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The Right of Elderly Patients to Refuse Life-sustaining Treatment

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THERE ARE NAMES THAT WE KNOW NOT BECAUSE of what they did, but because of how they died: Karen Ann Quinlan, Joseph Saikewicz, Brother Fox, Earle Spring, Claire Conroy, and William Bartling, to mention some of the most prominent. We know their names because there was conflict about *how* they would die, what medical interventions should be used to prolong their lives, who should make this decision, and on what basis. We know their names because representatives of these individuals, families, friends, and physicians went to court for guidance and protection in making these decisions. They felt obliged to seek court intervention because there are no statutes that define the rights of individuals in their circumstances, and the courts have emerged as the primary public forum in which issues about medical intervention and the rights of patients have been debated for the past decade.

This article deals primarily with appellate court decisions regarding the withholding or withdrawal of life-sustaining treatment for elderly patients. This judicial focus was chosen because the courts have created almost all of the relevant law in this area by adjudicating individual cases on the basis of common law and constitutional law principles. Because of the complex nature of the issues, legislatures and regulatory

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agencies have remained relatively silent. Traditional methods, like guardianships and durable powers of attorney, have been used in some instances, but usually without changing their original, much broader compass. More recently, adult protection services and public guardianship services have developed, but with a much broader agenda. The only type of legislation directly aimed at the withholding and withdrawal of life-sustaining treatment is "living will" legislation. Although drawn very narrowly to date, the debate on such legislation has helped to inform the public about these issues. Accordingly, we provide brief descriptions of traditional statutory mechanisms to protect elderly patients, and a detailed analysis of "living will" legislation.

Why Cases Come to Court

In a society dedicated to fostering the ideal of equality and "equal protection under law," the courts serve to protect individuals from exploitation by others. In the area of withholding and withdrawing life-sustaining treatment, the courts generally have not been involved in retrospective punishment through criminal proceedings, but have increasingly become involved in prospective decisions about treatment. These cases center on enforcing individual rights and establishing corresponding duties. Such cases have been presented to the courts for two primary reasons: (1) participants who have already agreed on a course of action want a guarantee of legal immunity before actually withdrawing or withholding medical treatment (e.g., Earle Spring);¹ and (2) appointment of a legal guardian is sought with specific authority over a treatment decision because of a dispute between family and providers over what course of action to take (e.g., Karen Ann Quinlan).²

The role of the courts in each type of case is the same: to protect the rights of the incompetent individual about whose care others are making decisions, and to enforce the rights of competent patients to make their own decisions. The courts do this in a variety of ways, including (1) making the process public; (2) appointing individuals to represent the patient in court and in the health care setting; (3)

¹ *In the Matter of Spring*, 405 N.E.2d 115 (1980).

² *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

using legal principles to decide cases; and (4) giving reasons for their decisions.

Definitional Problems: "Life-sustaining Treatment"

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983, 24) recognized that "phrases like 'right to die,' 'right to life,' 'death with dignity,' 'quality of life,' and 'euthanasia' have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred." This problem has been endemic in discussions concerning the treatment of the elderly patient.

The term "life-sustaining treatment," for example, is found in the title of this article and used throughout it. It is not a term we are particularly happy with because of its vagueness. Courts and legislatures have used terms like "life prolonging," "life saving," "terminally ill," and similar terms. When examined closely, these terms are not useful. What is the difference between "prolonging life" and "saving life"? If a life is extended for five minutes or five hours, or five days or five years, has it been "prolonged" or "saved"? Is someone terminally ill because he will imminently die of an identified disease? If someone has a disease we know will lead to death in ten years, is he terminally ill? Should the rights of a person be dependent on whether we deem him "terminally ill" or whether we deem his treatment "life prolonging" as opposed to "life saving"? We have found all these terms useless in analyzing the rights of patients. We have chosen the term "life-sustaining" reluctantly, although it is somewhat more emotionally neutral than the alternate terms. In this article, "life-sustaining treatment" means any treatment that extends the length of a person's life, whether for a minute or for 50 years. It applies whether or not a person is "terminally ill" and whether or not the treatment is "life prolonging" or "life saving." Thus, while we are not particularly enamored of the term, we frankly could not think of a better one.

"Withholding" and "withdrawing" are clumsy words as well, but have the advantage of being descriptively accurate. More conceptually correct, but probably less intuitively clear, is the simple phrase "treatment refusal," which conveys the notion that we are dealing with *all* forms of treatment, and a refusal on the part of or on behalf of the patient. We think it is especially important to note that we do not distinguish

between various forms of medical treatment on the basis of their utility, side effects, number of moving parts, novelty, expense, or on other grounds. Such distinctions tend to be made on inherently arbitrary grounds, and detract from focusing on the individual patient, and his rights and welfare.

Likewise, we do not think it is useful to distinguish among categories of adults (18 years of age or over) on the basis of age. Thus, while this article is concerned with elderly patients, it should be emphasized at the outset that the elderly have neither more nor fewer rights than the rest of the adult members of society. It is for this reason that, although a number of cases we discuss do not involve elderly patients, all of the principles derived from them are directly applicable to the elderly. The primary factor that compromises one's rights to refuse treatment is not age, but incompetence, an issue dealt with later in this article. Definitional problems are also dealt with in more detail in a later section, where statutory approaches are discussed.

The Right to Refuse Treatment

The Right of a Competent Adult to Refuse Treatment

General Rules. Individuals have a common-law right to be free from nonconsensual bodily invasions. An unconsented-to invasion is a battery. As early as 1905 an Illinois court held:

Under a free government at least, the free citizen's first and greatest right which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician . . . to violate without permission the bodily integrity of the patient by a major or capital operation.³

More recently, courts have found that for the patient's consent to be valid, the physician must provide the patient with enough material

³ *Pratt v. Davis*, 118 Ill. App. 161 (1905), aff'd 224 Ill. 30, 79 N.E. 562 (1905).

information about the proposed procedure that the patient can give an "informed consent."⁴

In essence, the requirement that a physician obtain a patient's informed consent prior to performing a treatment is designed to ensure that the patient has some basic information prior to being asked to make a "go" or "no go" decision regarding treatment. The physician has specialized knowledge that is essential to the making of a reasoned decision, and the patient is the party who is to apply some of that knowledge to his own situation. The California Supreme Court explained this dyadic relationship as follows:

A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of a decision not to undergo the treatment, and the probability to a successful outcome of the treatment. But once this information has been disclosed, that aspect of the doctor's expert function has been performed. The weighing of those risks against the individual fears and hopes of the patient is not an expert skill. *Such evaluation and decision is a non-medical judgment reserved to the patient alone.* A patient should be denied the opportunity to weigh the risks only where it is evident he cannot evaluate the data, as, for example, where there is an emergency or the patient is a child or incompetent [emphasis added].⁵

Courts thus view the decision whether or not to undergo treatment not as a medical one, but rather as a personal decision by the individual who will be directly affected. It follows that if a person is empowered by law to decide to undergo medical treatment, he is also empowered to decline such treatment. If a person cannot decline treatment, the "right" to decide whether or not to undergo a treatment becomes a sham, equivalent to a "right to agree with your doctor."

In addition to the common-law right to refuse treatment, some courts have recognized a fundamental constitutional right to refuse treatment. In the *Quinlan* case, for example, the New Jersey Supreme Court decided that the right of privacy enunciated by the

⁴ *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972); *Harnish v. Children's Hospital*, 387 Mass. 152, 439 N.E.2d 240 (1982).

⁵ *Cobbs v. Grant*, 104 Cal. Rptr. 505, 502 P. 2d 1 (1972).

United States Supreme Court "is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances."⁶ That well-known case involved a young woman who was in a permanent coma and on a mechanical ventilator. The Massachusetts Supreme Judicial Court concurs in that holding. The case involved a 67-year-old severely retarded ward of the state who had cancer for which chemotherapy offered the only chance for a remission.⁷ Where the right to refuse treatment is seen as a fundamental constitutional right, a state's authority to abridge the right is very narrow, and must be based on demonstrating a "compelling state interest." Four potentially compelling state interests were mentioned by both the *Quinlan* and *Saikewicz* courts: (1) protecting human life; (2) preventing suicide; (3) protecting innocent third parties; and (4) protecting the integrity of the medical profession. In neither of these cases, however, were any of these state interests found sufficiently compelling to outweigh the right of the individual patient, as exercised by a proxy. The proxy could withhold chemotherapy (in the case of Joseph Saikewicz) or withdraw mechanical ventilation (in the case of Karen Ann Quinlan), both of which could prolong their lives (Annas 1979, 373–75).

"Life-sustaining" Treatments: *Jehovah's Witness blood transfusion cases*. The right to refuse treatment is not limited to those patients for whom such a refusal would be of little or no significance. A close reading of the case law makes it apparent that competent adults who seriously express a desire to refuse treatment are permitted to do so, even when such a refusal would result in death.

The early cases in this area of the law almost invariably involve Jehovah's Witnesses who need blood transfusions in order to survive. When one analyzes the facts of the various cases, it becomes readily apparent that these are *not* forced treatment of competent patient cases. Perhaps the most famous and widely cited case is *Application of the President and Directors of Georgetown College*.⁸ In this case, a 25-year-old mother of a seven-month-old child was brought to the hospital

⁶ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

⁷ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

⁸ *Application of the President and Directors of Georgetown College*, 331 F. 2d 1000 (D.C. Cir. 1964).

with a bleeding ulcer, having lost two-thirds of her blood. Both the patient and her husband were Jehovah's Witnesses, a religion that prohibits the injection of blood into the body. Exactly how this religious tenet is applied, however, is subject to interpretation. Thus, when the judge in this case spoke to the husband, the judge reported: "He advised me that on religious grounds he would not approve a blood transfusion for his wife. He said, however, that if the court ordered the transfusion, the responsibility was not his." The judge then went to the patient's room and found: "It is obvious that the woman was not in a mental condition to make a decision." The judge asked the patient if "she would oppose the blood transfusion if the court allowed it. She indicated, as best I could make out, that it would not then be her responsibility." The court was thus *not* dealing with a competent patient who *opposed* transfusions if ordered by a court, but rather with a patient who could not give her own consent to it. The court's decision cannot be construed as forcing blood on a patient who refuses it: the patient and her husband were relieved to place this responsibility on the court's shoulders.

Although a petition for a rehearing en banc was denied for technical reasons, a number of judges expressed the opinion that the single judge who decided this case had no authority to do so, and that if he did have such authority, that his decision was wrong. Circuit Judge (later Chief Justice) Burger asked in his opinion: "If the patient has objections to that treatment based on religious conviction, or if he rejects the medical opinion, are the courts empowered to decide for him?" He later answers this question by stating: ". . . there are myriads of problems and troubles which judges are powerless to solve; and this is as it should be. Some matters of essentially private concern and others of enormous public concern are beyond the reach of judges."

Another so-called "forced treatment" case involved a 39-year-old father of two who had lost 60 to 65 percent of his red blood cells and refused to consent to a transfusion.⁹ According to the court, the patient was competent and rational. When the judge entered the hospital room, the first thing the patient said—before the judge asked any questions—was that he would not agree to the transfusion, but would in no way resist if the court ordered it. He maintained if the

⁹ *United States v. George*, 239 F. Supp. 752 (Conn. 1965).

court ordered the transfusion it would be the court's will and not his—the responsibility for the act would be “on the court's conscience.” The judge explained that he had no power to order the transfusion and the patient would be free to resist the transfusion by putting his hand over the site where the needle would be inserted. Mr. George responded that he would in no way resist the transfusion once the judge signed the order.

These cases can be compared to one in which a 34-year-old father of two who was seriously injured refused necessary blood transfusions.¹⁰ Mr. Osbourne told the judge that if the court ordered him to be transfused, he would be deprived of “everlasting life.” The patient said: “It is between me and Jehovah, not the courts. . . . I'm willing to take my chances. My faith is that strong. I wish to live but with no blood transfusions. Now get that straight.” No transfusion was ordered.

These examples illustrate that it is essential to distinguish between cases in which people truly refuse treatment, and those in which people refuse to consent affirmatively to treatment, but are willing to voluntarily undergo or “assent” to treatment if ordered by a judge. Ordering treatment in the former case violates the individual's privacy rights, while in the latter case there is no such violation.

Unfortunately, much of our modern jurisprudence regarding the refusal of medical treatment is based on a *misinterpretation* of these and other early Jehovah's Witness cases. They were often initially decided in an emergency situation in which adequate deliberation is necessarily precluded. They were unusual in the sense that the courts are dealing with patients who seem to have anomalously consented to very serious physical invasions, such as major surgery, but not to the much less serious intrusion of blood transfusions. The amount of invasion the court “orders” is, therefore, much less than the patient has already consented to. None of the patients affirmatively refused to have the transfusions, and many seem to have believed that their religion forbade consent to blood transfusions, but not transfusions ordered by the court. Finally, none of these early cases dealt with the constitutional right of privacy, which has played such an important role in the contemporary cases.

¹⁰ *In re Osbourne*, 294 A.2d 372 (D.C. Cir. 1972).

Life-sustaining Treatments: Representative Modern Cases. While Jehovah's Witness cases continue to come to court, more typical modern cases involve elderly patients who wish to refuse more invasive procedures on nonreligious grounds. An example is *In re Quackenbush*.¹¹ Mr. Quackenbush was a 72-year-old man who refused to have his gangrenous legs amputated. "His conversation did wander occasionally but to no greater extent than would be expected of a 72-year-old man in his circumstances." He had shunned medical treatment over the past 40 years. He was neither terminally ill nor comatose. If he had the operations, he would live indefinitely, but not having the operations would lead to his death. The court in this case explicitly held that the state's interest in preservation of life is not sufficiently compelling to override Mr. Quackenbush's right of privacy to decide competently his own future "regardless of the absence of a dim prognosis." Other courts, like those in Massachusetts and California have reached the same conclusion using similar reasoning.¹²

Contemporary courts have indicated that for competent patients the finding of a "good prognosis" is insufficient to provide the state with the power forcibly to treat these individuals. Whether or not a prognosis is "good" is not a medical issue, and not an issue capable of being resolved by an objective test. Rather, a prognosis is good or bad based on a subjective evaluation of the facts of a situation. Thus, Mr. Quackenbush's life would have been extended if his legs had been amputated. While this may seem like a "good" prognosis to physicians or judges, it did not seem like a "good" prognosis to Mr. Quackenbush. It is seldom, if ever, proper for a state to force its view of what a "good" prognosis is on a competent patient. The right to refuse medical treatment is not conditioned on the state's finding, or not finding, that the proposed treatment is "good." Rather it is based on the right of each citizen to make important personal health care decisions without interference by the state, in the absence of a demonstrable "compelling state interest."

¹¹ *In re Quackenbush*, 156 N.J. Super. 282 (1978).

¹² *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. 1978); *Bartling v. Superior Court*, 209 Cal. Rptr. 220 (Cal. App. 2 Dist. 1984).

Protecting the Rights of Incompetent Patients to Refuse Treatment

Substantive principles. Of course, individuals cannot actually be self-determining after they become incompetent and lose their capacity for self-determination. Nonetheless, the proposition that an incompetent patient should be afforded the “right of self-determination” he could exercise if competent, insofar as possible, has been upheld by every court examining the issue since *Quinlan*. For example, the Massachusetts Supreme Judicial Court has strongly declared that the right to refuse treatment must extend to incompetent as well as competent patients “because the value of human dignity extends to both.”¹³ Courts could probably come to no other conclusion without seriously undermining the rights of the weakest members of society: the mentally incompetent who are unable to protect their own interests. It is critical to the protection of liberty for all of us that our basic rights continue to be respected after we are no longer able to protect them ourselves. As legal scholar Ronald Dworkin (1978) has argued:

The bulk of the law—that part which defines and implements social, economic and foreign policy—cannot be neutral. It must state, in its greatest part, the majority’s view of the common good. The institution of *rights* is therefore crucial, because it represents the majority’s promise to the minorities that their dignity and equality will be respected. When the divisions among the groups are most violent, then this gesture, if law is to work, must be most sincere. . . . [Taking rights seriously] is the one feature that distinguishes law from ordered brutality.

In this regard, the law protects the “dignity and equality” of incompetent patients by attempting to honor, in some measure, their right to self-determination. Since dignity and equality extend to all human beings, respect for the rights of self-determination cannot be limited by medical diagnosis (e.g., Alzheimer’s disease) or medical prognosis (e.g., irreversibly comatose or vegetative), but should extend to all incompetent persons. The challenge is to devise a reasonable

¹³ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

mechanism to discern what their wishes would be, if they could in fact exercise self-determination.

Substituted judgment. Since, by definition, an incompetent patient is unable to exercise his or her own self-determination by making decisions regarding treatment, this right must be exercised on behalf of the incompetent person by someone else or it is forfeited. To avoid loss of this right, the surrogate should utilize the "substituted judgment" standard, i.e., the surrogate should make a good-faith effort to make the treatment decision in the manner in which the patient himself would have made it if competent, provided there is sufficient evidence on which to base such a determination. As previously noted, the patient's choice concerning treatment is the primary relevant variable when we are dealing with a competent patient. Therefore, in order to afford the incompetent the right to self-determination, we must focus on the patient's previously expressed desires concerning treatment as the most critical factor in affording the now incompetent patient the right of choice, using other factors like lifestyle, values, and religious beliefs where relevant. The primacy of the "substituted judgment" test was recognized by the New Jersey Supreme Court in *Quinlan*, even in the absence of a clear declaration on Karen Quinlan's part, by granting the power to the "guardian and family of Karen to render their best judgment . . . as to whether she would exercise [her right to refuse treatment] in these circumstances."¹⁴

Preference for the substituted judgment test has been legally acknowledged by other courts dealing with the issue, and endorsed for both legal and ethical reasons by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983). In the *Saikewicz* case, for example, even though the patient had never made any decisions for himself, the court required a determination of the patient's own "actual interests and preferences" in ascertaining what decision the incompetent person himself would make if he could speak for himself:

The decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of

¹⁴ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976), 41.

the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.¹⁵

The New York Court of Appeals, in the "Brother Fox" case, was able to avoid many troubling issues by focusing on the individual's right to make his own decision. Brother Fox, an 83-year-old member of the Society of Mary, who, following routine hernia surgery, was left in a permanent vegetative state on a mechanical ventilator, had previously expressed an oral desire not to be maintained by "extraordinary means" if he were ever in a situation like Karen Ann Quinlan. As the court noted, the issue of whether or not someone else can speak for the patient "is not presented in this case because here Brother Fox made the decision for himself before he became incompetent."¹⁶ Since, unlike the more casual statements of Karen Quinlan, Brother Fox's prior statements of desires were "obviously solemn pronouncements," the court ruled that they must be followed. As the New York court properly noted, prior declarations can provide "clear and convincing" evidence of a person's wishes, and in the absence of evidence to the contrary should be considered the best evidence of the declarant's actual preferences.

The President's Commission has likewise argued that whenever possible "decisionmaking for incapacitated patients should be guided by the principle of substituted judgment." The commission argued that this was morally and legally necessary to respect the person's autonomy by permitting the person the ultimate authority to determine for himself the meaning of health and well-being. Since individuals frequently disagree on these concepts, the person with the greatest interest in how they are determined, i.e., the patient himself, should be afforded the right to have the final say when possible. While we strongly agree that the substituted-judgment test is the primary and preferred test, we should note that in the absence of some competent prior expression by the patient, it is subject to abuse. The case of Mary Hier provides an example.

At the time her case was first heard in court, Mary Hier was a 92-

¹⁵ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

¹⁶ *Matter of John Storar, In the Matter of Philip Eichner*, 52 N.Y.2d 363 (1981).

year-old woman who suffered from senile dementia, thought she was the Queen of England, and had been institutionalized for more than fifty years. Based primarily on the fact that she pulled out her gastrostomy tube (through which she received all her nourishment because she was unable to take food orally) a lower court judge determined that she would reject such artificial feeding if she were competent to decide.¹⁷ Ironically, it is only by attributing competent motives to this act of an incompetent, aged, mentally ill, nursing home patient that the courts could justify not replacing the gastrostomy tube. Indeed, the appeals court pictured her as a competent patient in agony:

Mrs. Hier's repeated dislodgments of gastric tubes, her resistance to attempts to insert a nasogastric tube, and her opposition to surgery all may be seen as a plea for privacy and personal dignity by a 92-year-old person who is seriously ill and for whom life has little left to offer.

As this example illustrates, with a patient who has *never* competently expressed a preference, "substituted judgment" can serve as a rationalization to mistreat or terminate treatment on patients who are undesirable or difficult in some way. Luckily for Mrs. Hier, her guardian ad litem, Robert LeDeux, succeeded in returning the case to court and getting the court to order the gastrostomy tube replaced based on new evidence. Mrs. Hier is alive as of this writing.

Best interests. In cases in which it is not possible to ascertain reasonably or accurately the patient's choice or preference (and this should always be the primary test used to protect autonomy) two avenues are open to us: either we adopt a rule that certain types of treatment can *never* be discontinued; or we permit the discontinuance of treatment under certain clearly specified conditions. Courts have found the former rule too rigid and not protective of incompetent patients, since competent individuals can and do reject proposed treatments. The latter rule, however, requires careful articulation to prevent potential abuses. Under the *parens patriae* doctrine, the state requires that surrogates make decisions for incompetent individuals that serve the best interests of the incompetent. Cases in which the "best interests"

¹⁷ *In re Mary Hier*, 18 Mass. App. Ct. 200 (1984).

test must be used include not only those in which previously competent adults have not expressed a preference regarding treatment decisions, but also all cases of individuals who have *never been competent* to express such a preference: young children and the severely mentally retarded. The dangers of treating elderly patients using an "always treat" rule are well illustrated by the New York case of John Storar.¹⁸

John Storar was a profoundly retarded 52-year-old resident of a state facility who had a mental age of about 18 months. His closest relative was his mother, a 77-year-old widow who lived near the facility and visited him almost daily. In July 1979 he was diagnosed as having cancer of the bladder, and his mother was appointed his legal guardian to consent to radiation therapy, which produced a remission. Internal bleeding began again in March 1980, and his bladder was cauterized in an unsuccessful attempt to stop the bleeding. In addition, the cancer metastasized to his lungs, and his condition was considered inoperable and terminal. Nonetheless, in May the physicians asked the mother for permission to administer blood transfusions. She reluctantly agreed, but in June asked that the transfusions, which were given every two weeks, be discontinued because of the distress they caused her son. Because the physicians believed Mr. Storar would eventually bleed to death without the transfusions, they sought a court order to do them, even though with the transfusions they agreed he had only three to six months to live because of the cancer. The trial court agreed with the mother on the basis that it thought she was in the best position to determine what her son would want. The New York Court of Appeals, unfortunately and we believe wrongly, reversed the decision and ordered the blood transfusions continued.

The *Storar* court incorrectly determined that a medical treatment decision for a terminally ill, *adult*, mentally retarded person had to be made on the same basis as if the adult was a *curable child* who would live a normal life after a blood transfusion. Accordingly, the court held that it was *always* in the incompetent patient's best interest to continue to receive blood transfusions even when the transfusions merely painfully prolonged the dying process for him. This analysis

¹⁸ *Matter of John Storar, In the Matter of Philip Eichner*, 52 N.Y.2d 363 (1981).

is manifestly incorrect since Storar was dying of cancer. The court's heart was surely in the right place, but its mind, unfortunately, did not follow. It very properly wanted to protect children and other incompetents from those who would deny them life-sustaining medical treatment for reasons other than the patient's best interests. But it failed to recognize that there may be times when such treatment only prolongs suffering and is, therefore, itself cruel; and it failed to suggest any test that parents, families, or trial courts can apply to decide if it is ever legally permissible to withhold life-sustaining treatment from this category of patients.

The "best interests" test arguably promotes self-determination since, in the absence of any idiosyncrasy or a previous declaration to the contrary, it can be fairly assumed that the patient himself would make a decision consistent with his own objective best interests. Specifically, the best interests test is an objective test based on a notion of what most reasonable individuals in society would be likely to do in the same or similar circumstances. For example, in *Quinlan* the court noted that a decision by Karen's parents to remove her from the respirator would be in her own best interests by using the following rationale: "This decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them."¹⁹ Of course, one can equally argue that the core of the best interests test is aimed at protecting the patient's *welfare*, as objectively viewed by society as a whole.

But there are conceptual problems. In *Conroy*, for example, the New Jersey Supreme Court attempted to articulate a hierarchy of "best interests" tests. Under the "limited objective test," life-sustaining treatment may be withdrawn if "there is some trustworthy evidence that the patient would have refused the treatment, and . . . it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him." Under the "pure objective test" (i.e., when there is no evidence about what the patient might want) "the net burdens of the patient's life with the treatment should clearly outweigh the benefits that the patient derives from life . . . [and] the recurring, unavoidable and severe pain of the patient's life

¹⁹ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane.”²⁰

As to the “limited test,” if there *is* “some trustworthy evidence,” it should be followed if sufficient and ignored if insufficient. Seen in this light, it is simply another way of expressing the “substituted judgment” test. The “pure objective test,” focusing exclusively on “recurring, unavoidable and severe pain” as the *only* basis for withholding or withdrawing treatment, is far too narrow. There may be other things like impossibility of recovery, and the use of restraints, in addition to pain, that objectively make continued treatment more burdensome than beneficial to the patient. Such a test tends to ignore the plight of the individual patient, by justifying actions that otherwise could not objectively be viewed as in their “best interests.”

Procedural Mechanisms. Once the substantive principles are agreed upon (i.e., that we want to follow the wishes of the patient if reasonably possible, and, if these cannot be ascertained, then we want to take that action which is in the patient’s “best interests”), what remains is developing a *procedure* that ascertains the patient’s wishes or best interests accurately, fairly, efficiently, and in a manner that is societally acceptable (Cramton 1982). Courts have become the primary forum in which both substantive and procedural guidelines are being debated and defined. The reason is *not* that courts are more intelligent than physicians, families, or other third parties. The reason is simply that judges (and not physicians, families, or others) have a social mandate to distill the values and morals of society on which most of these cases must ultimately be decided (Annas 1979, 384). In the words of Justice Benjamin N. Cardozo (1921, 135–36):

You may say that there is no assurance that judges will interpret the mores of their day more wisely and truly than other men. I am not disposed to deny this, but in my view it is quite beside the point. The point is rather that this power of interpretation must be lodged somewhere, and the custom of the Constitution has lodged it in the judges. If they are to fulfill their function as judges, it could hardly be lodged elsewhere. Their conclusions must, indeed, be subject to constant testing and retesting, revision and readjustment; but if they act with conscience and intelligence,

²⁰ *In the Matter of Claire Conroy*, 486 A.2d 1209 (N.J. 1985).

they ought to attain in their conclusions a fair average of truth and wisdom.

The mechanisms courts use to determine incompetency and patient preferences, appoint guardians, determine the authority of guardians, and grant legal immunity, are explored in the next section.

The Role of Competence in Decisions to Refuse Life-sustaining Treatment

American law properly presumes that every competent adult is at liberty to consent to or refuse *any* proposed medical treatment or intervention. A further appropriate legal presumption is that all adults *are* competent, and the burden of proof is on those who would declare them incompetent. Accordingly, competence has become a central issue in all discussions of the "right to refuse treatment" (Annas and Densberger 1984).

Unfortunately, as individuals age, the reality is that health care providers, family members, and others are more likely to conclude that actions that would not indicate incompetence at a younger age, all of a sudden do in the elderly. This is not a new problem. Sophocles's sons brought a proceeding against him to obtain his property, and supported their argument that he was a lunatic on the basis of his preoccupation with writing his play, *Oedipus at Colonus*. In his defense, Sophocles read from the play and asked the jury if it seemed the work of an imbecile. The jury reportedly applauded the reading and declared Sophocles competent. One modern legal commentator opines that, under contemporary statutes, use of this defense could result in the sons walking out of the courtroom "in control of his property" (Atkinson 1979). Indeed, many states retain "advanced age" as sufficient grounds for appointment of a conservator over one's property. It was only in 1976 in California and 1978 in Illinois that an individual could not be found incompetent merely because he was "old and sick" (Atkinson 1979).

Society does not view all ages as having equal value, and generally holds the "demented aged in low esteem" (Cassel and Jameton 1981). Physicians are likely to mirror this societal prejudice. For example, Earle Spring was a 77-year-old man in a nursing home with irreversible

kidney disease and severe senile dementia. At a hearing to decide whether or not to discontinue his renal dialysis, his dialysis physician testified that in determining whether or not it is appropriate to continue dialysis treatment he considers "whether a person is a *real person*, whether the person is happy to be alive, *whether other people around him or her are happy to have him alive* [emphasis added]." ²¹ These loose and subjective quality-of-life standards are clearly inappropriate. Even though the evidence of Mr. Spring's actual wishes regarding continuation of kidney dialysis was virtually nonexistent, the Massachusetts Supreme Judicial Court nonetheless affirmed a lower court decision that Mr. Spring would, "if competent, choose not to receive the life prolonging treatment." What really seemed to be at stake was the court's (and society's?) view that older people in Mr. Spring's condition, by virtue of their physical and mental limitations, do not have much to live for. The family testimony, for example, was to the effect that Mr. Spring had led a vigorous, active life, which he was no longer able to do. The fact, of course, is that it is almost always true that as people get older, their level of activity declines, and is often severely curtailed. It does not follow from this, however, that such a person would prefer to be dead.

Because of such prejudice, the aged may be treated not as competent adults, but as incompetent children. The medical presumption may often be that the aged are presumed incompetent to refuse medical treatment until they can demonstrate to the physician's satisfaction that they are competent.

In this context, a competence proceeding, and the subsequent appointment of a guardian, can be used as a weapon against the elderly. The results can be devastating. Reduced to the status of a child in the eyes of the law, "most statutes deprive the ward of the right to buy or sell property, to contract, to sue and be sued, to make gifts, to write checks, and generally to engage in financial transactions of any kind . . . of the right to vote, to marry, to operate a motor vehicle, and to consent to or refuse medical treatment" (Hortsman 1975; Regan 1981).

Because of the centrality of a competence determination to individual self-determination and well-being, it is critical that those assessing

²¹ *In the Matter of Spring*, 405 N.E.2d 115 (1980) (quotation taken from lower court transcript).

competence have a clear understanding of its legal meaning, and that the individual whose competence is being questioned be afforded due process of law. Due process, however, is meaningless if the concept of competence itself is not well understood and articulated. In this regard the courts have consistently utilized the notion of competence as a *capacity* to perform certain tasks and have been willing to find individuals competent to perform some tasks (e.g., to decide where to live) while incompetent to perform others (e.g., to give away one's home or all of one's belongings). In the medical context, it will be concluded that the most reasonable way to conceptualize competence will be to ascertain the individual's capacity to understand and appreciate the information needed to give an informed consent or an informed refusal to the treatment under consideration. Thus, capacity is proportioned to the seriousness of the decision, although what often seems to be at stake is the degree of certainty courts require concerning incapacity to perform a specific task. The less important the task in terms of its consequences to the individual, the more certainty we require to find someone incompetent to perform it.

Definition of Competence

Informed Consent and Competence

The informed consent doctrine requires that a patient be given material information (information that might influence a patient's decision) about his condition, the proposed treatment (including its risks and benefits), and its alternatives (Annas, Glantz, and Katz 1977, 1981). Implemented in good faith by the physician, informed consent enhances both self-determination and rational decision making. It is assumed that an informed patient has sufficient information on which to base a decision to accept or reject proposed treatment. Thus, it is important to assess the patient's capacity to understand and appreciate the information required to be disclosed so that we can be confident it is the patient's decision when he makes it.

Infants and comatose patients provide clear examples of patients who are incapable of making decisions regarding medical care. There are equally obvious cases where the patient is capable of making such decisions. Unfortunately, there are also many borderline cases from

the perspective of the physician, who wants both to honor the patient's wishes (respect autonomy) and deliver good medical care (promote the patient's well-being), when these two objectives seem to conflict. There are, for example, cases in which the capacity of elderly patients to participate in the medical decision-making process appears questionable or where the physician believes that the patient's refusal is not reflective of his own values and preferences, but is instead a product of psychological or sociological factors. Such cases are dealt with in a variety of ways with varying degrees of arbitrariness, including sincere attempts to determine patient competence objectively.

Approaches to Competence

A variety of approaches have been suggested to determine competence. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) identified three: outcome, status, and function. Under the *outcome approach*, actual decisions by patients which do not reflect community values are used as evidence of incompetence. Under the *status approach*, an individual's competence is based solely on his physical or mental status (i.e., consciousness, age, mental or physical diagnosis). The *functioning approach* focuses on the individual's actual understanding and processes in decision-making situations.

Most commentators have assumed that the functioning approach is the correct approach, and have tried to define better the attributes needed to function competently. One philosopher has suggested, for example, that we can require any one of four increasingly strict standards: (1) free action, which involves a voluntary and intentional choice; (2) authentic decision, which is a decision that reflects the individual's values; (3) effective deliberation, which is an evaluation of the specific alternatives and their consequences; and (4) moral reflection, which is, in addition to effective deliberation, reflection on and acceptance of the moral values upon which the decision is based (Miller 1981). Two psychiatrists used an analogous classification of increasingly difficult tests and suggested the following four possible tests: (1) evidencing a choice; (2) evidencing an understanding of relevant issues; (3) rationally manipulating the relevant information; and (4), in addition to (2) and (3), an appreciation of the nature of the situation. In their words,

"[a]ppreciation is distinct from factual understanding in that it requires the subject to consider the relevance to his immediate situation of those facts he has understood previously in the abstract" (Roth, Meisel, and Lidz 1977). The authors regard this as the "strictest" standard. It is also the most reasonable one and, if fairly applied, the one that is most appropriate in hospital and nursing home settings.

A "functioning" approach, incorporating the appreciation requirement, avoids the pitfalls of second-guessing an individual's personality implicit in the authentic-decision and moral-reflection test. The functioning approach also helps ensure that the decision the patient makes is one he realizes will have consequences for himself that he understands and finds desirable or acceptable. In addition, the test has a solid legal pedigree in the context of treatment refusals.

The functioning test, including the appreciation requirement, is the one most often used by the courts, and was the key factor in two major cases of refusal of life-saving amputations by elderly patients. The cases were decided by appeals courts in Massachusetts and Tennessee about the same time, 1978, and did not refer to each other. The Massachusetts case involved Mrs. Candura, a 77-year-old widow and a diabetic who was suffering from gangrene in her right foot and lower leg.²² She had undergone two previous amputations (a toe and a portion of her right foot) and at the time of the second amputation, an arterial bypass had been performed in an attempt to decrease the probability of recurrences of gangrene. Her attending physicians recommended that the leg be amputated without delay. After some vacillation, she refused the operation and persisted in that refusal. The trial court held that Mrs. Candura was:

incapable of making a rational and competent choice to undergo or reject the proposed surgery to her right leg. To this extent her behavior is irrational. She has closed her mind to the entire issue to the extent that the court cannot conclude that her decision to reject further treatment is rational and informed.

The trial court concentrated on its finding that she had "closed her mind" and the court thus seemed to focus on "autonomy as effective

²² *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. 1978).

deliberation.” Ultimately, however, this appears to have been less important to the trial court than her actual decision which the court characterized as “irrational,” thus falling into the “outcome approach” trap. The appeals court, on the other hand, concentrated on her ability to “appreciate” her situation and its alternatives. The appeals court reversed the trial court’s decision and stated that “Mrs. Candura’s decision may be regarded by most as unfortunate, but on the record in this case it is not the uninformed decision of a person incapable of *appreciating the nature and consequences of her act* [emphasis added].”

The court noted that “[u]ntil she changed her original decision and withdrew her consent to the amputation, her competence was not questioned.” The doctors readily accepted her consent to the two initial amputations, and only questioned it when she disagreed with their judgment about her treatment. The court made it clear that competence is not to be judged by a standard of medical rationality, that is, what her physicians consider the only reasonable decision. Rather, the relevant factors were her understanding of the proposed operation and the consequences of refusing it. According to the court, “[Mrs. Candura] has made it clear that she does not wish to have the operation even though that decision will in all likelihood lead shortly to her death.”

In an enlightening footnote, the court noted that one of the two psychiatrists who testified at the trial thought Mrs. Candura *was* competent. Asked why he differed from the other psychiatrist, he replied, “I think it is just a personal philosophy type of thing where I believe persons ought to be given the benefit of the doubt as to what they want to do with their lives, whereas, Dr. Kelley, I guess, is more protective.” The point is not which psychiatrist was “correct,” but that they differed over the issue of the appropriate criteria for competence, based on their own “philosophical” views. It also points to the importance of physicians understanding and respecting the *legal* definition of competence. Because of the “philosophy” of a particular psychiatrist, Mrs. Candura was deprived of her right to make her own decisions by the trial court. Obviously this type of testimony will not be very useful to a court or other decision maker charged with determining an individual’s competence on the basis of the standard legal test.

The Tennessee case involving Mary Northern is similar, although

in that case the court found the 72-year-old woman incompetent to consent to or refuse amputation.²³ As a result of frostbite, both of Mary Northern's feet were necrotic. They were coal black in color, "shriveled, rotting and stinking." According to the testimony, Ms. Northern was perfectly lucid and understood everything *other than* the condition of her feet. She believed her feet would heal without surgery, and refused to consider the possibility that she might die without the amputation. Because she would not explicitly acknowledge that she would rather die than have her feet amputated (she responded "possibly" when that question was put to her), the court determined that she was refusing to make a choice, and was "mentally incapable of comprehending the facts which constitute" the danger to her life. The court used the following definition to find her incompetent:

Capacity means mental ability to make a rational decision, which includes the ability to perceive, appreciate all relevant facts and to reach a rational judgment upon such facts.

The court did not adopt the "outcome test," i.e., it did not object to her refusal *per se*. Rather it was her capacity to make an informed decision that the court objected to: "On the subject of death and amputation of her feet, her comprehension is blocked, blinded or dimmed to the extent that she is *incapable of recognizing facts which would be obvious to a person of normal perception* [emphasis added]." The major fact Ms. Northern consistently was incapable of recognizing was that her feet were "dead, black, shriveled, rotting and stinking." As Judge Drowota wrote in a concurring opinion:

If this Court could in good faith find that she perceived as facts that her feet *do* look and smell as they do, and that her doctors are telling her that she needs surgery to save her life, we would not interfere with whatever decision she made regardless of how much it conflicted with the substance of her medical advice or with what we ourselves might have chosen.

The judicial test of competence is based then on an individual's capacity to understand and appreciate the nature and consequences of

²³ *Department of Human Services v. Northern*, 563 S.W.2d 197 (Tenn. 1978).

one's decisions. It can be restated in the medical care context by saying that if an individual understands and appreciates the information needed to give an informed consent, then that individual is competent to give both an informed consent and to refuse consent, assuming, of course, that the decision is made freely and voluntarily. The type and quantity of information that must be understood and appreciated will vary with the actual treatment options, and the risks and alternatives that face the patient, but not with the status of the patient (status test) or the actual decision made by the patient (outcome test).

Relation of Competence to Other Factors

Use of the "outcome approach" by physicians, as in the *Candura* case, is probably the rule rather than the exception. Typically, competence is questioned only when a patient refuses to consent to a recommended treatment. Testimony before the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982, 61) is consistent with this view: "Coherent adults are seldom said to lack capacity (except, perhaps, in the mental health context) when they acquiesce in the course of treatment recommended by their physician."

Without a specific, consistent basis for questioning and determining competence, the patient's refusal—an easily identifiable target for criticism because it conflicts with the physician's view of the patient's well-being—can easily become a justification for paternalism. This may result in the substitution of the physician's own judgment and values for those of the patient, including the physician's conception of a "good" or "bad" decision. The physician may also attempt to establish a cause-effect relation between some kind of mental or physical factor (e.g., depression or blood loss) and the undesirable decision, thus enabling him to invalidate that decision on "medical" grounds and to proceed with his own decision.

A patient's age alone should *never* be a sufficient basis for a declaration of incompetence. But there are complicating factors. A patient may vacillate in a decision to accept or refuse treatment. This by itself does not constitute incompetence, but a patient who vacillates poses a problem to the physician attempting to discern what the patient wants. One sound approach is to incorporate a reasonable waiting period for nonemergency cases into the competence assessment, such

as the case of an elderly person with a nonemergency medical condition, so that the patient's actual desires can be ascertained.

The difficulty in formulating policy for the vacillating patient lies in determining what constitutes a "reasonable period of time" to wait before making a judgment as to the patient's actual desires. If a question persists, treatment cannot be forced until a determination is made (either at the bedside or in court) that the patient is incompetent to make the decision regarding his care in the specific instance. Treatment can continue, however, if the patient gives simple assent. This is because it is a much lesser harm to liberty to continue treatment to which the patient has at least assented than to force treatment against a person's will.

Another potential complicating factor is mental illness. The existence of mental illness does not always constitute incompetence, although it may. In one famous lower court decision, a 65-year-old schizophrenic woman refused surgery for breast cancer.²⁴ At the trial, Ms. Yetter indicated that the operation would interfere with her genital system, affecting her ability to have babies, and would prohibit a movie career. Her caseworker testified, however, that based on conversations with her six months previously, at the time she refused surgery, she was informed and she was "conscious of the consequences" of her refusal. The judge concluded that although her refusal "may be irrational and foolish to an outside observer," and although it is now "accompanied by delusions," the delusions do not appear to be her primary reason for rejecting surgery. Accordingly, he upheld what he described as "her original understanding but irrational decision," on the basis that health care providers have an obligation to follow the competent and understanding wishes of their patients, even if their patients later become delusional or suffer other mental illnesses that bring their current competence into question.

On the other hand, the *Northern* case, discussed above, provides an example where a specific delusion *will* be sufficient to determine incompetence where the delusion concerns facts material to an informed decision (in that case, the inability to appreciate that her feet were necrotic, and that she would probably die if they were not amputated).

The limited amount of literature on treatment refusals has placed

²⁴ *In re Yetter*, Northampton Co. Orphans Ct., No. 1973-533 (Williams, J.) (Pa. 1973).

a heavy emphasis on the difficulties of dealing with a patient's "transient feelings of despair and hopelessness" and feelings of depression. Depression may often be a perfectly understandable and healthy response to catastrophic disease or injury. Moods affect the patient's decision-making capability, but do not necessarily render the patient completely incapable of making decisions regarding his or her care at all times.

Moods such as depression and anger are fairly common among patients who may be heavily medicated and away from their homes, in strange environments, and separated from their loved ones. Such separation and isolation is, of course, the condition of almost all elderly patients in nursing homes. It is understandable that one might feel depressed under such circumstances. Elderly patients in isolated nursing home situations are also likely to be devalued by physicians, and even some courts.

Seriously injured persons, such as those suffering spinal cord injuries or serious burns, may experience shock, grief, pain, depression, and adverse psychological effects from powerful drugs. Sometimes such feelings can be effectively treated with "supportive psychotherapy" or antidepressant drugs. If these treatments are indicated and not refused by the patient, it is certainly appropriate to pursue them. On the other hand, if the competent patient refuses such treatment and persists in a refusal of treatment, that refusal should be honored. The relevant question is whether a mood such as depression has become so severe as to undermine one's ability to understand and appreciate the nature and consequences of one's decisions. If it has not, it alone does not justify a determination of incompetence.

Appointment of a Legal Guardian for an Incompetent Person

Method of Appointment

Legal guardians can only be appointed by courts, and the requirements for such appointment are set forth in state statutes. The state's power to grant authority over an individual to a guardian is part of its *parens patriae* authority (a term derived from the English common law concept of the King's role as father of the country). The notion is that the state will provide a "father" or guardian for incompetents, formally

limited to “idiots” and “lunatics.” In common law in England, a jury of twelve determined the mental status of an individual. “If an incompetent were determined by the jury to be a lunatic, the Chancellor committed him to the care of some friend, who received an allowance with which to care for him” (Hortsman 1975). Modern statutes generally provide for a formal hearing before a judge, although the procedure can be expedited and completed in less than a few hours in an emergency medical situation in which a temporary guardian is appointed for the purpose of making a medical treatment decision.

Almost all of the most well-known cases involving elderly patients in treatment refusal or withdrawal circumstances have involved the appointment of a legal guardian for the elderly person who has been judicially declared incompetent. This has been the case, for example, in the *Northern* and *Candura* (although reversed on appeal) cases, as well as the cases of Earle Spring (77 years old, withdrawal of kidney dialysis); Brother Fox (80-year-old comatose individual, withdrawal of ventilator); Claire Conroy (80-year-old severely demented individual, withdrawal of artificial nutrition); and Joseph Saikewicz (67 years old, refusal of chemotherapy for cancer). If incompetent persons must have guardians appointed for them to dispose of property, it certainly seems appropriate for guardians to be required for treatment decisions that pose serious risks to the individual or have life or death consequences.

The first major guardianship case did not involve an elderly person, although the age of Karen Quinlan was not a factor in the court's decision. Karen's father sought appointment as Karen's guardian *for the purpose* of ordering her mechanical ventilator removed. The hospital and physicians had informed him that they would not remove the ventilator. The lower court judge refused to appoint Mr. Quinlan the guardian, or to grant any guardian the authority to remove the ventilator. The New Jersey Supreme Court reversed this, and awarded legal guardianship to Karen's father. It disagreed with the lower court that his closeness to Karen might cause him anguish and distort his “decision-making process.” Instead the court held:

While Mr. Quinlan feels a natural grief, and understandably sorrows because of the tragedy which has befallen his daughter, his strength of purpose and character far outweighs these sentiments and qualifies him eminently for guardianship of the person . . . of his daughter.²⁵

²⁵ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

The court also noted that next of kin were statutorily preferred for guardianship, and there was “no valid reason” to negate this presumption in refusal of treatment cases.

Authority of Legal Guardian in Treatment Refusals

Guardians have the legal authority to *refuse* all types of medical interventions when such refusal is based on what the ward would want (substituted judgment) or on the best interests of the ward (when applying the substituted judgment test is not possible). On the other hand, in some jurisdictions, guardians may *not* have the authority to *consent* to certain types of treatment, like sterilization and use of psychotropic drugs where conflicts of interest may exist.

For example, in Massachusetts it has been determined that a guardian cannot consent to the forcible administration of antipsychotic drugs for either an outpatient²⁶ or an inpatient.²⁷ The courts based their rulings on the findings that antipsychotic medication has “devastating and often irreversible” side effects, that the treatment is extremely intrusive, and that guardians (such as parents) may be in a conflict of interest because they derive benefit from the control of the patient’s behavior. Because of these findings, these courts concluded that only courts, not guardians, could authorize the forcible use of antipsychotic medications.

Similarly, the New Jersey Supreme Court has ruled that only a court, not a guardian, could authorize the sterilization of an incompetent.²⁸ What these courts have done is to decide that certain *procedures* are either too risky, or so subject to abuse, or both, that courts must oversee their use. It is far from clear what the impact of such cases might have on the treatment-withholding or treatment-withdrawing cases. The *Grady* case is interesting because it was decided by the *Quinlan* court. In *Quinlan*, the court specifically held that judicial intervention in treatment-withdrawal cases was neither necessary nor desirable. It then decided *Grady*, a case that *required* court involvement to sterilize incompetent people. Following *Grady*, the New Jersey

²⁶ *Guardianship of Richard Roe*, 385 Mass. 415 (1981).

²⁷ *Rogers v. Commissioner of Mental Health*, 390 Mass. 489 (1983).

²⁸ *In the Matter of Lee Ann Grady*, 85 N.J. 235, 426 A.2d 467 (1981).

court decided *Conroy* which, like *Quinlan*, did not require court authorization to withhold treatment (although it did require the intervention of an ombudsman and court-appointed guardian). It is apparent that courts are willing and able to carve out exceptions to the rule that guardians are empowered to consent to (and therefore refuse) medical treatment for their wards. They have not chosen to do so in the general treatment-withholding or treatment-withdrawing cases, but could do so in the future if abuses become apparent or conflicts of interest exist. In addition, there has been enough uncertainty concerning the guardian's authority to provoke considerable litigation. The *Quinlan* case is again the best example. After declaring Mr. Quinlan the guardian of his daughter, the court went on to spell out his authority regarding the termination of her mechanical ventilator with "full power to make decisions with regard to the identity of her treating physicians." Other courts have followed this general path: responding to a request for a judgment that both requests the appointment of a guardian, and asks for specific, judicially sanctioned authority to terminate treatment. Alternatively, legal guardians, who have already been appointed for other reasons, have petitioned the court for specific authority to order the removal of life-sustaining treatment.

For example, in the case of Mrs. Edna Marie Leach, a 70-year-old housewife with amyotrophic lateral sclerosis, her husband first sought guardianship (after Mrs. Leach's physician refused to honor his request to remove her from the ventilator), and then separately sought a court order as guardian to have all life-support systems removed from his wife (and ward). The court granted the guardian's request, but only under certain conditions, and only after a hearing at which a separate guardian ad litem was appointed to argue on Mrs. Leach's behalf.²⁹ Likewise, in the case of Bertha Colyer, a 69-year-old heart attack victim who was resuscitated only to wind up in a persistent vegetative state, her husband and legal guardian sought a court order to have her removed from the ventilator. In that case the Supreme Court of Washington held specifically that while a court always had to be involved in appointing a legal guardian, the statutory authority of

²⁹ *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (Ohio Ct. Comm. Pleas, 1980).

such guardians in Washington “enables a guardian to use his best judgment and exercise, when appropriate, an incompetent’s personal right to refuse life-sustaining treatment.” The court made it clear that once the guardian was appointed “the courts need not be involved in the substantive decision to refuse life-sustaining treatment.”³⁰

We believe it is fair to characterize the Colyer court’s statement as “the law.” Specifically, only a court can appoint a legal guardian. However, once a legal guardian is appointed, that guardian can make the decision to order withdrawal of life-sustaining treatment on the basis of substituted judgment, or, if the ward’s wishes are unknown, on the basis of the ward’s best interests. With the exceptions of psychotropic drugs and sterilization, no court has held otherwise, and all courts that have ruled on the substantive issue of *whether* treatment may be withdrawn in a particular instance have done so upon the *request* of a physician, family member, legal guardian, or some other third party.

Whether or not the appointment of a “legal guardian” is always required to authorize the withholding or withdrawal of life-sustaining treatment from an incompetent person is a difficult question. There are *some* circumstances where the benefits from continued treatment are either nonexistent or so extremely slight that some courts have indicated that appointment of a guardian is unnecessary if a close family member acts in the name of the patient. This makes good sense. The issue has, however, only been directly discussed in three cases, all of which involved patients like Karen Ann Quinlan who were in (or nearly in) persistent vegetative states, and thus had no reasonable possibility of regaining consciousness.

The first case is that of Mrs. Shirley Dinnerstein, in which the court was asked if prior approval of a court was necessary to write an order not to resuscitate a 67-year-old woman suffering from end-stage Alzheimer’s disease and a variety of other disorders which left her confined to bed in an “essentially vegetative state.”³¹ The Massachusetts Appeals Court decided that where there was no real hope for the patient, treatment would be in her best interests only if there “was some reasonable expectation of effecting a permanent or temporary cure or

³⁰ *Welfare of Colyer*, 99 Wash.2d 114, 660 2d 738 (1983).

³¹ *Matter of Dinnerstein*, 380 N.E.2d 134 (Mass. App. Ct. 1978).

relief from the illness or condition being treated . . . at the very least, a remission of symptoms enabling a return towards a *normal, functioning, integrated existence*" [emphasis added]. Accordingly, the court concluded that the question of the "do not resuscitate" (DNR) order was "a question peculiarly within the competence of the medical profession of what measures are appropriate to ease the imminent passing of an irreversibly, terminally ill patient in light of the patient's history and condition *and wishes of her family*." In such a circumstance, i.e., where the critical question is the medical appropriateness of withholding specific treatment based on its potential to benefit the patient, neither guardian nor court approval was necessary.

The other two cases involved patients in permanent comas. The second case was a Florida case involving a terminally ill elderly gentleman, Francis Landy, who had signed a "mercy will" prior to entering an "irreversible coma" and "essentially vegetative state."³² In addressing the specific question of whether, under these circumstances, the appointment of a guardian was necessary to exercise Mr. Landy's wishes under his "mercy will," the court held:

The right of a patient, who is in an irreversibly comatose and essentially vegetative state to refuse extraordinary life-sustaining measures, may be exercised either by his or her *close family members* or by a guardian of the person of the patient appointed by the court.

While the court insisted that judicial appointment of a legal guardian was not required, it did require that "at least two other physicians" certify that "the patient is in a permanent vegetative state."

In the third case, the Supreme Court of Washington was asked explicitly to reconsider its requirement of a court-appointed guardian in *Colyer*.³³ The case involved a 42-year-old severely mentally retarded gentleman who, as a result of pneumonia and hypoxemia, suffered complete destruction of cerebral activity. He had no known relatives and was a ward of the state. Accordingly, appointment of a guardian was required. On the other hand, the court accepted the request that

³² *John F. Kennedy Memorial Hospital v. Bludworth*, 452 So.2d 921 (Fla. 1984).

³³ *Guardianship of Hamlin*, 689 P.2d 1372 (Wash. 1984).

it reexamine its holding in *Colyer*, and modified it to conclude that in cases of persistent vegetative state diagnosis, “guardianship proceedings are [not] a necessary predicate to effective decision making.” On the other hand, in the absence of a court-appointed guardian, *unanimous* agreement on the prognosis and treatment decision must be obtained from “the immediate family [and] the treating physicians . . . to protect against abuse and therefore eliminate the need for added judicial oversight through the guardianship procedure in this limited category of cases.”³⁴

These cases, and the vast majority of similar ones that never find their way into court, demonstrate that there is still considerable confusion regarding the necessity of a guardian in treatment-withholding decisions. In the Earle Spring case, for example, the Massachusetts Supreme Judicial Court reviewed the history of guardianships in medical-treatment decisions, and noted that in the past they had required “consent or its equivalent” (sometimes using consent of a spouse as “equivalent”) for treatment decisions, and only turned to guardianships when “consent or its equivalent” was not available. The court also noted in passing the tradition of treating an unconsented-to treatment as “battery” and opined that it might be more useful to view this area of the law in terms of negligence.³⁵ We think the court is on the right track. For example, while it *is* a battery to treat someone without their consent, it is certainly *not* a battery to refrain from treating (or to withhold or withdraw treatment). It would seem more reasonable to look at the withholding and withdrawal area as negligence. The critical issue is thus not consent (although consent or its equivalent might be required under certain circumstances), but negligence: i.e., is the treatment one that a reasonably prudent physician would not give under the circumstances? If so, it may be appropriate to withhold or withdraw such treatment without consent. For example, an incompetent patient could have a DNR order properly written *without a guardian's consent*, if CPR was not something a reasonably prudent physician would initiate under the circumstances. The next question is whether the guardian, if needed, must apply for specific authority to make medical treatment decisions.

³⁴ *Guardianship of Hamlin*, 689 P.2d 1372 (Wash. 1984).

³⁵ *In the Matter of Spring*, 405 N.E.2d 115 (Mass. 1980).

The issue of requiring a legal guardian's decision to be approved in advance by a court was first raised in the *Quinlan* case (and declared unnecessary), and raised shortly thereafter in Massachusetts. The case involved a severely retarded 67-year-old man who was a ward of the state.³⁶ He was diagnosed as having cancer, and chemotherapy was the recommended treatment. After a hearing, a probate judge decided that Mr. Saikewicz would be better off without the treatment, and the Massachusetts Supreme Judicial Court (SJC) affirmed this decision less than two months later. Two months later still, Mr. Saikewicz died. It was another 14 months after his death that the SJC released its now-famous opinion, which followed the *Quinlan* case in every major particular except one.

The SJC *rejected* the *Quinlan* court's delegation of immunity-granting authority to an "ethics committee," even in narrowly circumscribed persistent vegetative state cases. It held that if physicians and others wanted a grant of immunity before withdrawing life-sustaining treatment, such a grant could only be obtained from a court. Some commentators and some courts read this case to mean that *all* decisions by guardians to withdraw life-sustaining treatment must be approved in advance by a court of law. In part because of this misinterpretation of their holding, and subsequent confusion about it, the SJC clarified its ruling in 1980 in the case of Earle Spring, the 77-year-old nursing home resident with senile dementia whose family wanted him taken off of kidney dialysis (his son had been appointed temporary guardian) because they believed that was what he would want. On the specific issue of whether it was always necessary for a guardian to seek prior court approval of such a decision, the SJC was clear:

Our opinions should not be taken to establish any requirement of prior judicial approval that would not otherwise exist.³⁷

The most recent case on guardianship authority is the New Jersey case of *Claire Conroy*.³⁸ This case is important not only because it is the most recent, but also because it is a carefully considered opinion

³⁶ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

³⁷ *In the Matter of Spring*, 405 N.E.2d 115 (1980).

³⁸ *In the Matter of Claire Conroy*, 486 A.2d 1209 (N.J. 1985).

by the same court that penned the *Quinlan* decision. Unfortunately, this case has served to make treatment-withdrawal decisions by guardians for elderly incompetent persons, at least those who are in nursing homes, far more difficult in New Jersey. Indeed, almost a year after the decision, *no* treatments have been terminated on elderly patients using the procedures defined in *Conroy* (Sullivan 1985).

The case was brought by Ms. Conroy's only living relative, a nephew who had previously been appointed her legal guardian, who sought an order to have her nasogastric feeding tube removed after her attending physician refused this request. The New Jersey Supreme Court held that a legal guardian did have such authority *without* added court intervention, but only after a court had made a specific finding that the ward was incompetent to consent or withhold consent for the *particular* treatment in question. If such a determination has not been made, and "if the patient already has a general guardian, the court should determine whether that guardian is a suitable person to represent the patient with respect to the medical decision in question." This will involve a court examination of the guardian's knowledge, motivations, and possible conflicts of interest.

The court took special note of the New Jersey ombudsman statute, which was designed to help protect the rights of the institutionalized elderly in the state. Its decision, which it tried to limit to nursing home residents, requires the guardian to notify the office of the ombudsman whenever action to terminate treatment is "contemplated." The ombudsman is instructed to treat such a notification as a possible case of "abuse" and investigate it immediately. This investigation is to include the appointment of two physicians, in addition to the patient's attending physician, to examine the patient to confirm the medical condition and prognosis. If all involved, including the ombudsman, agree that withdrawal would be what the ward would want in this circumstance, then the ward's wishes should be carried out. If such a decision cannot be reached then either of two best-interests tests can be applied. Under the *limited objective test*, life-sustaining treatment may be withdrawn if "there is some trustworthy evidence that the patient would have refused the treatment, and . . . it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him." Under the *pure objective test* (i.e., when there is *no* evidence about what the patient might want), "the net burdens of the patient's life with the treatment should

clearly outweigh the benefits that the patient derives from life . . . [and] the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane." This very strict test, which centers on severe pain, is adopted because the majority's belief that "when evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life"; and not to adopt this conservative posture "would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps." When either of these tests is used, the patient's family, including spouse, parents, and children, "must concur in the decision to withhold or withdraw life-sustaining treatment." If all of these steps are taken "in good faith," then all actors have legal immunity for their actions.

There are a number of problems with this procedural approach. First, it seems wholly unnecessary where the patient has written an explicit living will and designated a proxy through a durable power of attorney to carry out his wishes. Second, as Justice Handler argues persuasively in dissent, the "pure objective test" that focuses exclusively on "recurring, unavoidable and severe pain" as the *only* basis for withholding or withdrawing treatment seems too narrow. There may be other negative considerations like probability of benefit, use of restraints, invasiveness, etc., in addition to pain, that objectively may make continued treatment more burdensome than beneficial to the patient. Third, to require the ombudsman always to assume the withdrawal or withholding of treatment is abusive until proven otherwise will likely discourage families and others from using this mechanism, even if doing so would fulfill the clear wishes of their nursing-home-bound relative. Fourth, although the court acknowledges that a major problem in nursing home care is finding a physician who will go there, it requires not one, but *three physicians* to examine the patient and report on the patient's condition. One outside consultant should suffice to confirm the medical condition and options. Finally, although many of the flaws in the *Quinlan* case have been clarified, the court persists in delegating its immunity-granting authority to third parties. In *Quinlan*, the delegation was to an "ethics committee" (which has properly been renamed a "prognosis committee"). In *Conroy*, the court delegates immunity-granting authority to a undesignated group that must concur, but need never meet: the guardian, attending physician,

two consulting physicians, the ombudsman; and, where either of the two best-interests tests are used, the patient's family or next of kin.

These problems seem to flow from a too narrow reading of the facts. For example, pain was seen as a major issue by all parties, but there was conflicting evidence about Ms. Conroy's pain at the trial level. Pain is *a* major issue, but it should not be the only issue. The central issue is, as the court makes clear in most of its opinion, the wishes of the patient if they can be discerned, and, if not, the patient's best interests.

Likewise, the attempt to limit the opinion to encompass only nursing home patients is troubling and fatally flawed. It neglects the fact that *all* of the relevant medical decisions regarding Claire Conroy were made not in the nursing home at all, but during her four-month stay at the Clara Maas Hospital, where her nasogastric tube was inserted, removed, and reinserted, and where her guardian first requested that it be permanently removed. The dichotomy between nursing home and hospital is not only artificial and misleading in Ms. Conroy's case, it is artificial in the case of almost every elderly patient. Almost all will be transferred to hospitals when they require invasive treatment, and a large number of them will initially enter the nursing home via a hospital. The reasons provided by the court suggest a procedure that might be different in degree, but not so extreme as to set one up different in kind. The five reasons given are the patients' average age; their lack of surviving parents, siblings, or children; the limited role of physicians in nursing homes; general understaffing and reports of inhumane treatment; and the less urgent types of treatment decisions that are made in nursing homes. Of these, the patient's age, family status, and needed treatment, are all unaffected by the physical setting.

This leaves the lack of physician contact and the general bad impression one has about nursing homes as justifying different kinds of procedures. Neither is sufficiently persuasive. Almost all previous nontreatment court cases have originated in hospitals, and this seems to be the setting in which patient wishes are most frequently ignored. There are more treatment decisions per patient per day made in hospitals, but the court gives us no reason to assume that they are made so much better. By focusing on the nursing home setting, the court tended to ignore the plight of Claire Conroy, just as the *Quinlan* court wound up concentrating on physician liability and ignoring the interests of Karen Ann Quinlan herself (Annas 1985). Because of this failure

and the extremely complex procedural mechanisms employed, the "New Jersey" solution is not likely to be a useful one for other states to follow.

Responsibility of Hospital and Physicians to Patient Who Refuses Life-sustaining Treatment (Including Transfer)

The thrust of almost all of the judicial decisions to date has been to grant prospective legal immunity to physicians for following the wishes of competent patients or their legal guardians. In a few rare instances, however, physicians may refuse to honor the wishes of a competent patient. Traditional abandonment principles require physicians to find another physician to care for these patients if they require continued care (Annas 1975).

Anticipating this problem, as noted above, the New Jersey Supreme Court in the *Quinlan* case explicitly gave Mr. Quinlan, as guardian, the legal authority to seek out other physicians for his daughter. Competent patients, of course, retain the right to hire and fire their individual physicians as well. But what if, for some reason, alternate physicians cannot be found? Is the competent patient's physician then at liberty to ignore the patient's wishes, or is the physician obligated to follow them even if following them is against his best medical judgment or his conscience?

This difficult question was addressed directly in the case of William Bartling, a 70-year-old man confined to an intensive care unit, and intubated with a mechanical ventilator, who asked that the ventilator be removed.³⁹ His physicians, conceding that Mr. Bartling was competent, nonetheless refused to remove the ventilator because it would cause his death and they did not think this was a proper action for a physician to take. The hospital in which Mr. Bartling was residing, Glendale Adventist Hospital, aggressively opposed their patient and went to court to argue against removal of the ventilator. Attempts by Mr. Bartling's lawyer to find other physicians for him were unsuccessful because of the publicity generated by the case.

A lower court refused to order the physicians to remove the ventilator.

³⁹ *Bartling v. Superior Court*, 209 Cal. Rptr. 220 (Cal. App. 2 Dist. 1984).

The day before the appeals court heard the case, Mr. Bartling died, still in the hospital on the ventilator. Accordingly, the primary issue the appeals court had to address was the obligation of a physician and hospital to fulfill the patient's wishes when transfer was impossible. The court found that Mr. Bartling had a constitutionally guaranteed right to refuse treatment and that the strongest argument that the physicians and hospital could make was that the hospital, Glendale Adventist, was a "Christian, pro-life oriented hospital, the majority of whose doctors would view disconnecting a life-support system in a case such as this as inconsistent with the healing orientation of physicians." The court, while not doubting the sincerity of these ethical beliefs, was emphatic that *in a conflict, the patient's interests are paramount and must control*:

If the right 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.

Previous cases are in accord with this view.⁴⁰ Indeed, the court went further in a footnote, saying that if Mr. Bartling was still alive, it would have issued the following order:

ORDERED AND ADJUDGED that William Francis Bartling, in the exercise of his right of privacy, may remain in defendant hospital or leave said hospital free of the mechanical respirator now attached to his body and all defendants and their staffs are restrained from interfering with Mr. Bartling's decision.

A majority of states now have "living will" statutes which provide a mechanism for a patient to refuse treatment after he or she is no longer competent. Using a document called a "living will" or prior declaration, a patient can set forth his or her wishes concerning cessation or withdrawal of life-sustaining treatment after becoming

⁴⁰ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977); *Satz v. Perlmutter*, 362 So.2d 160 (Fla. App. 1978), *Aff'd* 379 So.2d 359 (Fla. 1980).

incompetent. In such cases it may happen that their attending physician disagrees with their decision or refuses to carry it out for "ethical" reasons. These statutes generally require the physician to transfer the patient to a physician who will carry out the terms of the declaration. Likewise, the Uniform Rights of the Terminally Ill Act, adopted by the National Conference of Commissioners on Uniform State Laws in August 1985 provides, in Section 6: "An Attending physician or other health-care provider who is unwilling to comply with this Act shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider." This uniform act, and other living will statutes are discussed in detail in the following section of this article.

Legislative Approaches to Withholding and Withdrawing Life-sustaining Treatment for Elderly Incompetent Patients

Recent debate has centered on four basic legislative approaches to protecting the rights of adults in the context of medical treatment decisions: "living will" statutes, durable power of attorney statutes, guardianship, and adult protective services and public guardianship. The last three are generic approaches designed to perform all or most of the tasks needed by elderly or incompetent individuals. The first, "living wills," is the only one specifically designed to permit a currently competent individual to have some say about medical treatment after the individual becomes incompetent to participate in treatment decisions. Because of their generality, the last three schemes will be dealt with rather cursorily, with major attention focused on living will proposals.

Guardianship

As specifically applied to medical treatment decisions, guardianship has already been discussed in some detail. Some more general observations, however, seem appropriate as they relate to measures the legislature might take to improve guardianship as a means to protect patients. A guardian is a judicially appointed individual who makes decisions on behalf of an incompetent individual, termed a ward. All states have statutes that provide for the appointment of a guardian

in certain circumstances under the state's *parens patriae* power. Although the purpose of guardianship is to *protect* the ward, allegations are frequently made that the system often actually devalues the elderly, who are viewed as useless and burdensome (Butler 1975; Nolan 1984).

Procedures differ between states, but, in general, a court must formally declare an individual incompetent to make certain decisions in order to appoint a guardian to make decisions for him. With the number of guardianship petitions increasing sharply in recent years, however, courts have been criticized for giving very little time to each case, and often making determinations with little or no evidence and without the legal representation of the ward (Sherman 1980; Dewey 1965).

A petition for guardianship may usually be filed by any interested party, with notice sent to the alleged incompetent person. This notice requirement can be waived by the judge in some jurisdictions, and often is when the prospective ward is in a hospital. The quality of the notice also varies, and may not convey what is at stake to the alleged incompetent. The alleged incompetent is often not present at the hearing, and is rarely represented by counsel. There is commonly no evidence presented on his behalf (Regan 1985). This happens although all states *permit* the alleged incompetent to be represented by counsel.

The theory under which guardianship proceedings have become one-sided, nonadversarial proceedings is that their intent is to protect and *benefit* the ward, so an adversarial proceeding is not seen as needed and is not deemed appropriate. This does not seem to reflect reality, and a requirement of such representation would be much more protective of the alleged incompetent.

The court may grant the guardian carefully defined "limited" or "partial" powers to perform specific tasks or "plenary powers" to make all decisions on behalf of the ward (Frolik 1981). The two can also be "combined," as in the *Quinlan* case where her father sought both plenary guardianship powers, and, in addition, specific authority to order the removal of the ventilator.⁴¹ The guardian's plenary powers have been divided into three areas: (1) disposition of the ward's financial assets and income; (2) decisions about where and with whom the ward

⁴¹ *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

will live; and (3) decisions about medical treatment (Kapp 1985). Limited or partial guardianship statutes may require that the guardian's powers be delineated as narrowly as possible (e.g., Illinois), or they may permit, but not require, such a narrow grant of authority (e.g., Wisconsin).

Once appointed, the guardian is usually obligated to make decisions consistent with the previously expressed values and preferences of the ward (substituted judgment) or alternatively, to make decisions objectively in the "best interests" of the ward (best interests). Elderly incompetent individuals often have no friend or relative willing or able to act as their guardian. This problem has prompted a number of states to develop some form of "public guardianship" under which a government agency can function as a guardian of last resort.

Adult Protective Services and Public Guardianship

Adult protective services have their genesis primarily in federal law, specifically Titles VI and XX of the Social Security Act. The general definition was developed in 1975 under Title VI (Grants to States for Services to the Aged, Blind or Disabled):

Protective services means a system of service (including medical and legal services which are incidental to the service plan) which are utilized to assist seriously impaired eligible individuals who, because of mental or physical dysfunction, are unable to manage their own resources, carry out the activities of daily living, or protect themselves from neglect or hazardous situations without assistance from others and have no one available who is willing and able to assist them responsibly (45 CFR 222.73).

In 1981, Title XX of the Social Security Act (Block Grants to States for Social Services) encouraged the establishment of protective services for "adults unable to protect their own interests." States have responded in various ways, many concentrating on the prevention of "elder abuse and neglect." In this sense, adult protective services are the analog to "child abuse and neglect" programs, aimed at preventing abuse and neglect in a specific portion of the population. As previously discussed, New Jersey's elder abuse scheme has been adopted by its highest court as the appropriate method to investigate and rule on

termination of treatment decisions involving elderly nursing home patients in certain circumstances.⁴²

Virtually all states provide some form of adult protective services under Title XX (Burr 1982). The program consists of social service intervention. When this is not sufficient, however, the courts will be used to help "manage" the adult for his own benefit. When an appropriate individual is not available to be appointed as a guardian, a public agency may be utilized to fill this role.

Public guardianship generally refers to a state or local governmental agency designated to act as guardian by the court in those cases where the incompetent individual has no friends or relatives available to serve in this capacity (Schmidt et al. 1981). Most states have explicit or implicit statutory provision for public guardianship; some rely on regulations and policies developed under their adult protection services (Burr 1982; Schmidt et al. 1981). When a specific agency is appointed to serve as a public guardian, it is usually the same agency that is in charge of the ward's social welfare services, even though this presents enormous potential conflict of interest (Schmidt et al. 1981). The system could be greatly strengthened from the wards' perspective if public guardianship agencies were completely independent of service agencies, although some have suggested that the system can be so repressive that it should be abolished altogether, and public agencies limited to providing services to willing clients (Regan 1982).

Durable Power of Attorney

A power of attorney is a written instrument in which one person (the principal) confirms the authority of another (the "attorney" or agent) to perform specific tasks on the principal's behalf. In common law the power of such an individual agent or attorney was automatically revoked when the principal died or became legally incapacitated (Fowler 1974). This rule was designed to protect the principal's "right of supervision" over the agent. Thus, an ordinary power of attorney could not be used to delegate decision-making authority in the event of mental incompetency, since the "triggering" event is simultaneously the event that terminates the agent's authority to act (President's

⁴² *In the Matter of Claire Conroy*, 486 A.2d 1209 (N.J. 1985).

Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 144) Because the power terminated precisely when it became needed to make medical decisions, it could not be used for this purpose. This deficiency, and the problems with formal petitioning for guardianship, including the time and expense involved, prompted the search for a new solution in the form of a "durable power of attorney," i.e., an agency authorization that survived the later incapacity of the principal.

A few states adopted the durable power of attorney strategy early. But it was not until 1979 when the National Conference of Commissioners on Uniform State Laws included the "Uniform Durable Power of Attorney Act" in the provisions of the Uniform Probate Code (Eftland 1975) that large numbers of states began to adopt language identical or similar to that set forth in Section 5-501 et seq. of the Uniform Probate Code. The operative section, 5-502, provides:

All acts done by an attorney-in-fact pursuant to a durable power of attorney during any period of disability or incapacity of the principal have the same effect and inure to the benefit of and bind the principal and his successor in interest as if the principal were competent and not disabled.

To avoid potential conflicts with a court-appointed guardian or conservator, the Uniform Probate Code (Sec. 5-503) provides that the guardian has the same power to revoke or amend the power of attorney as the principal would have had if he were not incapacitated, and that the court shall make appointment of a guardian in accordance with the principal's most recent nomination (in a durable power of attorney) except "for good cause or disqualification."

All 50 states now explicitly permit a principal to execute a durable power of attorney by statute, with only the District of Columbia still having no enabling legislation (Collin et al. 1984). The statutes do, however, vary in some respects. Most notably, they either become effective immediately ("immediate power") and remain unaffected by subsequent incapacity of the principal, or, alternatively, they may be permitted to take effect only upon the incapacitation of the principal ("springing power," i.e., springs into effectiveness upon incapacity) (Collin et al. 1984).

Nothing in their language in any way precludes or limits the use of durable power of attorney statutes as a device for delegating medical decision-making authority, and no court has ever ruled that they possess such a limitation. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983, 147) noting the "flexibility of the statutes" that permits "directives to be drafted that are sensitive both to the different needs of patients in appointing proxy decisionmakers and to the range of situations in which decisions may have to be made," encourages the use of existing durable power of attorney statutes "to facilitate decision-making for incapacitated persons." The commission did, however, note the "possibility of abuse inherent in the statutes" that did not contain even the types of due process requirements of a guardianship petition. Accordingly, it called for careful study of what additional safeguards might be required based on experience with this device.

Procedural safeguards are important, but as the guardianship experience has demonstrated, they may add more to form than substance in protecting the principal (Regan 1985). California, for example, recently enacted a durable power of attorney statute specifically tailored for medical decision making. Its provisions are so complex and cumbersome, however, that the statutory procedures are unlikely to be used except in the most exceptional cases. Thus, while due process may be achieved, the price is making the device almost useless. Other states that have adopted statutes specifically dealing with the durable power of attorney's application to medical decision making are Delaware, Virginia, and Pennsylvania. Delaware's provisions are especially rigorous in regard to the qualification of witnesses to the document, disqualifying anyone related by blood or marriage, entitled to take any portion of the principal's estate, financially responsible for medical care of the principal, or employed by the hospital or facility in which the principal is a patient.⁴³ We believe the procedural problems can be remedied in the medical treatment context by combining the durable power of attorney with an explicit "living will." This is discussed in detail in the section that follows.

⁴³ Del. Code Ann. Title 16, Sec. 2503(b) (5) 1983.

Living Will and Natural Death Acts

Overview

The term "living will" was coined by Luis Kutner in 1969; it describes a document in which a competent adult sets forth his wishes concerning medical treatment in the event he becomes incapacitated in the future (Kutner 1969). In this sense, it is like a "will," but since it takes effect prior to death, it is termed a "living" will. More than five million such documents have been distributed by Concern for Dying, a New York educational organization, over the past decade. Public interest is intense in this mechanism, but due to the absence of specific judicial sanction, and the lack of clear rules regarding their execution and use, many individuals and organizations, like the Society for the Right to Die, have long advocated that states pass specific statutes supporting the "living will."

California enacted the first living will statute in 1976, designating it a "natural death act," a term that many other states have used as well. California should receive considerable credit for enacting the first statute, but the price was very high. The statute is *extremely* narrow. A "binding" declaration can only be executed fourteen days or more *after* the declarant has been diagnosed as suffering from a terminal illness, making the person a "qualified patient." In order to qualify as "terminal," death must be "imminent," i.e., the patient must be dying soon *whether or not* life-sustaining procedures are used. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983, 142) has noted, the fourteen-day waiting period under such circumstances requires "a miraculous cure, a misdiagnosis, or a very loose interpretation of the word 'imminent' in order for the directive to be of any use to the patient."

Even though the California statute was inspired in part by the *Quinlan* case, as Professor Alexander Capron (1978) has noted, the statute does not apply to cases like hers because Karen was not terminally ill and her death was not imminent:

The only patients covered by this statute are those who are on the edge of death *despite the doctors' efforts*. The very people for whom

the greatest concern is expressed about a prolonged and undignified dying process are unaffected by the statute because their deaths are not imminent.

Most states have similar limitations on the individuals covered, generally denoting them "terminally ill." This removes from their protection the very categories of patients who are likely to need this protection the most, patients like Earle Spring, William Bartling, and Claire Conroy. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983, 142) noted, "such a limitation greatly reduces an act's potential."

By January 1985, 22 states and the District of Columbia had enacted legislation; and by the end of 1986 at least 20 additional states had enacted legislation on this subject. All of the statutes are different and none is ideal. All statutes include specific instructions which must be followed in the execution of an advanced directive, and most set out a model directive in the statute itself. Some contain California's "imminent" dying language, and some permit the declarant to refuse only "artificial life-sustaining procedures."

Three states (Florida, Louisiana, and Virginia) expressly recognize oral directives as well as written ones, while most of the others expressly require a "writing." Four states (Arkansas, Illinois, Nevada, and New Mexico) require that the declaration be executed in conformance with the laws of the state regarding execution of a will. Almost all statutes require the declarant to attest that he or she is of sound mind at the time of the execution of the declaration, and more than a dozen states require attestation to the voluntariness of the act as well (Gilmore and Thorpe 1985).

Revocation is dealt with in all the statutes, but the circumstances under which a declaration can be revoked vary, including cancellation, destruction, written revocation, and oral revocation. Most states require communication of the revocation to the attending physician as well. Penalties for not following advance directives are few. The California statute stipulates that a physician's failure to follow a *binding* declaration, or transfer the patient to a physician who will, shall constitute unprofessional conduct. The Texas statute says only that such an act *may* constitute unprofessional conduct. The vast majority of statutes contain no penalties at all.

Major Limitations of Current Statutes

In addition to their lack of uniformity, the potential conflict of laws raises the question of the statutory differences when someone dies in a state other than the one in which his declaration was executed. Current "living will" statutes also suffer from the following general infirmities:

1. They are generally restricted to the terminally ill, and thus exclude from their protection the vast majority of elderly individuals, and the term "terminally ill" is so vague that it is subject to arbitrary interpretation and application;
2. They generally limit the types of treatment a person can refuse to "artificial" or "extraordinary," thus excluding many burdensome treatments, and the vagueness of these terms leads to arbitrary interpretations;
3. They do not permit an individual to designate another person to act on his behalf (like a durable power of attorney) and do not set forth criteria under which the person so designated is to exercise this authority, thus greatly restricting the usefulness of the document in cases not precisely predicted by the individual;
4. They do not require health care providers to follow the patient's wishes as set forth in the declaration, thus the rights of the *patient* are not seen as superior to those of the health care providers;
5. They do not explicitly require health care providers to continue palliative care to a patient who refuses other medical interventions.

Because of these shortcomings, "living will" statutes are unlikely to help resolve the many complex issues discussed in the previous sections of this article. As presently drafted, what these statutes primarily do is provide that if a patient is terminally ill, and if the physician can do nothing to sustain the patient's life, and if the patient does not want his life sustained, and the doctor agrees with the patient's decision, then the doctor *may* (but does not have to) follow the patient's desire, and be assured criminal and civil immunity for his actions.

Two major approaches have been suggested to help remedy the current unsatisfactory state of living will legislation: the approach of the National Conference of Commissioners on Uniform State Laws, to draft a uniform act that clarifies existing legislation; and the approach of the Legal Advisers of Concern for Dying, to draft a "second generation"

act that advances the rights of patients by directly addressing the shortcomings discussed above.

The Uniform Rights of the Terminally Ill Act

The National Conference of Commissioners on Uniform State Laws charged its drafting committee to develop a uniform state living will statute, but imposed a number of critical limitations. Most important, the statute was to be limited to patients in a "terminal condition," and the use of proxies or a built-in durable power of attorney was precluded. Accordingly, the act does not (and could not) deal with these two critical limitations of the current statutes. The act also restricts itself to competent adults, thus excluding mature minors from its coverage, and limits the types of treatment that can be refused to those that "serve only to prolong the dying process."

But developing a more useful or more comprehensive model statute was not the drafting committee's purpose. Instead, as stated in their final "draft for approval," the purposes of the uniform act are threefold: (1) to encourage the effectiveness of a declaration in states other than the state in which it is executed through uniformity of scope and procedure, (2) to avoid the inconsistency in approach and quality which have characterized the early statutes, and (3) to present an act which is simple, effective, and acceptable to persons desiring to execute a declaration and to physicians and health care facilities whose conduct will be affected.

Goals 1 and 2 are modest and are, by definition, achieved by a "uniform act." Goal 3, however, is much more elusive and although the act is "simple" and "acceptable," its "effectiveness" depends upon one's criteria for judgment. The full text of the act is set forth in appendix 1.

Specific attention is drawn to the following provisions.

Two definitions merit comment. First, "life-sustaining treatment" is defined as "any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process." The type of treatment a patient can refuse is thus limited to those which *only* serve to "prolong the dying process." It is unlikely there are any such treatments, and, if they exist, neither medical ethics nor medical practice sanctions administering such "treatment"

to a patient. Thus, if this definition is taken seriously, the act has no or almost no application in the real world. Second, "terminal condition" is defined as "an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time." Like the California progenitor, and most other existing statutes, this limitation to "terminally ill" patients drastically restricts the application of the statute, and will lead to all of the problems caused by the term "imminent," since there is little, if any, difference between "imminent" death, and "death within a relatively short time." It does, however, properly limit the use of this term to the time *without* "the administration of life-sustaining treatment," thus not requiring that death come soon "whether or not" treatment is continued. The definitional limitations mean the act would not apply to people like Karen Quinlan, Earle Spring, Claire Conroy, or William Bartling.

The revocation section (3a) provides that "a declaration may be revoked at any time and in any manner by the declarant without regard to mental or physical condition." This simply seems to be a mistake. The revocation of a declaration by an incompetent patient or one unable to understand what he or she is doing should not be effective, since it negates the very essence of what the act seeks to promote: self-determination.

The pregnancy limitation section (5d) appears unconstitutional when applied to the period of pregnancy prior to fetal viability, and the reason for discriminating against terminally ill pregnant women in this manner seems unjustified. Many statutes have similar provisions, and all seem designed to deprive pregnant women of the right to refuse treatment they would otherwise possess.

The transfer section (6) provides: "An attending physician or other health-care provider who is unwilling to comply with this act shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider." This should be the heart of the act. Unfortunately it begs the relevant question: What do "all reasonable steps" mean, and what if after taking them the physician is still unable to transfer the patient? If one believes in taking the rights of patients seriously, the act should require the physician to either transfer "as promptly as practicable" *or* to carry out the wishes of the patient if transfer is not promptly arranged, even if the health care provider disagrees with them.

The second part of the immunity section (7b) provides: "A physician or other health-care provider, whose actions under this act are in accord with reasonable medical standards, is not subject to criminal or civil liability or discipline for unprofessional conduct." This provision is extremely curious. It seems to permit the physician to do whatever he or she wants regardless of the patient's stated views in the declaration, as long as those actions "are in accord with reasonable medical standards." If this interpretation is correct, this provision invalidates all of the otherwise mandatory aspects of the act by permitting physicians to do whatever is "in accord with reasonable medical standards," which, one must presume, was the law prior to enactment of the act.

Finally, there are penalties for failure to transfer, willfully failing to record a determination, willfully concealing, cancelling or defacing or forging a declaration, etc. But there are *no penalties for failure to follow a declaration*. This, of course, should be the whole point of the act, and without a penalty for failure to follow the declarant's wishes, physicians are left in the same "optional" position they were in prior to the act.

In short, while the act *does* provide a uniform approach, it is not a particularly useful one since it severely limits its application to tiny categories of patients and treatments. Moreover, it does not provide for a proxy or setting standards for proxy decision making; does not require health professionals to follow the terms of the declaration; and does not explicitly require the provision of palliative care. Thus, the act addresses only one major shortcoming of current laws: the lack of uniformity. It leaves the other five major shortcomings intact; worse, it seems to institutionalize and approve them.

The Right to Refuse Treatment Act

In addition to the Uniform Rights of the Terminally Ill Act, three other major model statutes have been developed on the subject of consent to medical treatment. All were reviewed and discussed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983, 147–48). The first, the Society for the Right to Die's "Medical Treatment Decision Act" is substantially identical to many of the existing natural death acts and so shares their problems. As the President's Commission

described it, it “shares the narrowness of application of most such acts and makes no explicit provision for designating a proxy for medical decision making.”

The second proposal is, like the Uniform Act, from the National Conference of Commissioners on Uniform State Laws. It is entitled a “Model Health Care Consent Act.” Unfortunately, despite its title, it does not have consent as its central concern. As the President’s Commission correctly noted, it should more accurately be described as a “substitute authority to decide act.” And even in this area it is extremely narrow and “imprecise.” The President’s Commission properly criticized it for failure to provide any guidance on what standard a proxy should use in making health care decisions, imprecision in the determination of capacity to consent, and uncertain provisions regarding revocation and redelegation of authority. A leading commentator described it as “confused and ultimately misguided,” and thought it could be more accurately entitled “The Summer Camp Health Care Act” (Capron 1983). It does *not* address the major issues discussed in this article.

The third proposal is the “Right to Refuse Treatment Act,” a “second generation” living will act developed by the Legal Advisers Committee of Concern for Dying and set forth in its entirety in appendix 2 (Concern for Dying. Legal Advisers Committee 1983; President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983, 428–31). Of this act the President’s Commission wrote:

The Act enunciates competent adults’ right to refuse treatment and provides a mechanism by which competent people can both state how they wish to be treated in the event of incompetence and name another person to enforce those wishes. *In terms of its treatment of such central issues as the capacity to consent and the standard by which a proxy decision-maker is to act, the Uniform Right to Refuse Treatment Act is carefully crafted and in conformity with the Commission’s conclusions.* Greater opportunity for review of determinations of incompetency and of proxy’s decisions may be needed, however, to protect patients’ self-determination and welfare [emphasis added].

The act has been introduced in the Florida and Massachusetts legislatures. Following a lower court decision in Massachusetts in the case of Paul Brophy, a 43-year-old former fire fighter and EMT, which

refused to permit the withdrawal of artificial nutrition via a gastrostomy tube on Mr. Brophy although he was in a persistent vegetative state, and despite a judicial finding that he would refuse such artificial feeding if he was competent, the *Boston Globe* editorially recommended the act to the state legislature. This recommendation was based on the fact that unlike other current statutes and proposals, the act would specifically permit patients to refuse any treatment, including artificial feeding, through a living will and/or designation of a proxy to make this decision consistent with their desires. The lower court decision was reversed in 1986 and the hospital ordered to transfer Mr. Brophy to a facility that would comply with his wishes.⁴⁴

Most sections of the Right to Refuse Treatment Act are self-explanatory, but some deserve specific comment. No model form or document is included, because the drafters believed that the individual's wishes would be more likely to be precisely expressed if they were required to be set forth in his own words. The right affirmed by the act is the right to refuse treatment, as viewed as implicit in any meaningful concept of individual liberty. Living will statutes, on the other hand, have often relied on a vaguely articulated "right to die" notion that has no legal pedigree. Both adults and mature minors are included in the purview of the act, because the drafters believed that minors who understand and appreciate the nature and consequences of their actions should be afforded self-determination and not forced to undergo medical treatment against their will.

To meet the objections of narrowness in the other acts, this act aims at protecting the autonomy of *all* competent individuals, not just those who have been diagnosed as "terminally ill," because all persons merit respect and autonomy. Moreover, if we do not raise our sensitivity regarding respect for the nonterminally ill patient's right to autonomy, it is extremely unlikely that the rights of terminally ill patients will be afforded respect. The act would also apply to patients like Karen Ann Quinlan and Paul Brophy, who although in hopeless, persistent vegetative states, did not suffer from an underlying, terminal illness. It would also apply to patients like Earle Spring and William Bartling (Concern for Dying. Legal Advisers Committee 1983).

⁴⁴ *In re Brophy v. New England Sinai Hospital*, 497 N.E.2d 626 (Mass. 1986).

The most critical definition in the act is that of "competence," which is defined as the ability to "understand and appreciate the nature and consequences of a decision to accept or reject treatment." The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981, 159) noted that "by combining a proxy directive with specific instructions, an individual could control both the content and the process of decision-making about care in case of incapacity." The act incorporates this suggestion by permitting the declarant to define both what interventions are refused (including artificial feeding), and to name an authorized individual to make decisions consistent with his desires as expressed in the declaration.

The Right to Refuse Treatment Act recognizes that some health care providers may have different belief systems than their patients, and attempts to outline a realistic transfer procedure that respects the ethical views of both parties. The act recognizes, however, that the patient is most immediately affected by the treatment-refusal decision, since the patient's own future and quality of living and dying is at stake. Consequently, it provides that a patient's directive must prevail over the physician's views in the rare occasion where transfer is impossible. This may seem harsh, but the drafters believed that the balance between the physician's personal ethics (or the ethics of the medical profession) and the liberty interest of the patient would always be tipped in the patient's favor by the patient's interest in being free from nonconsensual medical interventions.⁴⁵

Providers who follow the procedures outlined in the act are relieved of liability under any civil, criminal, or administrative action. On the other hand, providers who abandon their patients or refuse to comply with valid declarations are subject to punishment. These offenders may face civil actions including charges of negligence and battery, and administrative sanctions including license revocation and suspension.

Other important sections of the act make it clear that this method of refusing treatment is not exclusive, that refusal of treatment is not suicide, does not affect insurance policies, and that regardless of

⁴⁵ *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977); *Barling v. Superior Court*, 209 Cal. Rptr. 220 (Cal. App. 2 Dist. 1984).

refusals, palliative care *must* be given unless it is specifically refused by the patient. No time limit is placed on the validity of the declaration, just as there is no time limit on ordinary wills or on donations made under the Uniform Anatomical Gift Act. Nonetheless, those who worry that the declaration might not reflect the currently held views of the patient will want to add some provision for updating or reaffirming one's advance declaration. The primary protection regarding the wishes of the patient is the requirement for two witnesses to certify that they believe the person understood what he was signing and did so voluntarily. The drafters did not restrict the individuals who can either be witnesses or authorized persons, because they believed this unnecessarily implied bad faith on the part of whole categories of individuals (e.g., relatives, those making the will, health providers), and unnecessarily restricts the autonomy of an individual to pick his own witnesses and proxies. Those who disagree with this analysis, as the President's Commission may have, will want to consider disqualifying certain individuals who seem to have a built-in conflict of interest with the declarant.

An additional protection of the declarant is that revocation is made simple. But the intent to revoke must be specific. Merely signing a blanket hospital admissions form that "consents" to whatever treatment physicians at the hospital may wish to render is insufficient indication of revocation of a declaration. While a relative may sabotage a patient's wishes (by reporting a verbal revocation that did not in fact take place), the act relies on good faith and criminal penalties to discourage this practice.

In summary, the act is designed to promote the autonomy of competent individuals and respect for their decisions by enhancing their right to accept or reject medical treatments recommended by their health care providers. It protects all patients who were once competent, both while they are competent, and, if they execute a declaration, after they become incompetent. It provides that patients may execute a written, signed declaration setting forth their intentions on treatment and refusal decisions and permits them to designate authorized individuals to make treatment decisions on their behalf should they become incompetent in the future. The act upholds and clarifies recognized patient rights consistent with the ethics of the medical profession and shields complying physicians, witnesses, and authorized persons acting in good faith from legal liability and provides penalties for those who violate its provisions.

Of course, there are major limitations to this act as well. Primarily, it applies *only* to competent individuals who either refuse treatment while competent, or actually execute a declaration while competent. It does not apply to those individuals who were never competent, or to formerly competent individuals who never executed a declaration. Thus, it leaves the issue of what to do with these categories of individuals unresolved.

Conclusion

The individual's right to self-determination in deciding whether to accept recommended medical care hinges upon the doctrine of informed consent and the constitutional right of privacy. The appellate courts have been remarkably consistent in enunciating and enforcing this right, and in permitting competent individuals to refuse *any* medical intervention. For the elderly patient the right to self-determination is often lost due to a health care provider's or trial court's wrongful assumption of incompetence. To protect the elderly, their competence must be judged on the same basis as everyone else's: an ability to understand and appreciate the information needed to give an informed consent. The appellate courts are in accord on these issues, and current debate continues primarily around defining when, if ever, the state has a sufficiently compelling interest in forcing treatment on a patient. Pregnancy and child-dependency have been the major such potential interests cited, but neither is likely to apply to the elderly. Although their rights are clear, the remedy is often difficult, especially when the health care provider refuses to either follow the patient's decisions or transfer the patient. While courts will enforce the rights of the patient, health care providers should honor patient decisions without resort to the courts. Appropriate legislation might serve both to codify existing rights, and to clarify mechanisms to enforce and enhance them.

Appendix 1

Uniform Rights of the Terminally Ill Act

Section 1. Definitions

In this [Act]:

- (1) "Attending physician" means the physician who has primary responsibility for the treatment and care of the patient.
- (2) "Declaration" means a writing executed in accordance with the requirements of Section 2(a).
- (3) "Health-care provider" means a person who is licensed, certified, or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.
- (4) "Life-sustaining treatment" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the dying process.
- (5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, government, governmental subdivision or agency, or any other legal entity.
- (6) "Physician" means an individual [licensed to practice medicine in this State].
- (7) "Qualified patient" means a patient [18] years of age or older who has executed a declaration and who has been determined by the attending physician to be in a terminal condition.
- (8) "State" means a state, territory, possession, or commonwealth of the United States and the District of Columbia.
- (9) "Terminal condition" means an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time.

Section 2. Declaration Relating to Use of Life-sustaining Treatment

- (a) Any individual of sound mind and [18] years of age or older may at any time execute a declaration governing the withholding

or withdrawal of life-sustaining treatment. The declaration must be signed by the declarant, or another at the declarant's direction, and witnessed by 2 individuals.

- (b) A declaration may, but need not, be in the following form:

Declaration

If I should have an incurable or irreversible condition that will cause my death within a relatively short time, and if I am no longer able to make decisions regarding my medical treatment, I direct my attending physician, pursuant to the [_____ Uniform Rights of the Terminally Ill Act], to withhold or withdraw treatment that only prolongs the dying process and is not necessary to my comfort or to alleviate pain.

Signed this _____ day of _____, _____.

Signature _____

Address _____

The declarant voluntarily signed this writing in my presence.

Witness _____

Address _____

Witness _____

Address _____

- (c) A physician or other health-care provider who is provided a copy of the declaration shall make it a part of the declarant's medical record and, if unwilling to comply with its provisions, promptly so advise the declarant.

Section 3. Revocation of Declaration

- (a) A declaration may be revoked at any time and in any manner by the declarant without regard to mental or physical condition. A revocation is effective upon communication to the attending physician or other health-care provider by the declarant or by another who witnessed the revocation.
- (b) The attending physician or other health-care provider shall make the revocation a part of the declarant's medical record.

Section 4. Recording Determination of Terminal Condition and Declaration

Upon determining that the declarant is in a terminal condition, the attending physician who knows of a declaration shall record the determination and the terms of the declaration in the declarant's medical record.

Section 5. Treatment of Qualified Patients

- (a) A qualified patient has the right to make decisions regarding life-sustaining treatment as long as the patient is able to do so.
- (b) A declaration becomes operative when (1) the declaration is communicated to the attending physician and (2) the declarant is determined by the attending physician to be in a terminal condition and no longer able to make decisions regarding administration of life-sustaining treatment. When the declaration becomes operative, the attending physician and other health-care providers shall act in accordance with its provisions or comply with the transfer provisions of Section 6.
- (c) This [Act] does not affect the responsibility of the attending physician or other health-care provider to provide treatment, including nutrition and hydration, for comfort, care, or alleviation of pain.
- (d) Unless the declaration otherwise provides, the declaration of a qualified patient known to the attending physician to be pregnant shall be given no force or effect as long as it is probable that the fetus could develop to the point of live birth with continued application of life-sustaining treatment.

Section 6. Transfer of Patients

An attending physician or other health-care provider who is unwilling to comply with this [Act] shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider.

Section 7. Immunities

- (a) In the absence of knowledge of the revocation of a declaration, a person is not subject to civil or criminal liability or discipline for unprofessional conduct for carrying out the declaration pursuant to the requirements of this [Act].
- (b) A physician or other health-care provider, whose actions under this [Act] are in accord with reasonable medical standards, is not subject to criminal or civil liability or discipline for unprofessional conduct.

Section 8. Penalties

- (a) A physician or other health-care provider who willfully fails to transfer in accordance with Section 6 is guilty of [a class _____ misdemeanor].
- (b) A physician who willfully fails to record the determination of terminal condition in accordance with Section 4 is guilty of [a class _____ misdemeanor].
- (c) An individual who willfully conceals, cancels, defaces, or obliterates the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another is guilty of [a class _____ misdemeanor].
- (d) An individual who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 3, is guilty of [a class _____ misdemeanor].
- (e) Any person who requires or prohibits the execution of a declaration as a condition for being insured for, or receiving, health-care services shall be guilty of [a class _____ misdemeanor].
- (f) Any person who coerces or fraudulently induces another to execute a declaration under this [Act] shall be guilty of [a class _____ misdemeanor].
- (g) The sanctions provided in this section do not displace any sanction applicable under other law.

Section 9. General Provisions

- (a) Death resulting from the withholding or withdrawal of life-sustaining treatment pursuant to a declaration and in accordance

with this [Act] does not constitute, for any purpose, a suicide or homicide.

- (b) The making of a declaration pursuant to Section 2 does not affect in any manner the sale, procurement, or issuance of any policy of life insurance or annuity, nor does it affect, impair, or modify the terms of an existing policy of life insurance or annuity. A policy of life insurance or annuity is not legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining treatment from an insured qualified patient, notwithstanding any term to the contrary.
- (c) A person may not prohibit or require the execution of a declaration as a condition for being insured for, or receiving, health-care services.
- (d) This [Act] creates no presumption concerning the intention of an individual who has revoked or has not executed a declaration with respect to the use, withholding, or withdrawal of life-sustaining treatment in the event of a terminal condition.
- (e) This [Act] does not affect the right of a patient to make decisions regarding use of life-sustaining treatment so long as the patient is able to do so, or impair or supersede any right or responsibility that any person has to effect the withholding or withdrawal of medical care.
- (f) Nothing in this [Act] shall require any physician or other health-care provider to take any action contrary to reasonable medical standards.
- (g) This [Act] does not condone, authorize, or approve mercy-killing or euthanasia.

Section 10. Presumption of Validity of Declaration

A physician or other health-care provider may presume, in the absence of knowledge to the contrary, that a declaration complies with this [Act] and is valid.

Section 11. Recognition of Declaration Executed in Another State

A declaration executed in another state in compliance with the law of that state or this state is validly executed for purposes of this [Act].

Section 12. Effect of Prior Declarations

An instrument executed before the effective date of this [Act] that substantially complies with Section 2(a) shall be given effect pursuant to the provisions of this [Act].

Section 13. Severability

If any provision of this [Act] or its application to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of this [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

Section 14. Time of Taking Effect

This [Act] takes effect on _____

Section 15. Uniformity of Construction and Application

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

Section 16. Short Title

This [Act] may be cited as the Uniform Rights of the Terminally Ill Act.

Section 17. Repeal

The following acts and parts of acts are repealed:

- (1)
- (2)
- (3)

Appendix 2

Right to Refuse Treatment Act

Section 1. Definitions

“Competent person” shall mean an individual who is able to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

“Declaration” shall mean a written statement executed according to the provisions of this Act which sets forth the declarant’s intentions with respect to medical procedures, treatment or nontreatment, and may include the declarant’s intentions concerning palliative care.

“Declarant” shall mean an individual who executes a declaration under the provisions of this Act.

“Health care provider” shall mean a person, facility or institution licensed or authorized to provide health care.

“Incompetent person” shall mean a person who is unable to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

“Medical procedure or treatment” shall mean any action taken by a physician or health care provider designed to diagnose, assess, or treat a disease, illness, or injury. These include, but are not limited to, surgery, drugs, transfusions, mechanical ventilation, dialysis, resuscitation, artificial feeding, and any other medical act designed for diagnosis, assessment or treatment.

“Palliative care” shall mean any measure taken by a physician or health care provider designed primarily to maintain the patient’s comfort. These include, but are not limited to, sedatives and pain-killing drugs; non-artificial, oral feeding; suction; hydration; and hygienic care.

“Physician” shall mean any physician responsible for the declarant’s care.

Section 2.

A competent person has the right to refuse any medical procedure or treatment, and any palliative care measure.

Section 3.

A competent person may execute a declaration directing the withholding or withdrawal of any medical procedure or treatment or any palliative care measure, which is in use or may be used in the future in the person's medical care or treatment, even if continuance of the medical procedure or treatment could prevent or postpone the person's death from being caused by the person's disease, illness or injury. The declaration shall be in writing, dated and signed by the declarant in the presence of two adult witnesses. The two witnesses must sign the declaration, and by their signatures indicate they believe the declarant's execution of the declaration was understanding and voluntary.

Section 4.

If a person is unable to sign a declaration due to a physical impairment, the person may execute a declaration by communicating agreement after the declaration has been read to the person in the presence of the two adult witnesses. The two witnesses must sign the declaration, and by their signatures indicate the person is physically impaired so as to be unable to sign the declaration, that the person understands the declaration's terms, and that the person voluntarily agrees to the terms of the declaration.

Section 5.

A declarant shall have the right to appoint in the declaration a person authorized to order the administration, withholding, or withdrawal of medical procedures and treatment in the event that the declarant becomes incompetent. A person so authorized shall have the power to enforce the provisions of the declaration and shall be bound to exercise this authority consistent with the declaration and the authorized person's best judgment as to the actual desires and preferences of the declarant. No palliative care measure may be withheld by an authorized person unless explicitly provided for in the declaration. Physicians and health care providers caring for incompetent declarants

shall provide such authorized persons all medical information which would be available to the declarant if the declarant were competent.

Section 6.

Any declarant may revoke a declaration by destroying or defacing it, executing a written revocation, making an oral revocation, or by any other act evidencing the declarant's specific intent to revoke the declaration.

Section 7.

A competent person who orders the withholding or withdrawal of treatment shall receive appropriate palliative care unless it is expressly stated by the person orally or through a declaration that the person refuses palliative care.

Section 8.

This act shall not impair or supersede a person's legal right to direct the withholding or withdrawal of medical treatment or procedures in any other manner recognized by law.

Section 9.

No person shall require anyone to execute a declaration as a condition of enrollment, continuation, or receipt of benefits for disability, life, health or any other type of insurance. The withdrawal or withholding of medical procedures or treatment pursuant to the provisions of this Act shall not affect the validity of any insurance policy, and shall not constitute suicide.

Section 10.

This Act shall create no presumption concerning the intention of a person who has failed to execute a declaration. The fact that a person has failed to execute a declaration shall not constitute evidence of that person's intent concerning treatment or nontreatment.

Section 11.

A declaration made pursuant to this Act, an oral refusal by a person, or a refusal of medical procedures or treatment through an authorized person, shall be binding on all physicians and health care providers caring for the declarant.

Section 12.

A physician who fails to comply with a written or oral declaration and to make necessary arrangements to transfer the declarant to another physician who will effectuate the declaration shall be subject to civil liability and professional disciplinary action, including license revocation or suspension. When acting in good faith to effectuate the terms of a declaration or when following the direction of an authorized person appointed in a declaration under Section 5, no physician or health care provider shall be liable in any civil, criminal, or administrative action for withholding or withdrawing any medical procedure, treatment, or palliative care measure. When acting in good faith, no witness to a declaration, or person authorized to make treatment decisions under Section 5, shall be liable in any civil, criminal, or administrative action.

Section 13.

A person found guilty of willfully concealing a declaration, or falsifying or forging a revocation of a declaration, shall be subject to criminal prosecution for a misdemeanor [the class or type of misdemeanor is left to the determination of individual state legislatures].

Section 14.

Any person who falsifies or forges a declaration, or who willfully conceals or withholds information concerning the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures from a person, and who thereby causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be subject to criminal prosecution for a felony [the class or type of felony is left to the determination of individual state legislatures].

Section 15.

If any provision or application of this Act is held invalid, this invalidity shall not affect other provisions or applications of the Act which can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.

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