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George J. Annas

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The "Right to Die" in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian

George J. Annas*

INTRODUCTION

The topic of my talk is different from those you have been dealing with in this conference in one critical aspect—it's one that all of us are going to confront—we're all going to die. And death is not a subject anyone can escape because it has both professional implications—what the law should be, how we should decide disputes when they arise, and practical ones—how we should order our own lives, and what we should do to try to make our death easier if not on ourselves, at least on our loved ones.

I'm going to discuss the last twenty years of so-called right to die litigation. Pennsylvania with In re Fiori,1 is still trying to decide where it stands on the right to die. Courts generally have done a very good job in this area. The only time courts go wrong is when they view these cases as having something to do with abortion—and I'm going to argue they have nothing to do with abortion—or when they look at these cases as disability rights cases.

We'll see what the major issues are, how they've been dealt with, where they led to dead ends, how we got to where we are today and how we might resolve our current confusion.

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I. THE RIGHTS OF COMPETENT PATIENTS

The law divides patients into two categories—competent and incompetent. If you're competent you have a right to refuse any treatment, for any reason.2 Physicians always needed the patients' consent to treat, and an unconsented-to medical treatment was historically treated as a battery. More recently the adjective "informed" has been added to the consent requirement.

Informed consent litigation began in earnest in the 1970's as a response to medical paternalism. The historic Hippocratic ethic was paternalistic; doctors know best so doctors get to say what patients need. Physicians make all the important decisions. Medical paternalism was rejected in a series of informed consent cases, and the ethic now is that patients should decide what's to be done with their body because it is their body. Patients should have self-determination, and some courts have also talked about decision making as a privacy interest protected by the U.S. Constitution.

The doctor-patient relationship is an inherently unequal relationship. The doctor has the power and knowledge, and the patient is sick and has to trust the doctor. Courts, such as the California Supreme Court, have termed the doctor-patient relationship a "fiduciary" or trust relationship; and therefore put extra obligations on physicians that they wouldn't have if the doctor-patient relationship was an arm's length business transaction.3 The theory is—let the patient decide based on information about risks, benefits, and alternatives, because the patient will have to live with the results.

In 1984, in California, in one of the most outrageous incidents in American medicine and jurisprudence, a competent adult, William Bartling, was treated against his will for six months. He was suffering from five fatal illnesses, but none terminal.4 His lung collapsed during a biopsy to determine if he had lung cancer—he did. Mr. Bartling wanted to be taken off his mechanical ventilator and to leave the hospital. The hospital wouldn't


let him refuse treatment, and wouldn't even let him get off the ventilator—they tied his hands down. Mr. Bartling lived the last six months of his life in the intensive care unit ("ICU") where he died while the California courts were still arguing about his rights. The day after Mr. Bartling died, the California Court of Appeals ruled that he had the right to refuse treatment. What the hospital did to him, with the slow-acting law's blessing, was outrageous. Nonetheless, that's the last case I know of in this country where a competent person was forced by a judge to endure treatment against his or her will.\footnote{The only similar case involved a young woman, Elizabeth Bouvia, paralyzed from the neck down, who wanted to starve herself to death. That is a suicide case rather than a right to die case, but when it came back the second time through court, she could only eat a little bit and the doctors thought that wasn't enough. Well, doctors don't have any right to give you more calories than you can eat even if they think it's best for you, and ultimately the courts agreed with her. Bouvia v. Superior Court, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986). See George J. Annas, Elizabeth Bouvia: Whose Space is this Anyway?, 16(2) HASTINGS CENTER REP. 24 (1986).}

So the law is, and has always been, that competent adults have the right to refuse any treatment for any reason. Competent adults don't even have to give a reason—if they give a reason, that's fine, as long as it's not one that makes them look incompetent. Of course there's an irony here. Most Americans believe there should be a "right to health care;" instead what they have is a right to refuse health care.

II. THE RIGHTS OF INCOMPETENT PATIENTS

The legally difficult cases concern incompetent patients, patients who can't tell you what they want. We're going to look at decision making for them from medical and legal perspectives.

A. Medical Decisions

Even though we are anti-paternalistic, we know that there are some decisions that physicians must make; and we let them make some very specific ones without consulting anybody. The best example is deciding when a person is dead. We allow doctors to pronounce death as long as they do it on the basis of accepted criteria. Likewise, in an emergency, I always teach my medical students to treat first and ask legal questions later. We don't want doctors discussing the law in the emergency department—we want them taking care of people, and they're privileged to do that.
Let's review determination of death by brain criteria in some detail. That was never an issue until heart transplantation was first used in humans in the late 1960's, and physicians needed to take a beating heart out of one body and put it into another. To prevent heart transplantation from involving a single, if not a double homicide, society needed a definition of death that permitted physicians to declare someone dead while their heart was still beating. That turned out to be brain death, and it makes perfect sense. Robin Cook responded to brain death by writing Coma, which upset a lot of people. But coma is not death—you may never wake up again—but you're not dead. Brain death is death, but even physicians have a hard time accepting the notion that someone who is breathing (albeit with the aid of a ventilator) and has a beating heart, is dead.

The American Medical Association at first opposed brain death laws, and others got so stressed that they later demanded that brain death statutes be passed that granted physicians civil and criminal immunity for declaring death on brain criteria. In 1981, there were seven different brain death statutes. So theoretically (but not really) you could put someone in an ambulance in California and drive them across the country to Pennsylvania and they'd be dead, alive, alive, dead, alive, dead, dead, alive, dead, dead, and arrive in Pennsylvania alive. That's ridiculous. Our death criteria must be uniform—you can't be dead in one state and alive in another state. This became recognized by everybody, through judicial decisions, legislation, and medical standards. An individual who sustains either irreversible cessation of circulatory and respiratory functions—the old heart lung definition—or irreversible cessation of all functions of the entire brain, including the brain stem, is dead. That is the law today and I believe that's been the law for the last twenty years, because the law still is that you're dead when the doctor says you're dead (as long as the doctor makes that determination on the basis of good and accepted medical criteria).

7. In Massachusetts, the Supreme Judicial Court had to state that there is no legal basis or duty to administer medical treatment after death. See In re Spring, 405 N.E.2d 115 (Mass. 1980). This observation came as a result of physicians asking whether they had to continue treating a corpse.
8. As Peter McL. Black, a leading neurologist from Massachusetts General Hospital has put it:

Brain death is not a kind of coma that goes on forever in which a patient just happens to be on a ventilator to increase their oxygenation or something like that, it's really a condition in which without the kind of artificial support that we now in the 20th century can provide, the patient will stop breathing and the heart will stop. I think it's very important to recognize that when
Some test cases that we have had recently in the courts have involved anencephalic infants like Baby K. An anencephalic infant has no upper brain. Well, aren't they dead? They are if they can't breathe. But if they can breathe on their own, they must have a functioning brain stem, so they're not dead under existing brain death criteria. They are in very bad shape, and there is nothing we can do to benefit them. We certainly have no obligation to treat them. On the other hand, under the law we can't kill them either because a breathing anencephalic infant is a live person. The wishes of some couples to donate the organs of their anencephalic children before they die—while they're still breathing and their heart is still beating—have been rejected by every court, and properly so.

B. Legal Decisions

The most famous "right to die" case still is In re Quinlan from your neighboring jurisdiction of New Jersey, in 1976. Karen Quinlan was twenty years old at the time she suffered two periods of not having breathed for fifteen minutes probably from a mixture of alcohol and drugs. She was rushed to an emergency room in New Jersey, successfully resuscitated, and put on a ventilator. Her parents wanted everything done for her, and continued to want everything for about six months. Finally, they were persuaded, as the physicians were, that there was no chance she was ever going to recover, that she was in a persistent vegetative state ("PVS").

My neurologist friend, Dr. Ronald Cranford of the University of Minnesota, describes this best: "A persistent vegetative state is different than a coma." A person in a coma has eyes closed and some reasonable chance of recovering and realizing what's going on. With persistent vegetative states, people have sleep/wake cycles, but are not aware of their physical surroundings, and never will have any awareness of their physical sur-

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10. E.g., In re T.A.C.P., 609 So. 2d 588 (Fla. 1992).
roundings. As Dr. Cranford puts it, "They are awake, but unaware." Because PVS patients have sleep/wake cycles, there have been many cases in the courts where loved ones and nurses have sworn that the patient looked at them or responded to them.

People in persistent vegetative states have commonly been the subject of court hearings, and almost all of the important right to die cases turn out to involve patients in persistent vegetative states. A practical reason for this is that most critically ill patients, no matter what you do to them, either recover or die in a short period of time. If judges delay the case long enough, the terminally ill patient will usually die and the judge won't have to decide the case. Trial court judges hate to make "life or death" decisions. But persistent vegetative state patients can live for decades, and often do. That's what makes these cases so hard for families; but it also means that judges can't avoid deciding them by simply waiting for nature to take its course.

Karen's case became known under the slogan "right to die," even though the case did not involve this "right." It was a right to refuse medical treatment case. It's not as if we have any choice in the matter whether or not we'll die. It's a right most of us would choose not to exercise if we did have the choice, but we don't, we're all going to die. The question is whether, when we're dying, we have an obligation to accept all the wonderful things that modern medicine has to offer, to agree to submit to whatever can be done medically to postpone death.

That was one of the questions in Quinlan: did Karen have a legal obligation to stay on the ventilator if that's the only thing that's keeping her alive? Well, unless we want to make medical technology our master, the answer has to be no. The doctors who had originally tried to get the Quinlans to agree to take Karen off the ventilator knew this. Nonetheless, because the case seemed unprecedented, they consulted their lawyers. The lawyers told them they thought ventilator removal was fine, but just to be sure, they said they would feel better if the Quinlans went to court to get the doctors prospective legal immunity for any kind of liability, criminal or civil, before they removed the ventilator. That was bad legal advice, although the Quinlans felt they had no choice. The case did go to court, and a lower court judge heard incredible testimony from the very physicians who had wanted to remove the ventilator. The physicians testified that it was against medical ethics to take Karen off the ventilator.

The case was immediately appealed to the New Jersey Supreme Court. Governor Richard Hughes was the Chief Justice,
and thought this case of first impression should be decided quickly to help the Quinlan family. He did decide it quickly (within four months of the trial judge's decision) for a unanimous bench, ruling that Karen had a constitutional right to refuse treatment based on the then-recent abortion decision *Roe v. Wade.* The court said that Karen didn't lose her right to refuse treatment by becoming incompetent, and that her parents could exercise it on her behalf, based on what they thought she would want done.

Virtually every subsequent court has followed Judge Hughes in those findings, but the New Jersey court went further than that. It asked, in effect: "What are we going to do with the doctors who testified at trial that it's against medical ethics to take Karen off the ventilator?" The court was stuck with that testimony, so what it did with it was very interesting—Chief Justice Hughes said: Well, we know these are honorable doctors and we believe what they say about medical ethics. But obviously their perception of liability influences them a lot in terms of how they articulate the medical profession's ethical standards. They're really worried (and should be worried) about legal liability, about whether they'll get sued. Nonetheless, I think that if they took these physicians into a soundproof room and asked them what they thought the right thing to do was, they'd say "turn the ventilator off."

Because the New Jersey Supreme Court believed that doctors adopted their ventilator discontinuance standards based on their worry about lawyers and liability, and because the court wanted doctors to do good, the court set up a mechanism to provide doctors with immunity from criminal and civil liability. The court did this by granting an ethics committee the authority to provide legal immunity to physicians and others, at least in cases where the patient has no reasonable possibility of returning to a "cognitive sapient state"—i.e., the patient is in a persistent vegetative state. If the ethics committee agrees, the doctors can stop treatment, and everybody will be immune from liability. That's New Jersey's solution—to grant physicians immunity.13

*Quinlan* did not energize ethics committees—although ethics

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13. Since the New Jersey ethics committee only deals with medical prognosis, it was quickly renamed a "prognosis committee" and its membership limited to neurosurgeons and neurologists. Karen herself lived another nine years in a PVS after her ventilator was removed. Her parents never seriously considered removing her feeding tube.
committees were set up many places—but did energize the living will movement in the United States. The problem that a lot of people had, including the courts, with Karen was that she had never said clearly what she'd want done if she was in a persistent vegetative state. Not until Quinlan did most people say to their loved ones something like "I'd never want to be like Karen Ann Quinlan." Most people have said that, and many people have actually signed forms to this effect as well. Almost all states passed statutes in the wake of Quinlan to encourage citizens to sign living wills (documents which are "living" because they take effect while you're still alive, and which are wills in the sense that they say what you would want after you're no longer able to say it yourself).

There were at least eighty-four appellate cases on the "right to die" decided in the United States before the case of Nancy Cruzan got to the United States Supreme Court in 1990.\(^{14}\) Nancy Cruzan was a young woman in exactly the same condition as Karen Quinlan, except all she needed was a feeding tube to continue to live. She was in a persistent vegetative state caused by an automobile accident. There was no hope for her to ever recover, and her parents ultimately asked that the tube feeding be removed. Unlike almost every other case, the lower court judge in this case, Judge Teel, agreed with the parents that Nancy would not want to be tube fed in her persistent vegetative state.\(^{15}\)

The Attorney General of Missouri, however, decided to appeal the case. He said that if the right to refuse treatment really is based on informed consent, he wanted an informed refusal. He wanted evidence that while she was alive, Nancy Cruzan said something like, "If I'm ever like Karen Quinlan, I don't want tube feeding even though I know that I'll die without it." The Missouri Supreme Court agreed with the Attorney General, and held that the State of Missouri had the constitutional authority to require clear and convincing evidence of an individual's personal decision before life sustaining treatment is removed, and to refuse to let family members make a proxy decision for an incompetent person.\(^{16}\) The Cruzans appealed to the United

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15. Trial court judges have a terrible time deciding cases in this area when the patient is still alive, because the judges feel like they're being asked to end the patient's life. What they're really being asked to do is vindicate the patient's right to make their own decision, or in some cases where the patient hasn't spoken, the family's decision on the patient's behalf.
States Supreme Court, and to date it's the only "right to die" case, again, more properly labelled a right to refuse treatment case, that the Court has decided. In a five-to-four decision, with Justice Sandra Day O'Connor and Justice Antonin Scalia writing separate concurring opinions, the Supreme Court affirmed, ruling that Missouri had the constitutional authority to require clear and convincing evidence that the individual personally made the treatment refusal decision. And that's bad, because people don't leave such specific instructions, and loving families are the best surrogate decision makers. Nonetheless, there are some good things that came out of that case.

One good thing was resolving the question of whether fluids and nutrition delivered through nasal gastric tubes or gastrostomy tubes should be treated like all other medical treatment (especially like ventilators). All nine Justices treated them the same; fluids and nutrition artificially delivered are the same as other medical treatment. Certainly there's no constitutional distinction. If Americans have the right to refuse one we have the right to refuse them all, and we know already that we have the right to refuse them all.

Second, in dicta, a majority of the Justices said they believed that competent people have the constitutional right to refuse any treatment, including artificially-delivered fluids and nutrition. Another ray of hope in this case is Justice O'Connor's concurring opinion, where she said requiring clear and convincing evidence is not realistic.\(^\text{17}\) It's not realistic to think that twenty-year-old women or men are going to think about how they're going to die and plot what things doctors might have available to postpone their deaths. Justice O'Connor said essentially that she believed that if Nancy had just said something like "If I'm ever not able to make medical decisions for myself, I want my mother to make them," that would have been a constitutionally-protected delegation of authority. Put another way, that statement would have been clear and convincing evidence that Nancy wanted her mother to make those decisions, and her mother would then have had the legal authority to make them. Justice O'Connor's concurring opinion energized the health care proxy movement in this country. Obviously we don't have the entire court saying that such a delegation of authority is constitutionally-protected, but I think we have at least seven members of the Court who would agree with that.\(^\text{18}\)

\(17\).  *Cruzan*, 497 U.S. at 287-92 (O'Connor, J., concurring).

After the opinion, the Cruzans went back to Judge Teel and three of Nancy’s friends testified that she had told them that if she was ever like Karen Ann Quinlan, she didn’t want to be tube fed. Judge Teel found that this testimony constituted clear and convincing evidence of Nancy’s wishes. The Attorney General had by that time figured out that he was on the wrong side of this issue (he wanted to run for governor), so he did not appeal. Nancy died on December 26, 1990, shortly after her feeding tube was removed.

Cruzan is obviously the most important case ever decided on this issue because it’s the only Supreme Court opinion. But it is a very unsatisfactory one. In addition to accepting a burdensome standard of proof which is more likely to frustrate rather than further autonomy, only Justice John Paul Stevens discussed the alternative best interests standard. How should this work for PVS patients? How do you figure out what’s in the best interest of someone like Nancy Cruzan?

Some courts have talked about burdens and benefits, but someone in a persistent vegetative state has neither burdens nor benefits. There is no awareness—you can’t help them, you can keep them alive—but you can’t make them better. You probably can’t hurt them either, because they have no awareness of pain or suffering. Justice Rehnquist states in Cruzan that we should err on the side of life and maintain the status quo by doing that. Justice William Brennan thought that in general that’s right. In an emergency, doctors should treat first and ask legal questions later. If life has a side, that’s an easy choice, if it’s life or death. But Justice Brennan noted that in Cruzan it is not life or death, it’s a choice of death and death. So when you’re not in that kind of a situation where the “life or death” slogan doesn’t make sense, what do you do? This is the question.

The question is important because if you make a best interest determination for one person in a PVS, you make it for everybody, because everybody in a persistent vegetative state has exactly the same “best interest” (since we’re making this determination objectively). No one in a PVS will wake up, so none of them can be burdened or benefitted. This is an issue that our society is not willing to face right now, but for good or evil the insurance companies and health plans will face it; and they will not pay. Within the next few years, you’ll see health plans paying for a limited number of days of institutional care for people

20. Id. at 316-17 (Brennan, J., dissenting).
in persistent vegetative states, and after that the family is on its own. The family can pay privately, but private insurance won’t cover it anymore. I think courts will uphold those types of restrictions if they are put in the contract, because such limitations are not against public policy. It’s also probably the only way we’re going to solve this “PVS problem,” because doctors and lawyers aren’t going to do it.

Another strand that runs through these cases is that courts don’t want to make the decisions themselves. But they also don’t quite trust the families—they almost trust the families, but not quite. Quinlan set up an ethics committee which was quickly recognized by the New Jersey Attorney General for what it was—a prognosis committee—and it’s been replaced by two neurosurgeons or a neurologist and a neurosurgeon to confirm that someone really is in a persistent vegetative state. The Fiori case in Pennsylvania does the same thing, it says that we don’t want a judge to make these decisions. You don’t have to come to court and that’s right, but it does require that the family get two independent neurologists to confirm the diagnosis of persistent vegetative state. I don’t know how you enforce that requirement, and I don’t know what that means, but I understand the discomfort of just letting families say what should be done.

Judges would really appreciate it if people would fill out living will forms. Tell us what you want done, or better yet, appoint someone as your health care proxy to make decisions for you. It is better to delegate the authority to make decisions to another person because it gives the doctor somebody to talk to. Forms are always susceptible to interpretation and misinterpretation, and doctors are uncomfortable with making decisions on the basis of a form. It’s much better for you, for them, and for everybody, if doctors have someone to talk to. And not just someone like the next of kin who traditionally, by custom, has legal authority to make decisions, but a healthcare proxy who, by statute, and court decisions, has the same legal authority to make the decisions you would have made yourself. The current trend is state legislation that designates a proxy for you if you haven’t done it yourself, and this makes perfect sense.

C. The Baby Doe Regulations: The Discrimination Model

This still leaves some people who have never been able to make any decisions, who could never tell us what they want or who they want to make decisions for them, like newborns and young children. We’ve had fifteen years of controversies about how to make decisions with handicapped newborns in this coun-
try, dating back to the beginning of the Reagan administration—the Baby Doe regulations. In 1982 the federal government required every hospital to post signs in the delivery rooms, the neo-natal intensive care units, and the pediatric ward, that any person having knowledge of a handicapped infant being discriminatorily denied accustomed medical care should contact this Baby Doe hotline in Washington and investigators would come out and investigate. This lasted for about eight months.

In the more than 100 cases that were investigated, they were able to find no case of any infant in the United States who was discriminatorily denied food or customary medical care.21 Not that it doesn’t happen, but this mechanism did not find it. What was found was that many infants get more care than they should; that it’s virtually impossible to get physicians in neo-natal ICU’s to stop aggressively treating handicapped newborns until they die. Discrimination was not a general problem, but it was a problem for kids with Down syndrome. The original Baby Doe was a child with Down syndrome whose tracheoesophageal fistula (a hole between the trachea and the esophagus that made it impossible to feed the child), was not repaired because of the child’s retardation. That was clearly wrong. If that was acceptable medical behavior twenty years ago, it’s not anymore. But outside of that, most physicians follow the rules related to child neglect and child abuse, and provide medically-indicated, customary care.

Courts have used all five of the following phrases (they’re all basically the same) to describe the legal duty of physicians: physicians must provide customary medical care, beneficial treatment, reasonable medical care, care which in their reasonable medical judgment is indicated, and appropriate treatment to children because we assume that they want to live rather than die. The problem often is that there is no customary standard of care nor accepted medical treatment. There is no routine way to separate Siamese twins or determine how extremely premature newborns should be treated. The quest to get a smaller and smaller baby to live is a giant experiment, and there are no real standard treatments to take care of most of these very young, underdeveloped neonates. It’s not a matter that physicians are trying to discriminate against the handicapped; they’re trying to figure out how to treat them. And yes, some neonates are treated differently than others—but not because of race or

creed, but because their different medical conditions require different treatments. The whole notion that there is a massive campaign to discriminate against handicapped children or handicapped adults is just wrong; there is no evidence to support it.

On the other hand, we have an extraordinarily high standard for stopping treatment on a newborn or a child. It's the best interest standard translated by the courts as "better off dead." You really can't stop treating a child until you can make a credible argument that the child is better off dead than alive. It's kind of a restatement of the err on the side of life logic, only in a context where the available medical technology is almost overwhelming. We probably need a more nuanced standard. We should always give kids the benefit of the doubt as long as there really is some doubt. But we shouldn't insist on 100% certainty before we call off the intensive care unit.

D. The Role of the Family and Futility

What should the role of the family be in decision making for incompetent patients? We can begin to answer this question by looking at the case of Helga Wanglie,²² perhaps the best known futility case. Mrs. Wanglie was an older woman in a persistent vegetative state. Her husband, a leading attorney in Minnesota, insisted that everything be done for her—a ventilator and tube feeding—hoping for a miracle. The doctors, for the first time in the United States, tried to make an argument in court that it was wrong to treat someone in a persistent vegetative state once the diagnosis was certain. They argued that treatment was futile, unnecessary, non-beneficial, and doctors shouldn't do it. It was a very difficult argument to make when we know that at least 10,000 people are now being treated that way in the United States. Doctors do it—it's currently medically customary treatment.

The question is how to change medical custom. If courts won't say people in persistent vegetative states are better off dead (based on a best interests analysis), and the legislatures won't say it, and up until now the insurance companies haven't said it, can the doctors say it? The answer is that doctors should say it and say it through their professional associations. They haven't been able to say it yet, they won't say it, for all kinds of reasons, but some doctors at least are trying. The Minnesota physicians went to court on a guardianship petition, and asked that Mr.

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Wanglie be removed as guardian on the basis that he wasn't acting in the best interests of his wife. The petition was denied—end of story. The court never got to the discontinuance of treatment issue. Mrs. Wanglie died shortly thereafter.

A case in Massachusetts, involving a patient named Catherine Gilgunn, which is currently on appeal, is another famous futility case. It involves an elderly woman who was in an ICU at the Massachusetts General Hospital. This woman spent the last sixty days of her life in and out of an ICU, being vigorously cared for. Her daughter refused to agree to a do not resuscitate ("DNR") order. The doctors, with the chair of the ethics committee, and everybody else involved on board except the daughter, did write a DNR order because they believed it was impossible to resuscitate her anyway, i.e., it would be futile. The mother died, and the daughter sued. It is a very bizarre case, because she sued for negligent infliction of emotional distress on her by not resuscitating her mother.

The judge asked the jury to decide whether the mother would have wanted to be resuscitated, and whether the doctors were correct in not resuscitating her. The jury found first that the mother would have wanted to be resuscitated. But second, the jury found that the doctors were right not to resuscitate her. What's going on here? I think the jury came to exactly the right decision, because there was nothing that could possibly be done for the woman. On the other hand, many physicians have overinterpreted this case, saying it means they can now do whatever they want, that they can decide when treatment is futile, and it doesn't matter if patients want to be treated or not, if the doctors say they shouldn't be treated—you can't. This illustrates the danger of the futility issue: it can bring us back to medical paternalism which is where we started.

But mostly we have the answer—competent adults can refuse any treatment for any reason. The government never has more interest in your life than you have in it yourself, so the government can't force you to be treated. With incompetent people, doctors can make some decisions, whether you're dead, hopeless, or need emergency treatment. Courts have been open to declaratory judgments, and in some cases courts have granted physicians prospective immunity against homicide and negligence.

Most of the debate now is about the issues of substituted judgment and best interests. For substituted judgment we try to get

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people to sign forms and tell their relatives what they want, and to appoint someone else to make decisions for them. For best interests, we still have a hard time when someone hasn’t told us what they want done, and we usually decide that it’s best for them not to be dead, at least for children.

Death obviously is very hard for us to face. With persistent vegetative states and other diseases that result in severe brain damage, you’re not dead. Nonetheless, you’re in such bad shape that we know by surveys that 90% of Americans would not want continued medical treatment in a PVS. The presumption in these cases should be changed. It’s wrong to continue the presumption in favor of continued treatment in someone in a persistent vegetative state when we have overwhelming evidence that Americans don’t want to continue to live like that.

III. SUICIDE

I’m going to spend the remainder of my time on current events—suicide and active euthanasia—which are very hot topics in the courts now. We’re going to look at cases in the Ninth Circuit24 and the Second Circuit25 on suicide. The issue is whether Washington and New York laws against assisted suicide are constitutional as applied to physicians writing lethal prescriptions for their competent, terminally ill patients. The Second Circuit decided that these laws deny equal protection to people who unlike Karen Quinlan and Nancy Cruzan don’t have any medical intervention to refuse. The Second Circuit rightly noted that you have the right to refuse a ventilator, even if the result is death. But what if you don’t need a ventilator? Shouldn’t you have the right to get some help from a doctor in dying then too, and isn’t that denial of equal protection when the doctor can’t help you die but he can help someone who needs medical intervention to continue to live? Of course this line of reasoning only makes any sense if you have reconfigured the right to refuse treatment not just to a “right to die,” but to a “right to hasten death” with a physician’s assistance.

The Ninth Circuit’s eight-to-three en banc opinion follows an earlier one by a three judge panel about six months ago, and I’ll discuss it soon. Another case before the Ninth Circuit, which they haven’t decided yet, is Oregon’s new initiative (“Ballot Measure 16”) which gives physicians legal immunity for prescribing

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lethal drugs to terminally ill patients if, among other things, the patients ask for those drugs three times in a row over a fourteen day period.\footnote{Lee v. Oregon, 891 F. Supp. 1429 (D. Ore. 1995).} The district court judge in Oregon also used a superficial discrimination argument based on an equal protection analysis. He said that Ballot Measure 16 denies equal protection to people who are terminally ill, essentially because it doesn't permit physicians to prescribe lethal drugs to nonterminal people. Therefore, by carving out this category of people with less than six months to live, we're devaluing their lives by giving doctors immunity for helping them die. Again, that's a handicap-discrimination analysis, which I think is wrong for the same reason the Baby Doe strategy was wrong. Nonetheless, there are other substantial problems with the Oregon statute.\footnote{See George J. Annas, Death by Prescription: The Oregon Initiative, 331 New Eng. J. Med. 1240 (1994).}

The physician-assisted suicide movement began in the U.S. when Derek Humphrey came here from England. He left England because he thought he was going to be prosecuted for giving his first wife a lethal overdose of drugs when she was dying of breast cancer. He came to the United States and started the Hemlock Society to try to get what he had done legalized. A couple of years ago he wrote Final Exit\footnote{DEREK HUMPHREY, FINAL EXIT (1991).} which was a best-seller on the New York Times "do it yourself" list for a long time, showing that Americans are actually quite interested in this. Americans don't trust doctors to take good care of them when they're in extremis, and mostly they're right about that. Doctors have a terrible reputation in this country regarding how they take care of terminally ill patients. They treat them aggressively, but don't medicate them sufficiently for pain, and ultimately abandon them.

When you ask people, "how would you like to die?" most people say they'd like to die quickly, in their sleep, at home surrounded by loved ones and out of pain. But almost all Americans die in the hospital surrounded by strangers, in pain and in terrible shape. So we have a big cultural lag with the way we take care of dying patients and the way they want to be taken care of. Humphrey tapped into this American malaise—the way we fail to take care of our dying. What Derek Humphrey recommends is that just after you take the drugs, you put a plastic bag over your head and tie it tight, so that if the drugs don't kill you, you'll suffocate to death.
Jack Kevorkian thinks that's too horrible, so he invented—he is an inventor and a pathologist who actually never had a live patient in his life—the "suicide machine." He puts an IV in your arm, then you turn on the IV to deliver saline. You automatically get an anesthetic, and then you finally get a death-producing drug—potassium chloride. The theory is that he doesn't kill you—you kill yourself. Kevorkian has been charged with homicide a number of times in Michigan and he has had some of his cases dismissed, and he actually was found not guilty by juries in two cases. The Michigan Supreme Court recently sent back two other cases to be tried for assisted suicide rather than homicide.29

Kevorkian's first "patient" was Janet Adkins, who came to Michigan from Oregon after she saw him on the Donahue show. She had early Alzheimer disease. She was in pretty good shape, but she knew that some time in the future she would not be in such good shape, and she wanted to die while she was still able to make a decision herself. She had seen people with Alzheimer disease who were unable to recognize anyone, who didn't know where they were, and she said she'd rather be dead than be in that shape. I think most of us might say that too. On the other hand, what we'd also likely say is what we'd like to do is die the day we get that way, but not a day before, certainly not years before, the way she did. But again, she didn't trust anybody, so she came to Kevorkian. After this first case, Kevorkian was unable to insert an IV, so he switched to the carbon monoxide machine, which he's used ever since. Carbon monoxide, of course, is not a controlled substance or a medical drug; many people use that method of suicide with their automobile in their garage.

I don't know what you think of Kevorkian, but I've called him a serial killer. Medical ethicist Arthur Caplan calls him a serial mercy killer, and I guess that's nicer. But whatever you think of him and his machines, they are not a medical means, and he's not acting like a doctor when he does this. Nonetheless, he does get a lot of credit for having been a doctor, and the fact that he once was a licensed doctor, rather than a plumber or an electrician, is why he's still on the streets today in Michigan, and why he still has a lot of support in this country. Even people who don't think they would ever use Kevorkian think he should be available because in America we don't want to limit our

“choice,” even our choice of how to die. That says pretty horrible things about the state of American medicine today, and how we fail to care for dying people.

I also think it’s worth at least mentioning that virtually every case, including Kevorkian’s first eight cases, involved men killing women, or assisting them to die. Derek Humphrey was involved in the deaths of his first two wives, one directly and one indirectly. Kevorkian’s first eight victim-patients were women (when he got a lot of grief that he was just killing women, he started with men). Dr. Timothy Quill’s patient was Diane, and we have Karen Quinlan and Nancy Cruzan. Virtually all of these cases involve men making decisions about how women will die. There’s a heavy-duty feminist analysis we could do with this whole assisted death movement too, but for today let’s just note that the most famous physician in the world is Jack Kevorkian, a man who made his reputation helping to kill women.

In the past the distinction of being the world’s most famous physician has gone to doctors like Christian Barnard, who performed the world’s first heart transplant, and William DeVries, who implanted the world’s first artificial heart—doctors trying to keep people alive rather than make people dead. And that’s a major change, a major cultural change, in the way we look at medicine. I’m not saying we want doctors to kill us now and we wanted them to keep us alive before, but we’re much more ambivalent about the role of physicians in society today than we’ve been in the past. Maybe we really have become what the Pope has described as a “culture of death.”

The debate over the legality of physician-assisted suicide dramatically moved to a discussion of constitutional issues with the two U.S. Circuit Courts of Appeals decisions previously mentioned. In both cases, physicians and their terminally ill cancer and AIDS patients brought suit asking that the laws against assisted suicide be declared unconstitutional as applied to them. 30

The Ninth Circuit adopted the term “physician-assisted suicide” to describe “the prescription of life ending medication for

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30. In the Ninth Circuit, four physicians and three patients (one dying of AIDS, one of cancer, and another of emphysema) challenged a Washington law that prohibits aiding another to commit suicide. In the Second Circuit, three physicians and three patients (two dying of AIDS and one of cancer) challenged New York laws that prohibit aiding another to commit or to attempt suicide. None of these patients was currently suicidal, but all wanted drugs available so that they could take them at some time in the future if their suffering became unbearable. All the physicians said that they felt unable to comply with the requests of these patients because of these laws against assisted suicide (there are no laws against suicide).
use by terminally ill, competent adult patients who wish to hasten their deaths," but was not happy with it, saying "we have serious doubts that the terms 'suicide' and 'assisted suicide' are appropriate legal descriptions of the specified conduct at issue here." Instead of ruling simply that the assisted suicide laws do not apply to such prescriptions, however, the court reconceptualized previous U.S. Supreme Court decisions to find a new constitutional right in the due process clause of the 14th Amendment, the right "to determine the time and manner of one's death." To do this it made the common mistake of adopting the abortion analogy, and quoted *Casey*: "These matters, [contraception, procreation, marriage, and child rearing] involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment."31 Again referring to *Casey*, the court concluded that "like the decision of whether or not to have an abortion, the decision how and when to die is one of 'the most intimate and personal choices a person may make in a lifetime,' a choice 'central to personal dignity and autonomy.'"

The other major case the Ninth Circuit relied on is *Cruzan*, which as we have seen upholds a liberty interest in "refusing unwanted medical treatment," but which the court reconceptualized as having "necessarily recognize[d] a liberty interest in hastening one's own death." Most centrally, the Ninth Circuit refused to distinguish the right to refuse treatment from the right to demand assistance in suicide. It did this because the Ninth Circuit believed in *Cruzan* (where the U.S. Supreme Court refused to permit a feeding tube to be removed from Nancy Cruzan) that the Court nonetheless sanctioned "suicide by starvation." It thus uncritically adopted the political "right to die" slogan as a statement of law. The Ninth Circuit also rejected the principle of the double effect, alleging that physicians who remove feeding tubes and respirators always do so with the explicit and single intent that the patient die—and not to honor the patient's right to refuse treatment.32

32. The language in the 1992 *Casey* opinion is broad, but it is much narrower than the 1973 *Roe v. Wade* decision, since it reduces the abortion decision from a fundamental right to a protected liberty interest. Moreover, "These matters," which the operative quote from *Casey* refer to all relate to marriage, procreation, contraception, family relationships, child rearing and education—not suicide. The Court refused to expand these rights even to encompass consensual sodomy in *Bowers v. Hardwick*, 478 U.S. 186 (1986) and *Casey* itself applies only to abortion, a medical procedure that has long been recognized as *sui generis*. 
The Second Circuit summarily rejected the substantive due process analysis of the Ninth Circuit, concluding simply: "The right to assisted suicide finds no cognizable basis in the Constitution's language or design, even in the very limited cases of those competent persons who, in the final stages of terminal illness, seek the right to hasten death." But, as previously noted, the Second Circuit did find a right to a doctor's prescription based on the equal protection clause of the 14th Amendment. While this is superficially a different approach than the Ninth Circuit's, in fact the Second Circuit also had to invent a new right before it could conclude that the right was being granted unequally by the state. It did so by concluding that the right to refuse treatment is actually the same as the right to "hasten death;" and that there is no distinction between a terminally ill person on life-support equipment and one who is not. Neither conclusion is tenable, but the court accepted both almost without analysis. As to the first, the Second Circuit concluded that New York treats similarly situated people unequally because its law permits individuals "in the final stages of terminal illness who are on life support systems . . . to hasten their deaths by directing the removal of such systems," but those not so attached cannot hasten their death "by self-administering prescription drugs."

The primary cases the Second Circuit cited for this proposition are Cruzan and In re Eichner, even though neither patient in these two persistent vegetative states cases was terminally ill, and neither had expressed any desire to commit suicide. Indeed, it is likely that Brother Fox, a Catholic brother (whose confessor was Fr. Eichner), would have been horrified at the notion that his refusal of a ventilator was suicide. As Cruzan makes clear, the right at stake is the right to refuse treatment (even if this results in death), not the right to commit suicide with assistance. Nor is there any requirement that a person be either

terminally ill or in pain to exercise this right. Americans have never been obligated to accept any or all manner of medical treatment to prolong life; patients have the right to decide, medical technologies do not have the right to be used. As we have seen, the right at stake is the right to be free from unwanted bodily invasions.

Even more glaring, however, was the Second Circuit's belief that removal of artificially-delivered fluids and nutrition causes "death by starvation . . . or dehydration." In the court's remarkable words: "The ending of life by these means is nothing more nor less than assisted suicide." Here the court applies the philosophical argument that all things being equal there is no moral distinction between an act or an omission to act (true in trials of therapy) to a situation where all things are not equal—especially duty, consent, and intent. Because it considered both treatment refusals and taking lethal drugs as suicide, the court believed that the state must treat them both the same.

The patients presented to these two court cases are all sympathetic, and it is not surprising that these courts wanted to help them. What is surprising is that these courts failed to explicitly acknowledge that there has never been anything illegal in prescribing pain medication that a competent terminally ill patient may use to commit suicide, as long as the physicians' intent is to foster the patient's well-being by giving the patient more control over their life, and the drug has an independent legitimate medical use. Such conduct is not assisted suicide, but is simply good medical care in appropriate cases, most of which will involve cancer and AIDS. This is all that the six patients in these two cases wanted, and what Dr. Timothy Quill, the lead plaintiff in the Second Circuit case, has already openly done and had legally and medically approved in New York. Specifically, he prescribed lethal drugs to his terminally-ill cancer patient, Diane, who later used them to commit suicide. Neither court could point to even one case of a physician ever being prosecuted for the conduct they approve of, and both courts would have been on much stronger ground by simply acknowledging that intent matters in criminal law, and that causation is a matter of public policy such that prescriptions under these circumstances are not assisted suicide by definition. It is no more assisted suicide to take the risk that your patient might commit suicide than it is attempted homicide to risk your

34. Annas, supra note 27.
patient's life on the operating table.

Related to this, it is impossible to accept either court's logic regarding the cause of death from treatment refusals. If one accepts that Nancy Cruzan "died of starvation" and not of her condition that made continued artificial feeding necessary for her survival, one would also have to accept the conclusion that when physicians stop cardiopulmonary resuscitation ("CPR") on a patient in cardiac arrest, the patient dies not from the arrest, but rather the physician kills the patient by intentionally stopping the heart beat. Since failure to perform CPR always "hastens death," under each court's analysis, patients who refuse CPR would always be committing suicide (and doctors who write DNR orders would always be assisting this suicide). The failure to distinguish real causes of death from the existence of various medical tools and techniques that may temporarily substitute for particular bodily functions is a fatal one to the logic of both these opinions. Since the vast majority of deaths in hospitals occur after some medical intervention is refused or deemed useless, under the court's logic there is an epidemic of suicide and homicide in the nation's hospitals—a patently absurd conclusion.

36. Almost the only good news I see on the horizon is that Americans don't actually want everything at the end of life. They do want experimental drugs, artificial hearts, whatever's available. But one thing so far they haven't demanded is to be cryogenically preserved—have their bodies preserved and hope that some day in the future, aliens from outer space, or even some scientists in the United States, can figure out how to thaw them out and let them live again.

One of the more interesting cases, even though it's always been talked about as just being a bizarre case, is a case in California of a gentleman who was dying of a brain tumor—a fast-growing astrocytoma. He had done a lot of research on his brain tumor and did research on cryogenic preservation, and he had four or five weeks to live. And here's what he said to the judge: "Look, judge, I'm dying, no question about it, and I'm going to be dead in a month, no question about that either. I want my brain cryogenically preserved because I think someday they're going to be able to figure out how to treat my tumor. Nobody knows the answer to that, it's speculative, but I'm not so dumb as the rest of these people who go to Alcor and have their brain frozen after they're dead, I know there's no resurrection. Once your brain is dead, you're dead. I want my brain frozen before I die while I'm still alive. Then I'll at least have a chance to live in the future." What's wrong with that? Assume the guy is competent, he studied this, he knows every treatment known to man, and he is definitely going to die of this brain tumor and now he's asking you for his final request. Usually people's final request is either to take them off the ventilator or give them an experimental treatment. His final request was let someone freeze his brain so he could be brought back to life when a cure was discovered. I think this is just another way to talk about homicide, that this is just killing him and freezing his brain. Nonetheless, this should certainly be permissible under the assisted suicide decisions of the Ninth and Second Circuits. See Donaldson v. Lungren, 4 Cal. Rptr. 2d 59 (Cal. Ct. App. 1992).
CONCLUSION

By ignoring two decades of post-Quinlan jurisprudence (state supreme court cases that explicitly hold that treatment refusals are neither suicide nor homicide), failing to make such basic distinctions as those between the right to refuse treatment and the "right to die" slogan, between abortion and suicide, between suicide and assisted suicide, and between discrimination and good medical care, these courts virtually guarantee that their decisions will not be the last word on the subject. Since states have a compelling interest in protecting all citizens, especially terminally ill and vulnerable citizens, it seems likely that the U.S. Supreme Court will ultimately uphold state laws that criminalize assisted suicide. The Court is also likely to permit states to decriminalize physician-assisted suicide if they so wish.

There are real problems with how patients die in America under a physician's care. The SUPPORT study, for example, found that the families of 50% of their sample of patients who died in the hospital believed that the patients "experienced moderate or severe pain at least half the time during their last 3 days of life."\(^3\)

The marvel is not that a small group of patients ask for physician-prescribed medications to end their lives—it is that more don't make this request. Physician prescriptions for lethal medication should remain a limited legal option as it has always been under the admittedly over-romanticized "Quill model;" but we should all work hard to make actual use of these drugs by patients a last resort rather than a first resort. This will require universal health care coverage, including hospice care, adequate pain control, and psychological support at the end of life. It is one of the great paradoxes of contemporary America that we have spent more time on the right to refuse treatment than the right to obtain treatment in the past two decades, and that we currently would rather give patients the "right to die" than medical care to help them live.

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