment with the patient’s or family’s concurrence, could support a charge of homicide in the jurisdiction of the California court (.5).

FINDINGS AND IMPLICATIONS

The common law right of self determination guarantees the basic right of every individual to determine what shall be done with his or her body. The constitutional right of privacy protects the individual's right to make personal medical decisions. Although the U.S. Supreme Court has not addressed the question of whether the right of privacy includes a right to refuse life-sustaining medical treatments, several State courts have held that it does. Taken together, the right of self-determination and the right of privacy support the right of individuals to be informed about and to consent to or refuse proposed medical treatments.

The legal doctrine of informed consent requires physicians to disclose to a patient his or her diagnosis and prognosis, the proposed treatment, alternate treatments, the risk and benefits of all options, and the consequences of not intervening at all. With this information, the patient is expected to make a decision and instruct the physician how to proceed.

Exceptions to the informed consent requirement have been recognized for several situations, including emergencies and waiver situations in which the patient has expressed a desire not to receive the information. Some observers believe that elderly people are more likely than younger people to waive their right to informed consent. These observers argue that waivers of informed consent should require an explicit statement by the patient that he or she does not wish to receive the information and should not be based only on a tacit understanding between the patient and the physician.

Many problems interfere with implementation of the legal doctrine of informed consent. They include the fast pace of modern medical practice, the training and socialization of physicians in medical school, internship, and residency, and assumptions by some physicians and other health care providers that elderly patients in particular will not be able to understand the information.

Moreover, research indicates that informed consent as envisioned in the law is largely absent from clinical practice, that patients are seldom given information about proposed treatments before a decision about the treatment is made, and that even when patients are fully informed about proposed treatments, they act as if the doctor should make the decision (73). Research also indicates that the model of medical decisionmaking that underlies the doctrine of informed consent–a model that involves discrete decision points at which treatment options are clear and one can be selected-may be invalid in some clinical situations. Further analysis of the applicability of the informed consent doctrine to various decisionmaking situations is needed.

A patient's legal right to refuse unwanted medical treatment is a corollary of the right to consent to medical treatment. Strong as it may be however, the patient right to refuse treatment is not absolute. Four societal interests have been identified by courts as potentially worthy of overriding a patient's right to refuse treatment:

1. the preservation of human life,
2. the protection of third parties,
3. the prevention of suicide, and
4. the protection of the ethical integrity of the medical profession.

Only rarely, however, have societal interests been used by courts to justify the use of unwanted medical treatments.

With regard to the societal interest in the protection of the ethical integrity of the medical profession, however, courts have handed down contradictory rulings about whether health care providers and facilities must participate in withholding or withdrawing treatment when such participation violates their convictions. Further legal debate on this question is expected.

In practice, hospital patients who wish to refuse medical treatment confront a strong institutional commitment to curing disease and preserving life. Hospital and nursing home patients may experience a feeling of loss of control associated with institutionalization and may fear that they will be abandoned by their caregivers if they refuse recommended treatment. Finally, although American law presumes that adults are compe-

tent unless a court has determined that they are incompetent, health care providers and others often assume that elderly persons, particularly those who are severely ill or debilitated, are incapable of making decisions. For each of these reasons, patients may experience difficulty in refusing unwanted treatment.

A great deal of confusion and controversy surrounds the issue of determining decisionmaking capacity in persons whose decisionmaking capacity is questionable or fluctuating. It is generally agreed that decisionmaking capacity should be determined in relation to a specific treatment decision and that the tests of decisionmaking capacity should be based on the values of patient autonomy and patient well-being. Yet the specific tests that have been proposed reflect differing societal judgments about the relative importance of these two values.

There is also controversy about the appropriate role of the courts in determining decisionmaking capacity. Some observers believe that it is seldom necessary or advisable to turn to the courts for a determination of decisionmaking capacity. Others believe that a court hearing is the appropriate forum for such determinations, especially when health care providers disagree among themselves or disagree with family members about a patient's decisionmaking capacity.

Courts have ruled that elderly people who are decisionally capable have the same rights as other adults to consent to or refuse medical treatment. Elderly people who are decisionally incapable are also considered to have the same fundamental rights. Case law and statutes in different States provide several methods for designating a surrogate decisionmaker for persons who are decisionally incapable. These include durable power of attorney, guardianship, and family consent statutes. In addition, some living will statutes allow individuals to appoint a surrogate decisionmaker in advance of becoming decisionally incapable. In practice, however, most decisionally incapable patients do not have a surrogate designated by any of these methods, and health care providers usually obtain consent for proposed treatments through informal discussions with family members or friends of the patient. Although this informal method frequently works well, it is potentially fraught with difficulties if family members or others disagree about who should be the surrogate decisionmaker or about whether a specific treatment should be provided. Increased use of formal methods for designating a surrogate decisionmaker could provide greater protection from legal liability for health care providers and at the same time provide greater assurance that someone is explicitly designated to exercise the patient right to consent to or refuse proposed treatments.

Courts have identified two standards for surrogate decisions–best interests and substituted judgment—again based on the values of patient autonomy and patient well-being. The substituted judgment standard requires the surrogate to use the patient's personal preferences and values for health care decisions. The best interests standard requires the surrogate to make a decision from the perspective of a hypothetical "reasonable person)" considering factors such as the usefulness or futility of the proposed intervention and its risks, benefits, and burdens.

Courts have generally preferred the substituted judgment standard, provided there is evidence of the patient's preferences. Courts indifferent States have differed, however, on what constitutes acceptable evidence. Prior declarations of patients made while they were still decisionally capable, including living wills, have been regarded as the best evidence of the individual's preferences. In the absence of a prior declaration, courts have looked to the values of the patient and opinions of relatives and friends about the individual's likely preferences.

Whether a court must review surrogate decisions for decisionally incapable patients varies in different States as a result of court rulings in each State. Whereas some courts have determined that judicial review is required at least in some circumstances, other courts have ruled that these decisions may be made without court review as long as certain procedures are followed. Inconsistencies in court rulings on this issue result in uncertainty among health care providers about the required decisionmaking procedures and intensify their fear of legal liability when life-sustaining treatment is withheld or withdrawn.

Living wills provide an explicit expression of a patient's preferences about life-sustaining treatments. Although 38 States and the District of Columbia have now enacted legislation authorizing living wills, there is considerable variation among States in the form and procedures required to execute a valid living will, the specific medical treatments that may be withheld or withdrawn pursuant to a living will, and the condition of the patient that warrants nontreatment (i.e., the definition of terminal illness). Because of differences among States in the provisions of their living will statutes, living wills that are valid in one State may not be recognized in another State. Only four States specifically recognize living wills from other States.

In addition to problems with living wills that may arise because of the lack of uniformity among States, reservations about living wills include the concern that individuals may not be able to accurately predict what their treatment preferences will beat an undetermined time in the future, that living wills are not sufficiently specific to direct treatment decisions and that they do not allow individuals to request as well as refuse treatments. A durable power of attorney for health care can meet each of these objections, and many commentators favor the durable power of attorney over the living will as a method of assuring that an individual's treatment preferences are known if he or she becomes decisionally incapable. Some commentators suggest that the best approach may be a living will that includes the designation of a surrogate decisionmaker. Living will statutes in a few States specifically allow the designation of a surrogate decisionmaker.

Guidance in decisions about withholding or withdrawing life-sustaining treatment is provided in some circumstances by nonjudicial consultative sources. These sources include ethics committees in some hospitals and nursing homes, guidelines for decisionmaking issued by professional societies and associations that represent health care facilities, and institutional policies for decisionmaking. Many questions about the specific legal import of these sources remain unanswered.

There is general agreement that the criminal law is not an appropriate context for judicial review of physicians' decisions about life-sustaining treatment. In the single case in which physicians have been accused of a crime for withdrawing life-sustaining ***treatment, Barber v. Superior Court,*** the California Court of Appeal dismissed the charges, concluding that withdrawal of treatment can only be a crime if the physician has a duty to act, and that a physician does not have a duty to act if the treatment is ineffective, the prognosis is hopeless, and the family wishes to discontinue treatment. The ***Barber*** court and several other courts have expressed great distaste for using criminal law to review the decisions of physicians acting in good faith.

From the discussion in this chapter, it is clear that, in general, decisionally capable adults have a legal right to consent to or refuse proposed medical treatments and that such treatments may be legally withheld or withdrawn from decisionally incapable adults under some circumstances. Nevertheless, there is uncertainty and disagreement about some aspects of the law relevant to these treatment decisions. Areas of consensus and consistency between States appear to be increasing. Yet inconsistencies in court rulings and statutes in different States, and sometimes in court rulings in the same State, make it understandable that health care providers are unsure about their legal obligations to patients and their permissible range of action.

In addition to the fundamental question as to whether the constitutional right of privacy includes a right to refuse life-sustaining treatment and to the very controversial legal issues pertaining to withholding or withdrawing nutritional support and hydration that are discussed in chapter 8, the primary areas of uncertainty are:

- the application of informed consent doctrine in clinical situations in which decisionmaking is virtually continuous and discrete decision points are not obvious,
- the appropriate criteria and procedures for determining decisionmaking capacity,
- the methods by which individuals may express their preferences about life-sustaining

treatments in the event that they become decisionally incapable in the future, and

- the appropriate criteria and procedures for surrogate decisionmaking for individuals who have not executed advance directives.

Each of these areas requires further analysis, discussion, and debate involving both legal experts and the physicians, nurses, and other health care providers who care for critically and terminally ill and severely debilitated patients on a daily basis.

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