

4: The Liberty to Refuse Medical Treatment

A. "Euthanasia" and the Refusal of Treatment

In its etymological sense the word "euthanasia" simply means "good death." A word with such an origin can mean many things. For example, it could be taken to express the concept which some Christians express by "happy death," the concept of dying in Christ at peace with God. But in fact, until the last decade or so, "euthanasia" generally was taken to mean the act of putting to death someone suffering from a painful or prolonged mortal illness or injury.

In this sense euthanasia is mercy killing; it involves an activity: someone's doing something in order to bring about death. In recent discussion "euthanasia" in this sense often is called "active euthanasia." Active euthanasia might be done to persons *with* their consent, in which case it is called "voluntary active euthanasia," which we shall consider in chapter six; or it might be done to persons *without* consent on their part, in which case it is called "nonvoluntary active euthanasia," which we shall consider in chapter eight.

Distinguished from active euthanasia in much recent discussion is the withholding or termination of medical treatment when such treatment would be required to preserve or prolong life in someone suffering from a painful or prolonged mortal illness or injury, or in someone suffering permanent impairment considered to be incompatible with living a meaningful life. Such withholding or termination of lifesaving medical treatment has been called "passive euthanasia."

Passive euthanasia can also be distinguished according to whether it is voluntary or not. In chapter nine we shall consider the requirements of justice in the provision of medical treatment for noncompetent persons—that is, for persons unable to demand or forgo, to give or to refuse consent to treatment. If medical treatment needed to preserve or prolong life is withheld from such

persons or terminated in their cases, one might speak of "nonvoluntary passive euthanasia." In the present chapter we consider the liberty of persons who are competent to give or to refuse consent to medical treatment upon themselves. If this liberty is exercised to refuse treatment which would be lifesaving in order to avoid pain or hasten death or both, one might speak of "voluntary passive euthanasia." Voluntary passive euthanasia in recent discussion also has been called "natural death" and "death with dignity," although the latter expression sometimes is used to refer to other forms of euthanasia.

At the time of this writing (March 1978) eight states have enacted legislation—so called "natural-death" or "right-to-die" laws—to facilitate voluntary passive euthanasia. In this chapter we shall consider this legislation and propose an alternative to it.

Accordingly, in the present chapter we shall not be considering the question of medical treatment for legally noncompetent persons—children, the severely retarded, the permanently insane, the senile, or, in general, those who are legally unable either to give or to refuse consent to treatment upon themselves—except to the extent that some such persons once were competent and while so might have made decisions about their own future treatment.

To put the point affirmatively, in the present chapter we are concerned with the liberty of persons to refuse medical treatment *for themselves*. This liberty is generally accepted when exercised by competent persons with respect to the present. We shall consider to what extent and by what means the law ought to facilitate the exercise by competent persons of this liberty with respect to the future when they may become unable to make decisions.

Much discussion of this problem is confused because the difference between moral questions and jurisprudential questions is ignored. Here we will not consider whether and under what conditions it might be moral for a person to refuse lifesaving treatment. We shall discuss this moral question in chapter twelve. In some cases acts morally wrong must be permitted by law, for the sake of just regard for liberty. Hence, in the present chapter we are concerned exclusively with the extent to which law should protect and facilitate the exercise of liberty; we are not concerned with the conditions under which one's exercise of the liberty to give or to refuse consent to medical treatment is morally good or evil.

B. The General Primacy of Patient Choice

Anglo-American law takes for granted as a rule that every competent adult is at liberty to seek medical treatment and not to seek it, and to give or to refuse consent to any treatment which is proposed. No police officer takes

one to the doctor; one chooses to go. If one is negligent about one's own health, one cannot be charged with any offense or sued for damages by anyone else. If one does not like the treatment which physicians propose, one can dismiss them and find other physicians or one can refuse to follow directions, not take one's medicine, reject the suggestion that one go to the hospital, refuse to sign forms consenting to surgery—in general, be an uncooperative patient. The physician has no choice but to put up with one's uncooperativeness or to withdraw from the case.

In a 1914 New York case, Judge (later Justice) Cardozo stated this proposition clearly:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.¹

The underlying concept is that a person has a basic right to bodily integrity and intangibility. Nobody can cut a person or even so much as touch a person who is not willing to be cut or touched without violating that person's rights and providing him or her with a legal claim to compensation for the violation. In principle, this claim is no less against a physician who treats a person without consent than it is against someone who attacks another in anger or with premeditated malice, for although the latter might be guilty of a crime of which the physician would be innocent, the *personal* offense is the same.

In effect, the law intends to enclose everyone in an invisible shield and to give to each person the right to decide when to lower the shield and when to keep it in place. The underlying theory, which surely is sound, is that bodily contact can be repugnant—if not harmful, distasteful—and that each person is the best judge of what contact is acceptable.

In the medical context the mere fact that one puts oneself into the hands of physicians does not mean that they can proceed as they see fit. They have a duty to explain what sort of treatment they propose and why, and to point out any significant risks or reasonable alternatives. They also have a legal duty to limit treatment to that to which one has consented. If they go beyond the boundaries, even for the patient's good and with good results, physicians violate the patient's rights.²

For several reasons the basic legal situation with respect to the primacy of the patient's judgment is not as clear in most people's practical experience with physicians and hospitals as it is in theory.

In the first place, consent to the contact involved in medical treatment generally is implicit in the fact that one seeks treatment and cooperates in it; many persons do not realize that they have a right to be informed and to make decisions even after they have put themselves into the hands of a

physician. Because talking with patients is time-consuming and can be a nuisance, physicians are not likely to make matters more explicit than necessary. Some legal decisions even have accepted the principle that physicians need not inform patients when the information itself might make the patient worse.³

In the second place, most people learn while children how to deal with physicians. Parental authority is transferred to the physician, who tends to remain a parent figure; the physician's technical skill adds reinforcement to this attitude, and the dependency one normally feels when ill and in need of care leads to childlike submissiveness in most patients.

Corresponding to the submissiveness of patients many physicians take a paternalistic stance. They hardly respect more than the law demands the right of patients to know what their condition is, what they are getting into with particular forms of treatment, and what the outlook is.⁴ In defending their attitude physicians sometimes point out that they are not mere technicians, like auto mechanics or plumbers, who should be expected to do what patients want; physicians are professionals with their own judgment as to what is good and responsibility for carrying out this judgment. Indeed, even an auto mechanic or a plumber has some expertise. The status to which such physicians fear being reduced might better be compared to that of a simple laborer or servant: people who do no more than what they are told.

However, if physicians ought not to be viewed as mere servants (and they certainly ought not) and if physicians have professional knowledge and responsibility which a patient is rash to challenge and arrogant to invade (and any good physician has), still the patient must not be treated as a mere patient—that is, as an individual wholly incapable of action. Health and even life itself is only one good among many in which persons are interested. Individuals are at liberty to decide to what extent they wish to subordinate other concerns for the sake of pursuing this good. Hence, every patient has the right to set limits to the trouble, the inconvenience, the expense, the painfulness, the mutilation—in a word, the cost in the widest sense of “cost”—to be tolerated in even the soundest and most competent course of therapy.⁵

Any physician who cannot see and wholeheartedly accept this right of the patient is imposing a judgment not about a matter within medical competence but about the patient's hierarchy of values, which is a matter for moral and religious teaching and for personal decision. Of course, if a patient sets limits, the expectation of benefit from the physician's care must be limited correspondingly. And law must recognize this limit; it clearly would be unjust to hold a physician responsible for the poor health or death of patients who will not accept treatment which the physician proposes and which is in no way faulty from the point of view of medical judgment.

Moreover, if a physician proposes treatment and a patient is unwilling to

accept the proposal and to cooperate with it, then the physician must be free to withdraw from the case. Legally physicians may do so provided they give sufficient notice to permit another arrangement to be made.⁶ At the same time, if physicians use their right to withdraw as a lever to compel a patient to change a *nonmedical* judgment as to what is best, they act unfairly, unless the patient's judgment cannot be followed according to the physician's own good conscience.

C. Presumed Consent and the Physician's Liability

There is one very important and very common exception to the requirement that the physician proceed only on the basis of informed consent by the patient. The exception arises in the case of emergency, where the patient is unable either to give or to refuse consent. The physician may proceed provided the treatment supplied is medically appropriate and such that a reasonable person normally would consent to it, and provided the physician has no knowledge that the particular patient would not consent. In other words, when a patient cannot decide about treatment, the law establishes a reasonable assumption that the ordinary person who needs care would want the treatment a normally competent physician can give. Were this assumption not made, the intangibility of those few who would refuse treatment if they could do so would be held paramount to the actual desires as well as to the well-being of most people.⁷

Very often in emergency situations consent to proposed medical treatment by a spouse or other adult family member will be sought. In concept this procedure makes little sense insofar as the basic rights of the noncompetent adult are concerned, since no one else can exercise one's liberty on one's behalf and since one's need and incapacity to consent by itself is a sufficient basis for the physician to proceed with treatment.⁸ However, by requiring consent by a close relative for treatment to a noncompetent adult the physician gains some protection against subsequent claims from the family and also some guarantee of payment of medical costs.

Once physicians begin to treat patients, they are held to carry on the treatment with the degree of care and skill usually exercised in the treatment of similar patients by the average physician under similar conditions. A specialist must meet the standards of the specialty; a physician working in a well-equipped hospital must use facilities as is customary there. The failure of one rendering medical treatment to act with that degree of knowledge, skill, and care commonly exercised in the same community under like circumstances by the average careful and reputable member of the profession is considered by law to be *malpractice*. Medical malpractice is a form of negli-

gence; if the patient suffers any injury, loss, or damage—even if someone else whose interests depend upon the patient's being properly treated suffers in some way—the physician can be sued and the patient and/or others damaged can recover.⁹

The law's presumption of consent to treatment of a noncompetent adult in any emergency situation together with the constant concern of physicians to avoid anything which might be considered malpractice can combine to require physicians to proceed with great caution and inflexibility in caring for adults who are neither able to give nor able to refuse consent. In cases of this sort the physician does have primacy of judgment which would belong to the patient if the patient were able to decide. The wishes of the patient's family are not legally in control, except to the extent that each adult member of the family can relieve the physician of liability to himself or herself.

A physician might suspect from the patient's previous attitude and remarks that the particular patient would prefer that treatment be limited or terminated, but physicians cannot rely upon such suspicions, nor even on firmer evidence, since they cannot be confident that a court of law, which is the ultimate judge of evidence and legal responsibility, will reach the same construction of the patient's wishes. Moreover, in some jurisdictions the malpractice case law itself tends to press physicians toward meeting the ordinary standard of practice in order to avoid malpractice, even when they are quite sure that the patient would prefer treatment other than—perhaps much less than—the average careful and reputable practitioner in the community would provide under the circumstances.¹⁰

Some critics of natural-death or right-to-die legislation have argued that such legislation is wholly unnecessary, since patients now have primacy in deciding upon their own care. Such legislation, it is argued, somehow replaces patient primacy with an implicit supposition that physicians are masters of their patients unless patients take legal action in advance to limit what physicians may do. Such a supposition, on this view, tends to shift the locus of power in cases in which no legal action is taken in advance from the patient to the physician.¹¹

In the light of the explanation we have given of the law's presumption of consent and enforcement upon physicians of the standard of practice common to their colleagues this argument is unconvincing. When an adult patient cannot decide personally, physicians are in control whether they wish to be or not, since they will be held responsible for the treatment they provide, and the extent to which their responsibility is limited by earlier wishes of the patient and by current wishes of the patient's family is at best marginal and doubtful. We shall consider later in the chapter a proposal to remedy this situation simply by assigning full and definite authority to the patient's family. But this is not the current state of American law.

Indeed, the case of Miss Karen Quinlan exemplifies the problem. Miss Quinlan was an adult, not a child legally under her father's parental care; she had been legally competent, but was no longer competent to give or to refuse consent to treatment; her earlier expressed beliefs and attitudes about the care she would wish under such circumstances were considered by the courts insufficient evidence of her nonconsent to treatment; the physicians caring for Miss Quinlan had assumed responsibility under circumstances of medical emergency with a noncompetent adult; the physicians believed that standard medical practice required that they *not* remove her from the respirator; the wishes of her family could *not* be considered determinative. Hence, Mr. Joseph Quinlan sought to be appointed legal guardian of his daughter so that his decision could control her care. The facts and existing law were perceived in the same way by the Superior Court and by the Supreme Court of New Jersey; however, the lower court did not grant Mr. Quinlan's request while the higher court did.¹² Regardless of what one thinks of the outcome, this case aptly illustrates the existence of a problem which so-called natural-death or right-to-die legislation is attempting to solve.

D. Limits of Patient Liberty

Apart from the problems which exist with respect to adults who have been competent but become noncompetent, there is some question in existing case law as to the extent to which even competent adults may legally refuse treatment *required to preserve life*. Several excellent studies have been done on the relevant cases, and so we shall not review these cases in detail. However, a summary of the results of the studies is in order.¹³

The leading case usually cited was decided in Kansas in 1960. In *dictum* the judge said:

Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception.¹⁴

Many of the cases have to do with the refusal of blood transfusions by Jehovah's Witnesses, who believe that receiving such transfusions violates a divine prohibition of eating blood. However, some cases are concerned with the refusal of other treatment, especially by elderly persons who prefer the consequences (including an earlier death) of forgoing life-preserving treatment to the pain and other disadvantages of accepting it. From the very general

principle set down in the case cited one would suppose that all of these refusals of treatment by competent patients would have been honored and supported by the authority of the courts. But such is not the case.

In the first place, in some cases medical treatment is required by law in the interests of public health and safety. The leading precedent in this matter is a United States Supreme Court decision that the interest of a state in protecting its members from smallpox overrides the right of persons to refuse treatment—in this case vaccination—both insofar as this right is based upon bodily intangibility and insofar as it is based upon religious liberty and conscientious objection to treatment.¹⁵ This case is followed by many others asserting the priority of the public interest to individual liberty, even religious liberty, in several matters that involve medical care, examination, and so on.¹⁶

In most cases the assertion of the priority of the public interest seems to us reasonable enough. In some cases, perhaps, liberty and especially religious liberty ought to be given more respect than sometimes has been the case. However, this problem is not especially related to euthanasia, and it must be argued on its own merits. Hence, in what follows we assume that any plan to protect the right of individuals to refuse treatment must allow for the right of legislatures by general laws and the courts by judgments in particular cases to order treatment in the interest of public health and safety even over religiously based objections to such treatment.

In the second place, courts have ordered medical treatment in some cases at least partly on the basis that without treatment patients probably would be incapacitated, by death or otherwise, to fulfill responsibilities to minor children. In one case the ground was that without treatment an unborn child might be harmed.¹⁷ In other cases courts have not used this ground for ordering treatment, perhaps at least partly because the evidence did not show serious likelihood of harm to the children.¹⁸

This ground for compelling adults to accept treatment must be distinguished from the quite different question of the medical treatment of children themselves, which we shall consider in chapter nine. Commentators disagree as to whether courts ought to order the treatment of competent adults on the basis of their responsibilities to their dependents.¹⁹ No one seems to have considered other cases in which an individual's responsibilities might be such that the public welfare would demand medically indicated treatment despite the individual's refusal. What, for example, might the public have a right to require if a Jehovah's Witness came to hold some high public office, required and refused blood transfusions, and in so doing imperiled a significant public interest in orderly government?

It seems to us that here the claims of liberty must to some extent be limited by other demands of justice. The specification of kinds of cases under which the public interest might reasonably require compulsory care hardly seems

possible. To legislate the priority of the interests of dependent children to the liberty of parents to refuse treatment, especially if that refusal is religiously grounded, seems excessive, and yet there are some cases—for example, that of a pregnant woman in the late stages of pregnancy and that of a sole parent of children who might be left orphans with no support—in which the welfare of others establishes a public interest which seems very significant.

Hence, in what follows we assume that any plan to protect the rights of individuals to refuse treatment must allow courts by orders in particular cases to order treatment in the interest of the public welfare if lack of treatment probably would incapacitate an individual, by death or otherwise, to fulfill grave noncontractual obligations to others. In this area a refusal of treatment on religious grounds seems to warrant greater deference and so require a more compelling state interest to override than a refusal strictly on the ground of the right of bodily intangibility.

In the third place, in some cases courts have overridden the refusal of treatment by a person when competent on the basis that by the time of adjudication the individual had become incompetent; in some cases courts have expressed a suspicion that the person who was refusing treatment actually desired it.²⁰ No one seems to defend judicial opinions such as these. Such opinions suggest two requirements which any sound plan to protect the rights of individuals to refuse treatment should meet.

First, provision should be made to consider and act upon evidence that an individual when competent had made absolutely clear an unwillingness to accept certain kinds of treatment. For example, an individual who is well-known to be a Jehovah's Witness and who has made clear adherence to their belief and practice in respect to blood transfusions should not have blood imposed by a court order when an emergency arises on the ground that at that time the individual is noncompetent, hardly competent, unable to deliberate about the matter, really anxious to live, and so forth. (Of course, if a particular Jehovah's Witness gives some real sign of personal consent, that is another matter.) Second, provision should be made that the mere fact of refusing life-preserving treatment may not itself count as evidence of noncompetence.

A fourth class of cases in which courts have overridden refusal of treatment involved the basis that death resulting from such¹ refusal would be suicide, and so contrary to public policy.²¹ Legal commentators have been uniformly critical of the introduction of this consideration into issues about refusal of treatment.

In the first place, suicide involves both the intent to bring about one's own death and the setting in motion of the self-destructive process. When people refuse treatment of an existing condition, the intent often is lacking and cannot be presumed; the destructive process is not self-initiated. In the sec-

ond place, whatever public policy considerations stand against liberty to commit suicide—a matter we shall discuss in chapter five—the liberty to refuse life-preserving treatment has an established legal status and reasonable ground which significantly distinguishes the refusal of treatment from suicide. The law must respect the liberty to refuse treatment even if it can be abused in some cases with self-destructive intent, but public policy considerations perhaps preclude equal respect for the liberty to commit suicide.²²

Quite distinct from the case in which an individual simply refuses medical treatment is the case in which someone does in fact attempt suicide or self-mutilation and is in need of medical care to limit or repair the damage or injury accomplished. Generally speaking, existing law supports interference with genuine suicide attempts.²³ Since many who attempt suicide are reasonably assumed to be acting irrationally and without deliberate intent, the imposition of emergency medical treatment seems warranted, even if it must be given despite the express refusal of the patient.²⁴

Physicians dealing with suicide emergencies cannot be expected to decide about the legal competence of the patient, nor should such physicians be subject to liability for any treatment they render with due care in such cases. Hence, we think that any plan to protect the liberty of individuals to refuse treatment must include a specific exception authorizing refused medical treatment if it is required by one who needs care because of an attempt at suicide or self-mutilation.

The fifth and last set of problem cases are those in which courts have ordered medical treatment partly on the basis that honoring the patient's desire not to have it would infringe upon the rights of the physician or the hospital or both.²⁵ The concern of the courts in these cases seems to be made up of two different considerations, confused with each other. First, as we have explained, physicians and hospitals are threatened by the law of malpractice. Potentially, they might be subject even to criminal charges if a patient dies due to criminal negligence. Second, the medical profession has its own standards of ethics, and physicians have their own conscientious responsibility. Legal commentators are agreed that neither of these considerations warrants the legal overriding of a patient's liberty to refuse care.²⁶

Considerations of physician and hospital liability provide good ground for seeking judicial determination of a problem, and the courts should be readily available to make decisions in cases where there is serious doubt about grave responsibilities. But once a case reaches court, it is unreasonable for the court itself to use potential liability as a ground for overriding the patient's choice. The court can assume the liability and cannot be held for its mistakes.

The standards of ethics and the demands of conscience on the part of the physician are another matter altogether. The professional judgment of a physician cannot reasonably be held to override patient choice; to take that

position would be to eliminate consent altogether and to absolutize the standard of good medical practice and the good of life and health on which it is based. If a physician has real conscientious objections to treating a patient within the bounds of the patient's willingness to be treated, however, the solution is to permit the physician to withdraw, not to compel the patient to accept unwanted treatment.

E. Privacy and the Refusal of Treatment

The Constitution of the United States and much other law seek in many ways to protect persons against unwanted intrusion by officials and even by other persons into matters which those protected wish to keep hidden, secret or confidential. These legal protections safeguard privacy, understanding "privacy" as it traditionally was understood. As we have explained in chapter two, section G, beginning in 1965, the United States Supreme Court has been withdrawing certain areas of liberty from regulation by criminal law—for example, the liberty to use contraceptives and to have abortions—and calling these immunities "privacy" in a new sense.

In 1973 a lower court in Pennsylvania considered the case of a woman who refused proposed surgery for possible cancer. Although confined to a mental institution as a chronic schizophrenic, the woman was ruled competent to give or to refuse consent to the treatment proposed. She had a number of reasons for refusing the surgery, among them a concern, based on the experience of a relative, that she might die as a result. The court vindicated her liberty to refuse treatment, stating:

In our opinion the constitutional right of privacy includes the right of a mature competent adult to refuse to accept medical recommendations that may prolong one's life and which, to a third person at least, appear to be in his best interest; in short, that the right of privacy includes a right to die with which the State should not interfere where there are no minor or unborn children and no clear and present danger to public health, welfare or morals. If the person was competent while being presented with the decision which she did, the Court should not interfere even though her decision might be considered unwise, foolish or ridiculous.²⁷

The novel element in this decision is its reliance on the new right to privacy and its extrapolation from privacy of a right to die.

The introduction of "right to die" into this decision is indeed strange. Dying was not the good protected, since the proposed treatment was not clearly necessary to preserve life; treatment was not refused with a view to death but in fact refused due to a possibly unwise fear of death. In an earlier

case, involving a Jehovah's Witness, the Supreme Court of New Jersey also injected an irrelevant discussion of a "right to choose to die," which the court rejected, although it was not at issue; in that case the court proceeded to impose treatment because it denied the existence of any such constitutional right.²⁸

~ In the context of the question of the liberty to refuse treatment, talk of a "right to die" is unnecessary and confusing. "Right to die" is ambiguous. In one sense it suggests a liberty to be immune from coercive interventions which would prevent death; in another sense it suggests an entitlement to the means, including an act by another, required to bring about death. The liberty to refuse treatment always has been protected without mention of any "right to die" in the first sense, and so in this context the expression is unnecessary. But it is used by proponents of euthanasia in an effort to lay the foundation for asserting a "right to die" in the second sense. Obviously, active euthanasia must be permitted by law if there is a right to die in this sense. But to assert such a right at the beginning of a discussion of active euthanasia is to beg the question, since the question whether active euthanasia ought to be permitted precisely is the question whether a person is entitled under certain circumstances to be killed.

In the Quinlan case the Supreme Court of New Jersey did not reverse its earlier view; this decision posits no right to die but posits only a right of self-determination to terminate medical treatment and allow Miss Quinlan's life to end by natural forces. Indeed, the court is careful to distinguish this liberty to let nature take its course from any sort of active killing.²⁹ However, the decision does rely upon the new right of privacy, which it contrasts with the bodily invasion of the means used to keep Miss Quinlan alive. The court denies that Mr. Quinlan's own right of privacy is involved; the sole right is that of the patient herself. The decision is that this right may be asserted on Miss Quinlan's behalf by her guardian:

If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative 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. It is for this reason that we determine that Karen's right of privacy may be asserted in her behalf, in this respect, by

her guardian and family under the particular circumstances presented by this record.³⁰

Thus the liberty to give or to refuse consent to treatment is unmentioned, and instead an appeal is made to privacy, with an argument from the universalizability of the decision to terminate treatment—this is what most people would choose in the circumstances—to the conclusion that *subject to qualifications* the privacy right can be exercised on Miss Quinlan's behalf by her "guardian and family."

If the new right of privacy is nothing but certain aspects of liberty, as we argued in chapter two, section G, then the common-law right of bodily integrity and intangibility, which always grounded the liberty to give or to refuse consent to medical treatment, is more a principle than a consequence of privacy. In any case, the liberty of individuals with respect to medical treatment was well established in the law long before 1965 and quite independently of any claim to privacy.

Moreover, one can question the wisdom of gathering long-recognized liberties into the new category. As matters were, the liberty to give and to refuse consent to treatment was at least something with which the law had a good deal of experience; the rules for playing that game were very well developed. If this liberty is now to be regarded as an aspect of the new right of privacy, the whole development must begin again.

The decision of the Supreme Court of New Jersey in the Quinlan case shows some of the difficulties of doing so. Had the case been treated in terms of the long-recognized liberty rather than in terms of the new right to privacy, the court might more fruitfully have confronted the real problem presented by the case: Under what conditions does the ordinary assumption that patients would desire and consent to treatment in accord with the usual standard of good medical practice give way? In other words, when must constructive consent—that is, the assumption that the patient would consent—to medical treatment be reconstructed in view of the special conditions of a patient which seem to make treatment no longer useful? This was in fact the question which the court sought to answer in its argument that almost anyone in that situation would want the respirator turned off.

The court did not explain how the usual assumption of consent can be reconstructed when physicians believe, as happened in the Quinlan case, that continuation of treatment is required and others concerned with a patient's well-being think the treatment should stop. The liberty of the patient to give or to refuse consent is crucial; what is needed is a sound way of determining what assumptions to make about the exercise of this liberty when the person cannot in fact exercise it.

The court suggested that a hospital ethics committee be consulted. If such a

body existed and had authority to override the judgments of other parties to a dispute, it could resolve issues. But if it lacked such authority, any committee would seem simply to complicate the controversy by bringing into it an additional party. The authority of the proposed committee was not clarified.

F. Clarification of Standards a Partial Solution

Although the committee system enjoined by the Supreme Court of New Jersey seems to us misconceived, part of the problem of deciding what the noncompetent patient is assumed to consent to could be alleviated by committees of physicians, and the medical profession needs no new authority to deal with this part of the problem. As we have explained, physicians are not negligent provided they treat patients in line with the usual standard of good medical practice. Noncompetent patients are assumed to consent precisely to such treatment. It follows that if physicians who work together under similar circumstances can reach a consensus about how to handle certain sorts of cases, their consensus will shape the assumption of consent by the noncompetent to treatment in cases of those sorts.

We are not suggesting that physicians can or should arbitrarily change standards. The matter is not one for professional politics and it cannot be helped by taking votes. But a really representative committee of physicians in any locality might consider cases of sorts in which many people would consider the continuation of treatment to be futile and of no benefit to patients. If with discussion a genuine consensus is found to exist, and if this consensus is considered reasonable by competent colleagues in other localities, then the communication of the fact of this reasonable consensus to all physicians working in the community would be a useful guide to judgment in such cases. If one followed this guide in judging what treatment was *medically indicated* in a particular case, and if the judgment were challenged, one would have solid evidence that the usual standard of good medical practice had in fact been met.

Where consensus among physicians of average skill and carefulness is that a certain treatment is of no benefit to a patient, then consent to the treatment cannot be assumed. To continue the treatment in such a case is just as surely malpractice as to limit or terminate treatment which is usually given for the sake of its benefit—at least in terms of comfort—to the patient. For example, it is sometimes said that some physicians repeatedly attempt to resuscitate dying patients because they fear liability for malpractice. If they do the procedure repeatedly and do not regard the effort to be of any value to the patient, they are acting contrary to the consent which they should assume, namely, to treatment likely to help the patient. In cases like this discussion could clarify mat-

ters, for very likely in any given community of physicians there are some cases in which no one or hardly anyone would regard resuscitation as appropriate.

Physicians might hesitate to carry out the proposals we are making. But they do some of this work of looking for consensus already and should not shirk doing as much of it as necessary if they do not wish to have others intrude upon the sphere which properly does belong to medical judgment. Also, there might be hesitation to reduce standards of practice to a code which might inhibit rather than facilitate sound judgments in particular cases. But the consensus which is discovered need not be expressed in affirmative standards stated in general terms. It can instead be expressed in a way more familiar to clinical practice, by describing some actual cases and indicating kinds of treatment which by consensus are *not* required according to the usual standard of good medical practice in the community.

Such committee work would not have helped matters in the Quinlan case unless it had discovered and communicated a consensus that in a case such as Miss Quinlan's the use of the respirator was not *medically indicated*. Had such a consensus existed and been known to the physicians, their obligation to respect the boundaries of assumed patient consent—that is, its limitation to beneficial treatment in accord with the usual standard of good medical practice—would have led them to the conclusion that the respirator had to be discontinued.

In the absence of such a medical consensus—as well as in cases in which medical consensus does not settle the issue—there are only two ways to prevent similar cases. One is by clarifying the extent to which law ought to mandate the medical treatment of noncompetent patients. We shall consider this question in chapter nine. The other is by providing more effective ways for persons, when competent, to make known their own judgments in regard to their treatment during a future time of incompetency. This is the problem still to be solved in the present chapter.

G. A Critique of Existing Legislation

A plan for facilitating the exercise of one's liberty to give or to refuse consent to future medical treatment really will solve the problem only if it meets four conditions.

First, the liberty protected with respect to the future should extend precisely as far as the liberty an individual has at present. Thus, on the one hand, the limits upon refusal of consent set by the public health, welfare and safety, and other factors we discussed previously must be respected. On the other hand, to facilitate liberty in refusing treatment only when one's life is artificially sustained and one's condition is terminal hardly is adequate to protect

those who wish to refuse treatment in other circumstances. For example, Jehovah's Witnesses hardly are treated fairly if others are helped by law to avoid unwanted treatment while unwanted blood transfusions are given them when they happen to be unconscious and this treatment is medically indicated. Other people might prefer not to have treatment they consider too costly, too risky, too painful, too mutilating; for all these reasons and others people might wish to make sure that the unwanted treatment will not be given if they happen to be unconscious, although not dying. If a liberty is to be facilitated for some, all have a right to have their lawful exercise of the same liberty facilitated. Bills which focus exclusively upon the terminally ill are discriminatory; they violate the right to equal protection of the laws.

Second, if physicians are to be restricted by a more effective exercise of the liberty to refuse consent, they must be relieved of liability for respecting the restriction as they are legally bound to do. It may be that there is no *real* liability to be relieved of, but that is not the point. In the concrete there are possibilities and probabilities, not clear-cut facts. Physicians have a right to know where they stand; they cannot be expected to take constant risks of incurring liability by walking an infinitely fine and unclear line between treating up to standard but beyond consent and treating within consent but short of standard.

Third, the interests of patients in being treated competently and up to standard when they do consent must be protected. Patients who refuse consent to certain treatment should not have to forgo legal protection against negligence in the treatment they do accept. The release from liability ought not to be a blank check. The patient must assume the risks of doing without the treatment refused, but it is wrong to make a patient pay for this by assuming risks for bad consequences which an average skilled and careful physician can take care of. In other words, the usual standard, adjusted by the refusal, must still apply when some treatment is desired and given. Moreover, there must be a very strong guarantee that the rights of patients who do consent or should be presumed to consent will not be violated by their being mistakenly treated as if they had refused consent to some treatment. Any plan which facilitates the liberty of some to refuse by undermining the security of others to receive the care which they want—which, in fact, most people want—sacrifices fairness to all for the sake of the liberty of some.

Fourth, a sound plan for facilitating the exercise of one's liberty to refuse consent to medical treatment for the future must provide a workable procedure. The refusal has to be expressed and communicated. The genuineness and validity of the communication must be certain. What is being refused must be definite, so that physicians will know just how far to go and where their responsibility and legal liability falls. The person who wishes to refuse

consent must have open as many ways as possible of specifying what treatment is accepted and what refused.

With these four conditions in mind we can look briefly at some of the methods already proposed to facilitate the liberty to refuse consent. One approach is embodied in the so-called right-to-die or natural-death statutes which at the time of this writing (March 1978) have been enacted in eight states. The other approach is that individuals should be able to have a legally recognized agent or representative who can authoritatively give or refuse consent as treatment proceeds upon the noncompetent patient. The former requires a person to say beforehand *what* is refused; the latter only requires an advance decision concerning *who* can refuse. There are variations on these two main themes, but we do not think they need to be examined here.³¹

The first natural-death statute was passed by California in 1976; in 1977 seven other states—Texas, Oregon, Idaho, Nevada, North Carolina, New Mexico, and Arkansas—enacted such legislation.³² The Texas and Oregon acts closely follow that of California and may be considered with it, as may the Idaho and Nevada acts, although they differ more significantly from the California model.

The California Natural Death Act proceeds on legislative findings that medical technology makes possible “the artificial prolongation of human life beyond natural limits.” This “may cause loss of patient dignity and unnecessary pain and suffering.” Persons have a right to decide about their own treatment, including the decision that when they are in a terminal condition, life-sustaining procedures will be withheld or withdrawn. Although the use of such procedures in such cases provides “nothing medically necessary or beneficial to the patient,” physicians and lawyers are unsure of the legality of terminating their use even when a competent patient explicitly demands this. Hence, in recognition of the “dignity and privacy which patients have a right to expect” the act recognizes the right of a terminal, adult, competent patient to direct the physician to withhold or withdraw life-sustaining procedures.

The definitions in this act are important. A “terminal condition” is one which the physicians believe will cause death with or without life-sustaining procedures that would “serve only to postpone the moment of death.” A “qualified patient” is one certified in writing by two physicians to be terminal. A “life-sustaining procedure” is a “mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death” in the terminal patient.

The act authorizes persons to direct by means of a standard form that if they become incurable and terminal, then when death is imminent life-sustaining procedures shall be withheld or withdrawn so that they will “be permitted to die naturally.” The directive refers to itself as the exercise of the legal right to

refuse treatment. It includes a provision nullifying it in case of pregnancy. A special paragraph is completed only if the patient has been diagnosed as terminal at least fourteen days before the directive is made. The directive is in force for five years but may be reinstated or revoked by a competent person at any time, and competency cannot be questioned in case of revocation. If a person is noncompetent when the directive expires, it stays in force until communication is possible once more. Special requirements must be met if the person making the directive is in a nursing home. Any directive is valid only if witnessed by two persons not having a special interest.

Anyone involved in causing the withholding or withdrawal of life-sustaining procedures from a terminal patient is relieved of all liability for so doing provided it is done in accord with the requirements of the act. However, the physician is held responsible for making sure that the directive complies with the requirements of the act. If the patient is competent—a judgment the physician is held to make—the directive becomes irrelevant, for then the physician is required to ascertain the patient's current desires. If the patient did not make or reinstate the directive after the fourteen-day period after the patient became terminal and qualified, the directive becomes optional for physicians, who can take into account other factors as they see fit. Only if the directive was made after the fourteen-day period after certification of the patient as terminal and if the patient is noncompetent is the physician bound by it either to withhold life-sustaining procedures or to turn the patient over to a physician who will.

Compliance with the act does not constitute suicide, nor can it affect life insurance. People cannot be required to make a directive in order to obtain health insurance. The provisions of the act are not to be taken to lessen any right or responsibility lawfully to withdraw or withhold life-sustaining procedures which anyone had before the act. This last provision is an important one to prevent anyone's omission of the making of a directive from being interpreted as requiring treatment which would not be legally required had the act not been passed.

If someone purposely destroys or interferes with a directive to render it ineffective, this is a misdemeanor; if someone to hasten death forges a directive or conceals the fact that it has been revoked, this is homicide. Finally, the act includes a very important proviso: Nothing in it is to be taken to condone "mercy killing, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying" in accord with the statute.

The Texas statute follows the California pattern closely. It requires that the directive be certified both by the maker and the witnesses before a notary public. Those withholding treatment are relieved of liability only if they avoid negligence. The physician need not judge the maker's compliance with other

provisions of the act if the form complies with the act. The special provision for those in nursing homes is omitted.

The Oregon statute, like that of Texas, does not require the physician to assume the role of a judge of the patient's compliance with the provisions of the act. Oregon omits the clause nullifying the directive in case of pregnancy. The witnesses assume liability if they do not act in good faith. Within the context of a directive the patient's family may change physicians or hospitals if necessary to find one who will withdraw treatment.

The Idaho statute differs more significantly from the California model. A single physician can diagnose a terminal condition and need not certify it in writing. "Terminal condition" is defined rather loosely as an incurable illness "which reasonable medical judgment determines shortens the lifespan of the patient." But "artificial life-sustaining procedure" is defined strictly, as in California. The directive is to be made *after*, but at any time after, the terminal illness is diagnosed. The maker and witnesses must certify the document before a notary. There is nothing in this statute declaring that it does not authorize mercy killing—although it does not—nor specifying penalties for forging a directive, nor specifying what happens if a physician simply ignores the directive. One might argue that all these matters are implicitly covered by existing law.

The Nevada statute also differs significantly from the California model, but in other ways. "Life-sustaining procedure" is defined loosely to include any mechanical or artificial method of supplying or helping a vital function. The patient need not be diagnosed and certified as terminal; the act envisages declarations made in advance and mentions no waiting period. A "terminal condition" is an incurable condition such that the application of life-sustaining procedures serves only to postpone the moment of death. A directive under the act need not be in the prescribed form, and one section of the act seems to be intended to validate existing "living-will" documents. The prescribed form would put the directive into effect only when the patient is unable to communicate and death is imminent. The directive must be witnessed but need not be certified. Physicians are in complete control under the directive; they can take into account any other factors which seem to them important and can follow the directive or not, as they see fit. Physicians are relieved of all liability in either case.

Considering these statutes by the criteria we have stated and explained above, we find them highly unsatisfactory in many respects.

First, they do very little to facilitate the liberty to refuse treatment, since they apply only to life-preserving treatment in terminal illnesses—cases in which treatment probably could be withheld or withdrawn in accord with the usual standard of good medical practice without the statutes. Some of the laws make their provisions cumulative with existing rights and responsibili-

ties, but others do not. Those which do not may be interpreted as restricting existing possibilities in the limited domain with which they deal. Moreover, all of these statutes give physicians more or less discretion which infringes upon the principle of the liberty of the patient.

Second, in general these statutes are generous in relieving physicians of liability, in some cases too much so. But in one respect they impose new duties, which are not medical ones. This is especially clear in the California statute which requires the physician to determine not only that the directive is in proper form but that the maker has complied with the substantive conditions of the act. This seems to require a decision more judicial than medical.

Third, in some of these statutes it seems that a person directing the withholding or withdrawal of treatment has to forgo the usual right to careful treatment, since the release from liability does not exclude negligence.

Fourth, despite attempts to define terms, exactly what is being refused is none too clear. Almost anything done to a person by a physician involves something artificial. Accordingly, the Nevada definition authorizes the total withholding of treatment. And the Idaho definition of "terminal condition" is loose enough to make any chronic illness terminal. Even the tighter definition of both expressions in the California statute cannot avoid vagueness in expressions such as "serve only to postpone the moment of death" and "death is imminent." The problem with such language is that patients may take it to mean one thing and physicians another. Perhaps the possibilities of misunderstanding are unavoidable, but here the terms are prescribed by statute, so that patients do not have their own choice among ambiguities and vaguenesses.

Finally, the requirement of a witnessed document, in some cases with the certification of a notary, clearly tends to protect persons against being allowed to die by malice or mistake. But such a document is easily destroyed, and care also requires that the conditions for revocation be easy and the punishment for false revocation relatively light. Thus the patient's own wishes could easily be defeated by any family member.

The North Carolina statute is not based on the California model. The key expression is "extraordinary means," which is defined rather loosely as "any medical procedure or intervention which in the judgment of the attending physician would serve only to postpone artificially the moment of death by sustaining, restoring, or supplanting a vital function." This would cover insulin and pacemakers. But action is triggered only by the opinion of two physicians that the patient's condition is terminal and incurable, although these words are undefined. A form is provided but need not be adhered to. The statute fails to specify at what age a person is competent to make a declaration, and it thus leaves open the possibility that a child's declaration would be considered valid. The act seems to intend to give legal force to "living-will" documents. However, the declaration must be witnessed by persons not having a special inter-

est. And it must be certified by a clerk or assistant clerk of a county superior court. The latter provision is unique, and it assigns the clerk judicial functions in determining the genuineness of the document, especially if the witnesses are not available. There is nothing in the statute about what happens if the physician ignores the document and nothing about penalties for falsifying a document. There is an anti-mercy-killing paragraph, but nothing to indicate that the act is not to be taken as setting aside present patient's rights.

The North Carolina statute infringes on liberty as the others do and fails to facilitate the liberty to refuse treatment in most cases where this is really needed: where the means are ones a physician considers necessary for good medical practice. The effort to make sure that the document is genuine shows a reasonable concern for security, but the assignment of an important judicial function to a clerk or assistant clerk of a court is questionable. The key definition—that of “extraordinary means”—is deplorably loose. Most patients cannot be expected to know what this expression means, for it is current neither in the sense defined in the statute nor in the sense in which physicians are likely to take it—as referring to means not required for good practice.

The New Mexico and Arkansas acts differ from the rest in including provisions whereby declarations can be made on the behalf of minors—and in Arkansas of noncompetent adults. These aspects of these acts will be considered in chapter nine. These acts are also phrased in terms of a “right to die” rather than in terms of “natural death.”

The New Mexico act turns on the definition of “terminal illness” as an “illness that will result in death . . . regardless of the use or discontinuance of maintenance medical treatment” and the definition of “maintenance medical treatment” as “medical treatment designed solely to sustain the life processes.” Both of these definitions are loose. The declaration is to state that in case of terminal illness, maintenance medical treatment is not to be utilized. No prescribed form is provided for the declaration. It is to be made with the formalities for making a will. Terminal illness is to be certified by two physicians. The good faith of physicians is presumed, and they are relieved of liability unless it is proved they failed to exercise reasonable professional care and judgment. The act does not disclaim interpretation as an authorization for mercy killing. It does make its provisions cumulative with existing rights and responsibilities in respect to the termination of treatment.

This statute seems to us to have most of the disadvantages of those drawn on the California model, which, as we have seen, are concerned only with terminally ill patients. At the same time, its vagueness in definition and minimal requirements for judging the patient's wishes in terms of a witnessed but uncertified document, together with its great generosity in protecting physicians, begins to become dangerous. If the act were maliciously abused, it would be necessary to show that the physician had not acted in

good faith in accord with the vague directive. The forger of a declaration, if found, could be punished. But a false document could easily be produced, its origin easily concealed, and anyone needing any sort of medical care to survive be done away with by two cooperative physicians, proceeding in a way which apart from this act would be gross negligence. Thus, in our judgment the New Mexico act not only seriously fails to protect liberty but also infringes upon justice by unnecessarily endangering the security of life of those whom it can be used to kill by omission.

The Arkansas statute is the shortest of all. It asserts the right of every person "to die with dignity." Anyone can at anytime execute a document with the formalities required for a will refusing and denying the use by anyone of "artificial, extraordinary, extreme or radical medical or surgical means or procedures calculated to prolong his life." No certification of terminal illness is required. Anyone acting or refraining from action in compliance with such a document is relieved of all liability.

This statute comes close to saying that anyone can refuse any medical treatment at all, since all medical treatment could be included under one or another of the four vague words: "artificial," "extraordinary," "extreme," or "radical." But persons signing such a document may not realize how broadly it could be understood, especially since it applies regardless of whether one is dying, terminal, or living with one's pacemaker. The lack of formalities beyond those required for a will opens up possibilities of abuse. The act does not even specify a penalty for the forging of a document. Thus, Arkansas has managed to go farthest in protecting the liberty to refuse treatment but has done so with a statute which—even more than the New Mexico statute—is open to dangerous abuses.

H. A Critique of Other Proposals

A quite different approach from that of the eight statutes we have been discussing is the legal establishment of provisions for an agent who would have the authority to make decisions on behalf of a person who is no longer competent to make them. Luis Kutner, who originated the proposal of a "living will," originally suggested that it be conceived as a revocable trust established by one over one's own body.³³ Scott R. Cox also developed a trust concept, apparently more with a view to limiting costs of terminal treatment than with a view to facilitating the liberty of persons to decide what care would be acceptable to themselves.³⁴ Judge Michael T. Sullivan urged that the law recognize a proctor, appointed by a court, to act for a dying person; in making this proposal Sullivan did not seem to envisage the situation in which a dying individual might be noncompetent.³⁵

A very different approach suggested by Jeffrey Allen Smyth seems to accept the concept that once one delivers oneself into a physician's hands, medical standards prevail unless limited at the outset. Smyth, considering the patient-physician relationship insofar as it involves a contract, urges that the patient specify limits explicitly at the outset and thus provide that treatment be limited.³⁶

Resisting the view that one's physician should also have the somewhat conflicting role of one's agent in deciding about the appropriateness in personal terms of medical care, Robert M. Veatch suggests that individuals might appoint a legal agent to refuse any treatment the agent considered inappropriate. Veatch also would have the agent for a noncompetent individual authorized to seek a court order to enforce a refusal if it were not honored. Veatch thinks persons appointing an agent with such a power might specify guidance for their agent's judgments or not, as they chose.³⁷

Of these proposals only Veatch's moves from a limited consideration of the problem of the dying patient to the larger problem of facilitating the exercise of personal liberty in the decision about one's own medical care. All of these proposals involve some sort of transfer of authority to an agent of one's choice. The authors of all of them express doubt as to whether their proposals could be put into effect without legislation (or simply assume they could not be).

Sullivan's idea of a proctor has the very real advantage of requiring a judicial hearing and authorization, which would provide an opportunity to examine the evidence that the person for whom the proctor was to act really desired this representative; the court's authorization also would make the proctor's authority clear to everyone involved. Veatch's agency proposal does not include such safeguards; the appointment document would simply be a signed and witnessed statement. In view of the powers of the agent some sort of probate procedure seems to us to be needed.

After making the rather interesting agency proposal, Veatch goes on to propose legislation in some ways narrower, which would facilitate the refusal of treatment "on the grounds that the dying process cannot be morally prolonged." This bill would establish a hierarchy of authorized decision-makers for noncompetent persons, beginning with an agent appointed by the individual when competent. If no appointment were made, the spouse or a person of the first degree of kinship would have authority, and there would be rules to determine authority if there were several such persons. If there were no appointment and no family, the court would appoint a guardian. In determining the authority of the patient's representative a court would honor any document one executed with the formalities of a will when competent, in which one stated grounds for disqualifying a potential decision maker. The bill also would release physicians from liability when they act in good faith in accord with its provisions.³⁸

In this proposed legislation Veatch does not make clear whether or not he thinks a court order would be required in each case. Without a judicial hearing, situations would easily arise in which someone would appear claiming to be an authorized agent, family members would begin acting individually, and physicians would be in doubt about whom they could accept as legally qualified. Veatch's proposal also might lead to decision-making in some cases by a family committee, which may be acceptable as an informal device but hardly seems attractive as a legal institution.

However, what is most unsatisfactory in Veatch's proposed statute is that it does nothing for the nondying person, for the person who could benefit from treatment but does not consent to it, for the person who wishes to refuse certain specific kinds of treatment or all treatment and does not want any committee or guardian. In other words, like the legislation recently enacted, Veatch's proposal facilitates liberty only within very narrow limits. His proposal is far more acceptable than many narrower ones, but it still discriminates in favor of people who trust agents to make ad hoc decisions and does little for those who know precisely what they want and what they do not want.

We have specified four conditions which good legislation facilitating the liberty to give and to refuse consent ought to meet. Nothing we have seen begins to meet these conditions. This is not surprising, for they are not easy to meet. Matters do not get easier, as we have explained, if one considers the entire field in which some persons might wish to reject medically indicated treatments during some period when they might become noncompetent. Dangers to persons who could be misrepresented as refusing consent must be guarded against, for it is unfair to everyone if new opportunities for homicide are created. At the same time, the ways in which consent can be refused for the future—by specific statements or through an agent—should not be limited. Any standard form which goes beyond necessary formalities seems to be an imposition on liberty. And in some cases even to insist upon a formal statement is too much. Individuals who have made their wishes clear—for example, that they wish no blood transfusions regardless of consequences—should expect these wishes to be determinative.

I. A Model Statute to Protect the Patient's Liberty

A good law must cover all of the various cases, solve all of the problems. To do so, we see no way but to require a judicial hearing in each and every instance in which a physician treating a noncompetent patient is to be limited from proceeding according to the usual standard of good practice. If the requirement of a hearing is established, then anyone can be at liberty to create, in any way he or she prefers, sufficient evidence to make clear what is

to be done. The court, not the physician and not a clerk, must judge the evidence and direct the execution of what is determined to be the will of the noncompetent person. In this way, one's wishes cannot be overridden by someone's revoking a document which is the sole evidence of one's wishes. Those without families, people not in their home states, and others also can be treated equitably.

In practice, of course, individuals will not have to create their own evidence without assistance. Organizations have circulated the "living will." While a court might well refuse to accept such a document as evidence of anything, because it is too vague and ambiguous to be translated into operational terms, these organizations surely will be quick to suggest and publicize schemes for refusing treatment which courts will be able to interpret and make effective.

The proposal that there be a hearing and judicial decision for each case probably will be objected to on the ground that this procedure will create too much litigation. But every will is probated, every divorce passed on by a court, and even small claims get some sort of adjudication. To protect both the liberty of those who wish to refuse treatment and the security of everyone who does not wish to be mistaken to be a refuser of treatment, consideration of the evidence and a decision about one's wishes by a court seems a reasonable requirement. The hearing need not become complex and prolonged if the evidence is clear and the decision not disputed. And the necessary relief of the physician from liability need not extend beyond that for which he really is not responsible: limitation of treatment so that it conforms to the patient's lawfully exercised liberty.

A good statute might well begin with a statement of legislative findings summarizing the legal situation, the problem, and the solution along the following lines.

The legislature finds that the liberty of competent adults to give and to refuse consent to medical treatment upon themselves has been recognized at common law from time immemorial and has in general been protected by the law of this State. This liberty is an aspect of the right of every person to bodily integrity and intangibility, a right closely related to the right to life. The administration to any person of medical treatment without informed consent is an assault upon that person. Such an assault is justified neither by the beneficent intentions of the one who commits it nor by any good result which might follow from it.

The legislature also finds that the liberty of competent adults to give and to refuse consent to medical treatment upon themselves may be regarded as a right reserved to the people by the Ninth Amendment and as a liberty or immunity protected by the Fourteenth Amendment of the Constitution of the United States, as well as by _____ of the Constitution of this State.

The legislature also finds that this liberty neither presupposes nor implies that any person has a right to die. Since every act which causes death or hastens it is a crime, no person can have a duty to do such an act, and so no person can have a right to die which would correspond to such a duty. There can be no right to die with dignity, although there certainly is a right to the protection of one's dignity from the very beginning of one's life until its end, including those times when one is sick, injured, and dying.

Moreover, if anyone attempts to commit suicide, then his or her liberty to refuse treatment may be lawfully ignored.

The legislature also finds that the liberty to give and to refuse consent to medical treatment is not an aspect of the right of personal privacy, which protects certain forms of behavior from criminal sanction. No criminal sanction ever has been attached to the exercise of this liberty. Moreover, this liberty was recognized in our law long before the right of privacy was extended to the protection of abortion and other behavior previously held criminal by our law.

Having clarified the nature and true foundation of the right to be protected, the legislative findings might continue with a statement of the need and purpose for legislation. This might be phrased along the following lines:

The legislature further finds that although the liberty to give and to refuse consent to medical treatment is well established in our law, certain problems require that this liberty be clarified and further protected by statute. Judicial decisions in some jurisdictions have imposed medical treatment upon persons despite their refusal of it, even when the refusal has been on religious grounds. Also, some doubt exists about the liability of physicians and health-care facilities when persons refuse consent to treatment yet do not altogether withdraw themselves from care. Moreover, there is a reasonable public demand that the liberty to refuse consent be facilitated, so that the personal decisions of individuals will continue to control treatment of them when they become noncompetent.

The legislature also finds that some people choose to refuse all or certain forms of medical treatment on religious and other deeply held conscientious grounds; that others choose to refuse or to limit treatment on grounds of cost, painfulness, or mutilating effect; that others choose to refuse treatment which might preserve life but which they consider to be futile; and that others choose to refuse treatment for other reasons.

The legislature finds that there are certain conditions under which the liberty of a competent person to give and to refuse consent to medical treatment may be justly overridden. Such conditions exist if the administration of treatment to a nonconsenting person is required by the public health, welfare, or safety; if it is required for self-inflicted injury, when the person must be considered temporarily unstable; and if refusal of treatment is likely to lead to incapacity to fulfill lawful responsibilities of a grave kind toward dependent children or others.

Apart from such exceptions, the legislature finds that all choices to refuse medical treatment upon oneself are lawful. The legislature considers itself bound as a matter of justice to protect and facilitate all lawful choices in a way which will afford equal protection of the law to all persons in this State. The legislature recognizes that some persons may abuse their liberty to refuse treatment by making foolish or immoral choices; nevertheless, the legislature finds that justice requires that this liberty be protected even if it is abused.

Having stated the purpose and need for legislation, a legislature might well make clear why the legislation it adopts is so different from that widely proposed and adopted by some other States:

The legislature also finds that no statute which would afford the equal protection of the law to all persons lawfully choosing to refuse medical treatment can limit itself to facilitating the wishes of those patients who happen to be terminally ill or who happen to especially dislike certain forms of treatment. Likewise, the legislature finds that it would be unjust to demand that people refusing treatment do so with certain intentions, since the intentions of persons exercising a liberty can be of no legitimate interest to the government. The legislature finds that proposals including such restrictions are unacceptable because they arbitrarily limit rather than protect and facilitate the liberty which citizens have enjoyed until now.

Although the statute will apply to the refusal by competent adults of treatment at the time treatment is proposed, the new and more important aspect will be its provision for effectively determining one's treatment during a future time when one may be noncompetent. This aspect may be explained in the legislative findings:

The legislature further finds that in the absence of evidence to the contrary most noncompetent persons must be assumed to consent to treatment provided that it is appropriate and rendered in accord with the usual standard of good medical practice for a condition of disease or injury from which they are suffering. Moreover, physicians and health-care facilities are required by law to proceed on this assumption.

The legislature therefore finds that if persons wish to refuse treatment which might be administered to them in accord with this assumption, then it is their responsibility both to provide evidence which will express and prove their choice beyond a reasonable doubt and to make sure that this evidence will come to the attention of physicians and health-care facilities which might provide unwanted treatment. The legislature finds and this act permits that persons might provide evidence of various chosen determinations about treatment in the event they become noncompetent: that regardless of their condition they refuse all or certain forms of treatment, that in certain circumstances they refuse all but palliative treatment, that they consent only to the treatment approved at the time of need by a certain

designated person or persons, or that they limit the usual assumption of consent in some other lawful way. The legislature finds that it is the responsibility of persons who wish to make their choices legally effective under the provisions of this act to express their wishes in a sufficiently clear and definite form that there will be no doubt what their wishes are, and in a sufficiently certain and binding form that there will be no doubt that these are their wishes.

The legislature further finds that it would be unwise and unjust to ask physicians and the administrators of health-care facilities to assume a judicial role in cases in which a patient provides evidence that consent is refused to treatment otherwise necessary to meet the usual standard of good medical practice. The legislature also finds that it is not in the public interest to lessen the responsibility of physicians and health-care facilities to provide standard care on the untested evidence that the ordinary assumption of consent does not correspond to the desires of a particular patient.

Accordingly, the legislature finds that if there is evidence that a noncompetent adult patient may not consent to treatment otherwise medically indicated, and if there is any doubt about the legal duty of a physician or health-care facility toward such a patient, then the duty is to administer the treatment immediately required and to seek promptly a judicial determination of the doubt. Only such a determination will settle whether medical treatment is to proceed on the usual assumption or is to be limited in accord with the proved limits of the noncompetent person's consent.

So much for legislative findings. We realize that so lengthy a rationale for a statute would be unusual, but it also could be very useful, for the statute might be badly misinterpreted without this rationale, which embodies many concepts which have not been given much publicity in the last few years.

The statute itself will require a number of definitions, which must be supplied in accord with the existing law of each state. For example, "medical treatment" must be defined as treatment provided by certain classes of persons and institutions acting professionally. One of the more important definitions will be that of "the usual standard of medical practice." A definition along the following lines would be appropriate:

"Treatment according to the usual standard of medical practice" in this act means medical treatment appropriate for an existing condition of disease or injury carried out in all respects in the manner in which a person practicing with the average professional skill and carefulness would carry it out in any case in which all of the relevant circumstances were the same or similar. Any limitation imposed upon a practitioner or health-care facility by refusal of consent to treatment which otherwise would be medically indicated shall be considered a relevant circumstance.

By this definition refusal of consent *changes* the usual standard of practice but does not release anyone from liability for failing to meet the standard.

Physicians thus will be required to take the patient's decisions as determinative in deciding how to proceed but will be held to do well whatever process of treatment is undertaken.

The statute also must make clear that it applies only to persons of an age judged to be the appropriate age for competency in consenting to medical treatment. We are not going to discuss the problem of the proper age of competency for this purpose, but it is worth noting that in recent years for many particular purposes the age of competency has been reduced. Perhaps it would be reasonable to regard young people as able to make decisions regarding health-care in general at an age younger, maybe even much younger, than eighteen.³⁹ Whatever the proper age for competency is judged to be, a clause along the following lines will be needed:

The existing law of this State with respect to all the conditions for lawful medical treatment of persons under _____ years of age and persons who have been declared legally noncompetent is in no way modified by any provision of this act, except insofar as a person declared legally noncompetent has made known his or her wishes concerning medical treatment during some prior period of competency.

This phrasing also takes care of the problem of persons who have been committed; their situation is a special problem which requires other legislation if it needs to be altered from the way it stands at present.

The statute also should contain a section excluding several likely misconstructions. These include misconstructions of its purpose and of its intended effect upon the existing situation. Something along the following lines might do:

- Nothing in this act is to be construed
- (a) as introducing or recognizing any right to die; or
 - (b) as authorizing any person to do or to refrain from doing anything in order to bring about the death of any person; or
 - (c) as creating any new obligation that a physician administer treatment above and beyond that required by the usual standard of medical care; or
 - (d) as causing any treatment to be required by the usual standard of medical care if such treatment prior to the enactment of this statute was commonly considered futile and useless by competent and careful physicians;
- or
- (e) as impairing or superseding any legal right or responsibility which any person would have had prior to the enactment of this statute to bring about the withholding or withdrawal of medical treatment in any lawful manner;
- or
- (f) as requiring physicians or health-care facilities to seek judicial determination of their duties in cases in which there would have been no doubt as to their liability if they failed to respect a patient's wishes had such cases occurred prior to the enactment of this statute.

Our intention in proposing this phrasing is to keep the present situation as much as possible just as it is for people who are satisfied with it.

The statute also must contain provisions regarding insurance. We doubt that the law can justly require that persons who limit or refuse consent be treated in all respects the same for insurance purposes as those who do not. This would unfairly impose the voluntary risks of some persons upon others, who do not choose them. But the statute definitely must include a provision excluding as unlawful any attempt to make a person refuse or limit care as a condition for granting an application for health or disability insurance and the like.

The statute also should contain severe penalties for forging or tampering with evidence as to any person's wishes in regard to his or her own medical care. In particular, the misrepresentation that a person refuses treatment on which life might depend should be classed as attempted first degree murder, and as first degree murder if the misrepresentation causes or hastens death.

The four main sections of a statute would be embedded in the middle of it, but for convenience we number them here as sections one to four. The first affirmatively states the liberty to refuse treatment and gives it all possible clarity:

Section one. It is a violation of the bodily integrity and intangibility of a person, subject to criminal and civil liability established in existing law of this State, to administer to any person without his or her personal, informed consent any medical treatment except in the cases specified in section two of this act unless such person be a minor or noncompetent person excluded by section_____from the provisions of this act.

Whenever a physician-patient or other medical treatment relationship is initiated and whenever explicit consent to medical treatment is sought, the person initiating the relationship with or seeking consent of the patient must if the patient be competent clearly and explicitly state that the patient is at liberty to give or to refuse consent to treatment. Evidence of the failure to inform the patient of the right to refuse consent shall be evidence of negligence which if willful and deliberate shall also be criminal.

The liberty is not only affirmed in its whole breadth but also defined and enforced by the requirement that patients be informed of it. The second section states and limits exceptions to the liberty to refuse treatment:

Section two. Notwithstanding the liberty of every competent person_____years of age or older to give and to refuse consent to medical treatment, no physician and no health-care facility shall be deemed to have administered medical treatment without consent if one or more of the following conditions is fulfilled:

(a) the treatment is authorized by statute to be administered without the consent of the person treated for the protection of the public health or safety; or

(b) the treatment is appropriate to remedy a condition of bodily injury or harm which the person treated has brought upon himself or herself in attempting suicide or self-mutilation; or

(c) the treatment either is ordered to be given by a court of law or is consented to by a guardian appointed and authorized by a court to act in the matter; or

(d) the treatment is administered to a person from whom consent cannot be obtained because of his or her inability either to give or to refuse consent to treatment, and the following three conditions also are met: (i) the treatment is an appropriate remedy for an existing condition of disease or injury; and (ii) the treatment is carried out in accord with the usual standard of medical practice; and (iii) there is no evidence known to persons administering the treatment or to administrators of any health-care facility in which it is carried out which a reasonable person would take to be sufficient to call into question the ordinary assumption that the noncompetent patient would consent to treatment which is medically indicated; or

(e) the treatment is administered to a person from whom consent cannot be obtained because of his or her inability either to give or to refuse consent to treatment, and the following two conditions also are met: (i) the treatment provided is immediately required to preserve the life or protect the health of the patient pending judicial determination of the case; and (ii) judicial determination is promptly sought.

Having limited the conditions in which consent can be overridden and created a situation in which any evidence putting in question the usual assumption of the consent of the noncompetent person to indicated treatment will provide a strong incentive for taking the case to court for determination, the statute must go on to direct interested parties to a suitable court and to indicate to courts what is required of them:

Section three. Upon a petition by a patient under medical care or by a representative of such a patient, by a relative of such a patient, by a physician or health-care facility responsible for such a patient, or by any other interested party, any court of_____of this State shall promptly schedule a hearing and give notice of it to all interested parties. At the hearing the court shall receive and examine all evidence produced by any party concerning the nonconsent of the patient to proposed treatment or to treatment already in progress.

Evidence considered may include but need not be limited to expert testimony concerning the probable utility and benefit of the treatment; anything which might show that the patient rejects all or certain kinds of medical treatment on the basis of religion or other deeply held conscientious convictions, that under specified conditions the patient refuses all but palliative care, or that the patient desires decisions to be made on his or her behalf by some designated person or persons.

In assessing the evidence the court shall consider the presumption of

consent to be in possession and shall not alter this presumption unless a different conclusion is established by the evidence beyond reasonable doubt. The refusal by any person of consent to medical treatment shall not itself be considered evidence of the noncompetence of such person.

If the court determines that one or both of the following conditions is met, then it shall direct that medical treatment be administered in accord with the usual standard of medical practice unrestricted by lack of consent: (a) if treatment of the patient is required by the compelling state interest of the public health, welfare, or safety; or (b) if the usual assumption that a noncompetent person does consent to treatment to which a reasonable and competent person usually would consent should stand in the present case, either because the evidence presented does not establish beyond reasonable doubt that the patient when competent exercised the liberty to limit or refuse consent, or because the evidence presented does not sufficiently show what limitation, modification, or termination of treatment would give effect to the patient's wishes.

In finding that treatment of a nonconsenting patient is required by the compelling state interest, the court must find that lack of treatment would be likely to result in substantial harm other than harm to the patient's own life or health. Such harm might include but is not limited to the probable resulting incapacity through death or otherwise of the patient to fulfill responsibilities to dependent children. If the patient's refusal of treatment is based on religious or other deeply held conscientious convictions, then the prospect of harm which grounds the state interest must be such as to constitute a clear and present danger.

If the court finds that neither condition (a) nor condition (b) is met, then the court shall cause treatment of the patient to be limited, modified, or terminated in accord with the proved will of the patient. In giving effect to the will of the patient the court may act by its own order or by appointing and authorizing a guardian to act on behalf of the patient or by both of these modes.

The court's assignment is to examine evidence about the patient's consent. This keeps the focus where it ought to be. Nevertheless, the usual assumption is that the patient consents to treatment in accord with the usual standard of medical practice, and such treatment is limited to that which is somehow of use and benefit to the patient. Hence, the court could consider expert testimony which would show that the treatment was not of use and benefit, and on this basis rule that nonconsent must be presumed.

The final section of the statute, as we have projected it, would be the limitation of liability:

Section four. Whenever medical treatment is restricted and delayed in conformity with section 2(e) or is limited, modified, or terminated in accord with a judicial decision under section 3, the provisions of this act and

what is done in accord with it shall be a material and relevant circumstance in determining the usual standard of medical practice. Neither physicians nor health-care facilities shall incur any civil or criminal liability for acting in accord with the usual standard of medical practice as determined with this circumstance taken into account.

If a physician proposes a medical treatment which would be in accord with the usual standard of medical practice if the patient consented to it, and if the physician is prevented from proceeding with such treatment because of refusal of consent in accord with the provisions of this statute, then the physician shall not be deemed to have abandoned the patient if the physician withdraws from the case provided that due notice of withdrawal is given to the patient or to others concerned with the patient's interests.

By this provision nothing in the way of protection of the patient's rights is given up, yet the physician and the hospital are given the assurance they need to do the best they can for a patient within the limits set by the patient. If a physician, because of reasons of conscience or other concerns, objects to working under such limitations, the statute provides a way out.

As philosophers we do not pretend to be legislative draftsmen. We have articulated our proposed alternative to "death-with-dignity" legislation in a formal mode, to give definite embodiment to our proposed alternative to the statutes now being enacted.

J. Replies to Some Objections

Many objections are likely to be made against any proposal along the lines we are suggesting. We conclude by considering some of them.

First, it is likely to be suggested that minimum and purely formal conditions be established for a written statement if it is to count as evidence at the judicial hearing. The difficulty with this is that in some cases an individual will not have met specified conditions but will have left enough evidence to establish beyond reasonable doubt what his or her wishes are. Either the specified conditions will become an obstacle to giving effect to such a person's intent or exceptions will be made. In the latter case the formal conditions will be only advisory, and such advice—which would be very useful—can as well be given apart from the statute. Decisions of courts made on a case by case basis also will begin to indicate very quickly what formalities are accepted as giving evidential weight.

Again, it is likely to be suggested that a line of authority be established if an individual has not made his or her personal position known. For example, it might be stipulated that in the absence of evidence about the noncompetent adult's wishes a certain family member would be presumed that person's

choice to act, and the court would so order. This idea has its appeal but involves the difficulty that it would alter the existing situation in a way which is not necessary for the purpose of the statute. Such an alteration ought not to be made unless it becomes clear that most people desire it. If the majority of citizens of a given State wish this or some other assumption established by the statute, there would be nothing unjust in including it.

Some might object that no new approach is needed at this time to deal with the liberty of competent persons to refuse treatment. Even legislation such as we are proposing will be open to amendment in the direction of facilitating voluntary euthanasia. The answer to this objection is that the movement favoring euthanasia has been gaining momentum consistently; it has not suffered a serious setback since 1967. In the battles up to 1973 opponents of abortion were able to appeal to a residue of traditional sentiment. Opponents of euthanasia will be able to appeal mainly to self-interest. A picture of a normal, unborn twenty-week baby has emotional impact; so, unfortunately, does a picture of a defective child, a psychotic, a senile person. Identification with such persons is more difficult for most of us than is identification with the infant. Self-interest can be served by limiting non-voluntary euthanasia to the noncompetent in institutions. Therefore, some new strategy is needed. We believe that legislation along the lines we are proposing will be less open to revision to facilitate euthanasia than will the common-law situation which still exists in most states, and will be a substantial obstacle to euthanasia in comparison with the natural-death or right-to-die legislation which provides both an ideological framework and some legal safeguards necessary for euthanasia.

Some might object that the legislation we propose will encourage people to make decisions about future treatment when they are considering death abstractly and at a distance, but those decisions might well be different when the consequences of refusing treatment are imminent. The answer is that under the legislation we are proposing people could leave the future decisions to be made as they are now or could assign responsibility to someone they trust to make them at the time. Moreover, there is nothing in the proposed bill to prevent people from changing their minds. Besides, we see no reason to suppose that a person's desires or hypothetical desires at the time treatment is needed are more likely to express his or her true self than the same person's free and deliberate choice made at some earlier and calmer moment.

Some might object that it is unwise to give people so broad a right to refuse treatment. The answer is that legislation along the lines we are proposing is not giving anyone a right; it is only recognizing and facilitating a liberty which people in principle already have. Of course, the proposed statute would help people make their wishes in respect to their own future more effective than is now possible. However, we can see no justification for limiting people's

liberty with respect to the future which would not equally justify limiting it with respect to the present.

While the state does have a duty to protect children and the permanently noncompetent from themselves and from the irresponsibility of others, it is of the essence of liberty that competent persons be able to make decisions about their personal lives and to have these decisions respected not only at the time they are made but also during the whole time to which they are meant to apply. Liberty may be exercised foolishly and even immorally, yet it must be respected. The alternative is a paternalism which might be benevolent but which cannot be just and is bound to be odious.

Some might object that if the liberty to refuse treatment is protected to the extent we propose, some people will abuse this liberty even to the point of using it to commit suicide, and that in consequence there will be further lessening of respect for human life. The answer is that nothing in our proposal lends color of lawfulness to suicide. On the contrary, we suggest provisions to make clear that suicide is against public policy. Still, someone might commit suicide by refusing treatment—understanding “suicide” in a moral sense. But this possibility already exists. The statute we are proposing only extends this possibility as an unwanted side effect of extending the just protection of the genuine liberty of persons to choose and refuse medical treatment. The grounds of this liberty are, not in any supposed right to die, but rather in the right of persons to bodily integrity and intangibility, which is closely related to the right to life itself.