LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY

THE LEGAL ISSUES

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LIFE SUSTAINING TECHNOLOGY AND THE ELDERLY: THE LEGAL
ISSUES

INTRODUCTION

A. THE LAW

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

The case law and statutes which address the physician-patient relationship present examples of both moral consensus and divergence. Certain fundamental and agreed upon principles, however, are clearly and uniformly reflected in the laws of all jurisdictions. The rules which define the rights of patients, and the responsibilities of physicians, within the context of a prescribed fiduciary relationship, have been accepted and sanctioned by all parts of society.

For example, it is now without legal contest, with the support of both the Common Law and Constitutional
law, that adult patients of "sound mind" have the right to bodily integrity and self-determination. They have the right to determine what medical interventions shall or shall not be applied to their bodies. Given that patients have this right, physicians therefore have the corresponding obligation to obtain the consent of their patients before they may begin a diagnostic procedure or therapeutic intervention. This rule of necessary consent was built upon a centuries old legal consensus that there can be, in general, no unconscintated to "touching" of a patient by a physician.

Consent, however, is not merely the articulation of an affirmative response. "True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each." (Canterbury, 1972). Physicians consequently have the duty to share information with their patients: a duty to disclose the diagnosis, the proposed treatment, the risks and benefits of that treatment, the availability of alternative treatments and their risks and benefits, and the consequences of not intervening at all.

A necessary corollary of the competent patient's right to be informed and give consent is the right to
refuse treatment, even if the consequence of the refusal leads to serious harm or death. Although in a minority of cases this right may be overridden by certain compelling state interests, it is clearly supported by both Common Law and Constitutional concepts. The choice of the patient to refuse treatment, however, should be arrived at in the same manner as the choice to consent: it should be an informed action. A refusal should not be accepted by the physician without full disclosure of all the attendant options and risks.

These patient empowering principles stand firmly etched in our statutes and case law. They provide guidance and direction for both physicians and patients. Despite this firm legal foundation, there is often tremendous uncertainty and anxiety among caregivers regarding their obligations to patients and their permissible range of independent action as physicians. The traditional paternalism that has historically infused the delivery of medical care still retains its grip on modern day providers. Much of the unclarity results from the fact that technological progress has outpaced the legal process. Contemporary dilemmas of medical practice often evade quick and easy resolution by law. Despite this fact, this chapter will address the present state of the law
with regard to the use of life-sustaining technology and the elderly.

B. The Elderly

As a characteristic in and of itself, age is an inappropriate marker for distinguishing one patient from another. In general, all adult patients should be treated equally: their right to self-determination should be respected, their need to be informed before consenting to or refusing treatment should be honored and their capacity to make such treatment decisions should be assumed. Adults who are not congenitally retarded are generally presumed legally competent to manage their affairs unless and until they are declared incompetent by a court of appropriate jurisdiction. The elderly are no exception.

This does not, however, negate the need to recognize the potential vulnerability of the elderly patient. There are numerous reasons why special attention to, and protections for, the elderly patient are often necessary. For example, the voice of the elderly patient in an acute or chronic care environment may be softer than the voice of a younger patient. As a consequence it may have less impact upon the caregiver. The elderly patient’s capacity to make decisions may fluctuate and may be dependent upon such diverse factors as the type and degree of
dementia, their toxic metabolic reactions to illness and medications, the strangeness of the environment or even the time of day. Inability to make a decision at one point in time does not, however, preclude the ability to make that same decision at another point. Capacity to make health care decisions is "decision specific," that is, decisions involving more complexity or greater risk may require greater ability.

The caregiver of the elderly patient must, however, walk a fine line between respecting the elderly patient's right to make decisions and protecting the patient from "abandonment," i.e., unscrutinized decisions to impose or withhold care. For example, a superficial nod to the tenets that underlie the right of adult patients to be informed, and to give or withhold consent, could leave a cognitively impaired elderly patient at the mercy of a non-autonomous decision. If the elderly patient does not possess the capacity to process the information necessary to render consent or refusal (see discussion of "Competency," below), then the caregiver's acceptance of this patient's articulated choice, simply because patients generally do have the right to make these choices, may constitute a mere mockery of the principles that underlie the concept of informed
consent. Patients who unknowingly make harmful choices need support and protection. The caregiver must therefore guard against this potential isolation of the decisionally incapable elderly patient, while at the same time respecting the right of those elderly who can make health care decisions for themselves.

THE LEGAL CONCEPTS THAT EMPOWER THE PATIENT

A. COMMON LAW CONCEPTS

I. Battery

In medieval England (the source of much of American Common Law) the interactions between physicians and patients were considered "touchings." Physicians were obliged to obtain the consent of the patient before attempting to touch and heal. If consent was not obtained, the physician could later be found guilty of having committed a "battery," i.e., a harmful or offensive nonconsensual touching for which he could be liable to the patient for money damages.

The law placed little emphasis, however, on the quality of the patient's consent. The focus of the law's concern was on the technical administration of an unconsented to procedure. The patient's comprehension of the nature of the touching commanded little attention or respect. Although the physician could not obtain consent through deceptive or
fraudulent methods, there was no encouragement for the caregiver to provide more than a superficial description of the impending procedure. The patient could be monetarily compensated for injury through a tort suit after the fact, but the physician was not obligated to provide much information material to the planned "touching."

II. The Right of Self-Determination

American case law has long recognized an individual adult’s right to be a "master" of himself; that is, an individual has the right to control and choose what happens to his own person. As early as 1891, the United States Supreme Court endorsed this fundamental right. "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." (Union Pacific Railway Co. v. Botsford, 141 U.S. 250 (1891)).

In the context of the doctor-patient relationship, this fundamental right of personal control was first clearly endorsed in the 1914 opinion of Justice Cardozo. "Every human being of adult years and sound mind has the right to determine what shall be done with his own body." (Schloendorff). A strong and
explicit restatement of this right appeared in the landmark informed consent 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." (Natanson, 1960).

The individual patient's right of self-determination is now firmly rooted in American case law and statutory law. It is one of the basic concepts underlying the patient's right to be informed, and it clearly supports the right of adult patients to consent to, or to refuse, proposed medical treatments. All recent courts that have ruled upon the adult patient's right to make health care decisions have unhappeningly endorsed this right of self-determination.

The term "self-determination" is often used interchangeably with the philosophical concept of "autonomy." The roots of "autonomy" come from the Greek words autos, meaning "self" and nomos, meaning "rule." The original intent was to denote the self-governing characteristic of Greek city-states. As applied to individuals, autonomy represents the concept of self-rule and independent action. The
ethicists Beauchamp and Childress have defined the autonomous person accordingly: "The autonomous person determines his or her course of action in accordance with a plan chosen by himself or herself. Such a person deliberates about and chooses plans and is capable of acting on the basis of such deliberations." (Principles of Biomedical Ethics (1983)).

The value and respect that Western philosophy and ethics have traditionally given to the concept of individual autonomy underlie the common law right of self-determination, which in turn supports the adult patient's right to give or withhold consent. Since society strongly endorses the notion that individuals are free to deliberate about their options, chart their own course and act on the basis of their choice, then it logically follows that individuals require both the information that allows them to fully consider their options and the freedom to act according to their decision. Physicians grant patients the dignity and respect that are due all persons when they share information with patients and abide by their fully informed choices.

B. CONSTITUTIONAL CONCEPTS

I. The Right of Privacy

The concept of a personal right of privacy first appeared in an 1890 Harvard Law
Review article co-authored by Louis Brandeis and Samuel Warren, in which they discussed the importance of the "principle of...an inviolate personality." ("The Right to Privacy," 4 Harvard Law Review 193 (1890)) Brandeis further championed this notion when, as a Supreme Court Justice, he stated,

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. (Olmstead v. United States, 277 U.S. 438 (1928), dissenting opinion).

This "right to be let alone," i.e., the right of privacy, is not explicitly articulated in any of the provisions of our Constitution. Nonetheless, it is generally considered to emanate from the "penumbra" of several of the guarantees of the Bill of Rights, including: 1) the First Amendment right of association, 2) the Fourth Amendment right of persons to be secure against unreasonable searches and seizures, 3) the Fifth Amendment right against self-incrimination, 4) the Ninth Amendment, which protects rights not explicitly enumerated in the Constitution, and (5) the Fourteenth Amendment.
guarantees of liberty.

In recent years, the Supreme Court has employed the right of privacy to protect the right of individuals to be free from intrusion when making fundamental and personal decisions. It has been the Constitutional basis used to protect such private individual decisions as: the use of contraceptives (Griswold v. Conn., (1965); Eisenstadt v. Baird (1972); Carey v. Population Services (1977); the termination of pregnancy through abortion (Roe v. Wade (1973); Doe v. Bolton (1973); and the refusal of psychotropic medications by those confined in mental institutions (Mills v. Rogers (1982)).

Although the United States Supreme Court has not yet addressed the issue, several state courts have used the constitutional right of privacy to protect certain health care decisions made by patients. In 1976, the New Jersey Supreme Court was the first to explicitly apply the right of privacy in the context of medical decisions. In the Matter of Quinlan, the New Jersey court held 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" (Quinlan, 1976). Thus, the
court declared that a decision by a 21 year old non
cognitive individual in a vegetative state, to
terminate the breathing apparatus which was thought to
be maintaining her life, was "a valuable incident of
her right of privacy." The court appointed her father
as her legal guardian with the express power to assert
that right on her behalf.

One and one-half years later, the Supreme Court of
Massachusetts concurred in this extension of the right
of privacy to include the right to refuse
life-sustaining treatment. In Superintendent of
Belchertown v. Saikewicz, the Mass. Supreme Court
asserted that the right of privacy "encompasses the
right of a patient to preserve (him or
herself)...against unwanted infringements of bodily
integrity in appropriate circumstances." Since the
Saikewicz case, several other courts have also
permitted patients to refuse life-saving treatment as
an exercise of their right of privacy. (See for
example, In the Matter of Colyer, (WA, 1985)).

Neither the constitutional right of privacy nor
the common law right to self-determination are
absolute. Generally, several state interests have
been found to potentially override these common law
and constitutional rights (see discussion below).
However, it is rare that any of these state interests
are so compelling as to trump the patient’s decision, and in most cases, these two rights stand firmly in support of the ability of patients to make personal health care decisions for themselves.

INFORMED CONSENT AND THE REFUSAL OF TREATMENT

A. THE DEVELOPMENT OF THE DOCTRINE OF INFORMED CONSENT

As described earlier, physicians had little obligation to disclose information in order to avoid liability for a battery. The tort law narrowly focused on the fact of a nonconsensual "touching" or intervention. Whether or not the patient truly understood what was being proposed, or even had enough information to consider the situation, was of little interest to the legal system. Even in the famous Schoendorff case, in which Justice Cardozo extolled the right of adults to control their own bodies, the court was not concerned about the information needed to exercise this control.

As a mechanism to mediate the relationship between physicians and patients, the battery theory was gross and insensitive. It did little to redress the imbalance of power created by medical training, medical institutions, social class and even the process of illness. With their only leverage being the ability to either give or withhold permission, patients, under the tort of battery, had little recourse in the face of
their need for medical care. The common law right to self-determination was thus of little use to patients if physicians had no obligation to disclose information necessary for patients to thoughtfully exercise this right. This was particularly true as newly developed treatments and procedures not only presented more options and benefits, but were surrounded by greater risk and complexity as well.

In the late 1950’s, the established duty of the physician to obtain consent was broadened to include the duty to disclose information. Merely obtaining the patient’s consent would no longer satisfy the physician’s obligation. Courts began to recognize that physicians should be bound by a certain standard of care. Included in this standard would be the obligation to disclose information which would enable patients to give or to withhold consent. If the physician obtained consent but failed to adequately inform, the theory of battery would not apply, but the physician could be liable for malpractice under the rubric of negligence. Negligence, as used in the law of torts, constitutes conduct that falls below the standard of care established by law. If the physician’s negligence caused harm to the patient, then the physician would be liable.

University Board of Trustees was the first to publicly use the phrase, "informed consent," but it was the landmark case of Natanson v. Kline (1960) which more fully articulated this expanded notion of a standard of care with regard to disclosure of information. The Natanson court, however, concerned about the creation of too onerous a burden on physicians, limited their duty to inform to "those disclosures which a reasonable medical practitioner would make under the same or similar conditions." This has become known as the "professional custom" standard and has been adopted by the majority of states which have legally recognized a recovery for lack of informed consent.

Criticism of the "professional custom" standard has focused on precisely the lack of custom in the medical profession to disclose information to patients before obtaining consent. The ancient Hippocratic admonition to physicians to "perform (duties) calmly, concealing most things from the patient while you are attending to him" still infuses medical education and practice. Thus, there is little training for, or support of, physicians who choose to disclose critical information to their patients.

Two cases subsequent to Natanson addressed this criticism of the "professional custom" standard. In Canterbury v. Spence (1972), the court
declared that

(T)o 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.

The court in *Canterbury* outlined a standard of "materiality;" that is, the physician must disclose all information *material* to the patient's decision. This standard was proposed as an objective one, however, for materiality was to be judged not from the subjective perspective of any specific patient but rather from an *objective* perspective. The information should be material to "a reasonable person, in what the physician knows or should know to be the patient's position." This reasonable-patient "materiality" standard was also put forth in the 1972 case, *Cobbs v. Grant*. Since 1972, however, the trend in most states has been to adopt the "professional custom" standard rather than the materiality standard. This is due mainly to lobbying by professional medical organizations, who perceived the risk of liability for physicians to be too great under the materiality standard.

It is generally agreed that in order to fulfill his obligation to inform, the physician must at least disclose the diagnosis, the prognosis, the proposed
treatment, alternative treatments, the risks and benefits of all options and the consequence of not intervening at all. There is, however, a generally recognized, though rarely warranted, exception to this duty to inform. This exception is known as the "therapeutic privilege." Under this exception, the physician is permitted to withhold information if, as a consequence of disclosure, the patient would likely experience direct and immediate harm or partake in self-destructive behavior. This decision to withhold information for therapeutic reasons is considered a medical judgment by the physician.

There is justifiable concern that the "therapeutic privilege" exception, if not stringently applied, could swallow up the general duty to inform. The court in *Canterbury* was keenly aware of this possibility.

The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forego therapy the physician feels the patient really needs. That attitude...runs counter to the foundation principle that the patient should and ordinarily can make the choice for himself.

The withholding of information stands directly opposed to the intent of the informed consent process. Patients are denied the information necessary for the intelligent exercise of their right to consent or refuse. Therefore, information should only be
withheld for therapeutic reasons "when the harm of its disclosure is both highly probable and seriously disproportionate to the affront to self-determination." (The President's Commission, MAKING HEALTH CARE DECISIONS).

B. THE PATIENT'S RIGHT TO REFUSE TREATMENT

Competent adult patients thus have a legally supported right to make health care decisions for themselves, and physicians have the concomitant obligation to provide the information necessary to exercise this right. Inherent in this patient-centered concept of decisionmaking is the permission for patients to make personal or even idiosyncratic decisions once they are supplied the requisite information. The particular subjective values and goals of the patient will obviously inform the patient's final choice. Informed consent accords the competent patient the ability to make a choice, and have it respected, even if the decision is "wrong," or one with which the physician does not agree, so long as it is a voluntary and informed decision.

The theory of informed consent, and the consequent case law and legislation which implement it, also support the right of the competent patient to refuse treatment, even if that refusal could lead to serious
harm or death. Patients and physicians may have different values and goals in the context of health care decisions. If, after full disclosure by the physician, the patient weighs the risks and benefits of a proposed procedure against her own individual fears and hopes, and decides to refuse the intervention, then this is a decision which the physician should respect. The physician certainly should infuse the informed consent discussion with all of his professional expertise and experience, and provide his advice and opinion accordingly; the physician is not a neutral observer but rather a skilled advocate of his position. It is the patient, however, who is ultimately vested with the right to decide whether or not to undertake the treatment. All decisionally capable patients have this right to make a voluntary and informed refusal.

In order to give an informed consent or refusal, however, there are three necessary prerequisites: the choice must be informed, voluntary and arrived at by a person capable of making decisions. The previous discussion has already examined the need for the sharing of information. Voluntariness requires that the decision not be subject to coercion or fraudulent manipulation. Caregivers must be sensitive to such factors as institutional biases, the nature of the
illness and the social and class distinctions between provider and patient, in order to guard against intimidating patients.

Finally, the patient must possess the requisite mental capacity to process the shared information and to make a voluntary health care decision. While most adult patients are either clearly capable or clearly incapable of making a decision, some patients, particularly the cognitively impaired or demented elderly, may have fluctuating or questionable capacity. There are no uniformly accepted criteria for determining capacity, although several distinct standards have appeared in both case law and bio-ethical literature (see discussion of "Comptency" below). There is general accord, however, that the capacity to make a decision should be assessed with specific regard to the choice to be made.

The decision to refuse treatment is a personal choice. Society, however, is not without some interest in these decisions. There are four societal interests which are, on rare occasions, considered to counterbalance and override the patient's rights to self-determination and privacy, which underlie the right to decline treatment. These societal interests are: 1) the preservation of life; 2) the prevention of suicide; 3) the maintenance of the ethical integrity
of the medical profession; and 4) the protection of the interests of innocent third parties. These interests are most often raised in discussions of the right of surrogate decisionmakers to refuse treatment, although they sometimes stand as barriers to the decisions of capable patients, particularly Jehovah's Witnesses who refuse blood transfusions.

There are few situations in which any of these state interests is so compelling that it can override the patient's fundamental right to make decisions for herself. For example, although the preservation of life is certainly a weighty societal interest, it does not diminish the tremendous value given to individual autonomy and privacy. As one court has stated, "The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice." (Saikewicz, 1978). In addition, the competent patient's decision to decline treatment, even life-sustaining treatment, is usually distinguishable from the self-destructive behavior that characterizes suicidal individuals. (cite most recent Bouvia decision).

In certain cases, there are cognizable third party interests in the patient's decision to decline treatment. Particularly when the patient has minor
children who would suffer financially or emotionally from the patient’s decision to refuse, or who would be abandoned because of the patient’s decision to decline life-saving treatment, the state, in its parens patriae role, may feel compelled to override the patient’s health care decision. As a result, this societal interest tends to be a more critical factor when younger patients, who are parents, refuse treatment.

Finally, there is the issue of the ethical integrity of the medical profession when a patient declines treatment. Established case law and bio-ethical theory, however, explicitly articulate that the ethical integrity of caregivers does not demand that patients accept whatever physicians propose, particularly if the treatment would be futile, or if the patient values other qualities above the preservation of life. Indeed, as has been continuously stated, the prevailing ethical standards place a premium on the patient’s right to bodily integrity and right of privacy.

The theories of patient self-determination and the right to refuse are of little value if they are not supported in the reality of medical practice. Indeed, the medical setting and the personalities of the parties involved may have as much, if not more, impact
on the patient's ability to decline treatment than the dictates of any ethical theory or legal decision. For example, the obligations of informed consent are not fulfilled by merely handing the patient a pre-printed form ready for the patient's signature. The sharing and disclosure of information, so that the patient's consent or refusal is truly informed, is a process that requires time, patience and the ability to communicate on the part of the caregiver. However, the realities of modern medical practice, particularly in the acute care setting, may leave caregivers with little inclination or time to translate terms or explain processes. In fact, empirical studies have demonstrated that above all other reasons, patients refuse treatment because they have not been adequately or properly informed. (Meisel, Roth study). Unfortunately, the doctrine of informed consent is more often honored in the breach than in the observance.

The right to refuse treatment also requires courage and personal force on the part of the patient. These may be difficult qualities for a patient to summon forth, particularly an elderly patient whose voice is diminished, or who is combatting the dominance of setting and caregiver. For example, in a setting where a patient is truly dependent for all of
his physical needs, as elderly patients may be in acute care or nursing home settings, there is little likelihood that the patient would risk the disapproval of, or rejection by, her caregivers by refusing treatment. Caregivers must attempt to mitigate institutional or individual biases, so that respect for patient decisionmaking is reflected not merely in bio-ethical and legal theory but in clinical practice as well.

COMPETENCY - PATIENT DECISIONMAKING CAPACITY

There is a presumption in the law that all adults are "competent"—that is, all adults are considered to be able to exercise the full panoply of rights afforded to them upon reaching majority. This legal presumption of competence is a global one. It is a blanket protection which grants individuals the freedom to act in numerous spheres of life. The legal presumption of competency is rebuttable, however, and in reality, not all adults have sufficient abilities to make adequate decisions; many make foolish and self-destructive decisions. However, all adults are considered competent in the eyes of the law unless and until a court of appropriate jurisdiction declares them "incompetent." Unless there is a formal challenge to an individual’s competency in a court this legal presumption, and all the attendant rights
it affords, remains in effect.

When an individual is described as "competent" to make a health care decision, it is unlikely that this label is meant to evoke the global legal presumption just described. Much more likely, the term is used to categorize the individual as one with the requisite capacity to exercise his right to self-determination in the context of the specific health care decision to be made. This more focused use of the term "competent" really identifies the patient as one who possesses the "decisional capacity" to consent to or refuse the particular intervention proposed. Using the label "competent" in this more focused sense also provides the same sort of protection and empowerment that the legal sense of the word provides. For the competent patient is one whose ability to make decisions is not challenged and therefore whose decision is binding.

In the realities of modern medical practice, "competency" is a regularly used and familiar term. It is rarely necessary for anyone to explain that the term is being used in its more limited sense, rather than as the global legal presumption. For purposes of this chapter, however, it is important for the reader to be aware that adult patients can retain their legal presumption of competency while being clearly incapable
of making a specific health care decision. Because of reader familiarity with the term competency, however, the word will be used interchangeably throughout the rest of this chapter with the phrase, "decisional capacity."

If patients are clearly capable, then their choices must be respected, provided their decision was informed and voluntary. For those patients clearly incapable (for example, the comatose patient or the patient afflicted with severe mental retardation or end stage dementia) decisions will have to be made by third parties on behalf of the patient (See discussion of "Proxy Decisionmaking," below). Especially among the elderly, however, there will be patients whose decisional capacity is not clear. Such patients may suffer from the early stages of multi-infarct or Alzheimer’s Dementia, or they may have some other cognitive impairments which diminish their ability to make some choices but may not negate it for all purposes. Their competency may fluctuate: at certain times they may appear quite lucid, while at other times they may seem confused and disoriented. There is no firm agreement in either the bioethical literature or case law about methods for determining whether these patients of questionable or fluctuating capacity possess enough ability to determine the
course of their care, even over caregiver objections.

As noted previously, the elderly may be particularly susceptible to certain characteristics of their illness, medication or environment that could compromise their capacity to make decisions. For example, medications may cause stronger metabolic reactions in the elderly than in other patient populations. Those who assess an elderly patient's competency need to be aware that a change in the type or dosage of medication could substantially affect the patient's mental abilities. Also, in strange, unfamiliar surroundings, where clothing and possessions are taken away (such as in the acute care environment), the elderly patient may become disoriented, as the items and environment that normally cue the appropriate responses are absent. Even the time of day may affect the elderly patient's decisional capacity. The phenomenon known as "sundowning," describes the diminished capacity that an elderly patient may experience as the day draws to a close, as light becomes less evident and vision becomes more difficult and distorted.

None of the above described factors necessarily negates an elderly patient's ability to make decisions for himself. The patient's capacity may fluctuate, but there is no reason that the patient cannot
exercise decisional capacity during intervals of lucidity. Such fluctuations may require assessment of the patient’s capacity to range over a period of time, rather than on a single visit in order to accurately reflect ability. In fact, experts Appelbaum and Roth ("Clinical Issues in the Assessment of Competency," 1981) suggest that, "Whenever the assessment of competency is being conducted in a nonemergency setting, more than one evaluation should take place... (there should be) a cautious approach to the evaluation of competency, represented by at least two contacts with the patient on at least two different days." The elderly patient may thus require the caregiver to spend more time than is typically necessary to assess competency, but the possible affront to a patient’s autonomy, due to hasty and incorrect competency assessments, demands this extra time.

The need to assess a patient’s capacity almost always arises in the context of a proposed diagnostic procedure or therapeutic intervention. There are no uniformly accepted procedures or criteria for determining competency. Who makes the assessment, and on what basis, is often affected by the setting in which consent is sought, the nature and risk of the proposed intervention and the particular
characteristics of the individual patient. In the reality of medical practice, if a patient gives consent for a suggested procedure, there is very little likelihood that the patient's competency will be challenged, even if in fact the patient lacks the capacity to make an informed and voluntary decision. This is particularly true if involved family members also agree with the patient (MAKING HEALTH CARE DECISIONS, p. 61). Assuming the proposed intervention promotes the patient's objective well-being, it is in no one's interest to probe the patient's capacity and undermine the patient's presumed autonomy. There is a valid presumption that if the patient were "competent," he would choose the option that promotes his objective well being anyway. If there is no evidence to the contrary, then there is no reason to challenge this presumption.

Refusals of therapeutic or diagnostic procedures thus trigger most competency assessments. It is admittedly appropriate that caregivers confirm that the patient is capable of making the decision when the patient's choice differs from what is thought to be in the patient's best interest. This is not to say that because the patient chooses differently than the caregiver, the patient must be incompetent. It is merely to suggest that when a patient declines an
intervention which would objectively be medically beneficial, it is prudent to make certain that the patient is accurately informed, acting voluntarily and is able, in some way, to reconcile her decision with her personal values and preferences.

The setting of the proposed intervention may often determine the procedures for assessing capacity. In the out-patient setting, where the patient could implement her refusal by walking out the door, there is probably little the caregiver can do to assess, or act upon his assessment of, the patient's capacity unless the patient is so blatantly compromised that the initiation of judicial competency or commitment proceedings would be appropriate (see discussion of "Proxy-Decisionmaking," below). In this setting, the caregiver has little recourse but to try to work with the patient to clarify the basis of the patient's refusal, and to try to allay any ill-founded anxieties or fears.

In the acute care or long term care environment, it is not so easy for the patient to "vote with her feet." In these settings, where the patient is more likely to constitute a "captive audience," the procedures used to determine decisionmaking capacity may involve more than the primary caregiver or attending physician. If a patient refuses a proposed
intervention, it is likely, at least in the acute care setting, that assessment from a consultation liaison psychiatrist will be requested. Whether or not the psychiatrist has the final word on the patient's capacity to make the decision depends upon many factors, including the policies of the institution, its sensitivity to the rights of patients and even the strength of the patient's refusal.

Caregivers may also turn to family members or other available parties (such as clergy or close friends) for help in assessing the patient's capacity to make a decision. Those who know the patient best can help the caregiver determine whether the patient's articulated refusal is consistent with the preferences and values that she has developed over her lifetime. For example, is the patient's refusal to agree to a proposed amputation consistent with the importance she has previously given to such factors as personal appearance or the ability to walk independently? Perhaps the patient previously told her loved ones that she would never want to lose her leg, even if her life were in jeopardy. Knowledge of these previously expressed personal values, if used expertly by persons sensitive to prior expressions and directives would strengthen the force of the patient's refusal and should make it less likely that the patient's
decision will be overridden. If the physician is aware that the patient is choosing in accord with previously articulated values, then there is little argument for the caregiver not to respect the patient’s choice, even though she is in doubt about the patient’s present capacity to make a decision. Labelling such a patient "competent" would permit the caregivers to respect her personal decision and it would be consistent with the "empowering" notion that underlies the concept of competency.

Finally, it is possible, though usually rare, for true competency assessments to be made outside of the confines of the acute care or long term care environment. On rare occasions, courts of law are presented with the question of whether or not the patient is "competent" to refuse treatment. Usually in the course of this action to the court, the petitioner will also be asking the court to appoint a legal guardian to make the decision for the patient (presumably in favor of accepting the proposed treatment), should the court declare the patient "incompetent."

If the competency assessment is presented to a court, it is likely that the court will strongly rely upon the opinions of the patient’s caregivers, and the assessment of the consultation liaison psychiatrist
(if there is one), as well as any testimony from family and even the patient herself. Judicial decisions often reflect the idiosyncrasies of the specific case. This type of judicial determination of decisional capacity, however, does not necessarily equate to a formal decision on the patient’s legal status as a competent adult (see section "COMPETENCY - DECISIONMAKING CAPACITY" supra). An individual may be considered legally competent, and therefore retain all of the attendant rights, such as the right to vote, make a contract or write a will, but still be declared incapable of making the specific decision in question. The converse may also be true: a guardian may be appointed to manage all aspects of the patient’s life, even though only one type of ability was in question.

Recourse to a court of law in order to determine decisional capacity is not routine, nor should it be (MAKING HEALTH CARE DECISIONS,p. 175). There is a natural disinclination among caregivers and families to seek court resolution on questions of capacity. Bringing these determinations to court is an expensive and often time consuming process. Although it is possible, in cases of emergency, to get quick judicial resolutions, in the ordinary situation, the wheels of justice grind very slowly. State court systems are already overwhelmed and backlogged. In practical
terms, this may preclude the option of a judicial determination altogether. Moreover, the public nature of judicial hearings may be exploitive and invasive in the context of these private, personal decisions.

There is also no evidence that the judges have a better analytic ability or ethical framework on which to decide these cases than those individuals who work in health care institutions. Judges have little experience with these types of cases, and, by and large, rest their decisions on the recommendations of the institution's experts. Little may be gained by bringing these determinations to court. Finally, there is the risk that once the assessment of decisional capacity is brought to the judicial forum, a judge may take it upon himself to rule on the patient's legal status as a competent adult. Not only could the patient be disempowered in the context of the specific health care decision, but as well she could lose all of the fundamental rights that accompany that legal presumption.

The foregoing discussion is not meant to imply that it is never appropriate to ask courts to decide upon a patient's decisional capacity. There may be patients whose refusal is 'so mute or vulnerable that caregivers require a judicial declaration before they are comfortable in accepting the patient's articulated
decision. Courts are the appropriate forums for the determination, and protection, of individual rights. The question of a patient's capacity can, however, be decided in the setting of the health care institution, in most cases, if caregivers are sensitive to institutional or provider biases that may affect the decision. These are difficult and troubling decisions, however. Some institutions even utilize institutional ethics committees to help with the assessment in particularly difficult or controversial cases (see discussion of "Ethics Committees," below).

Substantive Criteria for Determining Competency

There are few public judicial pronouncements on the substantive criteria for assessing decisional capacity. This may be attributed to several factors. First, as previously noted, judicial determination of decisional capacity in the context of health care decisions is rare. Therefore, courts have had few opportunities to consider the issue. In addition, those courts which have ruled in cases involving competency and medical decisionmaking have, for the most part, been presented with patients whose decisionmaking incapacity is clear. In those cases, the adjudication has focused not on the ability of the patient to make the decision, but rather on the ability of another, third party to make decisions on
behalf of the patient.

Nonetheless, two state courts of appeals have publicly discussed the requisite capacity necessary for a patient to decline a proposed intervention. In the case of *Lane v. Candura* (Mass., 1978), the court held that Mrs. Candura, a 77 year old widow who initially vacillated, and ultimately refused to give permission to caregivers to amputate her gangrenous leg, had "the legally requisite competence of mind and will to make the choice for herself." The court recognized that Mrs. Candura was "lucid on some matters and confused on others." The focus of the court's inquiry, however, was whether Mrs. Candura made a choice "with full appreciation of the consequences." With that perspective, the court found Mrs. Candura competent to make her "most unfortunate" but "not...uninformed decision." 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.

The *Candura* court cited for support two earlier cases, *In the Matter of Quackenbush* (NJ, 1978) and *In re Yetter* (PA, 1973), cases in which patients with fluctuating lucidity were also 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... (the)... act."

This focus on the patient’s ability to appreciate and understand the nature and consequences of the act was also important to the court in State Dept. of Human Services v. Northern (Tenn., 1978). Mary Northern was a 72 year old patient with two gangrenous feet who refused permission for both feet to be amputated. She was considered to be generally lucid and of sound mind. On the one issue of her rotting feet, however, Mrs. Northern would not recognize the seriousness of her condition or the possibility that her death might be a consequence of her refusal of surgery. In fact, the court stated, "she evinces a strong desire to live and an equally strong desire to keep her dead feet."

For the Northern court, it was this inability to publicly give evidence of "a comprehension of the facts of her condition," that led the court to hold Mary Northern incapable of making the decision. 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.

Thus, the courts in both of these state cases have
chosen to emphasize the patient's ability to comprehend and appreciate both the situation and the consequences of the patient's choice, when determining whether the patient has the requisite capacity to refuse life-prolonging treatment.

Commentators in both the legal and bioethical literature have also proposed various substantive standards for determining decisional capacity. There is general agreement that the goal of the standard is to construct a test which "best balances the rights of autonomy and protection." (B. Freedman, "Competence, Marginal and Otherwise, 1981). Yet these authorities differ in the language and stringency by which they measure competency.

In its seminal work, "Making Health Care Decisions," the President's Commission stated that decisionmaking capacity requires, to some degree, all of the following elements: (1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and deliberate about one's choices. These criteria require a fairly sophisticated level of patient functioning, and are much more comprehensive than the criteria utilized by courts. It should be noted that the Commission specifically dismissed the use of tests which either look at the outcome of the patient's
choice, or at the patient's status (age), in order to determine competency.

Roth, Meisel and Lidz ("Test of Competency to Consent to Treatment," 1977) described five various tests of decisional capacity, which become more stringent in order of appearance: (1) the ability of the patient to evidence a choice, that is, the mere presence or absence of ability to make a choice; (2) whether the outcome of the patient's choice is reasonable, i.e., would a reasonable person in like circumstances make that decision; (3) whether the patient's choice is based on "rational" reasons - this test looks at the quality of the patient's thinking; (4) whether the patient has the ability to understand the risks, benefits and alternatives to treatment; how the patient weighs or values these elements is unimportant; (5) whether the patient has actually understood the information about the treatment that she was provided.

The philosopher James Drake ("The Many Faces of Competency," Hastings Center Report, 1985) has put forth a "sliding scale" model to assess competency. Under this theory, there is no one single standard that can apply in all cases of determining capacity to consent to or to refuse treatment. Instead, Drake divides the types of medical decisions into three
categories; those that are low risk, and objectively in the patient’s best interest; those of more moderate risk or less certain benefit to the patient; and those in which diagnostic uncertainty is minimal, available treatment is effective and the result of a refusal is likely to be death. With each standard, Drane requires an increasing level of sophistication. For the first set of interventions, the patient need only be aware of the general situation. For the next level, the patient must be able to understand the risks and options, and then be able to choose based on that understanding. Finally, in the most serious situations, the patient must have the capacity to appreciate the nature and consequences of this decision. Under this “sliding scale” standard, then, as the risks from refusing grow larger, so, too, does the stringency through which patients’ refusals are screened.

Benjamin Freedman proposes only one standard, but it is quite a sophisticated one. Under his model to assess competency, the patient must be able to use the information which was provided during the informed consent process to formulate what he calls “recognizable reasons” to support the choice she makes. That is, the patient must articulate the premises on which her decision is based, and her
choice or conclusion must be related to these premises, although the premises need not be strong enough to justify the conclusion.

All of the above proposed tests tie the assessment of competency to the specific decision to be made. One noteworthy exception, however, is the standard put forth by Virginia Abernathy. Her test, based on her analysis of the Mary Northern case (see discussion above) is quite distinct. What Abernathy proposes is that competency should not be assessed in the emotionally charged atmosphere of a specific situation, which she claims can put too much emphasis on the outcome of the patient's choice. Instead, Abernathy proposes that, "A patient who was informable and cognitively capable of making ordinary decisions on matters unrelated to the crisis at hand would be held competent to refuse or accept medical interventions." ("Compassion, Control and Decisions About Competency," 1984). This model departs from the general consensus that decisional capacity is directly related to the specific decision to be made.

It is not the intent of this description to provide a detailed critique of each of the proposed models, or to try to synthesize all of these tests into one, understandable, easily applied standard. Rather, the existence of this variety of tests among
courts and commentators merely highlights the fact that determinations of capacity, while at times requiring just a common sense analysis, do, at the same time, reflect conflicting societal judgements about when patients should be given the freedom to decide as they please, and when protection, more than autonomy, is the primary goal.

THE ELDERLY PATIENT CAPABLE OF MAKING DECISIONS; THE EXERCISE OF RIGHTS IN CONTEXT

Those elderly who are clearly capable of making decisions, or who have been assessed to be capable, by whatever standard employed, have the same rights as all other adult patients in the context of making health care decisions. Their age in no way diminishes the recognition and respect that caregivers owe to all competent patients who face a proposed medical intervention. The competent elderly patient has the right to be informed about her diagnosis; the proposed intervention, the risks of that intervention, the availability of other options and their risks, and the consequences of not intervening at all. After receiving this information, the competent elderly patient can either give consent, or refuse the intervention, even if that refusal should lead to serious harm or even death for the patient. Supported by the common law right to self-determination and the
constitutional right of privacy, competent elderly patients are empowered to decide however they wish.

In the context of different settings, however, elderly patients may experience different degrees of difficulty in trying to exercise these rights. For instance, in the ambulatory care setting, where the patient receives medical attention in the physician’s office, patients may be in a better position to demand more from their providers. The setting may be less intimidating than an institutional setting, and there may be more equilibrium in the relationship between patient and physician. For example, the ambulatory patient may be in better health than the in-patient or institutionalized patient, and thus may overall be functioning better. The encounter between patient and physician can be scheduled at a time that the patient chooses, rather than at arbitrary times when the physician stops by the patient’s room. Finally, if the ambulatory patient is dissatisfied with the provider, or the information and options presented, the patient can simply walk out of the office and obtain the advice and services of another provider.

This apparent ease for the elderly patient in the ambulatory care 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 exist on fixed or low incomes. If a caregiver does not accept Medicaid, or requires the patient to pay a premium above the Medicare reimbursement rate, then that physician is, in effect, unavailable for a large percentage of elderly patients. Moreover, although living in the community, many elderly patients cannot easily travel from one caregiver to another. They may depend upon whomever is accessible in their immediate community. This may, as well, foreclose the option of "shopping around" for alternative providers.

There are no published judicial decisions which discuss the rights of the elderly patient in the outpatient, ambulatory care setting. There is, however, every reason to assume that the competent patient's right to make informed, voluntary decisions applies in this setting, and that this right could be judicially vindicated if necessary.

The In-Patient Acute Care Setting

Acute care hospitals are often overwhelming and intimidating institutions. They tend to be large, complicated and depersonalized. There is an attendant loss of privacy and self for all patients. Generally, patients do not wear their own clothes nor are they surrounded by objects that bring familiarity or comfort. Their visitors are restricted, and their
telephone calls are limited. Patients are continually subject to a barrage of providers and procedures, many of which do not even require the patient's consent. (This is particularly true with the administration of medications.) Overall, the patient has little influence or control over the daily course of events in the acute care institution.

The primary goal of acute care hospitals is the diagnosis and remedy of acute medical episodes, so that patients can return to their baseline functioning. There is a strong institutional bias and commitment toward effectuating a "cure" or toward preserving life, and sophisticated equipment and procedures are readily available to achieve these goals. The patient who declines these interventions, or refuses life saving or sustaining remedies, stands directly opposed to these institutional commitments.

As the President's Commission noted,

For a patient to decline procedures needed to make a definitive diagnosis, to reject vigorous treatment that might possibly bring longer life, or to find meaning in death and suffering is not only seen by most hospital personnel as aberrant or even suspect behavior, but may actually be very disruptive of the usual institutional routines and assumptions. ("Deciding to Forego Life-Sustaining Treatment," p. 107)

In the face of these institutional forces, patients, particularly elderly patients, may be discouraged from asserting their rights. Particularly
with the new prospective payment reimbursement schemas, the acute care environment may not be supportive of the elderly patient who requires a more time-consuming explanation, or who needs to weigh available options in his own time and manner. The economic forces that drive modern acute care hospitals may thus diminish the rights and protections afforded to competent patients.

Several state supreme courts, however, have affirmed the right of competent, hospitalized elderly patients to decline proposed interventions and to exercise their right to make health care decisions for themselves. These rights have even been upheld in the Federal District Court in Washington, D.C., for patients hospitalized in military hospitals (*Tune v. Walter Reed Army Medical Hospital*, Civil Action No. 85-0697, 1985).

In *Satz v. Perlmutter* (Florida, 1980), the state appeals court affirmed a trial court order which permitted a competent, terminally ill, hospitalized patient to be removed from the respirator which 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.

A more recent, and perhaps stronger case upholding the rights of competent, elderly patients in the acute care environment, is the case of Bartling v. Glendale Adventist Medical Center (CA, 1984). Mr. Bartling was a 70 year old gentleman 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. Mr. Bartling agreed to a biopsy, during the course of which his lung collapsed. Mr. Bartling was placed on a ventilator, and efforts to wean him from it were unsuccessful.

When both Mr. and Mrs. Bartling requested that the ventilator be removed, the hospital refused to comply, and in fact, placed Mr. Bartling in "soft restraints" to prevent him from disconnecting the ventilator tubes. Mr. Bartling petitioned the court: he sought damages and asked for an order to restrain the hospital from administering any unconsented to medical care. The hospital, a religiously affiliated acute care institution, countered 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."
The appeals court first recognized that Mr. Bartling was competent to decide whether to have the ventilator disconnected. They found that he "knew he would die if the ventilator were disconnected but nevertheless preferred death to life sustained by mechanical means." In a clear statement of the right of competent hospitalized patients, the court also stated:

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. (emphasis added)

In most instances, the goal of maintaining or preserving life is a laudable one for acute care institutions. That is, in fact, part of their justification for existence. However, all of their technological empowerment and institutional biases cannot be permitted to negate the competent, elderly patient's right to choose whatever course she wishes. If the patient refuses the proposed intervention, and there are no other medical or palliative offerings available for the patient, then perhaps the patient no longer requires the acute care services of a hospital, although that setting may be the only one able to provide adequate comfort, care and support. But patients do not leave their rights at the door when
they enter acute care institutions. Hospitals cannot force treatment on competent, unconsenting hospitalized elderly patients.

**The Long Term Care Setting**

Over 80% of long term care residents are over 75 years of age. (Deciding to Forego... p. 108), and ___% are without living or involved family. With those statistics, one might expect that such facilities would be sensitive to, and protective of, the rights of elderly individuals. However, despite licensing and accreditation procedures and the guidelines put forth by various organizations and a Bill of Rights, the quality of care and the respect given to residents, varies greatly among individual institutions.

For certain elderly individuals, entering a nursing home can represent a positive transition; it can provide a chance to live in a supportive environment and to interact with other individuals. However, for many individuals, entering a long term care facility represents a relinquishment of hope. Once admitted, very few people leave nursing homes. There is even a phenomenon known as "transfer trauma," which describes the increased risk of morbidity for elderly individuals who reluctantly or unwillingly enter a long term care facility. With such an aura of resignation and defeat, it is not hard to understand how an elderly
and alone resident would choose not to fight aggressively for the exercise and protection of her rights. It is possible the individual would not even be cognizant about her rights as a nursing home resident, the patient Bill of Rights notwithstanding.

Residents in nursing homes are often chronically ill and dependent. Even if a resident has the full capacity to make decisions, the environments of many facilities engender extreme dependence and loss of control. Despite this, there is neither theory nor argument to distinguish the decisionally capable resident from other capable elderly. They possess the right to choose individually appropriate healthcare. Indeed, because of the number of elderly residents, and the inevitability of their morbidity, it could be argued that long term care facility caregivers and administrators have an affirmative obligation to support and encourage the exercise of rights. One suggested approach might be to document personal preference regarding health care interventions as part of the facility’s admission process.

There is one known (but unpublished) judicial opinion that discusses the right of the competent nursing home resident to refuse care. In Matter of Plaza Health and Rehabilitation Center (NY Supreme Court, 1984), the court stated that the resident, an 85
year old man, was competent at the time he began to refuse to eat ("he knowingly and willingly made that decision with the full understanding of the consequences, a hastened death") and therefore, the facility was neither required nor permitted to hospitalize the resident, in order 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." 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 to self-determination.

Elderly nursing home residents who possess the capacity to make decisions should not be treated differently because of their age or place of residence. As with all other competent adults, they have the right to be informed, and the right to voluntarily give or withhold consent, before any medical intervention is begun.

THE ELDERLY PATIENT NOT CAPABLE OF MAKING DECISIONS: THE EXERCISE OF RIGHTS IN CONTEXT

For those patients who are clearly incapable of making decisions, or assessed to be incapable of addressing the particular decision to be made, some
other third party must make the health care decision on behalf of the patient, even if that decision is to continue care already begun. The questions to be addressed are as follows: (1) Can treatment ever be refused on behalf of an incompetent patient? (2) If so, who is empowered to make that decision? and (3) What are the criteria that would guide a third party making a decision on behalf of such a patient?

Incompetent patients are not without rights with regard to medical decisionmaking. The common law right to self-determination, and the constitutional right of privacy survive the incapacity of the individual. Courts that have considered treatment decisions for incompetent patients have begun their analyses with the premise that the rights accorded to these patients are the same as for those capable of deciding. For example, in the *Saikewicz* case, which involved possible chemotherapy for a 68 year old congenitally retarded man, the court 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."

Since courts have recognized the uniform
applicability of the fundamental rights which protect and empower patients, the challenge has been to develop procedural and substantive criteria that protect the integrity of individual decisions, protect vulnerable classes and shield society from decisions for which no agreed upon norms exist. There are no uniform legal rules with regard to surrogate decisionmaking. Guidelines have been developed in cases, bioethical commentaries, and state legislation. The legislation has particularly focused on the appointment of proxy decisionmakers and procedures for documenting patient preference before incompetency sets in. There have been distinct variations in the policies put forth, and no one description will cover every jurisdiction. It is, however, possible to highlight the major judicial opinions, and the factors which appear to distinguish them.

The Setting

There are no published empirical data nor even anecdotal information on decisionmaking for the incompetent adult patient who lives in the community. Although surrogate decisions to withhold or withdraw treatment from patients living at home must arise, they exist out of public scrutiny. Moreover, since approximately 60-70% of all Americans die in acute care hospitals, and another 15% die in long term care
facilities ("Deciding to Forego," p. 106), it is reasonable to surmise that decisions about life-sustaining treatment for decisionally incapable elderly individuals infrequently arise in the home setting. The elderly who are that ill are more likely to be in either an acute care, or long term care, facility. When such treatment decisions do arise in the home setting, they are likely to be private decisions made by those who care for these incompetent adults, with or without the consultation of their physicians.

Most decisions to withhold or withdraw treatment from incompetent elderly patients arise within the confines of either acute care hospitals or institutional facilities (including long term care facilities and psychiatric institutions). In many cases, residents of institutions are transferred to acute care hospitals, where issues regarding the appropriateness of life-sustaining treatment will be resolved.

Courts that have considered these treatment decisions have generally made no effort to limit their decisions to specific settings. A notable exception was the New Jersey Supreme Court case, Matter of Claire Conroy (1985) which held to apply only to nursing home residents (see discussion
of Conroy, below). Scholars, therefore, have generally not categorized these cases on the basis of the setting of the decision. The institutional biases and interests of acute care hospitals and long term care facilities (as discussed, supra) should not be overlooked, however. They may affect the ability of third parties to make decisions on behalf of incompetent elderly individuals in the same way they affect the competent patient's right to make decisions for herself.

PROXY DECISIONMAKING FOR INCOMPETENT PATIENTS: THE PROCEDURES FOR APPOINTING SURROGATES

Patients who are not capable of making decisions require others to decide for them. These third parties are commonly known as a "proxy" or "surrogate" decisionmakers. Who that third party is depends on several factors, including: the directions, if any, left by the patient before she became incompetent; the availability of family or close friends of the patient; the consensus or controversy that surround the decision to be made; and, the case law and statutes of the jurisdiction.

1. THE PATIENT APPOINTED PROXY DECISIONMAKER

In many jurisdictions, adults have the legally authorized ability to appoint, in advance of incompetency, a third party to act as their proxy
decisionmaker. Depending upon the state, this can either be done through a durable power of attorney or in the context of a living will (see discussion below). In this way, should the individual subsequently be incapable of making health care decisions, an available and recognized surrogate will be empowered. This advance appointment obviously has several preconditions: the patient must have previously been competent, must have thought about the need to appoint a proxy in advance, and must have had some third party available who was willing to take on that role. For elderly individuals who are all alone in the world, this advance appointment of a proxy is obviously not feasible.

For those elderly individuals who do have an available surrogate, appointing this person in advance can avoid or minimize subsequent confusion, can clarify possible ethical dilemmas and may even prevent pain and suffering. Selecting a proxy in advance allows the patient to ensure that someone trustworthy and knowledgeable will be acting on the patient's behalf if she can no longer make decisions. It will also encourage the elderly individual to consider and discuss her values and preferences with regard to health care decisions, so that when decisions must be made for her, those decisions will mirror what she
would have chosen, were she able to choose.

There are, in general, two legally recognized routes for the advance appointment of proxy decisionmakers. First, eight states \(^1\) have "Living Will" statutes (see discussion, below), that specifically provide for the appointment of a proxy decisionmaker in the context of filling out a living will document. (Physician and the Hopelessly Ill Patient, 1985). Depending upon the specific state statute, proxies appointed through this method can serve several functions: (1) they can serve as a competent advocate for the explicitly documented preferences of the patient; (2) they can fill in gaps or clear up confusion based on the prior directives communicated by the patient; or (3) they can make decisions when no prior, explicit directives have been left at all. The legal authority of proxies who are appointed by this method, in states where living will documents have not been recognized by statute, is uncertain. There is, however, general recognition that even without a living will statute, an individual, while competent, can document explicit future directives and that respect should be given to these

\(^1\) Delaware, Florida, Indiana, Iowa, Louisiana, Virginia, Utah, and Wyoming
directives once the patient is no longer capable of making decisions.

The other method through which proxy decisionmakers can be appointed by the competent patient in advance, is through state "Durable Power of Attorney" statutes. Every state (except the District of Columbia) has such a 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 it survives, or continues, even if the principal subsequently becomes incompetent (although it ends at the death of the principal or agent). These statutes were originally drafted to permit financial or property transactions in the absence of the principal. Their applicability in the context of health care decisions is uncertain, although three states (California, Colorado and Pennsylvania) either expressly or implicitly allow this use.

2. Court Appointed Proxy Decisionmakers

Under their parens patriae powers, states have the authority and obligation to protect individuals who are incapable of protecting their own interests. This empowerment, which is derived from English common law,
grants courts of law the authority to appoint legal guardians, both for children (who are categorically considered unable to protect themselves) and for "incompetent" adults (some states require that the adult first be adjudicated "legally incompetent" before a general guardian will be appointed; other states recognize that adults can be "incompetent" or functionally incapacitated in only certain spheres, and will therefore appoint guardians for limited purposes). These appointment proceedings are alternatively known as guardianship, conservatorship or committeeship proceedings, depending upon the state statutes.

Resort to a court of law for the appointment of a legal guardian to make health care decisions on behalf of an incompetent patient is not typical. It is, however, most likely to occur when either: 1) the incapacitated patient has no family or close friends; (2) the treatment plan is considered controversial, and caregivers and family want judicial guidance and assurance about the appropriateness of their actions; (3) the patient has left no explicit directives for caregivers to follow; or (4) caregivers and family or close friends disagree on the action to be taken on behalf of the patient. Courts are willing to appoint legal guardians for the specific purpose of making health care decisions; some of the most noteworthy
state judicial decisions about the rights of incompetent patients have arisen in this context (including the Quinlan case (NJ, 1975)).

During judicial hearings for the appointment of a legal guardian for incompetent patients, courts will usually appoint someone to serve as the incompetent’s “guardian ad litem.” The guardian ad litem investigates the situation and makes a recommendation to the court with regard to the appropriateness of appointing a legal guardian. It should be noted that in many state statutes, there is a recognized preference for appointing a family member to be the incompetent’s legal guardian. It is not clear, however, whether guardians already appointed for general management tasks have the authority to make specific health care decisions for their wards.

3. The Informal Designation of Proxy Decisionmakers

In the realities of everyday health care delivery, not every incompetent patient has a court appointed guardian, or a surrogate whom he explicitly appointed before he became incompetent. The ordinary practice in acute care hospitals, and other health care institutions, is for caregivers to turn to next of kin or other close family or friends who appear to know the patient and have the patient’s best interests in mind. Oftentimes, a particular family member will step
forward and present herself to the caregiver as the family spokesperson. At other times, the caregiver may have to use her judgment to decide who among those present is best able to assist with the decisionmaking for the incompetent patient. If the caregiver cannot select someone, or if several family members disagree, for example, the caregiver may be forced to petition a court for a legal guardian.

In most states, there is no clear legal authority for family members to make decisions on behalf of their elderly relatives, although it is a common and widely accepted tradition. In general, family members are not, merely because of their relationship, legally empowered to act on behalf of their loved ones. Five states, however, in the contexts of judicial opinions, have recognized this common practice as a means of exercising the incompetent patient’s common law or constitutional rights (Physician and the Hopelessly Ill Patient, 1985). The assumptions which underlie this tradition of informally-designated family surrogates include, (1) the belief that the family is the most concerned about the patient’s "best interests," and (2) the belief that the family is the most knowledgeable

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2 California, Connecticut, Florida, Georgia and New Jersey
about the patient's values and preferences. If there is evidence to contradict either of these beliefs, then the physician is best advised to seek out legal counsel, and perhaps petition a court for appointment of a legal guardian.

THE SUBSTANTIVE BASIS FOR THE SURROGATE DECISION

By whatever method selected, the surrogate must possess the following qualities: (1) she should have no conflict of interest with the incompetent patient; (2) she should have the capacity to participate in the decisionmaking process in an informed and conscientious manner (with the necessary corollary that the patient's caregiver must provide the appropriate information); and (3) she should have the ability to advocate the incompetent patient's interests, and to maintain control throughout the decisionmaking process. (Capron, "Authority of Others to Decide About Biomedical Interventions with Incompetents," in WHO SPEAKS FOR THE CHILD, 1982).

As stated earlier, there are two primary values in medical decisionmaking: (1) to promote the patient's well being, and (2) to respect the patient's right to self-determination. On his own, the incompetent patient is unable to promote either of these. It is up to the surrogate to make decisions on behalf of the incompetent patient, in a manner consistent with the promotion
of these values.

There are two legal standards which generally guide proxy decisionmaking: the "substituted judgement" standard, and the "best interest" standard. Each standard guides decisionmaking from a different perspective. The substituted judgement standard requires the surrogate to look to personal values and preferences of the patient when the surrogate makes health care decisions. It is a subjective standard that necessitates that the patient at one time must have been competent, and must have expressed, in some manner, values and preferences that are relevant to the decision to be made. If the patient left no directives, failed to convey any preferences to anyone, or was never competent at all, then the surrogate must rely on the "best interest" standard for guidance. This standard focuses on more objective, societally shared criteria. The surrogate makes the decision from the point of view of the "reasonable person," and considers such factors as the relief of suffering, the usefulness or futility of the proposed intervention for the patient, (that is, is the treatment medically indicated), and the risks, benefits, and the burdens of the proposed intervention to the patient. Most scholars agree that benefits and burdens to family and society are irrelevant to the decision.
Under the 'substituted judgment standard, the surrogate's decision should be the same decision that the patient would have made, were she able to do so. As the court in the Saikewicz case stated, this standard requires the surrogate to "don the mental mantle of the incompetent." (What is interesting to note is that the Saikewicz court used this standard despite the fact that Mr. Saikewicz, a 67 year old congenitally retarded man, had never been competent to make this, or any other, decision.) The President's Commission recommended substituted judgment as the preferred standard, because it allows the patient's own definition of "well-being" to be in control, and thus, in a certain way, permits the incompetent patient to exercise her right to self-determination, although she in fact is unable to do so.

There are, in general, two types of substituted judgment cases: (1) those in which the patient made her wishes and preferences explicitly clear, through documentation or discussion prior to becoming incompetent; and (2) those in which the patient left no explicit statements, but because of a close familiarity with the patient, her lifestyle and patterns of behavior, the surrogate is able to infer what the patient would have wanted regarding the specific decision to be made. Some states, (notably New York)
require an explicit statement of the previously competent person, which is supported by "clear and convincing" evidence (Matter of Storar, In the Matter of Phillip Eichner, 1981). No inferences are permitted in those jurisdictions. Other states, such as Massachusetts, not only permit inferences, but they also extend the use of what they consider the "substituted judgment" standard to situations where the patient was never competent.

The most effective way for a patient to ensure that her surrogate will respect her values and preferences, should she some day be incapable of making decisions for herself, is through the use of an "advance directive." This is a generic term that refers to several sorts of instruments which can be executed by the patient before incompetency intervenes. Such instruments include living wills, durable powers of attorney, and specific state documents created by statute. In some circumstances an open and frank discussion with a physician, which is documented in a chart, may serve a similar purpose. However, this private and confidential notation can only be invoked by one person - it has no public existence, as do living wills and durable powers of attorney.

In the area of advance directives, the living will
has perhaps been the most promoted method for documenting patient preferences and desires. When such documents were originally developed, they had no legal sanctioning. Because they enunciated the specific preferences of the patient, however, they were considered morally persuasive and were consistent with the concept that the right to self-determination and the right of privacy extend to the incompetent patient as well. The need for such documents became clear, as medical technology was able to extend "life" beyond what many individuals considered a life worth living for themselves. However, early drafts of the document were criticized because their language was non-specific, terms were not adequately explained and thus surrogate and physician were left with substantial ability to interpret the documents however they wished.

In an attempt to give living wills more binding legal effect, and to standardize language, meaning and usage, many states began to enact legislation which established formal requirements for a living will, and permitted its use in certain prescribed situations. California was the first state to enact such legislation, and the name for its statute, the "Natural Death Act," has become the generic label for many state statutes which legally authorize such advance
directives. Since 1976, 36 living will laws have been enacted.

There is no real uniformity among the various state living will laws, which raises questions about the effectiveness of the document in a state other than the one in which it was executed. In general, however, these statutes tend to limit the authorized availability of the living will to certain, often narrowly defined, cases. For example, the statutes are generally restricted to use only by the "terminally ill," a term not often defined. This precludes the use of the documents for a large percentage of elderly who, although not critically or terminally ill, may nevertheless suffer from painful acute or chronic illnesses. Many of the statutes also employ such vague language as "extraordinary" or "artificial" treatment, without adequate definition. Few of the statutes provide for any punishment or fines for caregivers who fail to respect the terms of the document. In those states, physicians may disregard the living will with impunity.

Nonetheless, these state statutes have provided legitimacy for the idea of advance directives. They outline substance and procedure for patients, surrogates and physicians to follow, so that parties can act with some legal 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 the public conscience, and encourages more individuals to consider and document their preferences in advance of incapacity. There is widespread recognition that although these state statutes have flaws, they have provided the impetus for further discussion and more sophisticated legislation. In fact, in response to the vagaries of the present statutes, both the National Conference of Commissioners on Uniform State Laws, and the Legal Advisers of Concern for Dying (a New York-based educational council, devoted to the promotion of living wills) have each proposed model legislation which addresses many of the problems of the current statutes.

There are, however, many patients who, for various reasons, have failed to make their preferences known. For many individuals, consideration of a future period when they might not be capable of making decisions for themselves is troubling. An element of denial, or unwillingness to consider mortality, may prevent an individual from anticipating, and planning for, future incapacity. In addition, for those elderly who are alone or without family, there may be no one available with whom such discussions can be held. Although this
would not prevent an individual from documenting her preferences, many elderly may be simply unaware of the need to do so or, if aware, unable to secure assistance.

Despite the lack of an explicit prior statement, many jurisdictions are willing to permit the surrogate to infer what the patient would have chosen if able to, based on a familiarity with the patient's lifestyle and patterns of behavior. This is also considered to be a substituted judgment by the surrogate. For example, in the case of Matter of the Welfare of Colyer (Washington, 1983), 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 respirator, and remained in a comatose, unresponsive state. "Her prognosis for any sort of meaningful existence was zero." Mrs. Colyer's husband, acting as her guardian, asked a court for permission to remove Mrs. Colyer from the respirator. Although Mrs. Colyer had never explicitly stated her preferences regarding such an act, her husband was able to infer that this would have been her decision as well, had she been able to make it. The 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 are 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.

An exception to this general acceptance of an "inferred" decision by the surrogate, is the New York case, Eichner v. Dillon (N.Y., 1981). In that case, Brother Fox, an 83 year old member of the Society of Mary, was being maintained by a respirator in a permanent vegetative state. The local director of the society petitioned a New York court to have the respirator removed. The court explicitly stated that it was not dealing with a case where a third party was attempting to make the decision on behalf of Brother Fox, based on the patient's lifestyle. Rather "Brother Fox made the decision for himself before he became incompetent." That is, the court stated that there was "clear and convincing proof," not just inferences, that the now incompetent patient would wish "to terminate life sustaining procedures when there is no hope of recovery."

In Brother Fox's case, the proof was explicit. The court found:

he carefully reflected on the subject, expressed his views and concluded not to have his life prolonged by medical means if there were no hope of recovery... (this is) supported by his religious beliefs and is not inconsistent with his life of unselfish religious devotions. These were obviously solemn pronouncements and not casual remarks at some social gathering...
this was a persistent commitment is evidenced by the fact that he reiterated the decision but two months before his final hospitalization...What occurred to him was identical to what happened in the Karen Ann Quinlan case, which had originally prompted his decision.

Although the previously expressed views of Brother Fox were oral, rather than written, they were explicit; there were also multiple witnesses to these discussions. His previously expressed concerns were directly applicable to the situation which developed. It is not clear whether a New York court would accept evidence less clear and direct than this in order to permit the termination of life sustaining technology for an incompetent patient. It is, however, highly unlikely that a New York court would at present accept a surrogate decision based solely on the surrogate's general familiarity with the patient and her lifestyle.

In the New Jersey case, Matter of Claire Conroy (NJ 1985) the court discussed the 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 on what she would have wanted, so too did the New Jersey court outline relevant information. The 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. 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.

The Conroy court, in fact, set forth three alternative standards for surrogate decisionmaking, which depend upon the amount of evidence regarding the patient's preferences, and the benefits, burdens, pain and suffering which seem to attach to continued treatment. It must be noted, however, that the court restricted its opinion to cases involving, "nursing home residents, suffering from serious and permanent mental and physical impairments, who will probably die within one 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." The three standards are as follows: (1) a "subjective standard," where it is "clear that the particular patient would have refused the treatment under the circumstances involved"; (2) a "limited-objective test," which permits life-sustaining 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."

Procedural Review of Surrogate Decisionmaking

Whether or not a court of law must review a surrogate’s decision to decline or withdraw life-sustaining treatment on behalf of an incompetent patient, varies widely among jurisdictions. Even within the same jurisdiction, some types of cases appear to require more review than others, depending upon such factors as the setting of the decision, the treatment options available and the vulnerability of the class to which the patient belongs. In many jurisdictions, cases of first impression were brought to court precisely because of uncertainty regarding appropriateness of non-judicial resolution. In the context of deciding those cases, courts outlined the required procedures for surrogates to follow which may or may not require regular judicial involvement.

Examples of different state requirements for judicial review of surrogate decisionmaking can be gleaned from case examples from Washington, New Jersey and Massachusetts.

In the context of two cases, for example, (Matter of
Welfare of Colyer, 1983, and Matter of Guardianship of Hanlin, 1984), the Washington courts established the following procedures. If the family, treating physician and institutional "prognosis committee" all agree that it would serve the incompetent patient's best interests to withdraw or withhold life sustaining treatment, 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. The Florida Supreme Court has also concurred in this general sort of procedure (John F. Kennedy Hosp. v. Bludworth, 1984). The Florida court stated that the focal point of such decisions, once all parties agree, should be "whether there is a reasonable medical expectation of the patient's return to a cognitive life as distinguished from the forced continuance of a vegetative existence."

Alternatively, the Washington Supreme Court has stated that in cases where no family is available, a guardian must be appointed by a court. However, once there is a court appointed guardian, there is no need for judicial involvement in the substantive decision to withhold or withdraw life-sustaining treatment, if the guardian, treating physicians and prognosis committee are all in agreement. However, in both of these situations, any party is permitted to petition for court intervention, and furthermore, "if there is a disagreement between parties involved in the
decisionmaking process, court intervention would be appropriate." (Hamlin).

The New Jersey court, in the Quinlan case (1976) did not expressly address the issue of whether a court appointed guardian was necessary. However, in the case of Karen Quinlan, a 21 year old woman in a permanent vegetative state, the court stated that: (1) if the patient's family and guardian agree, and (2) the patient's attending physicians conclude there is "no reasonable possibility the patient would emerge from her comatose condition to a cognitive, sapient state, and that the life-support apparatus should be discontinued" then, (3) consultation should be sought from the institution's "Ethics Committee." If the Ethics Committee agrees with the attending's conclusion, then treatment may be withdrawn, judicial review is not necessary and there will be no attendant civil or criminal liability for any of the involved parties.

With regard to nursing home residents, in the context of the Conroy case (1985), the New Jersey Supreme Court spelled out special procedures, different from those articulated in the Quinlan 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." Thus, in a long term care facility, life-sustaining treatment can only be withheld or withdrawn from an incompetent resident if the
following procedures are followed: (1) There must be judicial determination that the patient is incompetent to make the decision, and if so, a court appointed guardian is necessary. This is required even if the patient has already been declared incompetent, and already has a general guardian, (2) If, based on one of the three articulated surrogate standards (see previous Conroy discussion supra), the guardian believes life-sustaining treatment should be withheld or withdrawn, then he must contact the State Office of the Ombudsman; (3) the Ombudsman will 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.

The procedures laid out by the New Jersey court have been criticized by some for their complexity and tendency to limit the applicability of the Conroy decision. Others have praised the protective nature of the rule, given the vulnerability of institutionalized demented elderly. Although judicial involvement in the substantive decision to withdraw or withhold life sustaining treatment is not required, there is need for the involvement and oversight of a state agency. It must also be remembered
that this decision, and its procedural requirements, are available only for certain, court-defined nursing home residents (See Conroy discussion, supra).

Finally, in a series of cases (Saikewicz, 1977, Dinnerstein, 1978 and Spring, 1980), Massachusetts set out somewhat confusing and unclear criteria for determining when judicial review of surrogate decisions is necessary. In the Saikewicz case, the Mass. court explicitly rejected the Quinlan procedures, and stated, "We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent." Mr. Saikewicz was a 67 year old institutionalized congenitally retarded man. He suffered from acute and terminal leukemia, and the court stated that only it could permit chemotheraphy to be withheld from him.

In the Dinnerstein case, the patient was a 67 year old woman with Alzheimer's Disease in a 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 the Saikewicz case as one involving treatment that could prolong life: that is, 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 threshold of death," the court considered a "Do Not Resuscitate" order a question for the attending physician, not for a court of law.

Finally, in the Spring case, the Massachusetts court attempted to clarify its two earlier opinions. The court articulated a list of factors that might influence the decision as to whether to seek prior judicial approval of surrogate decisions, although the court made no attempt to categorize which combinations of these factors would indeed 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 the treatment, the patient's understanding of the 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 in Spring 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 upon the jurisdiction, patient condition and setting of the decision. Different jurisdictions place different values on the roles of physicians, families, institutional committees,
state agencies, and courts in decisions to withdraw or withhold life sustaining treatment from incompetent patients. This again reflects the tension that underlies these decisions: a tension between permitting the preferences of previously competent, but now incompetent patients to guide surrogate decisionmaking, and protecting those incompetent patients who may be truly alone in the world from the potential abuses of surrogate decisionmaking.

Other Consultative Sources

1. Ethics Committees

In many acute care and long term care facilities, institutional "ethics committees" are available to assist patients, family and caregivers with difficult, ethically troubling decisions. These committees were first given public recognition in the 1976 New Jersey case, Matter of Quinlan. Although such committees were virtually non-existent at that time, the Quinlan court proposed these committees as "a more appropriate forum" than a court of law for the review of individual circumstances of ethical dilemmas.

The role of the ethics committee varies, depending upon the nature and policies of the institution. In general, the power and authority of such a committee is limited to the institution in which it sits; several state courts, however, have mandated that institutional ethics committees, or "prognosis committees" must be involved in all decisions to
withdraw or withhold life sustaining treatment from incompetent patients. In that context, the committee really serves to confirm the attending physician's medical diagnosis, rather than to assist with the ethical dimensions of the decision. (See Quinlan, Hamlin and Bludworth).

Not all institutional ethics committees, however, convene merely to confirm a hopeless prognosis or to review a treatment decision. In many institutions, these committees serve a broader role. As the Quinlan court envisioned, ethics committees can provide a forum for discussing ethically troubling aspects of specific cases, or more general social and ethical concerns that arise in the context of the health care institution. They can also assist with the formulation of institutional policies on issues such as resuscitation or artificial nutrition and hydration. Many of these committees are not only made up of medical professionals, but also of interested individuals such as clergy, attorneys, community agency representatives or administrators who add to the committee's diversity and perspective.

Despite this potential advisory and consultative role for ethics committees, the majority of health care institutions do not have such committees. A 1983 survey found that less than 1% of all hospitals had such committees (MAKING HEALTH CARE DECISIONS). The formation of these committees, however, is on the rise.
2. **Ombudsmen**

"Ombudsman" is a Swedish term for a person who acts as a "citizen representative." In order for nursing homes to receive Medicaid or Medicare funding, all states are required to have an "ombudsman" program. The ombudsman serves as an advocate for nursing home residents, and he is available to oversee and enforce the rights of these residents. Ombudsmen investigate complaints, and they can even initiate judicial proceedings, if necessary. The *Conroy* court (see discussion, supra), sensitive to the potential for abuse in decisions to withhold or withdraw life sustaining treatment, from incompetent nursing home residents, even incorporated the state’s ombudsman as a necessary party in these difficult decisions. Thus, in New Jersey, the state ombudsman must investigate and approve decisions to withhold or withdraw treatment from certain nursing home residents before such decisions can be implemented.

**Patient Advocates**

Many health care institutions have their own "patient advocates" or "patient representatives," who function strictly within the confines of these institutions. These advocates are available to patients and family, and they provide information and advice on such issues as hospital policy and patients’ rights. The helpfulness and effectiveness of these advocates depend upon the
specific institution, and its commitment to the role of patient advocates.

Professional Societies

Professional societies not only provide useful information to their constituents, but they can also utilize the combined expertise, experience and prestige of their members to develop and promote important public policies. In the context of health care decisionmaking, professional organizations of physicians, attorneys and even hospitals have often formulated policies that have had an effect upon the delivery of health care, and the rights of patients to make decisions.

For example, early in 1986, two professional organizations issued public policies regarding the withholding or withdrawal of life-sustaining medical treatment. In January 1986 the Los Angeles County Medical and Bar Associations approved a joint policy entitled, "Principles and Guidelines Concerning the Foregoing of Life-Sustaining Treatment for Adult Patients." This was a collaborative effort between attorneys and physicians, with the goal of assisting physicians with the legal and ethical implications of life-support decisions, and educating attorneys and patients as to the issues presented by more advanced medical technology.

Of more national prominence was the March, 1986 public
statement issued by the American Medical Association (AMA). Entitled, "Withholding or Withdrawing Life Sustaining Treatment, this statement publicly endorsed the right of the patient or his proxy, if available, to make such treatment decisions. More importantly, the statement added the AMA's voice to the public controversy over the nature of artificial nutrition or hydration. It declared that such artificial methods of feeding constitute treatment, and they, too, can be discontinued in appropriate circumstances. Although this AMA statement is not binding upon anyone, it is a strong statement from a prestigious organization, and it will most likely influence courts and legislators in their future decisions, regarding the use of artificial nutrition and hydration for competent and incompetent patients.

**Liability Concerns**

Physicians, like all professionals, are held to a certain standard of care. If they fall below that standard, and thus cause harm to their patients, they may be liable to their patients for money damages. On the rare occasion that the physician's behavior, as a health care provider, is so egregious as to fall outside of acceptable societal norms, the physician could even be criminally liable.

As stated earlier, in these days of advanced technological capabilities, the progress of technology has
often outpaced the legal process. At times, the current law of a jurisdiction is less than certain, or in flux. Variation among the laws of jurisdictions may also exist. In these periods of uncertainty, physicians have, not unreasonably, been concerned about their legal requirements. This concern has often been exacerbated, however, by misperceptions of settled law. The result of these concerns and misperceptions has been an obsession with potential liability, on the part of caregivers, to the detriment of other significant values and factors. In particular, there has been a tendency by physicians to do more, rather than less: that is, because of unfounded concerns about what the law requires, physicians have tended to "overtreat." Unnecessary tests have been ordered and unwanted treatment has been undertaken. Physicians have at times placed their own interests and concerns about civil liability above the clear and recognized rights of patients, particularly the right to refuse life-sustaining treatment.

The use of the criminal law as a mechanism to regulate medical decisionmaking is extremely rare. Indeed, there has only been one recorded case of an attempt to criminally prosecute physicians for withholding or withdrawing life-sustaining treatment from an incompetent patient. In that case (Barber and Nejdl, CA, 1983) a patient suffered a cardiac arrest after surgery. He was placed on a
ventilator, and his physicians informed his family of the patient's poor prognosis. He was not expected to recover from the deep coma he was in.

The family first requested that the patient be removed from the ventilator. Later, when the patient failed to die, the family asked that the patient's artificial feeding tubes be removed. The physicians complied and were subsequently charged with murder. However, the charges were eventually dropped.

The appeals court that finally ruled on the case commented that, "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." Moreover, the court concluded that in a case where the patient's prognosis, based on standard medical practice, is hopeless, and the family wishes treatment to be withdrawn (including the removal of artificial nutrition and hydration), then physicians have no legal duty to continue treatment, and their compliance with the family's request would not be unlawful. The court, in the Barber case, ultimately supported the physician's actions.

Although physicians, like all individuals, can never fully protect themselves against civil or criminal liability, they must remember that their concerns for their
personal interests should not diminish or negate their responsibility to respect the rights and dignity of the patients they treat.

Issues of the Future

The elderly represent the fastest growing segment of the American population. This change in demographics has affected the focus of present day medical care delivery. The elderly tend to suffer from chronic rather than acute illnesses and, due to the nature and type of illnesses that afflict them, the elderly may place more time demands upon physicians, and more cost demands on the health care system. Much of the cost of their care is borne by public reimbursement programs through the Medicare and Medicaid systems.

At the same time these demographics are shifting, there has also been a government push to contain health care costs. There is justifiable concern, therefore, that the elderly, who are so dependent upon the public largesse for the receipt of their health care, will disproportionately bear the burdens of federal and state cost containment measures. Moreover, as increasing cost concerns affect the availability of sophisticated but expensive technology, there is fear that the elderly, who are most often benefited by technology (although at times burdened by it) will be forced to make decisions not on the basis of their desires
to receive or refuse such technology, but rather, on the basis of what they can afford.

It is important that the federal government, as a protector of rights as well as a disburser of funds, not mingle these two roles to the detriment of elderly individuals. As the President's Commission stated, "Restrictions on marginally beneficial use of funds must avoid a real or perceived conflict between the role of the government as articulator of rights and responsibilities...and its role as allocator of collective financial resources." (DECIDING TO FOREGO...).

In addition to financial concerns, the shift in demographics will also further the debate over the availability and limits of life sustaining treatments for the elderly. More and more individuals will potentially benefit from these treatments, and yet more and more may be incapacitated by age and illness, and may therefore be unable to express their preferences with regard to the use of these life-sustaining treatments. There is the urgent need to encourage all individuals, but particularly those who are advancing in years, to plan ahead, in advance of future incapacity.

Finally, as the population gets older, the stigma attached to aging should decrease, and thus, so should the disparate treatment of the elderly. The increasing strength
and vocalness of such groups as AARP (American Association of Retired Persons) should help awaken all members of society to the realization that a person's age may have no bearing on her capabilities, and certainly, should have no effect on the rights she possesses as a citizen of this country.