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## Who Should Live-or Die? Who Should Decide?

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# Protecting Individual Rights

## Who Should Live— or Die? Who Should Decide?

**Editor's Note:** *Yale Kamisar, the Henry K. Ransom professor of law at the University of Michigan Law School, is the author of numerous books and articles on criminal justice as well as articles on euthanasia. TRIAL asked Professor Kamisar questions on legal and ethical issues surrounding the right to die, a subject attracting increasing interest across the country and around the world.*

### What is the difference between active and passive euthanasia?

This question has long been the subject of widespread and spirited debate by lawyers, doctors, philosophers, and ethicists. One group of commentators believes that the distinction between active and passive euthanasia is a crucial one. But another group of commentators has belittled the distinction, maintaining that it is morally evasive and disingenuous to condemn positive acts of euthanasia and yet approve negative strategies designed to achieve the same purpose. I agree with the second group.

Over the years, some proponents of euthanasia, such as the late Dr. Joseph Fletcher, the noted Protestant ethicist, have attacked the distinction, but many of his allies have sought to preserve it. They are well aware that the public is much more ready and willing to accept "letting die" than "killing" (even when it is in "mercy").

Unlike many proponents of the right to die, who deem it important to maintain the distinction so that passive euthanasia not be tainted in any way by the active euthanasia movement, I be-

lieve that passive euthanasia *should* be tainted by that movement. We should not withdraw or withhold life support when we know full well that that course of action will bring about death—indeed, when our very purpose is to achieve that result—unless we are willing to accept responsibility for what we are really doing. Perhaps passive euthanasia should be permitted in some cases, but only when direct, straightforward euthanasia would be.

I have considered the arguments made by proponents of the active/passive euthanasia distinction for a long time. I must say I do not find them persuasive. We are told, for example, that removing the ban against euthanasia would be to "embrace the assumption that one human being has the power of life over another." (*New York State Task Force on Life and the Law, Life-Sustaining Treatment* 42 (1987).) But withholding or withdrawing life-sustaining treatment embraces that very assumption.

We are also told by a group favoring passive euthanasia in certain circumstances that maintaining the prohibition against active euthanasia "prevents the grave potential for abuse inherent in any law that sanctions the taking of human life." (*Id.*) But passive euthanasia, at the very least, presents the same potential for abuse.

Indeed, I would go further. I would say that because of the repugnance surrounding active euthanasia—because it is what might be called straightforward or "out-in-the-open" euthanasia—it is

probably less likely to be abused than less readily recognizable forms of passive euthanasia.

### Will you elaborate with an example?

Many Down's syndrome newborns have been "allowed to die" through failure to remove an intestinal blockage or otherwise perform relatively simple surgery. Very few would have died if parents and physicians had had to consent to lethal injection rather than starvation or dehydration as the method of death. Very few of these newborn babies would have died if parents and physicians had been unable to deny what they had really done—if they had had to accept the responsibility for "killing" rather than "letting die."

I want to make one thing quite clear. I do not favor active euthanasia. Rather I am greatly troubled by the degree to which passive euthanasia has gained acceptance. My purpose in debunking the active/passive distinction is to get us to re-examine what we have been doing passively or negatively and to feel more uncomfortable about it.

But others who dismiss the distinction have a very different purpose. Convinced that negative or passive euthanasia is a fait accompli in modern medicine, this group is trying to belittle the active/passive distinction to get more doctors (and others) to engage in active euthanasia and to feel more *comfortable* about it. They are making a lot of headway, as the strong support for Washington state's "Death with Dignity" Initiative



Gregory Nemeec

119 illustrates. The initiative didn't pass, but until the last few weeks of the campaign it was supported by large majorities. In the near future voters in other states will be asked to vote on similar proposals. The way things are going, by the year 2001 proponents of euthanasia will succeed, at least in some states.

If law and ethics were entirely syllogistic, it would be hard to distinguish between active and passive euthanasia. But we can't overlook the psychological effect—the symbolic impact—of legalizing active euthanasia. In a speech I gave some years ago, I said that passive euthanasia had gained so much acceptance

that our "official morality"—the prohibition against euthanasia—had become "a woefully outflanked Maginot Line." But that doesn't mean we shouldn't grieve over the fall of the Maginot Line. When you erase the distinction between letting die or dying a natural death and direct killing, the Maginot Line falls.

**Is the distinction between active and passive euthanasia likely to be preserved in the future?**

I don't think so. In recent years I've talked to a great many people about this subject. Although they differ widely on other aspects of this problem, almost

everybody seems to agree on one point: Sooner or later the distinction will disappear—active euthanasia will "collapse" into passive euthanasia—and *both* forms of euthanasia will become widely acceptable.

We moved a significant step in that direction in recent years, when most courts and most bioethicists rejected any distinction between turning off the respirator and removing the feeding tube. In the 1960s and 1970s that distinction was deemed important. Recall that Karen Quinlan's parents did not request permission to remove the feeding tube that was to keep their daughter alive for an-

other nine years. If they had, they probably would have been rebuffed.

But the law and medical opinion moved very quickly in the decade and a half since the *Quinlan* case was decided. In a relatively short time, the right-to-die movement was powerful enough to override the once-formidable distinction between terminating artificial nutrition and hydration and ending other forms of life support. As a result of this, the psychological distinction between killing and letting die was significantly undermined.

**Define "dying" and "terminally ill." How are these terms different from "persistent vegetative state" (PVS)?**

The terms dying and terminally ill have been used very loosely. One reason is that those who favor refusing or withdrawing life-sustaining treatment find it good strategy to characterize the patient as dying or terminally ill. This positions them to say that removing or withholding life support is not terminating a life but merely preventing the "drawing out" of the "dying process."

As usually defined, and as defined in Missouri (where the *Cruzan* case arose) and in many other states, the terms dying and terminally ill mean that a patient's condition will shortly result in death regardless of the use of available medical treatment. Under this definition (and this may surprise a lot of people), neither Karen Ann Quinlan nor Nancy Beth Cruzan was dying or terminally ill.

Quinlan probably could have been kept alive if her respirator had not been removed. Indeed, she stayed alive for 9 years after it was removed. As for Cruzan, it is generally agreed that if kept on the feeding tube she might have lived for another 20 or 30 years.

Of course, one may say (and many people have) that PVS patients should have their life support disconnected because they "might as well be dead" or they are "better off dead." (This is the principal reason many people favor terminating life-sustaining treatment in cases like *Quinlan* and *Cruzan*.) But to say that is to wrestle with the very elusive question of a life not worth living.

If death is unpreventable—if the best that medicine has to offer can postpone death for only a short time—it makes some sense to say that the underlying illness "caused" the death or that discontinuing life support merely permitted death to occur. But when a patient can be kept alive for many years it is hard

to avoid the conclusions that we have made a quality-of-life judgment and that the removal of life support rather than the underlying illness brought about the patient's death.

**If Washington state voters had approved "Death with Dignity" Initiative 119 in November, they would have legalized voluntary euthanasia only for the terminally ill—those who have six months or less to live—who make a written request to die. Is a terminally ill limitation very important?**

Yes, but if the proposal had been ap-

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*I can't think of a problem that raises more fundamental moral, political, and legal questions than euthanasia.*

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proved, I don't think the distinction between euthanasia for the terminally ill and euthanasia for other severely ill people would have lasted very long.

Although proponents of voluntary euthanasia were defeated in Washington state, they will be back. They tell us they will soon try again in Oregon, California, and Florida. They will probably again propose active euthanasia only for the terminally ill. But their arguments outrun euthanasia for that limited group.

If, as proponents of euthanasia say, people ought to have the right to control their own destiny—the right to choose what they regard as the most "humane" or "dignified" way to end their lives—why should that right be confined to the terminally ill? Why don't these arguments apply, at the very least, to nonterminally ill persons who are gravely ill or seriously disabled?

It may be good strategy to limit voluntary euthanasia to the terminally ill—as a first step—but I am convinced that if and when such a proposal is approved, euthanasia for the terminally ill will turn out to be an intermediate phase in the movement toward more and more voluntary euthanasia and then, I am afraid, nonvoluntary euthanasia. If the modern history of the ethics of death and dying demonstrates anything, it is that what we cannot do—perhaps cannot even think seriously about doing—in one step we are often able to do in two or three.

Living will statutes generally demand

that a terminal condition be present before the living will becomes effective. But in response to strong criticism that such a restriction unduly limits the benefits of such legislation, some states have greatly relaxed the definition of terminally ill or eliminated the requirement altogether. The same pressures, I am afraid, are likely to expand the category of those eligible for active euthanasia well beyond the terminally ill.

**What is the difference between extraordinary and ordinary means of life support? Is this distinction likely to be preserved in the future?**

No. In fact, it has pretty much disappeared already. At one time this distinction may have been a helpful tool of analysis, but participants in the right-to-die debate soon poured into it all the factors relevant to appropriate moral decisions, however nonmedical they might be. As a result, treatment that is usual, even routine—antibiotics, simple surgery, intravenous feeding—was called "extraordinary" or "heroic" in light of a given patient's condition.

To say, as many did, that a simple operation to remove an intestinal blockage is a non-obligatory extraordinary treatment when the patient is a Down's syndrome baby or that the use of antibiotics to combat pneumonia is extraordinary when the patient is senile or that insulin is extraordinary for a diabetic patient who develops inoperable cancer is circular reasoning. Extraordinary treatment came to mean treatment that was considered undesirable or inappropriate in relation to the medical condition of a given patient.

But why was treatment inappropriate under the circumstance? Evidently it was because those who called the treatment extraordinary thought there was no point in keeping the patient alive under the circumstances. Thus, it became very difficult to distinguish the extraordinary means doctrine from advocacy of passive or negative euthanasia. Those who think termination of life-sustaining treatment is called for can simply label the treatment heroic or extraordinary.

The extraordinary/ordinary means distinction has been severely criticized (see, e.g., *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment* 82-89 (1983)) and is now widely rejected. And rightly so. The distinction became so

spongy and unilluminating that there was little to be said for retaining it.

But over the years this doctrine performed a function: It confused and seduced us. It led many to believe that only certain kinds of life support could be, and would be, terminated—that disconnecting an unconscious patient's respirator in some vague way constituted only a very slight and a very limited deviation from our official morality. This doctrine has moved us down the slippery slope.

**You have said that determination of a patient's condition must be made by doctors but that whether a patient should die is a "moral-legal-philosophical-political question" that should not be left to doctors. The courts are the place for deciding legal questions. Should anyone else be involved in the decision-making process?**

Every profession would like to police itself. Every group (and I include law faculties as well as police departments and school boards) resents an "outside" group looking over its shoulder.

But despite their expertise, we don't let the police decide for themselves when they can kill a fleeing felon. Rather we

say (and rightly so) that this is a legal policy issue to be decided by the legislature or the courts.

Doctors can tell us whether a person's condition is incurable or irreversible or whether a person is in a persistent vegetative state or in some other condition. But the typical doctor is not a lawyer or a philosopher or an ethicist. And deciding whether the life of a severely ill person is worth living—whether a patient's state of existence is sufficiently good to justify any further medical treatment—is not a question that doctors are uniquely, or even specially, qualified to answer.

Of course, doctors *have been* answering these very questions. That's because deciding these excruciating life-or-death matters is a "dirty business"—a subject that neither courts nor legislatures have been eager to get into. For a long time the legal system has more or less abdicated its responsibility and the doctors have filled the vacuum.

As many have said, this area is primarily one for the legislature, not the courts. We can't expect our courts to limp along without getting more guidance than they have been provided up to now. In considering and drafting legislation we

should welcome the input of many groups—medical ethicists, psychiatrists, psychologists, philosophers, people from different religious traditions, all kinds of health professionals—as well as input from lawyers.

I can't think of a problem that raises more fundamental moral, political, and legal questions than euthanasia. And if lawyers are not well equipped to play a large role in grappling with them, who is? We will not and should not relish the task. But neither should we shrink from it.

**How is a more conservative Supreme Court likely to rule in the future in cases like *Cruzan*?**

Although they did not achieve the result they desired in *Cruzan*, right-to-die proponents did secure two significant victories: The Court seems to have rejected any distinction (1) between the feeding tube and other forms of life support and (2) between dying or terminally ill patients and those whose conditions have stabilized and who could be kept alive for many years.

But two of the justices who supported a right to die have retired, and both of their replacements will probably join

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Chief Justice Rehnquist and the three justices who sided with him (Kennedy, Scalia, and White). (Although Justice O'Connor also joined the chief justice, her separate concurring opinion really put her at a considerable distance from him.)

As a result of the change in the Court's personnel, the chief justice's avoidance of the phrase "*a right to refuse treatment*" (emphasis added), one used by many state courts, and his preference for the phrase "*liberty interest in refusing unwanted medical treatment*" (emphasis added) take on added significance.

I share the view of Professor John Robertson of the University of Texas School of Law: By avoiding "fundamental rights" language—by declining to regard a right to refuse treatment as "encompassed by a generalized right of privacy"—the Court indicated that it would restrict this "liberty interest" on a lesser showing of need than it would require if that interest were regarded as a fundamental right. (See Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1174 (1991).)

The "opposite" of the typical right-to-die case has surfaced in Minnesota. A public hospital sought permission to remove a respirator from an 87-year-old woman in a persistent vegetative state whose family opposed the request. The hospital said continuing treatment was not in the woman's personal or medical interest. The family won; the woman died a day later. Does a patient have the right to demand unceasing medical treatment in a hopeless case? Is the outcome of this case likely to affect outcomes in more typical right-to-die cases?

A growing number of commentators are arguing that PVS patients should be viewed as dead or that the legal definition of death should be expanded to include such persons. A number of people find this approach appealing—so long as the family wants the life support to be terminated. However, many of these same people become uneasy when the family wants to keep the patient on life support.

Suppose a state defines a PVS patient or a person otherwise permanently unconscious as dead. That would mean that a hospital could require the termination of life support over the objection of every close family member. (I know of cases where a hospital has done just

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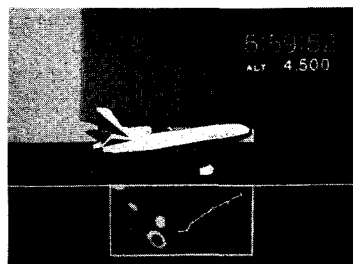
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that when the patient has met the then-current definition of the term "brain dead.")

Furthermore, I think that classifying a PVS patient as dead would mean that a hospital could require terminating life support even though, when still a vibrant person, the patient explicitly stated in writing a desire to be kept alive even if permanently unconscious. Dead is dead. Moreover, why bother turning off respirators or removing feeding tubes? Why not simply administer lethal injection? Again, dead is dead.

Up to now, most of our attention has been focused on the constitutional limitations, if any, that may be placed on a state like Missouri that takes a "vitalist" position, that is, regards all human life worthy of protection regardless of its quality. But the Minnesota case raises, or at least suggests, a different—and largely neglected—issue: What constitutional restraints, if any, may be imposed on jurisdictions that adopt a "nonvitalist" policy, that is, consider life worth protecting only if that life meets certain minimal or acceptable standards of quality?

Are PVS patients considered "persons" under the United States Constitution? If a state wanted to define such patients as dead, would the Constitution prevent it from doing so? Professor Robertson thinks not. If Robertson is right, what follows? Could a PVS patient be used if a state so elects as a source of organs for needy patients or as a subject of experimentation?

If a state has the constitutional power to define PVS patients or other permanently unconscious persons as dead, what next? If a number of states expanded their definition of death to include permanently unconscious persons, does anybody really doubt that 10 or 20 years down the road some states would expand the definition again—this time to include, at the very least, elderly, incompetent patients who could be described as minimally responsive or barely conscious?

The first case testing the constitutional power of a nonvitalist state in this regard could involve an elderly ward of the state who left no written directive, who either has no known family members or has been abandoned by them, and whose quality of life is "marginal." If such a case were to be argued in the U.S. Supreme Court, as well it may be someday, which side would be the "liberal" side and which the "conservative"? □

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