S. Hrg. 101-1168

LIVING WILLS

HEARING

BEFORE THE

SUBCOMMITTEE ON MEDICARE AND LONG-TERM CARE

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

ON

S. 1766

JULY 20, 1990

Printed for the use of the Committee on Finance

U.S. GOVERNMENT PRINTING OFFICE
37-339 WASHINGTON : 1991

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

COMMITTEE ON FINANCE

LLOYD BENTSEN, Texas, *Chairman*

DANIEL PATRICK MOYNIHAN, New York
MAX BAUCUS, Montana
DAVID L. BOREN, Oklahoma
BILL BRADLEY, New Jersey
GEORGE J. MITCHELL, Maine
DAVID PRYOR, Arkansas
DONALD W. RIEGLE, JR., Michigan
JOHN D. ROCKEFELLER IV, West Virginia
TOM DASCHLE, South Dakota
JOHN BREAUX, Louisiana

BOB PACKWOOD, Oregon
BOB DOLE, Kansas
WILLIAM V. ROTH, JR., Delaware
JOHN C. DANFORTH, Missouri
JOHN H. CHAFEE, Rhode Island
JOHN HEINZ, Pennsylvania
DAVE DURENBERGER, Minnesota
WILLIAM L. ARMSTRONG, Colorado
STEVE SYMMS, Idaho

VANDA B. MCMURTRY, *Staff Director and Chief Counsel*
EDMUND J. MIHALSKI, *Minority Chief of Staff*

SUBCOMMITTEE ON MEDICARE AND LONG-TERM CARE

JOHN D. ROCKEFELLER IV, West Virginia, *Chairman*

LLOYD BENTSEN, Texas
MAX BAUCUS, Montana
GEORGE J. MITCHELL, Maine
DAVID PRYOR, Arkansas
TOM DASCHLE, South Dakota

DAVE DURENBERGER, Minnesota
BOB DOLE, Kansas
BOB PACKWOOD, Oregon
JOHN HEINZ, Pennsylvania
JOHN H. CHAFEE, Rhode Island
JOHN C. DANFORTH, Missouri

CONTENTS

OPENING STATEMENTS

COMMITTEE PRESS RELEASE

ADMINISTRATION WITNESS

CONGRESSIONAL WITNESSES

PUBLIC WITNESSES

ALPHABETICAL LISTING AND APPENDIX MATERIAL SUBMITTED

COMMUNICATIONS

LIVING WILLS

FRIDAY, JULY 20, 1990

U.S. SENATE,
SUBCOMMITTEE ON MEDICARE AND LONG-TERM CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 9:33 a.m., in room SD-215, Dirksen Senate Office Building, Hon. John D. Rockefeller IV (chairman of the subcommittee) presiding.

Also present: Senators Daschle, Danforth, and Durenberger.

[The press release announcing the hearing follows:]

[Press Release No. H-43, July 12, 1990]

MEDICARE SUBCOMMITTEE TO HOLD HEARING ON PATIENT SELF-DETERMINATION ACT, INDIVIDUAL AND FAMILY DECISIONS ON MEDICAL TREATMENT TO BE DISCUSSED

WASHINGTON, DC.—Senator John D. Rockefeller IV (D., West Virginia), Chairman, announced Thursday that the Subcommittee on Medicare and Long-Term Care will hold a hearing on the Patient Self-Determination Act.

The hearing is scheduled for *Friday, July 20, 1990 at 9:30 a.m.* in Room SD-215 of the Dirksen Senate Office Building.

The bill, S. 1766, sponsored by Senator John C. Danforth (R., Missouri), would require Medicare and Medicaid providers to make available to their patients information about living wills and other advance directives. It would also require providers to ask their patients whether they have executed living wills.

Rockefeller said, "The recent Supreme Court decision on the Nancy Cruzan case highlights the need to take a closer look at how individuals and families make decisions concerning medical treatment. It's been estimated that over 1 million people in the United States are being sustained by life-saving technology."

"Making decisions about one's own health care is a very private and emotional decision. I am looking forward to this hearing which will probe whether or not certain measures would improve the ability of individuals to make informed choices about medical care," Rockefeller said.

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM WEST VIRGINIA, CHAIRMAN OF THE SUBCOMMITTEE

Senator ROCKEFELLER. This hearing will come to order. I hope and believe that we are beginning an important hearing. I am particularly grateful to the witnesses for being here, some of whom will have painful things to say. I think all of us will learn a great deal this morning and we ought to. This is the first time, I believe, that this committee has ever held a hearing about this subject insofar as I am aware. Which is in and of itself interesting, that something which is now so much on the minds of an increasing number of individuals has been so long ignored in terms of public policy.

Every day millions of Americans make decisions and choices about their personal health care. Sometimes they make those decisions in concert with doctors or with other providers of health care or family members. But for the most part, people make health care decisions personally. They make them without a great deal of fanfare and sometimes without a great deal of thought.

Most of us, I would guess, spend very little time thinking about, or discussing with those close to us, what we would want or what we would personally choose in the way of health care in the event of circumstances we would prefer to not think about. This is, in the event we were determined to be permanently unconscious and to have a very dim, or nonexistent, hope of recovery.

High tech health care, I think, has contributed to this. It has contributed to many things in a positive way, perhaps most things in a positive way. Certainly, it has improved the quality of health care for Americans. Procedures that extend lives that were considered absolutely unthinkable 10 years ago, 15 years ago, much less a generation ago, are today routine.

It has been argued by some that a side effect of some of the truly incredible medical advances that have been made is a situation where some individuals are in fact kept alive beyond a point, past a point that they themselves would want to be kept alive. But because of the small numbers of individuals who have chosen to make their wishes known beforehand, many families, friends, and health care professionals are left in a state of limbo trying to figure out what choices that person would make.

Only 9 percent of Americans, of adults, have living wills. My wife and I do; but most don't—91 percent of Americans, adults, do not have living wills. And far fewer than that have designated somebody, in the event that they don't have living wills, to make decisions about health care for them in case of incompetency. In spite of the fact that almost all States have enacted legislation setting up guidelines on advance directives, we still have this dilemma.

West Virginia, my State, enacted a law just this past March that established a durable power of attorney for health care decisions. It may be that it is generally assumed by most people that if they were in such a situation that a family member or a doctor would make the right decision and they would be allowed to carry out a decision on treatment choices in case of incompetency or inability to make decisions. I would assume that. It is a natural, human decision.

But it does not necessarily work out that way. It is a false assumption. And the recent Supreme Court decision, of course, involving *Nancy Cruzan,* appears to suggest that it is in fact crucial for citizens to make their choices clearly known beforehand.

Senator Danforth, who is on my left, in his bill, Senate Bill 1766, the Patient Self-Determination Act, has proposed one way of improving public awareness and educating health care providers about advance directives in the hope that more families will be able to deal with this very difficult situation. And, in fact, I, myself, am very grateful to Senator Danforth for suggesting this hearing and for his thoughtful work in this area.

He is joined in his bill by Senator Moynihan and Senator Pryor, both of whom sit on this committee. The cost of this bill in financial terms is extremely minimal, simply printing and distribution, and a bit of education; but the impact is potentially enormous.

A final word. One thing this hearing is not about is about the matter of when or if we "pull the plug." This is not that hearing. That hearing may come. But this is not that hearing.

Today's hearing is about figuring out how to best educate the public on current State laws regarding advance directives. This will not make any family decisions easier or the circumstances less painful, but it may provide some comfort to families to know that they are carrying out a decision—whether it is to do everything possible medically or to remove life supporting technology, that was made personally by the individual affected and reflects that person's own values and desires.

So I think this is an important hearing. We have some courageous witnesses. I want to call on Senator Danforth, whose hearing this really is, and for those of you who do not know, is not only a lawyer very knowledgeable about health care, but he is also an ordained minister and brings an extraordinary depth of view to this.

Senator Danforth.

OPENING STATEMENT OF HON. JOHN C. DANFORTH, A U.S. SENATOR FROM MISSOURI

Senator DANFORTH. Mr. Chairman, thank you very much for chairing this hearing and for your generous remarks. In the year that you and I were born—we being the same age—37½ percent of the people who died in this country died in hospitals. Most of the rest died at home. Today, about twice that percentage, around 75 percent of the people who die in America die in hospitals.

Often times the last days and weeks and months of peoples' lives are spent hooked up to machines under circumstances where the individuals can no longer think, can no longer express themselves, can no longer communicate. With modern technology it is possible to keep people alive, literally for years, under that set of circumstances.

I think in the *Cruzan* case it was believed that it was possible to keep Nancy Cruzan alive for maybe 30 years in a persistent vegetative state. All of us have the legal right to determine how much medical care we want or do not want for ourselves. If a physician or if a hospital recommended to us a certain type of medical procedure you and I have the right to say, "no, we do not want that," for ourselves.

The Supreme Court in the *Cruzan* case indicated that that was a Constitutional right. At the very least it is a common law battery to invade the body of another person against that person's will. The problem is that with so many people spending their last months and years in hospitals, those people lose the ability to communicate what their will is. That was the problem in the *Cruzan* case. Nancy Cruzan could no longer speak for herself.

What this issue is is about people's ability in advance to express their own wishes for the amount of health care they want, so that at the time that they can no longer speak for themselves, they will already have spoken in a way that is effective.

As you have pointed out, Mr. Chairman, most States do have provisions for living wills and/or for so-called durable powers of attorney. But the fact is that most people do not know anything about those laws, or about the availability of such documents. In one survey of physicians in Colorado it was found that 74 percent of the physicians in Colorado had no knowledge about the living will law of that State. And while 95 percent of the people in this country have indicated that they would like to make an advance directive about the future of their health care, as you have pointed out, Mr. Chairman, only 9 percent have actually done so. Only 4 percent of the hospitals in this country, according to one survey, ask people when they are admitted whether they have an advance directive or not.

This is a communications problem. It is not really a legal problem, although I am sure all States might benefit from looking at the laws they now have on the books and maybe clarifying them. But basically, it is a communications problem. It is one of letting people know that yes you can now take steps to assure that the worst nightmare of your lives does not eventually come to pass. And it is a nightmare.

I think that if many people were shown video tapes 10 years before of how they are going to spend the last months of their lives, they would have said, "Please, do not let this happen to me." Well in many cases it does not have to happen. But in order to execute a right it is important to know what that right is.

That is all this legislation does. It provides in substance that when people are admitted to the hospital they are told about the possibility of advance directives. And if they want to execute one or if they have executed one already, a record is made of that and their wishes are going to be implemented. That is all it does. It does not force anybody to implement it; it does not force anybody to do anything. It just says you have a legal right and we want you to know about it.

Now there are many ways I am sure of publicizing this legal right. The theory that we had, Senator Moynihan and I, is that when people are admitted to hospitals at whatever age, not just Medicare or Medicaid patients, but all patients at hospitals and other institutions that are a part of those systems; that is just a Government hook into the hospitals. But when people are admitted—say you are 21 years old for a tonsillectomy—they are asked as a routine matter, as 4 percent of the hospitals now do, "Do you know about advance directives and would you like to have one?" Very simple.

I appreciate the hearing, Mr. Chairman, and I hope that this bill is enacted into law. I do believe that even in advance of it being enacted into law the very fact that this issue is brought to public attention will have the effect of publicizing the fact that most Americans today have the ability and the right to state in advance what their wishes are should at some future time they become incapacitated.

Senator ROCKEFELLER. Thank you, Senator Danforth.

Senator Durenberger is the ranking member on this Subcommittee and is somebody I greatly admire. He knows an enormous amount about health care and is extraordinarily thoughtful, philosophical really. Senator Durenberger may have some comments.

OPENING STATEMENT OF HON. DAVE DURENBERGER, A U.S. SENATOR FROM MINNESOTA

Senator **Durenberger**. Thank you, Mr. Chairman. I do and I thank you for those very generous comments. I commend you for calling this hearing. If there is an issue that will attest how deep any of us think, this has got to be it. I compliment Jack Danforth and Pat Moynihan for continuing to deal with it enough, to the point where we have had this hearing.

The advance of technology always raises difficult issues. Medical technology which sustains life and bodily functions gets us to the most profound of ethical issues, the issues of life and death. When we created the new agency for Health Care Policy and Research last year we, as you recall, Mr. Chairman, specifically indicated our desire to know "what works and what does not." But when is high technology appropriate and can technology work too well?

These are the issues that Jack Danforth has been asking us for several years. Medical science is at a crossroads over the issue, and one that we can no longer ignore. Some have pointed out that the population over 65 in our country will triple to 87 million people in the next 50 years. And simultaneously, our ability to keep people with chronic conditions alive longer will also increase probably faster.

With accelerating health care expenses already straining our national economic resources they say that decisions must be made about who will receive what medical treatment. In this Senator's view the financing of access to medical care should not determine what treatments are given for medical conditions and for how long. Economics is simply not the whole story.

I have served three or four very frustrating years as a member of the congressional Biomedical Ethics Board that is not getting anything done because we cannot decide on who can chair the thing. It is a very frustrating process. So while I may differ in my approach to this subject of my colleague from Missouri, it is a matter of degree and not of substance. And I must say I am as frustrated as anyone here.

As I watched the people in Oregon try to deal with something they call "values" but what we are really talking about is the ethics issue, they are doing it because we have not done it here. And they cannot do it just in Oregon or they are going to be accused of rationing the poor out of the system This is a national problem crying for a national consensus and then hopefully a national solution.

I look forward to hearing from all of the groups represented today. Personally I have many unanswered questions and some I am sure I have not even thought of. It is important that the leadership of this Nation be willing to grapple with the difficult issues that impact on all of our futures. How we balance and respond to the needs of individuals, providers of health care and society at large will be increasingly scrutinized in this and in the coming years.

My final advice to my colleagues is, with regard to this bill or anything similar to it, to do it if it is the right thing to do. Not because it appears to be the necessary thing to do. When a society like ours reaches the point that it believes it is necessary to reduce access to life-saving technology because of cost or appearance, it ought first to seek alternative means to reduce those costs before it seeks to reduce the access.

Senator ROCKEFELLER. Thank you, Senator Durenberger.

Congressman Levin has introduced not precisely the same bill, but virtually the same bill in the House of Representatives. I understand that Ways and Means is already in mark-up and that this bill may be a part of that. And, therefore, Congressman Levin comes to us not just as an expert on health care and a lot of other human issues, but is somebody who is on top of this situation.

Sander Levin, we admire you here for many reasons and we welcome your testimony.

STATEMENT OF HON. SANDER LEVIN, A U.S. REPRESENTATIVE FROM MICHIGAN

Congressman LEVIN. Thank you very much, Mr. Chairman. It is a real pleasure to be able to appear before you who are so vibrantly active in the health field and your two colleagues who are likewise. Senator Danforth, Senator Moynihan and others, have provided such real leadership in this particular area, as the three of you have in so many areas relating to health. And I am privileged to be Jack Danforth's partner on this issue.

What I would like to do is to ask that my written testimony be placed in the record.

Senator DURENBERGER. Of course.

Representative LEVIN. And instead of referring to that in any detail what I would like to do if I might for a few minutes is to relate the experiences we have had so far in subcommittee as we have considered the companion legislation.

As I see it, this bill is about empowerment, not empowerment of the State, but empowerment of the individual. Without knowledge there is no power. And what this bill in the Senate and in the House attempts to do is capacitate people in terms of periods of incapacitation by providing them knowledge, informing them, and making certain that their wishes are noted in a useful way on the record.

I think that is in some respects what the *Nancy Cruzan* case is about. If she were able to speak I, at least personally, would have no doubt what she would say to the Congress. Empower the individual. The Supreme Court has thrown the issue back to the individual and it is in my judgment critical that we make sure that the individual person in this country knows of their rights and that their rights are appropriately recorded.

That is what this bill does. It attempts to ensure that people have some control in advance over their last days if they are unable to speak during those days. It is not an easy issue. But I think Senators Danforth and Durenberger, as well as yourself, Mr. Chairman, are so correct that we have an obligation here in the Government to make sure that individuals are empowered.

So let me run through three or four issues that have been raised as we have marked this bill up in subcommittee, the House subcommittee in the House. There has been some question—I think it has dissipated—why the need. And you and Senator Danforth have addressed that. In most States there is today statutory and/or regulatory frame work, but it is not being utilized except in about 10 percent of the cases. Ten percent of the people are using their opportunity under State law.

So there is clearly a need and the need has only heightened because more and more people are in the very human predicament that we are discussing this morning. It said, well how do you inform; why not do it some other way than through the hospital or the nursing home. There is some suggestion, just send it through the mail. There is also the suggestion that will come later, perhaps we give people the information when they go for renewal of their driver's license.

It seems to me the answer is pretty obvious. It should be in a health setting. It should be in a setting that has some relevance to this matter. If every physician were able to undertake this, if we could be sure that every physician could inform the individual of their rights maybe it would be best to simply leave it to the physician. But that is unlikely to happen. We are dealing with tens of thousands of units.

And to simply require that hospitals and nursing homes and other such units provide people with information upon admission and have that recorded strikes the authors as being the relevant, effective—or at least one relevant and effective—mechanism instrumentality for carrying out the empowerment, the informing of the individual.

It has also been raised, well how is this related to the goal of assuring quality care. I think it has everything to do with that. First of all, quality includes some adherence to the wishes of the individual. I think all of us in terms of values would say that is incorporated in our definition of quality.

And also, I think, if I might say so, I think Senator Durenberger has very much touched this point. Long before I would support rationing I would support options in the exercise of them by individuals. We are far from carrying that out. So I think it has everything to do with the goal of assuring quality of care.

It has also been said, we do not like to make this a condition of participation. Let me just say that I think it is very relevant to do that. We went through the other conditions of participation that are included. Two of them relate to hospitals providing at the time of admission a patient's Bill of Rights, explaining the right to treatment, payment for services, et cetera; and there is another one which requires hospitals to post information specifying the rights of individuals to not be turned away.

In terms of protections of the poor, that has also been raised. Within the bill we have introduced in the House—and there will be I understand similar protections in the Senate bill—there is a clear statement relating to these protections and not conditioning the provision of care on an advance directive.

Public opinion is very clear on this. A recent poll in Michigan, which is struggling with whether there should be a law on advance directives—and this is the last point I want to make—people were asked, "Do you think people in Michigan should be allowed to decide in advance what means will or will not be used to keep them alive if they fall into a coma from which they have no hope of recovering?" The answer is "yes"—94 percent.

When it comes to matters of life and death I think we should proceed cautiously. This is a cautious step. We have been very much assisted by the interest in the advice and the help of groups, private sector groups that cut across the spectrum, economically, religiously, culturally and every other way. And I am hoping through this hearing, Mr. Chairman, that you will be able to spotlight attention on this need and your and ours, in the House, responsibility to respond reasonably, rationally, and cautiously to this very human need.

Thank you so much for the opportunity to testify.

Senator ROCKEFELLER. Thank you, Congressman Levin.

[The prepared statement of Congressman Levin appears in the appendix.]

Senator ROCKEFELLER. Just one quick question from me. During your markup, one of the Congressmen expressed what you referred to a bit, and that is that this could work to the disadvantage of the poor because maybe they could be more easily, let's say, badgered or pushed into making decisions that may not be in their own best interest.

But it is true, is it not, that this bill allows for the poor, as well as anybody else, to say, "Yes, I want all life saving heroics possible. I want the full treatment." That people do not have to say, "I want the plug pulled." They can also say exactly the opposite, can they not?

Congressman LEVIN. Absolutely. Indeed, they are informed of their rights regarding advance directives. And if they do not wish to exercise their right there is nothing further and there is nothing to record. And in the House bill there is this specific provision not to condition the provision of care otherwise discriminating against an individual based on whether or not the individual has executed an advance directive and we are inserting some penalty provisions if there is any violation of it. And in the Senate bill there is language that prohibits coercion of any kind.

I think as our two committees work on this we can come up with additional language to make sure under no circumstances would there be coercion. This is the opposite of coercion. This is empowerment that we are after.

Senator ROCKEFELLER. Senator Danforth?

Senator DANFORTH. I think it is important to point out that the bill provides for telling people of their rights to execute an advance directive. The bill does not say what the advance directive should provide. People could theoretically executive an advance directive which says, "Do everything you can to keep me breathing for as long as you can possibly do it." People could do that.

That would be one form of advance directive. My guess is that very few people want to have their families and themselves put through that. Most people want to be able to say, look there comes a time when I am no longer me and I do not want to be kept alive artificially by machines when I am no longer myself. I think that is what most people would say. But we are not forcing people to say that.

In fact, if somebody wants to just "hang on" they could do that.

Congressman LEVIN. Absolutely. That was pointed out at a meeting. In some instances this advance directive will be a protection of an individual against an institution of disobeying their wishes to have their life prolonged under any circumstances.

Senator DANFORTH. Right.

Congressman LEVIN. You are motivated, as I am, because this is really a bill about freedom and individual choice, not about coercion. It is the opposite.

Senator DANFORTH. Sure. I mean why should institutions people have never known before, may have never even set foot in them before, people they have never seen, make decisions contrary to what they would have made had they been able to decide for themselves, and contrary to what their families want, and what their families believe they would have wanted.

Why should some impersonal institution—if 95 percent of this country die—or 75 percent, rather, of the people in this country die in hospitals, why should some hospital official or some group of lawyers never seen before by the individual be making these choices? And as you pointed out, it is empowerment. It is simply saying, this is your decision, nobody else's. It should not be anybody else's; it should be yours.

I want to thank you for what you have done, Congressman; and for the progress you are making. I hope we can catch up with what the House has been doing here in the Senate.

Congressman LEVIN. Thank you.

Senator ROCKEFELLER. Senator Durenberger?

Senator DURENBERGER. Mr. Chairman, I have never missed an opportunity to say that I came to the Senate with Carl Levin and I really enjoyed working with Carl. But the opportunity is to say what a treat it is to see Senator Levin at work. He has been over here on a number of occasions and on a number of committees and we have been on conferences together.

I admire you greatly. And on this issue, like all the issues you tackle, you always take the tough ways. This is my way of thanking you for taking the time to be involved in this issue and to come here today.

Congressman LEVIN. Thank you for your kind words.

Senator ROCKEFELLER. So there.

Congressman LEVIN. I think I had better leave.

Senator ROCKEFELLER. Thank you, Congressman, very much.

Congressman LEVIN. Good luck. You have been pioneering and I hope that your call will be heard.

Thank you.

Senator ROCKEFELLER. Our next witness—and incidentally, I will impose the 5-minute rule only on the fourth and fifth panels. In other words, for our next witness and then the two witnesses following that there will be no 5-minute rule; and then after that, there will be.

Gail Wilensky has the most difficult job in Washington. She does it extremely well. She is determined to rationalize and make sense of a whole serious of difficulties that confront not just providers but consumers of health care. Now she is dealing with a tough problem.

I look forward to your testimony, Dr. Wilensky.

STATEMENT OF HON. GAIL R. WILENSKY, PH.D., ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. WILENSKY. Thank you.

Mr. Chairman and members of the subcommittee, I am pleased to be here today to discuss advance directives such as "living wills," and their role in making personal health care decisions. As we move into the 1990's medical science and technology are performing life saving and sustaining treatments that were unthinkable a few decades ago. The growing use of sophisticated medical services increases the likelihood that individuals will have to make difficult decisions about whether to prolong care.

Providers of health care recognize that these decisions may place them in a troubling position from an ethical and legal standpoint. In this health care environment, living wills and other advance directives assume an even greater importance.

I commend Senator Danforth and the subcommittee for raising this complex issue for discussion. The Senate bill, the Patient Self-Determination Act of 1989, represents an ambitious effort to highlight the importance of advance directives, and to inform and educate the public about such directives. We share these goals.

I follow a guiding principal—the more knowledge people have about their health care options, the better able they will be able to make informed choices. I believe in the phrase that Sander Levin used, "empowering the individual." Your goal of educating health care consumers about living wills is entirely consistent with this principal.Even so, we need to ask questions. How can we best advance your goal of informing the public? And, what role should the Federal Government play in promoting public awareness of living wills?

S. 1766 would rely on the Medicare conditions of participation for health care providers to achieve these goals. We are concerned that this would manipulate the conditions to a purpose significantly removed from their primary objective—ensuring that quality care is rendered in a safe environment.

The bill would accomplish its goals by imposing additional Federal regulation and oversight of Medicare and Medicaid providers of health care. Specifically, to enforce the bill's requirements, we would have to publish regulations amending the conditions of participation. This new condition would describe the procedures and documentation necessary to ensure that facilities are in compliance with the requirements relating to advance directives.

We take our responsibility to enforce the conditions of participation very seriously. We cannot and do not take a casual approach to enforcing Federal requirements, especially when they are specifically mandated in law. Providers that fail to comply with living will standards will be required to take corrective action.

In fact, the nursing home reform legislation requires that there must be a remedy for every deficiency. The remedies include corrective action plans, fines, civil monetary penalties and bans on admissions. Failure to accomplish necessary corrections would ultimately subject a provider to termination of Medicare and Medicaid payments.

Under this scenario, the Medicare and Medicaid conditions of participation would be used to regulate an activity which does not directly relate to the conditions' immediate goal of assuring quality care. We believe this is a risky precedent and would encourage further use of Medicare conditions of participation to accomplish other unrelated activities.

Let's be clear about this. If the Congress believes that society will be better served by knowing about living wills, then let's find a way to provide that information directly. We should not obscure the issue by including it in a regulatory process that deliberately stays at arm's length from medical decisionmaking.

Our most important concern is for patients. We are concerned that the bill does not provide adequate safeguards for poor and vulnerable patients. Providers should not be given incentives to limit possible financial losses by pressuring indigent patients into making hasty decisions about living wills or by implementing these wills, too quickly.

A sick person may be unable to properly consider information about living wills while in a hospital or other facility. A discussion of living wills at a time when medical treatment is being sought may only serve to confuse patients or to create additional anxiety. Indeed, a patient could believe that his care might be compromised unless he gives specific treatment instructions.

Frankly, any decision about living wills should be made well before an individual enters a hospital. The bill's requirement places an unnecessary burden not only on the patient, but, we believe, also on the health facility that is required to provide this information.

We are concerned that the bill would require States to enact legislation regarding living wills as a condition of Medicaid funding as well. If a State does not comply, financial assistance critical to the medical care of the poor could be jeopardized.

The public information campaign required by the bill also presents some problems for us. It is true that a general informational campaign could increase the public's awareness of the value of living wills. However, such a campaign could not be fully effective without describing the varying legal requirements in each State. But I do not think the States would want the Secretary to interpret their laws. And because of the diversity of State laws, the Secretary could not assure that an accurate and consistent message about living wills would be delivered from State to State. States are better equipped than the Federal Government to effectively inform citizens about advance directives. Improved public awareness about living wills could be better accomplished without linking it to an intrusive, cumbersome Federal requirement.

The Government funds other educational programs that are not tied to a regulatory enforcement scheme. Why should education about living wills be singled out as a compliance issue? Instead, we need to develop a coordinated package of activities that will effectively inform the public about living wills, outside of a forced or coercive atmosphere.

For example, we could consider establishing a national 800 number where people could get answers to general questions and be directed to more specific State information. States could provide information at various points of contact with their citizens, such as when people apply for a drivers' licenses, similar to what is being done for the organ donor program.

In fact, States that want to elevate the importance of living wills could mandate that providers conduct information and educational activities as a requirement for State licensure, since this is where licensure occurs. We could also work with professional groups like the American Hospital Association and the American Medical Association to encourage voluntary efforts by hospitals and physicians. Informational material could be made available in waiting rooms. Physicians could participate in continuing medical education seminars to encourage informed discussions of advance directions with their patients. Community and advocacy groups can be enlisted to agree to work on living wills as well. These groups, along with trade unions, and senior citizens groups, publish regular newsletters which can target specific information to their members.

I intend to see that HCFA does its part as well. The next update of the "Medicare Handbook" will contain information about advance directives. I will also see that our new beneficiary education campaign addresses this important issue directly.

Further, we will consider other informational tactics such as using the check stuffer, which we often include in Social Security checks to provide important information to our beneficiaries. We can also work with other Federal agencies, such as the Administration on Aging and the Department of Veterans Affairs, to tap into their routine lines of communication with the people that they serve.

The options are practically endless. It will take a mutual commitment to develop an informational strategy that works, and HCFA will contribute its share to this effort. I want to reiterate my strong support for making the public more aware of the importance of advance directives.

However, given the sensitivity of the life and death decisions made through advance directives, actions by the Federal Government regarding their use should be carefully and cautiously considered. Any Federal requirement to advise and inform should not result in a tension or pressure that is inappropriate in personal treatment decisions. We can, however, work together to fashion cooperative programs that educate the public about living wills.

I thank you for the opportunity to discuss this important issue and would be happy to answer any questions you may have.

Senator ROCKEFELLER. Thank you, Dr. Wilensky.

[The prepared statement of Dr. Wilensky appears in the appendix.]

Senator ROCKEFELLER. I get a kind of a mixed message from your testimony. Because on the one hand it seems to me you are saying you want to help—talking about an 800 number and the "Medicare Handbook"—and on the other hand you are saying in a sense this should not be a Federal regulatory matter. And I understand your sensitivity about this because I leaned over to Senator Danforth and I said one of the admirable things that you are trying to do is to cut down on burdensome regulations. That is one of the things I think you have as objective in your Department. But on the other hand, I am not sure if this isn't a different kind of a situation.

You have an objection to tying Medicare to the enforcement of distribution or the disposition of advance directives. On the other hand, I believe that under current law hospitals, at least, must ask members of families if they are willing to donate organs of somebody who has just died and that this is, in fact, tied to participating in the Medicare program.

Dr. WILENSKY. No, that is not correct.

Senator ROCKEFELLER. I am incorrect about that? What is the situation on that?

Dr. WILENSKY. Okay. Let me back up and answer the first part about the confusion. I understand how that confusion could exist. I would like to clarify it.

I feel very strongly about the general objective that you are trying to undertake to inform individuals, to make information available, and to allow them to make their choices. I would like to make that as clear as I can. I have two different levels of objections to this particular strategy. One is an area in which I am generally sensitive to, and that is because it is such a forceful mechanism. There is an interest and tendency that I have heard during my brief tenure at HCFA, on probably a dozen occasions already, to tie things to Medicare conditions of participation.

We take a jaundiced view—I guess is the best way to put it—to doing that, unless we believe that the condition is directly and immediately related to the quality of health care that is provided, and to providing a safe environment in which health care is delivered. And anything which is somewhat extraneous, not unrelated to quality issues, but somewhat extraneous, on principle, we object to. We take the conditions of participation very seriously and enforce them very seriously. Violations can result in termination notices. Serious corrective plans of action need to occur. This is not something that we take lightly.

So, our concern is that we are taking something that we have an interest in, an interest in promoting knowledge about, but, which we believe is not directly and immediately related to the quality of health care provided, nor to the provision of a safe, physical environment and tying it to a directive.

Again, the example that you use with regard to organ donation is not a condition of participation. There was one which Congressman Levin did reference about patient's rights. I am also advised that the particular condition it is very difficult to enforce. That is, to ensure that patients are informed of their rights tends to be more of a paperwork process.

So, the living will provision is one requirement which, in fact, we believe would be very difficult to enforce requirement and we object, on general grounds about tying something to a condition of participation which we believe is not directly related to either quality or safety for the patient.

Senator ROCKEFELLER. Okay. It is possible that the American Hospital Association may not agree with your statement that they do not have to do this. Since they will be testifying later we will find out.

Dr. Wilensky, I guess what I am sitting up here trying to think is that you are raising——

Dr. **Wilensky.** We believe hospitals may already do this. Again, we are not objecting to hospitals doing this. We would like to work with the American Hospital Association, have information available, encourage hospitals, encourage physicians who we think are in an even better position than the hospital, which by its very nature is a highly stressful place to be, to discuss this information, to make it widely available, but not to force the provision of information as a condition of participation in Medicare.

We believe that there is a very indirect relationship between the general provision of information about advance directives and whether or not a hospital ought to be allowed to participate in Medicare.

Senator **Rockefeller.** I understand your answer.

I guess what is confusing to me is that as I was listening to your testimony I was waiting for you to say, "Of course we will participate in this." I somehow expected that. I had read your testimony. I knew it was not coming, but then I figured, well, no but she will—it will have changed by the morning. [Laughter.]

Senator **Rockefeller.** I am serious about that. As I indicated at the beginning, this is the first hearing we have had on something of this sort. The issue has gained considerable public attention. Social workers, providers, hospitals, nursing homes, all kinds of people provide care to the elderly and therefore who deal with Medicare and Medicaid. This is part of your bailiwick.

I guess I am confused because it seemed to me that you would, other than whatever the cost is of a toll-free number, which you have suggested, or the "Medicare Handbook," that you would sort of welcome a chance to do this because it is a——

Dr. **Wilensky.** I said we are going to do this with the "Medicare Handbook."

Senator **Rockefeller.** Well in that people are not aware, what is so ethically wrong or burdensome about requiring that kind of work for participation in Medicare? I mean, why is that so offensive?

Dr. **Wilensky.** Again, it is offensive to us on at least two grounds. I know that at the moment you are particularly concerned about this particular issue. It is not uncommon to want to use the conditions of participation for what are regarded as many generally appropriate good kinds of activities, like providing smoke-free environments, or doing AIDS testing and counseling.

As a general rule, we do not wish to have Medicare conditions of participation tied to things which we believe are not directly and immediately related to the quality of care being provided and the safety of the patient. We think there are lots of ways that HCFA and other parts of the Department of Health and Human Services can do things directly to increase the information available.

The point of this is to try to have people understand they have the right to make these kinds of decisions. That is the ultimate point. That means trying to make information more readily available than it currently has been.

The problem is not so much with the legal structure. Forty-two States acknowledge living wills, somewhat lesser have durable power of attorneys. But people are frequently not aware of it. They do not know where to go for information. They do not have easily available means of information. We think there are lots of ways to try to increase the availability of information.

We are willing to explore the notion of an 800 line, not to provide information directly on living wills. Obviously, that does not make a lot of sense. This is a personal issue. There are a lot of complicated questions. But rather we should direct people who have interests, if they do not know where to go in their State. And after all, State laws do differ. It is hard to give absolutely the same information in any sort of national way to make sure that people know where to go in their States.

The notion of putting information available like they do in many areas—they do in the District of Columbia—about organ donation where people pick up forms for drivers' licenses is simply a way to say, this is an area you may wish to know about. Here is where you can find out more about it. Working with the AMA, to try to encourage physicians to place information in their waiting rooms.

Senator ROCKEFELLER. Dr. Wilensky, all of this I applaud and I understand. I guess I can best ask my question by asking for a sense of priorities. Name five or six things for which you do require hospitals, providers, others to do as a condition of participating in Medicare. It is a way of trying to draw out a sense of priorities.

Dr. WILENSKY. Adequate staffing, cleanliness, involvement in quality assurance programs, medical review, fire safety codes. They are elements that directly relate to the quality of care being provided, literally the physical quality of care being provided to the patient as well as physical safety of the hospital environment with regard to fire and other safety remedies.

They are conditions which, if not met, we terminate the right of providing health care under the Medicare program. We do so either on an immediate basis, if they are immediate threats to the health and safety of individuals, or we do on a more frequent basis with a 90-day termination notice and a resurvey to establish whether or not hospitals will come in compliance with a particular condition of participation.

These are very serious, immediate, direct relationships to quality. There are a couple of exceptions that have occurred. We are trying very hard not to have conditions of participation be a vehicle that people use to hang important, worthy, laudatory goals on that are not directly and immediately related to quality of care and physical safety of the patient.

Senator ROCKEFELLER. Senator Danforth?

Senator DANFORTH. Dr. Wilensky, thank you very much for your being here to explain the doctrine of your Agency. I think that—as I said in my opening statement—every little bit helps. Every little reference to living wills, because if 74 percent of the physicians in Colorado do not even know what the law is there is a very significant information gap.

Dr. WILENSKY. I agree.

Senator DANFORTH. I do not agree with you that providing information constitutes pressure. I think that an informed public is very, very important. And for me to say that to provide simple information and to allow people to make their own choice somehow constitutes pressure is somehow wrong. But I do believe that every little bit helps. And while I think that having an 800 number or putting a paragraph in a handbook is not going to have any significant effect, maybe a few people are going to be informed by it and I would encourage HCFA to take whatever steps you have in mind however small they might be.

With respect to the requirement on providing information on organ transplant you might like to read Section 1138 of the Social Security Act. I thank you for being here.

Dr. WILENSKY. Thank you.

Senator ROCKEFELLER. I am reading Section 1138 of the Social Security Act. It is too long so I will not comment on it. Thank you very much for being here.

Dr. WILENSKY. My response to the reference to the Section is, I have been told that that is not incorporated into the conditions of participation as a point of fact.

Thank you.

Senator ROCKEFELLER. I will followup with you privately on this matter. I thank you very much for being here, Dr. Wilensky.

Our next witnesses are Julianne M. Delio of Queens, NY, and Kitty Allen, who is co-chair of the Public Policy Committee of the Alzheimer's Association of Houston, TX.

We are very happy that you are both here. You both have powerful, painful and important matters to put before the Congress. Ms. Delio, we would start with you if that is all right.

STATEMENT OF JULIANNE M. DELIO, QUEENS, NY

Dr. DELIO. Thank you. Chairman Rockefeller, Senator Danforth, my name is Julie Delio. I am from New York. In 1986 my husband, Daniel Delio, underwent a minor operation to repair a rectal fistula. Due to an act of negligence by the anesthesiologist his brain was destroyed rendering him permanently unconscious. Danny suffered not only cortical brain death but also the misfortune of having his heart revived even though his human essence had been destroyed. He had brainstem function only. He was 33 years old His life was essentially over. He had been thrown into a persistent vegetative state.

At this point medicine was able only to offer him an existence in oblivion. He was being kept alive by artificial nutrition and hydration forced through a jejunostomy tube into his intestines. He was entirely defenseless against medical technology that forced upon him an existence which he found abominable. He had been prepared to accept a natural death.

Danny believed the death of the cortex was synonymous with the death of the person. This belief stemmed from his extensive scientific understanding of the body as well as his philosophy on life.

Danny and I had had extensive, detailed discussions about vegetative states and artificial life support measures. He had made me promise never to let him live even 1 day in such a condition. His mother and I were the only ones left to speak for him. I requested termination of all life support, including artificial nutrition and hydration, so that the death initiated by the doctors who operated on him could finally conclude.

At that time I was employed as an assistant professor of medicine at New York Medical College, which is affiliated with Westchester County Medical Center, the facility to which my husband had been transferred for treatment after the operation that destroyed his brain. Despite the fact that Westchester County doctors privately agreed with my request to terminate life support measures the hospital officially ignored my request and forced me to resort to litigation. After filing my lawsuit I was fired from my job at New York Medical College.

My termination was a clear message to Westchester County physicians. Among other fears, the MD's were afraid of losing their jobs as I had lost mine. The hospital administration was making all decisions from a risk-management point of view. The medical staff who knew and understood the medical issues and Danny's family, who knew and understood his desires, were shut out.

Taking my case to court alienated me from the medical community. No physician ever called me after I filed my lawsuit. They continued treating him aggressively without informing me and without my consent until I threatened them with criminal assault charges. Then they made me sign refusal to consent to treatment forms each time they felt he required some form of treatment. They made me feel as if I was signing a death warrant each time.

The judicial process was devastating to me and my mother-in-law. The loss of my husband was tragic enough yet then I was then forced to plead publicly to strangers for his death. You cannot imagine the psychological trauma involved in pleading for the death of the person you love most in this entire world. I could barely concentrate in court and I was so afraid.

After 13 harrowing months in the court system, the New York State Appellate Division upheld Danny's right to refuse treatment even though he was no longer able to speak for himself.

After the court ruled in our favor the hospital still refused to terminate treatment. The day after the court order came down the feeding tube fell out of him as had so often happened throughout the year. I begged them not to reinsert it, citing the Appellate Court decision on our right to refuse this treatment. A doctor promised me that the tube would not be put back in. I left the hospital late that night only to return early the next day to find that they had not only reinserted this tube into my unconscious, defenseless husband, but they also stitched it in.

I will never forget the fresh blood on his emaciated stomach. There was no record of who reinserted the tube, who gave the order and no doctor would face me to explain. The administration had ordered this to be done against my husband's wishes and against my wishes as his court-appointed conservator.

The court ordered the hospital to terminate treatment or transfer Danny to another facility that would agree to abide by his wishes. Westchester County Medical Center said they would not appeal the decision as long as we agreed to transfer him. They simply wanted to wash their hands of this whole affair. Therein humanity added enormously to our private tragedy.

Families should not be stigmatized by County or public facilities and further traumatized by forced transfer as my family was, simply for requesting their legal rights. Why should a county hospital be able to refuse a patient's legal court-sanctioned rights when my husband's physicians in that hospital were willing to comply with the court order?

After a heart wrenching search Danny was transferred to a hospital in Manhattan. Ten days later he died quietly in my arms, surrounded by his mother and uncle.

But not even death gave him release from the bureaucracy of our medical and legal communities. Two hours before his funeral I was informed that the New York City Coroner's Office refused to issue a certificate of cremation. They demanded an autopsy on Danny's body. No one could tell me why. After his funeral they took his body to the city morgue and autopsied him. Two days later I was called to identify the body.

When Danny died I had donated all of his organs according to his wishes. I was then told by the doctors that his year in a vegetative state had left all of his organs, except for his corneas, useless to the living. Artificial nutrition was not even minimally able to keep him in an acceptable state for organ donation. Ironically, the power of medicine was only to further destroy his body.

Had my husband been allowed to die a natural death when his brain was first destroyed at least five others could have lived. Had the doctors been empowered to honor his wishes without me going to court, his heart, liver, kidneys, bones and skin could have been used to give back to others the joy of life which had been taken from my husband.

Even though the court system eventually worked for us we were brutalized by it. No one should ever have to go to court under these circumstances. Court is the last place a family belongs when they are facing their darkest hours.

Danny did not have a will. He never put his wishes in writing. I did not even have power of attorney for him even though we were a well educated couple and knew these things were important. We were young and enjoying a happy life. Who would have known what was to happen to us. We were not a typical family. Both of us had Ph.D.'s, had extensive scientific training, and had worked in a medical setting for years.

That Danny and I talked to extensively about vegetative states was amazing to most people. We were able to offer clear and convincing evidence of Danny's wishes. Most people have not and will not speak of these issues in the kind of depth our courts and laws seem to be requiring of our American families.

The Cruzan family and what has happened to them is far more typical. This system utterly failed them. Their case is a more horrifying example of how most American families will continue to fare in our present system. For us it is too late, but perhaps somehow we can lessen the devastation to others in the future.

Thank you.

Senator ROCKEFELLER. Thank you, Ms. Delio, very much.

[The prepared statement of Ms. Delio appears in the appendix.]

Senator ROCKEFELLER. Ms. Allen, we would welcome hearing from you.

STATEMENT OF KITTY C. ALLEN, CO-CHAIR, PUBLIC POLICY COMMITTEE, ALZHEIMER'S ASSOCIATION, HOUSTON, TX

Ms. ALLEN. Chairman Rockefeller, Senator Danforth, and members of the committee, my name is Kitty Allen and I am from Houston, TX. I am here to speak for my mother-in-law who has Alzheimer's disease and for my family who cares for her. I am also here as co-chair of the Public Policy Committee for the Alzheimer's Association and I have submitted this statement on behalf of that organization.

I want to commend this committee, and Senator Danforth particularly, for your leadership on this issue of patient self- determination. This committee, and especially you, Chairman Rockefeller, as head of the Pepper Commission, has been at the forefront of efforts to assure that all Americans have access to health care and to long-term care services to sustain and improve the quality of life.

It is appropriate that you should also be taking on the issue of how decisions are made about medical treatment, particularly as life nears its end. And we are grateful to you for the opportunity to be here today.

The Alzheimer's Association is the national voluntary health agency organized to support families caring for loved ones with Alzheimer's disease and, through research, to find the cause, the treatment and the cure for this horrible affliction. We work through 210 chapters and over 1,600 support groups throughout the country.

Alzheimer's disease is a degenerative disease that robs a person of memory, judgment, reasoning, everything that makes that person a unique human being. It is irreversible, untreatable and always fatal. One of the cruelest ironies of the disease is that the body often remains physically healthy long after the person inside has disappeared. Death is inevitable.

But by the time the patient reaches the stage where decisions have to be made about life-sustaining treatments, he or she is no longer capable of participating in those decisions.

I have come here today to tell you about Gran, my mother-in-law. My husband, Joe, is her only son. She and Papa have been married for 55 years. He worked on the docks for Exxon for 31 years, and she was a homemaker. Ten years ago Gran was helping me take care of my babies.

Senator Rockefeller. Take your time.

Ms. Allen. Today she is lying at my house in a fetal position. When Gran was diagnosed with Alzheimer's disease in 1981, we did everything we thought we were supposed to do to help her get her affairs in order. We updated her will, but no one ever mentioned a living will. We really thought those were more for organ donation. And they certainly did not mention a durable power of attorney for health care—neither the doctor, nor the lawyer.

Two years after her diagnosis, Gran and Papa sold their house and moved in with Joe and me and the little girls. She was still walking then, but she was gradually forgetting how to do the most basic things. She required constant supervision. She was already wearing diapers and she was forgetting how to eat.

Over the course of a year or so we went from feeding her table food to junior foods to strained baby foods. By 1985 she had shrunk from a 140 pound vital woman to an 80-pound shell of herself. One Thursday afternoon she forgot how to swallow and there was no way we could get any food or water into her body. In fact, anything we put into her mouth simply drooled out.

By Saturday it was clear to me that she was becoming dehydrated. I contacted the emergency room since her physician was out of town, but they completely dismissed our concerns and they said, "Oh, honey, she'll eat when she gets ready." By Monday when her doctor returned, we finally got someone to see her. However, they refused to listen to my explanation that that part of her brain had died on Thursday that told her how to swallow. They insisted that she must have some sort of obstruction.

So over our objections they took her away from us to do what they called a barium swallow. But because Gran could not remember how to swallow, they ended up pouring the barium into her lungs and inducing pneumonia. With that they had to admit her to the hospital and the doctors told us that in order to treat the pneumonia they would first have to insert a feeding tube to rehydrate her. They led us to believe that this was a very temporary procedure, really only necessary to kind of get her back to where she was.

In any case, in the condition that she was in they had already estimated she had no more than 6 months to live. We had agreed as a family long before this incident that there would be no extraordinary efforts to save Gran when it was time for her to go. Papa, and Joe, and I knew that was what she wanted. And had the doctors explained the implications of what they were doing to Gran, that they were in fact introducing a life support system that could never be disconnected, we would never have allowed that tube to be inserted. That was all 6 years ago.

Gran has not been out of bed since the day they put in the tubes. And because of the formula that she takes she is now so heavy we have to have a hydraulic lift to move her. She's at home, and she's alive, but not living. Now I don't know how many of you have ever seen just how invasive that treatment is, and it is painful. I know because we have to keep one arm restrained to keep her from pulling the tube out.

Our lawyers have told us that there is nothing we can do to remove the tubes and to allow the natural process of dying occur. Papa, her husband, is an 87-year-old man in frail health himself, and he spends his days taking care of Gran with me and part-time nursing help. He has an advance directive. Even so, he lives in constant fear of being hooked up to a machine and constantly reminds us that this must never happen to him.

Our story is not fancy and it is not unusual. That is probably the greatest tragedy of all. Because, in fact, it is a fairly typical story of a family dealing with Alzheimer's disease and one that can be told by any number, or any thousands, of people of families across the country.

This is not a minor issue. Four million people in the United States today have Alzheimer's disease. Half of us in this room, if we live to be 85, will be stricken with this devastating illness. In every case, if some intercurrent illness does not end life sooner, the patient will reach the stage Gran is in today—unable to perform even the most basic function of daily life, certainly unable to communicate their wishes with regard to medical treatments.

This is why our association so enthusiastically supports Senator Danforth's bill.

The association has adopted guidelines for the treatment of patients with advance dementia, and these guidelines include family members as a critical part of the decisionmaking process. Copies of these guidelines have been submitted with the testimony.

The Supreme Court in the *Cruzan* decision has now held, however, that the family does not have a constitutional right to makes these decisions for a loved one. That ruling underscores all the more the importance of clear advance directives, which not only specify a person's treatment wishes but authorize another to make sure those wishes are carried out if the person is not able to decide for himself or herself.

There is no doubt in our minds that Gran did not want to be kept alive the way she is today and that she did not want the feeding tube in her present condition. But because she had never written that down and had never named a durable power of attorney for health care decisions, we cannot honor her wishes. What a God send it would have been if when Gran would have entered that facility for the early diagnosis 10 years ago someone had talked to her, to us, about her rights to execute an advance directive and to make her wishes known before it was too late.

This very legislation encourages each of us to sit down with our loved ones and our doctors and to work through these issues when we are competent and healthy. A time of crisis is not a time for carefully considered rational decisions about medical treatments. Our family has learned the hard way the consequences of not making those decisions early before tragedy strikes.

Certainly the best decisionmaking occurs when there is good and open communication among everyone involved—the doctor, the patient and the family. By making discussion of treatment issues a routine part of health care you are encouraging that communication. This bill recognizes that execution of a legal document does not end the process but that providers have an affirmative obligation to continue to review treatment plans.

The association does recommend one minor change in the bill, but a very significant change. This is to ensure that this obligation of communication continues even when the patient loses the capacity to participate in the discussion. The bill establishes a clear responsibility of the provider to the patient—to inform him or her of their rights, to inquire about the presence of an advance directive, to honor the patient's wishes with regard to treatment, and to periodically review those wishes with the patient.

We recommend that language be added to the bill to make clear that the provider has these same responsibilities to communicate with responsible family members or the patient's guardian. Without that protection the bill would have little meaning for an Alzheimer's patient once that patient loses the ability to communicate about his or her wishes with regard to further treatments.

In conclusion, let me express once again the appreciation of the Alzheimer's Association for your efforts to protect the rights of all of us to make our own decisions about medical treatment and to assure that those decisions are respected. Enactment of this bill will not do anything to change the cruel reality of Alzheimer's or to halt the inevitable progression of the disease. That will require an expanded commitment to medical research to find the answers to the disease and the development of a long-term care system that provides help for its victims.

By encouraging early and clear decision making with regard to medical treatment, however, you can at least make it possible for patients and their families to come to the end of their ordeal with some final dignity and peace.

I would be happy to answer any questions. Thank you.

[The prepared statement of Ms. Allen appears in the appendix.]

Senator ROCKEFELLER. Thank you very much, Ms. Allen, and both of you for your courageous testimony.

It is incredible isn't it that this goes on? As you indicated, 4 million Americans have Alzheimer's. As you indicated, that disease is not going to turn around unless there is a cure. So much of this is going on but it takes place in private, and it is the most private of all agonies.

Therefore, the public and others—institutions, rules and regulations, the Government, even hospitals—do not know what to do, cannot face direct action. Perhaps they are scared. I do not know what it is. Why would it be? I mean Americans are a compassionate people. When people are starving in Ethiopia we turn the world upside down to try and help. One little girl falls down a well in Texas all news stops until that little girl comes out safely. We are an extraordinary nation and very compassionate people.

Why is it, do you think, that the situations that both of you have described go on and that we are somehow unable to confront them and to help families with this situation?

Ms. DELIO. From my experience, one thing that became very clear to me early on and throughout the entire year that my husband was in a vegetative state was that the physicians they sympathized with me, they had the medical knowledge to understand what the medical reality was for my husband, they agreed with me that this was the proper thing to do, but beyond that they were afraid to speak out on their convictions. Somehow they were overwhelmed by the administration and the administration's control over the situation.

And the level of ignorance amongst hospital personnel, including the physicians—the administrators, physician's assistants, nurse's assistants, nurses—was unbelievable to me, that they had no concept of what the patients' rights were, no concept of what their rights were, and no feeling of a sense of responsibility to learn what their rights were and what my rights were.

I can remember having discussions about the AMA's recent statement at that time, in 1986, about termination of treatment for the hopelessly ill, and the neurologist involved in the case knew nothing of this statement. I found out very fast as soon as I was confronted with this problem. And here they were dealing with these kinds of situations all the time and they knew nothing about this statement and they didn't seem to care. It was like, "well I simply cannot make that decision for you," and did not want to get involved.

Also in my case they were afraid to get involved because they were afraid of losing their jobs. It is unbelievable. But again, the level of ignorance amongst all the professional staff was intolerable. I believe it is very, very important that we educate not only patients of their rights, but the personnel who are delivering the health care to the patients.

Senator ROCKEFELLER. And don't you think that informing patients of their rights, families of their rights in the hospital in that setting is perfectly acceptable?

Ms. DELIO. I think it is perfectly acceptable because—I also see it as acceptable in other areas and in other methods. But within the hospital setting I can say from my own experience, my mother-in-law has a high school education, never dealt with these issues really to the extent that we were forced to face them at this time, and it took her a number of weeks to come to grips with what the reality was.

She had never thought of these issues in the depth that Danny and I had. But it took her quite a few weeks to come to grips with the fact that this is the time to let go. This is what Danny really would have wanted. And had she never been faced with that outside of the hospital, just talking about it philosophically outside the hospital environment, I don't think she ever would have come to grips with what was going on really. I don't think she would have had a full understanding of what kind of decisions we would have to face.

I don't know if I made myself clear.

Senator ROCKEFELLER. You did.

How long after your husband's surgery did you know that he was at the point that he would not want to continue in that condition?

Ms. DELIO. Well I knew almost immediately from the first night that his brain was essentially destroyed, but it was probably about 2 weeks because the physicians kept assuring me that—well they had to put him into a barbiturate coma to stop his seizures from occurring and they told me it would take about 2 weeks for those drugs to wash out before they would know really what the state of his brain was. So it was probably about 2 weeks after the incident, which is very early for many people.

There was another woman who went through this with her husband. It took her 2 years to come to grips with the reality that her husband was not coming back—2 years in the situation before she went to court for the right for her husband to refuse artificial nutrition and hydration. That was Pat Brophy in Massachusetts.

So I think people's understanding of what the reality is comes at different times. And even if you don't have an advance directive sometimes I think it is more important for the family to understand the issues at hand during the time of an incident so that they can make decisions based upon what they believe the patients would have wanted for themselves.

Senator ROCKEFELLER. Kitty Allen, in describing the situation of Alzheimer's, Ms. Delio, and we know that 4 million people are afflicted with Alzheimer's disease—in fact, one of the interesting things about that is up until recently we thought it was 2 million people; now we learn it is 4 million people. How in America with all of our information do we suddenly have the knowledge that there are 4 million rather than 2 million people who have Alzheimer's. I am not asking that as a question, but I am just sort of struck by that as a point of lack of information, a lack of understanding.

Ms. Delio, many people after hearing your testimony would say well, I do not know somebody like that and that probably will not happen to me. Human nature is to deflect and to defer.

Ms. DELIO. Yes.

Senator ROCKEFELLER. Unless there is an intervention which says, let's face now some things which possibly could happen later, so that we will be more realistic and more empowered by that time. In fact, the situation you have described to us with respect to your husband is not as unusual as people think it is, is it? Have you talked with numbers of other families?

Ms. DELIO. I always question every time I read a summary of the kinds of numbers of people who are in a vegetative state in this country. That number 10,000 always pops up; and I always wonder where the source of that number came from. When my husband was in Westchester County there were two other patients that I knew of—one younger than him, and one much, much older than him who were vegetative at the time. And in my own neighborhood, after my own case was done, a man who lived 2 miles from me gave me a phone call after reading about my case and told me his wife was vegetative and he was at a loss for what to do. He needed help in trying to win for her her rights, which he eventually did after going through another terrible court battle.

And since then I have been contacted by a woman in Nassau County and Suffolk County, actually quite recently. Again, one woman had a daughter who has been vegetative for 12 years, and she was absolutely frantic saying, "I never knew that I could do anything about this. I knew she never wanted to live like this, but I never knew I had any rights or ability to do anything about this."

So people on a personal level have contacted me and all within my area. And it makes me wonder if there are this many people right within my own neighborhood, then I suspect that that number is an underestimate and probably a gross underestimate of what the reality is in this country, but I do not know for sure.

Senator ROCKEFELLER. But in any event, the passage of Senator Danforth's bill would really help hundreds of thousands of people, wouldn't it?

Ms. DELIO. I think so. It is critical to raise the awareness and have people start talking about these issues. Because the best of all possible worlds people will talk about these issues and make their wishes known. Unfortunately, that is not what is out there now.

What happened to the Cruzan family is just a horror when I think back on it. That is more typical of the American family today. People have a gross sense of "whew, I wouldn't want that to happen to me," but that kind of testimony is not standing up in our courts and perhaps it should. Because people do not have the language and the verbal background to describe the types of medical technology they do not want.

I think it is unfair to the American population to expect of them to have knowledge of all the medical forms of treatment there are and list them specifically. And I think it is important that families should have the right to make decisions as the situations occur once they understand and see what is going on and what is happening to their family members.

Senator ROCKEFELLER. Ms. Allen, isn't it the obligation of everyone—whether it is hospitals, social workers, private individuals, State governments, Federal Governments, health care financing agencies—isn't it really the obligation of every single person, every single institution, every single force possible to make people aware that through knowledge they can save themselves the agony that you have gone through and that government ought to be doing all it can?

Ms. ALLEN. Without question, Senator. I think in particular the institutions where a lot of these people enter the system, so to speak, for the first time, this is an excellent way to start.

The Alzheimer's Association, through our newsletters as Dr. Wilensky suggested, encourages our members to take the initiative for their loved ones while they are still competent, to execute durable powers of attorney, living wills. We cannot do it all. And this kind of legislation is a tremendous first step towards that greater education effort.

Senator ROCKEFELLER. Thank you both very much.

Senator Danforth?

Senator DANFORTH. I want to express to both of you my gratitude for your willingness to be here and to relive for us your own stories. This is, of course, very powerful testimony and it is a terrible ordeal you have gone through. I appreciate your sharing it with us.

I take it, Mrs. Allen, that your view as well as Mrs. Delio's view is that you are not alone? I mean, this is not an unusual situation that you have gone through. It is very common. You know other cases?

Ms. ALLEN. Yes, sir. Very definitely.

Senator DANFORTH. HCFA you heard testify that they are concerned about piling more and more burdens on hospitals, and the paperwork, and the regulatory burden, and so forth. I guess everything that Government does should be the consideration of not trying to overburden the American people. There is always a question of balancing the good that can be done with the burden that is imposed.

Were you impressed with the regulatory burden argument? It just seems to me that it is such a simple matter to say to somebody, you know, "Here is a brochure and here are your rights."

Ms. ALLEN. No. I personally was not impressed with her claim that it would be an unreasonable burden on the administration. Quite the contrary. As I understood from the testimony in tying it into the—what was the term—the provider, the eligibility, and their fear of a risky predecent—I think was the language that was used—and her claim that it did not have a direct impact on the quality of care. Quite the contrary. I think it has a real direct impact on the quality of care and respect for the wishes of the patient.

Senator DANFORTH. Do you have anything you would like to add?

Ms. DELIO. I would agree. When I hear someone say it does not have an impact on the quality of care that statement is utterly astounding to me when I think of what they did to my husband for over a year and how they utterly ignored his wishes. I mean that was just so traumatic to me, to know that his desires were clear and his wishes were ignored and what they called caring for him at the time that he was receiving medical treatment. To me this was an abomination and a crime against him.

If that is not quality of care, I do not know what is.

Senator DANFORTH. Well again, I want to thank both of you for being here and for your very powerful testimony.

Ms. ALLEN. Thank you.

Senator ROCKEFELLER. Senator Durenberger?

Senator DURENBERGER. Thank you. Let me also say as one who sat here for many years learning most from the lay people, the non-experts, that those were very, very special and certainly in my case influenced my own understanding greatly. I thank you both for that.

I am going to ask what will sound like a legal question but it is not. I mean you are a better part of the understanding of the problem. But if I understand the majority in the *Cruzan* case correctly, and I am just sort of bottom lining this, they said that the State is entitled to guard against potential abuses, everybody's concern in the system.

People who are concerned about potential abuses, I think, look at what we have come to know as the more readily available advance directives, like living wills, as a great potential abuse. I mean my mom has a living will. I think she did it just because she felt she ought to do it, like so many people do. And certainly what Jack Danforth is doing with this bill would make her much better informed under a certain set of circumstances than she is.

But potentially the issue of informed consent is the difficult part that we wrestle with here. And whether it is a living will situation which in effect the doctor ends up making a decision in many cases or in many States or it is some other kind of situation which you are trying as a relative to determine not what you would want to have happen if it were you, not what you would want to have happen with Grandma or your husband, as the case may be, but trying to best reflect the consent and the intent of the person involved.

Do each of you have a recommendation about how we might best deal with that issue of informed consent and the instrument or the process or something that you wish had been in place at a particular time in your particular cases?

I mean it is a burden for you to carry too. I am assuming that in one way or another your cases are very different, but the decision making burden is not an easy one to carry either and there would be some comfort in the long run, years from now, when you think back on your husband, when you think back on your Grandma.

Is there a process that you have thought about or some kind of an arrangement, if you will, that would make you comfortable?

Ms. ALLEN. In our own personal decision I think when Gran was initially diagnosed—and she was in a hospital setting for that diagnosis—I think perhaps any patient that is given a fatal, terminal diagnosis should receive some additional counseling on how best to make the kinds of decisions perhaps they will be confronted with. That would have been very helpful to us.

And again, maybe that should have been from the physician, maybe there was a social worker in the hospital. I am not really sure. But it would have been really helpful if instead of just checking out, being told you're on your own, some special information about the kinds of decisions that would ultimately confront us would have been very beneficial.

Ms. DELIO. In my husband's case, I'm not really sure. Things were so clear to me what he wanted. Perhaps if there had been a form on entry into the hospital, at the point of admission, that would allow him to state his wishes as to who should make health care decisions for him, that might have been helpful. I really don't know though about that. One thing that has become very clear to me personally is that I am a strong believer in the ability of substitute decision making because as I said before most people cannot comprehend this situation until they are truly faced with it. Most people do not think about these things and they never will. And even if they think about them, they often times do not take action on it.

I mean as you well know, it is legal to write a will. How many people, you know, write a regular will, let alone a living will? I have a fear that starting to—well, it is good to make all of this more routine, to make advance directives and living wills part of our regular health care upbringing, but at the same time I have a bit of a fear that if a person does not have an advance directive, I would hope that they would not be stripped of their rights to execute their beliefs and their right to refuse treatment under certain circumstances. And I would hope that the families would still be able to, to the best of their abilities, determine what their family member would have wanted for themselves and still have the freedom to execute what they believe would have been in the best interests of the patient.

I didn't really read the *Cruzan* decision, but I heard that one of the statements was, "Well let's err on the side of life." And I must say that I have never seen a more destructive force in life as what I saw being done to my husband and being kept alive in a persistent vegetative state. I would never describe that as "erring on the side of life." I only describe it as a force that is far more destructive of life.

Senator ROCKEFELLER. Thank you both very much. It sounds silly to say that you have made an impact and you have contributed enormously. You have. We are grateful for your courage. Thank you for coming.

Ms. ALLEN. Thank you very much.

Senator ROCKEFELLER. Our next panel is the Reverend Richard McCormick, who is professor of Christian ethics at the University of Notre Dame; and Dr. Thomas Scully, who is director of the bioethics program, school of medicine, University of Nevada. If you gentlemen would have a seat.

We will now go to the 5-minute rule.

Senator Danforth just pointed out to me that we have a vote. What I will do is to call a 10-minute recess so we can vote and come back.

[Whereupon, the hearing recessed at 11:22 a.m. and resumed at 11:36 a.m.]

Senator ROCKEFELLER. Father McCormick, you are identified to me as Mr. McCormick by the sign in front of you. I think Father would be more appropriate, would it not?

Father McCORMICK. That is right.

Senator ROCKEFELLER. We would welcome your testimony, sir.

STATEMENT OF REV. RICHARD A. McCORMICK, S.J., JOHN O'BRIEN PROFESSOR OF CHRISTIAN ETHICS, UNIVERSITY OF NOTRE DAME, SOUTH BEND, IN

Father McCORMICK. Thank you. I am Father Richard McCormick, a Jesuit priest and a professor of Christian ethics at the University of Notre Dame. I have been in the field of Christian ethics for 35 years. I speak for myself, obviously, not the Catholic Church, nor do I speak for the Catholic Health Association, though I endorse with virtual unanimity their endorsement of S. 1766.

I want to explain in detail why I endorse this. Basically, I can put it this way: I consider self-determination and knowledge about it to be directly and immediately associated with quality care—a slight difference with a previous witness. I believe that hospitals which put the patient at the center of their concern should be key actors in the dissemination of the knowledge which is so key to their patients.

One of the greatest obstacles to the exercise of the right of self-determination in this context is ignorance about the right itself and about the tools of its exercise. I can personally testify in my own work throughout the country that this ignorance is widespread. Over and over people approach me after lectures and so on to inquire about living wills, durable powers of attorney, indicating that they do not really know a great deal about it.

S. 1766 is basically aimed at this serious lack of knowledge. The reasons for the bill are listed. I want to add two more, which is my judgment make this bill all the more urgent. The first dimension of health care in our time is its increasing depersonalization. I find three factors at work in health care that are playing a formative role—technology, concern for cost containment and legal public entities. Now by that I mean the courts, the legal profession and legislation.

It is my thesis that these factors—technology, cost containment, public entities—can affect the very matrix of the healing profession. This matrix is constituted by the conviction that medical decision making best serves the interests of patients when it is located within the triad of patient/physician/family. Decisions have to be tailor-made to the needs of the individual. They are like glove fitting an individual hand. They are personal.

These other factors I have just mentioned, however, are impersonal factors and they can very easily preprogram our treatment and lead to a form of oppression of the weak and dependent by the powerful and healthy. Whatever the case, in a depersonalized atmosphere patient self-determination easily gets submerged.

The second dimension I want to call attention to that makes this bill urgent is the attitude in our society toward death. The medical profession is committed to curing disease and preserving life. We take that for granted. But this commitment must be implemented within a healthy and realistic acknowledgement that we are mortal. The point seems so obvious as to be trivial and in a sense it is. But living it out is not.

The attempt to walk a balanced middle path between medical—moral optimism which preserves life at any cost, with all means regardless of diagnosis, prognosis, family history, patient preferences and so on, and medical—moral pessimism which takes life when it becomes onerous, boring, dysfunctional and hopeless is not easy, especially in a highly litigious atmosphere.

Symptoms of this abound in our society. I submit to the record medical statements indicating a certain idolatry of human life—really human existence rather than human life.

In conclusion, let me say it has been my experience that most decisional problems touching acceptance or rejection of treatment can be traced to a lack of communication. For this reason I believe that the notion of advance directives can relieve this problem. Advance directives such as durable powers of attorney and living wills, encourage discussion and documentation of views of sustaining treatment in advance.

I believe, once again, that institutions, such as hospitals that have the patient as the center of their concern, should be key agents about the center of the patient's concern, which is self-determination.

Thank you, Mr. Chairman.

Senator ROCKEFELLER. Thank you, Father.

[The prepared statement of Father McCormick appears in the appendix.]

Senator ROCKEFELLER. Senator Bryan will introduce Dr. Scully.

STATEMENT OF HON. RICHARD H. BRYAN, A U.S. SENATOR FROM NEVADA

Senator BRYAN. Mr. Chairman, I appreciate your courtesy and I realize the constraints your committee is under. I did want to request the opportunity this morning to formally introduce to the committee a long-time friend of mine, Dr. Tom Scully. He is a distinguished scholar, a distinguished physician, who served formerly as the dean of the school of medicine at the University of Nevada, and continues to remain on the staff. He and his wife are the authors of a thought-provoking publication entitled, "Making Medical Decisions." As a medical ethicist, I think you will find that his comments are very thought provoking.

I would be remiss if I did not add that as Governor I had the opportunity to appoint him to the State Board of Medical Examiners and my own son owes his career, at least in part, to Dr. Scully's good judgment in recommending him for admission to the University of Nevada School of Medicine, from which he has graduated and now in his residency.

So I thank you very much, Mr. Chairman and members of the committee.

Dr. Tom Scully.

Senator ROCKEFELLER. Thank you, Senator Bryan.

Dr. Scully, we welcome you, sir.

STATEMENT OF THOMAS J. SCULLY, M.D., DIRECTOR, BIOETHICS PROGRAM, SCHOOL OF MEDICINE, UNIVERSITY OF NEVADA, RENO, NV

Dr. SCULLY. Mr. Chairman and members of the committee, I appreciate the opportunity to speak in support of the Patient Self-Determination Act of 1990 and thank you for the invitation. Although I am a member of several organizations endorsing and supporting this bill I speak as a private citizen. I speak as a physician who has cared for mentally incompetent and permanently unconscious patients who never made known their wishes concerning medical treatment.

As a bioethicist who has frequently consulted with families, both privately and in the context of a hospital ethics committee, concerning decisions that had to be made for loved ones who never made known their wishes concerning medical treatment; and as a teacher and a medical educator who realizes who difficult it is to persuade young and old to acknowledge their vulnerability and mortality to confront their denial of death and to write down their wishes concerning medical treatment. As an author, who with my wife, has interviewed hundreds of patients about medical decision making or more often the lack of it in their families, telling their stories, some tragic and some hopeful and some joyful, in our book, "Making Medical Decisions."

I speak as the patient who has undergone major surgery four times, including a kidney transplant. I have survived a myocardia infarction and have gratefully experienced the benefits of high tech medicine provided by a multitude of knowledgeable, skillful, caring physicians, most of whom, however, were total strangers to me, knowing little or nothing of my life's goals, my aspirations, hopes, fears or anxiety—not to mention my religious beliefs or what I would wish to have happen to me should I be unable to make medical decisions for myself.

Prior to undergoing the first of those surgeries, I executed a durable power of attorney for Health Care in order to spare my family the additional anguish and heartache attendant to making difficult decisions to withhold or withdraw medical treatment from me if, as a result of those surgeries or illnesses I had become permanently unconscious or unable to make decisions for myself.

From all of these perspectives I see the urgent need for a Patient Self-Determination Act. A highly visible and aggressive public education program which stresses the importance of all adult citizens making their wishes concerning medical treatment known and in light of the most Supreme Court decision in *Nancy Cruzan,* making those wishes known in writing in the most "clear and convincing" manner.

Practical problems affecting the changes envisioned in this law arise I feel in the issues of public and professional education. A national campaign to inform the public will hopefully increase public awareness and create a demand to execute advance directives. But if the implementation awaits the admission of mostly Medicare and Medicaid patients to hospitals and nursing homes, then it will be much too late for many—young and old—already rendered decisionally incapacitated either by the injury or disease that brought them to the institution in the first place.

Public education should be directed to every citizen who subscribes to a health maintenance organization or joins a group health insurance program, is enrolled as Medicare or Medicaid recipient, is employed by the Federal Government, is enrolled as a public employee in a public retirement program, enlists in any Federal service, or is discharged and becomes eligible for Veterans benefits, and yes, registers to vote in a national election or completes a U.S. census form.

But most importantly, public education must begin early when every teenager takes a driver's education course and obtains a driver's license to drive on a Federally-funded highway. Remember that a large number of those in the persistent vegetative state and permanently unconscious are teenagers and young adults who survive serious automobile accidents which they never anticipated and which occurred prior to their ever having made their wishes known in a clear and convincing manner. And public education regarding the need for advance directives should continue each time a citizen renews his or her driver's license or registers an automobile.

The education and training of physicians, nurses, social workers, pastoral counselors, and others working in hospitals and health care facilities are absolutely essential to the successful implementation of this act. If communication with patients is perfunctory, hurried, callous, ending up in legal formalities and paper pushing, then more harm than good will result.

And in the process, patients must be free to sign or not to sign an advance directive, free of coercion. They must also be reassured concerning the quality and type of care to be provided so that the advance directive will not be misinterpreted as cutting them off from beneficial care that they may want and should receive. Patients must understand that as their wishes to minimize, withhold or withdraw active treatment are respected, they will still be cared for and they will not be abandoned.

In implementing this Act the physician is essential. It is the physician's responsibility not only to foster trust but under the ethical principals of autonomy and beneficence to help patients further their own legitimate ends—that is, the patient's legitimate ends.

In fostering communication discussion and dialogue with patients the physician must engage the patient in a process of shared decision making so appropriately called for by the President's Commission.

In my view, physicians and appropriately trained hospital personnel should routinely ask all patients about the existence of advance directives as called for in this Act. But more importantly is the inquiry about the existence of surrogate decisionmaking. A single page living will can easily be lost and misplaced, overlooked in a fast-paced complex world of high tech intensive medicine.

If a living will even gets from a patient's safe deposit box or the physician's office to the hospital record, the hospital record which expands exponentially with reports, consultations and progress notes, it may be lost.

It is far more important, in my view, for each person to designate in writing a surrogate decision maker either as a proxy or attorney-in-fact in a power of attorney. This should be done in addition to the living will. The surrogate can monitor the progress of the patient's progress.

I will end by saying I served as a surrogate for my 86-year-old mentally incompetent mother during the last few years of her life. I sat with her when she died quietly and peacefully, as she wished, without any futile last minute attempts to resuscitation, or attached to machines or tubes.

In conclusion, it is clear that the competent adult has the absolute right to accept or reject any or all medical treatment consistent with their private values and preferences, and that this right should continue through the mechanism of an advance directive. It is equally clear from the recent Supreme Court decision in *Nancy Cruzan* that there is a need for every adult to write down his or her wishes and preferences in advance of decisional incapacity; and as syndicated columnist Ellen Goodman said last month in her Travelers' Advisory—"Don't leave home without it."

Thank you very much.

[The prepared statement of Dr. Scully appears in the appendix.]

Senator ROCKEFELLER. Thank you, gentlemen. Senator Danforth and I were waiting for the subway downstairs. He turned to me and he said, isn't it incredible how painful it is that somebody—in this case Ms. Delio—would have to be in the position of arguing for her husband's death. Now you are in bioethics and you are in Christian ethics. It would seem to me that—and you discuss depersonalization and maybe cost containment is doing that to us, maybe the overwhelming medical load on physicians, hospitals, the provider community is doing it to us. I do not know what is doing it to us.

But it just seems to me that it would be fairly natural for doctors to do what was in the interest of their patient and that it would not be natural for a doctor if the patient was incompetent to—and the family felt very strongly about it not being fair that the patient continue in that condition—that a doctor would respond to that.

Dr. SCULLY. I would hope so. I agree with Mrs. Delio's comment early. It seems to me——

Senator ROCKEFELLER. My questions is: What is our problem here? Is it medical liability? I don't know much about Westchester Hospital. Are administrators a different breed? I mean, what is our problem here?

Father MCCORMICK. From my experience both as an observer and as a patient more than I care to remember many people do not understand what goes on in a contemporary hospital setting. When a patient goes to a hospital the hospital is organized in such a way that it responds in almost predictable ways. Things are done to you one after another, either preps or post-ops or—they are just done to you. The whole mass comes at you. It is not as if you are sitting there self-determining your way through this whole maze. It does not happen that way.

So I think in other words you are on the defense from the very moment you are a patient in one of these settings.

Senator ROCKEFELLER. Dr. Scully?

Dr. SCULLY. Well I think that the issue might be legalism. It seems to me that patients and their families ought to express themselves and ought to make decisions about themselves. I agree with Mrs. Delio that we need to look at the whole substituted judgment principal, whereby I having lived with my wife for 35 years have a much better idea of what she may or may not wish to have happen to her, whether she has written it down or not.

Now, in fact, she has. I am her durable power of attorney; she is mine. One of the concerns I have about this whole movement is that if we insist that the entire population of 250 million people write everything down, then I think we have lost our humanity. We have lost our essence as a community of caring, loving people. We have become a community of paper pushers. It seems to me we will lose that.

But until that occurs, until we reunite as a community of caring people for one another, I think we are forced to put things down. I also want to say for just a moment that I strongly disagree with the idea that empowering people is not a part of the quality of health care. I have been a patient a number of times and I have been close to death. One thing that happens to patients when they are seriously ill is loss of control. When patients cannot control anything else in their life they complain about the hospital food.

A critical part, an essential part, of healing is regaining some of that control. Part of that control is the whole process of the informed consent mechanism, part of it is through the process of shear decisionmaking, and part of the sense of loss of control being regained is my knowledge that my wife will step forward with my two sons and speak in my behalf. And right next to my credit card is a little thing that says I have a living will and you better call her.

That gives me a sense that in an impersonal, dehumanized, legalistic community that is not the kind of community that we ideally would like to be in, someone is going to be stepping forward. But I fear and I am concerned about those who do not express themselves, who do not have someone who can step forward. That is unfortunate.

To the extent that this bill submitted by Senator Danforth at least pushes that a little bit further, I support it wholeheartedly, and I think it should be a public education program. But I think that in the long run if we have to write everything down and end up with legal documents for every piece of decisionmaking, then my profession will have failed and I think our society will have failed as a caring, loving community.

Senator ROCKEFELLER. Senator Danforth?

Senator DANFORTH. Absolutely, Dr. Scully. The only question is to try to make it as easy as possible to show by clear and convincing evidence that the person who cannot speak for himself or herself has expressed an intent with respect to future medical treatment.

I would like to ask some questions to you, Father McCormick. You are a Jesuit. You are a professor of Christian ethics at Notre Dame. You have taught Christian Ethics and written in the field for 35 years. You say in your testimony that the Catholic Health Association endorses S. 1766.

So I would like to ask you some questions about the obligation or lack of obligation from the standpoint of Catholic medical ethics to squeeze out every last minute of life. Everyone in the country knows the commitment of the Catholic Church to life. And you are believed by many to be the foremost Catholic medical ethicist in the United States. I would like you to tell me your understanding of the tradition and position of the Catholic Church relating to whether or not there is an obligation to keep somebody breathing in a vegetative state.

Father McCormick. My understanding of the Catholic tradition on the preservation of life can be stated quite simply as follows: That human life while it is a basic good, as the condition of all other achievements and experiences, is not an absolute one. There are other values for which life may be sacrificed. Or flip the coin, see it negatively, we say that death is an evil to be avoided as a general rule; and yet, it is not an unconditioned evil.

It is that basic judgment on the meaning of life and death which is at the heart of the Catholic tradition. Basically, it begins to suggest that not all means have to be used to preserve life. Then we get into the casuistry of the preservation of life, into ordinary and extraordinary means. Ordinary should be used; extraordinary need not be and so on.

But at the heart is that basic value judgment about the meaning of life and death. If I can put that in another way, in a little more technical way, we try to view life and death within what we know as the Pascal Mystery. Now this is true of Christians, not just Catholics. The Pascal Mystery being the life, death and resurrection of Jesus. And just as Jesus rose from the dead and now lives, so we who believe in him, put our faith in him, will enjoy a similar future life.

It is within that context that life and death are to be viewed. That relativizes them a little bit so that the mere accumulation of minutes is not the criterion of good dying from the Christian point of view, and certainly the Catholic. Concretely, I have been involved in many of these incompetent cases from the very moment of Karen Quinlan's problem. I was involved in that case from the very beginning. The vast majority of these cases should never have gone to court and would have been easily solvable certainly within Catholic perspectives and I think even more generally Christian perspectives, without a great deal of bother.

Why did we get that way? That is a good question. I think that technology is running affairs far more than we would like to admit. But that is the answer I would give you.

Senator Danforth. Is your answer the same with respect to withdrawal of nutrition and hydration?

Father McCormick. Yes, it is. Although I admit that there is a minority on the other side of that point of view. Basically, a group of people who assert that keeping Nancy Cruzan and people in a persistent vegetative state, circulating and ventilating, is indeed a great benefit to these patients.

From a Christian point of view, I can make no sense of that statement.

Senator DANFORTH. Thank you very much.

Dr. Scully, you have written a book entitled, "Playing God"?

Dr. SCULLY. Yes, sir.

Senator DANFORTH. What do you mean by that title? What is the basic thesis of the book?

Dr. SCULLY. Traditionally, physicians have been accused of playing God, often in a pejorative sense—that is, that they have been the final arbitrators of who makes decisions either to treat or not to treat, to treat or withdraw treatment.

The thesis of my book is that if anybody is going to be playing God with you it ought to be you and nobody else. That requires some thought. It requires confronting your mortality. It requires saying, yes, I am going to die. It is requiring saying, everybody is going to die. There is no such thing as anyone—yet to my knowledge—entering immortality except in some existential way.

So that playing God is that each of us have to play God for ourselves. We have to decide what are our preferences, what are our goals, what are our likes and dislikes and then say these are the limits, these are the limits under which I am willing to live. These are the burdens. I am willing to accept the benefits I want. And certainly even looking at Pope Pius XII statement in 1957 about ordinary and extraordinary, he put it in the context of the analysis of relative benefits and burdens to the specific patient as seen by him, the patient, in that context; not as seen by anyone else.

So "Playing God"—which by the way, the title has changed—that is what I meant by that. And that is the thesis of my book. We hope, my wife and I, in the way we wrote it we will help others to look at themselves and make decisions for themselves. That is why I support your bill and cheered when I first read about it last fall.

Senator DANFORTH. I think what most people mean by "Playing God" is well, playing God to make the decision that certain people should die. I think it is also playing God if somebody makes the decision that some people who are in the process of dying should be arrested from that process artificially.

Dr. SCULLY. Absolutely.

Senator DANFORTH. It seems to me that what technology has done now is to create a situation where people who have no stake other than a professional stake as a health care provider do have the means now to play God. They have the means to artificially arrest something that is happening in the normal course of life and death; and they can do it for an extraordinary period of time. It is possible to keep somebody in a vegetative state for decades. Isn't that right?

Dr. SCULLY. Thirty-six years in the case of Elizabeth Espizito.

The worse thing that can happen to our society is the technological imperative taking over, in my view; where then I become subject to the machine, rather than the machine becoming subject to me. That is what we are facing.

Senator DANFORTH. You both have been very helpful and I thank you for your testimony.

Dr. SCULLY. Thank you.

Senator ROCKEFELLER. In the event that the Danforth bill passes, and that information is disseminated widely, and that people become vastly more aware of advance directives, living wills and all kinds of other things, it is also true that there will be teenagers and young people, as you have pointed out, who by reason of their youth, will never have thought that this would happen so nothing will be there. So a surrogate would be helpful.

On the other hand, there will also be people—probably large sections of the majority of people—who will still not know about this, and will not know that they can save themselves incredible and unimaginable pain—family destroying pain. So passing a bill to make information available is helpful, but it is not going to close the gap.

Dr. SCULLY. No.

Senator ROCKEFELLER. And therefore the question remains as to the gap and what the responsibility of providers—I guess specifically of doctors—and then of hospitals, in that hospitals develop rules either as individual hospitals or as associations. What is your judgment—and then, of course, there are the courts who rule.

What is your judgment as to how all of this will evolve with respect to the gap which is left?

Dr. SCULLY. A couple of points. First of all, you point out that hospitals make rules for doctors. I would argue that there are very few hospitals that exist without physicians bringing their patients there. And physicians, through hospital committees, have a great influence on the way hospital policies are developed. At least I think they ought to.

I would also argue that every hospital, as called for in this bill, has a Hospital Ethics Committee, and on that committee are several people who I would call community representatives. They are not members of the board of trustees; they are not members of the hospital staff; they are not employed by the hospitals. They are there to sort of say, hey, what is going on in our community. We help support this place. We want to have an influence on what happens. We want to be sure that the policies of this hospital, dealing with this specific issue of patient self-determination, have a community input.

I would argue that such an Ethics Committee—and I sit on two in my community—not only can have an enormous influence on the policy development, the education of the public, but also be called in on specific cases, which we do frequently, to try to help physicians and patients and families work through what is in the patient's best interests.

I would agree, Senator Rockefeller, that this is only one piece of that.

I would also argue that every medical school—and most are; mine is, and others—are developing more formalized courses in medical ethics for all of young physicians so that in the future they put into perspective not only their role in trying to cure a disease, but look at the other side of the coin which is to care for patients. And until we get back to a balanced approach between the curing and the caring, the technological imperative and what is in the patient's best interests, we will still have this gap.

I see it as an ongoing process. It is not going to end with this bill or 10 more bills that Congress can write. But it is a beginning. So I would hope and urge the Congress to pass this as the first step in pushing that debate forward.

Senator ROCKEFELLER. Thank you, Dr. Scully.

Father McCormick?

Father MCCORMICK. Well the gap, I am perhaps wrongly a great believer in progress by tragedy. I believe that it is only by a succession of cases like the *Cruzan* case that the public awareness is going to be stimulated, shocked really, into doing something against its instinctive tendencies.

By that I mean we still, culturally have a great reluctance to talk about death in any meaningful way. I am suggesting you may be seeing that in the response of certain physicians and even certain hospitals to this initiative. That may be a corporate manifestation of this reluctance to deal with death in any meaningful way. Until we can deal with that, I think that gap is going to be there.

Senator ROCKEFELLER. Gentlemen, thank you both very much.

Dr. Scully, before you go, as I look over your left shoulder I see another Tom Scully who I take it to be your nephew or your son?

Dr. SCULLY. My nephew and name sake and God child.

Senator ROCKEFELLER. Well in any event, he has an enormous influence in this country on health care. I work with him frequently and appreciate him greatly.

Senator DANFORTH. Could you tell him that the administration is all wet on this bill? [Laughter.]

Dr. SCULLY. If he and his wife accept my invitation for dinner tonight I will have that opportunity. [Laughter.]

Senator ROCKEFELLER. Thank you, gentlemen.

Senator DANFORTH. Mr. Chairman, prior to the next panel I ask that two documents be placed in the record of this hearing. One is entitled, "Christian Affirmation of Life," published by the Catholic Health Association which includes a living will form; and the second is a booklet entitled, "Choices for the Journey, Durable Power of Attorney and Health Care Decision Making for Religious," by Brother Peter Campbell, and it is also published by the Catholic Health Association.

Senator ROCKEFELLER. Of course.

[The documents appear in the appendix.]

Senator ROCKEFELLER. Our final panel consists of Charles Sabatino, who is the assistant director of the Commission on Legal Problems of the Elderly; Paul Rettig, who is executive vice president and director of the American Hospital Association; and Nancy Dickey, who is a member of the board of trustees of the American Medical Association.

Paul, since I know you best, why don't you start out.

STATEMENT OF PAUL C. RETTIG, EXECUTIVE VICE PRESIDENT AND DIRECTOR, WASHINGTON OFFICE, AMERICAN HOSPITAL ASSOCIATION, WASHINGTON, DC

Mr. RETTIG. Thank you very much, Mr. Chairman. The hospitals greatly appreciate the attention to this important issue being given by the subcommittee and commend Senator Danforth for his leadership in this area of advance directives and living wills.

The issue of keen interest to hospitals is one with which hospitals need to cope on a daily basis and their personnel need to cope with it. Something like 70 percent of deaths occurring in hospitals involve in some way a choice to forego life- sustaining treatment.

For years the AHA has been active in this area in attempting to provide policy guidance to hospitals on the role of patients' families, guardians, physicians, and hospitals themselves in the withholding or withdrawal of medical treatment. We filed a friend of the court brief in the *Cruzan* case.

Our view about this issue is that the most important thing that can be done is to educate the public about the importance and meaning of advance directives. As the name implies, the directives should be in advance. As a practical matter in many cases when the patient arrives at the hospital it is too late really to effectively deal with the situation.

Nonetheless, let me make it plain that we do recognize the obligation of the hospital to be involved in education of patients, hospital staff, and the community; and with some changes that have been under discussion with the Senator and his staff, we are supportive of this general notion.

Let me go on to say that the bill offers some hope that we can deal with a more serious problem that hospitals face in this area, that of patients who are when they arrive in the hospital or become afterwards incompetent or unconscious and have not provided some form of advance directive. Hospitals are kind of at a loss in this situation where the advance directives do not exist and where State laws, as they often do, conflict.

One recommendation we would make is that to the extent possible the Secretary would provide information that will be helpful to patients, families and hospitals in this kind of a situation where no advance directives exist. We recognize that the Federal Government can do this, but that also the State role is important because of the specificity of State laws.

We would like to thank Senator Danforth for his willingness to discuss concerns we have about the bill and to work with us. We understand that there is a willingness to make a series of changes in the legislation having to do with specific aspects of informing patients of their rights, the documentation of treatment wishes, the responsibilities of ethics committees, and so forth.

My statement contains more information on our concerns and what we understand to be the response. We want to continue to work with the Senator, and his staff, and this subcommittee to resolve a remaining concern we have which has some similarities to the one that Gail Wilensky mentioned—which is a concern that what Senator Danforth referred to as "the hook"—namely Medicare and Medicaid—is used for a number of issues and requirements on hospitals, though for good social purposes that are not specifically related to the issue of quality of care.

I must say that in this particular issue we have a lot more sympathy than some others. But there are a series of things for which Medicare participation has been used as a lever to force some action on hospitals and these build, so that a series of somewhat extraneous things begin to be required of hospitals and we hope to continue discussing that matter.

In summary, we are very supportive of the goals of the bill. We appreciate the willingness to discuss some concerns we have and help us be supportive.

Thank you.

Senator ROCKEFELLER. Thank you very much, Mr. Rettig.

[The prepared statement of Mr. Rettig appears in the appendix.]

Senator ROCKEFELLER. Dr. Dickey? And you have somebody you care to introduce?

Dr. DICKEY. I do.

STATEMENT OF NANCY W. DICKEY, M.D., MEMBER, BOARD OF TRUSTEES, AMERICAN MEDICAL ASSOCIATION, RICHMOND, TX, ACCOMPANIED BY MICHAEL ZARSKI, SENIOR LEGISLATIVE ATTORNEY, AMERICAN MEDICAL ASSOCIATION

Dr. DICKEY. I have with me Michael Zarski, a senior legislative attorney for the AMA. I am a family physician in Richmond, TX; and a member of the AMA's board of trustees.

We appreciate the opportunity to come before you and discuss advance medical directives, such as living wills. The right of a competent adult to control medical decisions affecting his and her body is deeply rooted in our laws and is grounded in the importance our society has traditionally accorded the autonomy of the individual.

The right to refuse treatment, however effective that treatment may be or however grave the consequences of the refusal, is an essential element of individual autonomy. While the right of patients to determine their own treatment has been recognized problems can arise when it comes to invoking that right under some circumstances.

The issue of determining whether artificial life support should be utilized or withdrawn frequently occurs when a patient is already unconscious or otherwise mentally unable to make that decision. In short, that person's right to decline artificial life support can be frustrated by a failure of the individual to leave sufficiently clear advance directives. We have heard numerous times this morning about an example of this; the *Cruzan* case.

There are two mechanisms by which an individual can avoid this problem—through written directives, like a living will; or through appointing a proxy to make decisions, a durable power of attorney for health care.

The AMA's Committee on Medicolegal Problems has studied these mechanisms for indicating decisions regarding life-sustaining treatment. It has looked at the advantages and disadvantages of each and these are described in a communication published in the May 2, 1990 Journal of the American Medical Association which is attached to today's testimony.

The AMA has also reviewed Federal legislation on this subject, including S. 1766—the Patient Self-Determination Act. There is strong support among physicians for the use of advance directives. It is extremely important that the wishes of our patients be known to the medical treatment team and that the voluntary use of advance directives should be strongly supported and encouraged by physicians.

The AMA, therefore, strongly supports the goal of S. 1766. We are, however, concerned with a few of the specifics within the bill, including the major focus on institutions in pursuing advance directives at the time of admission. The American Medical Association does not believe that the hospital or nursing home is the most appropriate place, nor that the time of admission is the most appropriate time to consider initially the issues of advance directives.

We understand that Senator Danforth, the sponsor of S. 1766, is developing some modifications to the bill. One proposed modification would specifically require that HHS develop informational materials to be made available to Medicare and Medicaid providers and possibly consider mailings of information to Social Security recipients. The proposed modifications would improve S. 1766 and make the bill more consistent with AMA principals.

Even without a legislative impetus, the association is committed to increasing awareness of advance medical directives and health care powers of attorney. In fact, at our annual meeting less than a month ago the House of Delegates passed a resolution encouraging the American Medical Association to make available to every physician in his or her office means of discussing this with their patients.

To this end, our office of general counsel is developing two brochures—one directed at physicians and one directed at patients—as well as model medical directive forms to be used by our patients. We are also exploring the possibility of offering our patient brochures to HCFA for distribution to their Medicare and Medicaid beneficiaries.

In conclusion, Mr. Chairman, we commend you for holding a hearing on this important matter. We have had the opportunity to discuss this issue a number of times and we can never overemphasize to our patients and the public the opportunity and perhaps even the obligation to make these health care decisions.

Although there may be different ideas regarding the responsibilities and the logistics for promoting the development and the use of advance directives, there is no doubt that everyone benefits from the existence of a clear expression of the individual's preferences in the provision of medical treatment and technology.

We are eager to incorporate the information and ideas developed by this subcommittee into our projects at the AMA, to work with the Department of Health and Human Services to promote the use of mechanisms for advance medical directives, and to continue to have input, as Senator Danforth and others look at this bill and find ways, hopefully, to best serve the needs of our patients.

Thank you. I would be happy to answer any questions.

[The prepared statement of Dr. Dickey appears in the appendix.]

Senator ROCKEFELLER. Thank you very much, Dr. Dickey.

Mr. Sabatino, when I introduced you I did not say you were representing the American Bar Association. We welcome your testimony.

STATEMENT OF CHARLES P. SABATINO, J.D., ASSISTANT DIRECTOR, COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY, AMERICAN BAR ASSOCIATION, WASHINGTON, DC

Mr. SABATINO. Thank you, Mr. Chairman, Senator Danforth, and members of the committee. I am Charles Sabatino, assistant director of the American Bar Association's Commission on Legal Problems of the Elderly and I submit these remarks at the request of our president, L. Stanley Chauvin, who sends his regrets because he cannot be here today. And I thank the subcommittee for the opportunity to appear and to express the ABA's support of the proposed Patient Self-Determination Act.

Mr. Chairman, the timing of this proposed legislation and hearing could not be more propitious, given the decision last month by the Supreme Court in the *Nancy Cruzan* case. While that decision is fraught with troubling and uncertain implications one thing is clear—it sends a sobering message to all adults that one's right to control life and death health care decisions may depend on each of us taking pen in hand and writing down as precisely as possible our treatment wishes while still competent.

Given such a message, then states, health care providers, the legal community, and the Congress must realize a corresponding need and obligation to inform the public, to educate the public, and to provide the means for people to formulate and express their wishes regarding health care. These goals are precisely the goals of the Patient Self-Determination Act. That is why the Act is timely and important.

In addition, the research mandate of this act, which has not been mentioned today, stands out as especially crucial, for we really do not have much experience in examining the practical and legal problems in using advance directives or other techniques for making health care decisions. We need to learn what works best and what enhances genuine communication among patient, family, physician and other health care providers.

The ABA has policies strongly supporting the principal that individuals have a right to consent to and to refuse suggested health care interventions and that appropriate surrogates may exercise this right on behalf of individuals who are incapable of making such decisions, especially through the use of advance directives.

During the last 3 years the ABA, particularly through the Commission on Legal Problems of the Elderly, has exerted considerable effort to educate both the public and the legal community about the nature and availability of advance directives, especially health care powers of attorney.

Let me dispel here one misconception as strongly as I can. Much of the discussion on this topic has centered on living wills. A living will would not have helped Nancy Cruzan, nor Mrs. Delio, nor Mrs. Allen, as most people in a persistent vegetative state or an advance stage of Alzheimer's disease are not considered to be near death as long as they are hooked up to the feeding tubes.

Almost all living will statutes today apply only when the patient is close to death. One needs something more than the traditionally conceived living will—either a health care power of attorney or a directive that is broader in scope.

Now one example of the ABA's efforts of education in this area is a recently released booklet on health care powers of attorney. Copies of that booklet, which are the blue and white one, are available here today. We make that booklet free to the public through the American Association of Retired Persons, which has cooperated with us on this initiative.

In previous testimony on the House version of this bill we highlighted certain challenges and pitfalls that face this kind of health legislation. I do not want to repeat all of that here. Today I wish to emphasize two particular concerns about the development of law in this field.

The first concern is the portability of advance directives. In the recent past, relatively few States have legislation regarding advance directives for health care. Today some 41 States, plus the District of Columbia, have living will laws and 31 States, plus the District of Columbia, have health care power of attorney laws.

The legislative frenzy in this area is demonstrated by the fact that 20 of these health care power of attorney statutes have been enacted in just the last 18 months. That is more than one enactment per month.

However, the increasing variability and complexity of these statutes raises a question. Will a validly executed instrument from one State be recognized in another? Of the 32 existing health care power of attorney statutes only six expressly grant recognition to out-of-state instruments that comply with the law of the other State. This is one area that Federal action through strategies suggested in our written testimony could make a dramatic difference in ensuring the rights of patients who by choice or by fate happen to cross State lines.

The second issue concerns the impact of advance directives on the poor and isolated. Clearly, the pendulum is swung too far away from the use of advance directives today. However, as we push the pendulum in the other direction, we need to be mindful of possible risks, especially for the indigent, poorly educated and isolated individuals who could be vulnerable to facile execution of documents urged upon them by over-enthusiastic caretakers.

However, this is not an insurmountable problem and we applaud suggested changes in the legislation such as clarifying the role boundary of providers and prohibiting discrimination based on the presence or absence of an advance directive.

In closing, I want to reemphasize the ABA's support of this initiative and offer our resources to assist you in fine tuning and implementing this act. I thank you very much.

[The prepared statement of Mr. Sabatino appears in the appendix.]

Senator ROCKEFELLER. I thank all three of you very much. It was just occurring to me as you were talking, and thinking about Father McCormick, about our inability in this country to deal with death. We avoid it. And the term "advance medical directive" somehow sort of symbolizes that to me. It is like we do not even want to say what we mean so we say an "advance medical directive."

Dr. Dickey and Mr. Rettig, and also Mr. Sabatino, Ms. Delio when she was describing her experience with the hospital—I am not asking you to be knowledgeable about that; I am asking you to sort of do the best you can to answer this question—described something that sounds like a movie, that I do not associate with the way the real world works and obviously I am wrong. She described a climate of fear, a climate of fear, potentially resentment. She was fired. Obviously the hospital did that for whatever reason. It sounded like a system which was really quite out of whack and that hospitals, doctors, and the laws put her and her husband in a situation of not only great difficulty but it would seem to me kind of an amoral kind of disadvantage.

I would care if you would each comment on your reflections on her description of what happened to her and to her husband.

Dr. DICKEY. I think, if I heard Ms. Delio correctly, and as I have read through the *Cruzan* case, and in all too many other cases, the patient and the physician, the primary care giver with that patient and the patient's family have frequently been in agreement, but some other entity has been intruded. It might be a hospital employee; it might be a hospital institution itself; it might even be some person who appears to have no business in the case and it ends up in a court room.

I think it is symptomatic of decisionmaking in health care by those who fear accusations that everything possible was not done, or that if an action is carried out without all of the "T's" crossed and the "I's" dotted that perhaps accusations and lawsuits will come later, not by the patient who will not be there anymore, but by someone who wasn't a part of the decisionmaking. This demonstrates some need for improvement in these kinds of decisions, but frequently it is not a problem between the individual physician and the individual patient, particularly where patients have a longstanding relationship.

The other problem, of course, is, as you heard from Dr. Scully earlier, that all too often in this day of technological medicine you may begin your medical care in a facility or with a physician close to home, but rapidly may be transferred into a high technology, much more impersonal situation where you have numerous care givers, numerous physicians and people who do not know you, your family or your situation.

Senator ROCKEFELLER. Paul?

Mr. RETTIG. All the several explanations that have been given earlier make a lot of sense to me. I have no explanation whatsoever for why a hospital would resist carrying out a court order. I do not think this situation—although there are many such situations, no doubt—is probably typical. In other words, as I said, something like 70 percent of the patients who die in hospitals are involved in some way with the decision to forego life-sustaining treatment. There are something like 1,300,000 such cases.

So I have to assume that these are extraordinary, however tragic they are. My assumption is as a non-lawyer is that there are many legal concerns that drive this and that is largely what is underlying it. As a non-lawyer I can ignorantly say that in a case where there was no advance directive, the *Cruzan* case, the court did not agree that the feeding tube could be withdrawn and these are feeding tube cases.

Senator Rockefeller. In agreeing with you and before I call on you, Mr. Sabatino, that is what ran through my own mind as she was testifying.

I think you are right. I think it is fear of law, fear of lawsuits, fear of—it is all of those things that come from a society that not only does not confront death but does not confront personal responsibilities and is one reason, Mr. Sabatino—I do not mean this to be ungracious—why lawyers do so well in this country. We would rather sue than confront our own inner thoughts and inner responsibilities both on a personal and on a societal basis. But that is just my own thoughts.

What are your thoughts, Mr. Sabatino?

Mr. Sabatino. Well there are many forces that drive an institution's behavior. Let me try to address just one of the legal forces. I think it was Justice Brandice who said that the law is behind the times. Well today, technology has leap-frogged over our romantic image of preserving life and over the simplistic legal view that death is the ultimate injury, and preserving life is the ultimate good.

Many institutions still adhere to what I think is an oversimplified romantic image of what is going on today. Technology has rewritten the whole scenario. I would just add one thing about the role of law in this area and somewhat parrot Dr. Scully's remarks that we should not "overcontractualize" the process of death, as I call it, and require everybody to need a legal draftsman to make sure everything is spelled out with every "I" dotted and "T" crossed. That document, that advance directive, or whatever we call it ought to be the outcome of a communication process. It ought to be its distillation and summary and not substitute for the process itself. We need to keep that perspective as we develop this whole area of law.

Senator Rockefeller. Paul, one question for you and then Senator Danforth may have questions.

You heard Dr. Wilensky testify that the organ donor program is not a Medicare condition of participation. What is your understanding of the requirement that hospitals must ask a family member whether they would be willing to donate the organs of a person who just died?

Mr. Rettig. Since this occurred some time ago, there has been time for your staff and ours to look into the matter a bit so I am better able now to tell you what the situation is. There is a requirement that hospitals, to participate in Medicare and Medicaid, establish protocols to assure that families of potential organ donors are made aware of the option of organ or tissue donation and their option to decline. There are some further details.

This is a free-standing requirement in the Social Security Act, Title 11, which in fact includes such programs as peer review organization and so forth that do apply to Medicare and Medicaid. So it is not—if I can get a little technical—there is a section of the law, Section 1861(E) that prescribes conditions of participation. These are really the health and safety specific quality issues.

There is another section that says hospitals—this is Section 1866—in order to participate, even if they meet the conditions of participation must agree to certain things. For example, to provide to the Medicare program sufficient financial information so that Medicare can pay the claims properly, and a series of requirements like that.

There is in addition—now this one, which is free-standing is neither literally the condition of participation nor the provider agreement section—but a free-standing requirement on any hospital that wishes to participate in Medicare and Medicaid and in any event it is a requirement, whether it is technically a "condition of participation."

Senator ROCKEFELLER. And is it one that proves particularly burdensome to the hospital?

Mr. RETTIG. My understanding is that it is not terribly burdensome, although it is in another touchy area in which hospitals in effect are encouraged and their medical staffs to talk to families of patients who are potential organ donors, which means they are seriously injured and near death.

So there is some resistance there. But, in fact, this is a requirement that hospitals, as I understand, are undertaking and attempting to do.

Senator ROCKEFELLER. Dr. Dickey, one final question from me. In our medical schools, how are young people being taught to deal with death, to deal with tough ethical and moral issues, deep areas, that we have been discussing this morning?

Dr. DICKEY. Well I can say in all honesty, far better now than a decade ago. It varies across the country. There are very specific courses at some medical schools. There are more informal mechanisms in other schools. Virtually every school now incorporates some education in medical ethics. A great many of them——

Senator ROCKEFELLER. What does it do? What does it teach?

Dr. DICKEY. A great many of them do very innovative things today using role models and acting out so that students actually have an opportunity to practice confronting the kinds of difficult situations they will certainly encounter at some point in their medical careers.

Many schools have on their staffs such superb ethicists as Dr. Scully and Dr. McCormick. They all incorporate throughout the training the specific aspects of medical ethics that may relate to individual fields, such as surgery or infertility, OB/GYN and neonatal nurseries.

Education in medical ethics has increased dramatically in the decade of the 1980's, partly because the technology has forced those kinds of decision making, partly because a decade ago with the *Karen Ann Quinlin* case, not only did the public become aware of the difficulty of dealing with these issues, but the medical profession became aware as well. And just as any other type of person involved, physicians vary in their willingness and their ability to talk to their patients about these issues.

Ideally the place to talk about these issues is in the doctor's office before the patient faces crisis decisionmaking. Then you have the opportunity to look down the road and see what kinds of decisions you and your family may be facing. Some doctors are better at bringing this up than others, but we are learning that we can teach all physicians the mechanisms for bringing up the issues and presenting them.

We not only see all of this incorporated in the medical schools, but we are seeing it as a very popular course in continuing medical education for practicing physicians who realize that they were not exposed to this a decade or two ago in school and yet they are forced to discuss technological treatment issues with their patients and the possibility of using or not using certain life-sustaining treatments for their patients.

So it is not only in the medical schools but as important, it is a very highly sought-after educational topic by those of us who are already in practice.

Senator ROCKEFELLER. Senator Danforth?

Senator DANFORTH. I would simply like to thank each of you for not only today but for the help that you have given my staff as we have progressed with this legislation. I would encourage you to work with us. We are very anxious to accommodate the specific concerns or at least most of the specific concerns that you have expressed.

It seems to me that the kind of legislation we want has to have a system to it. That is, it is not going to be sufficient, I do not think, to say well there is going to be an 800 number or that booklets are going to have paragraphs in them. I think that there has to be some way, some systematic way, of raising the issue with people. That is why hospital admissions is the way that we have conceived of. That is not to say it is the only way or the best way or that one of you might think of a better way to do it.

But it is a system rather than, well, if a doctor wants to spend another 15 minutes talking to a patient when he has a waiting room full of other patients, you know, maybe a discussion will take place. I think it has to be a system.

Secondly, I think it has to be a system which reaches people in a variety of circumstances and in a variety of ages. That is why I do not believe—maybe it is a good idea to send this out with the first Social Security check or something like that. But that would not have helped Mr. Delio. That would not have helped Nancy Cruzan. Because they were in one case—Mr. Delio was in his thirties and Nancy Cruzan was in her twenties. And Mrs. Delio said that she knew of another case in the hospital of somebody even younger than her husband. It can happen at a young age and people can be kept alive for decades.

So I think that there has to be a way of reaching people, and not just a paragraph in a book or if you are interested call an 800 number, but a way of putting it to people. Even if it is just in a minute or 2 minutes, do you have an advance directive; would you like one. Here is a simple way to get one.

That is what the legislation attempts to do. Maybe it does it in a clumsy way, maybe it does it in not a good way, maybe somebody can think of a better way to do it. But whatever we do, I do not want it to just be haphazard. Sort of a hortatory comment which is aimed at doctors, please talk to your patients.

There has to be some system. Why do we use Medicare and Medicaid? Because it is just a hook. What we are saying is that providers—that is people, institutions who are participants in a Federal program have to do it. It is simply a hook. That does not have anything to do with Medicare or Medicaid.

It is simply a method of getting hospitals to raise the question because the feeling is that most people at some time go to hospitals, and most people go to hospitals before they are in a position of dying. Most people go, you know, to have babies or to have their appendix removed or whatever. People go to hospitals.

It seemed to us that at the time when people are concerned about health maybe that is the time to say, do you have a living will. There is a hospital in Illinois where—somewhere in my stack of things here I have—here it is. They have posters on the wall. "We suggest you fill out the new Illinois Health Care Power of Attorney. Forms are available here. If you have a Living Will or Health Care Power of Attorney, please let us know."

I do not think that is coercive. I just think it says think about it. And then there is a little check on their admissions form. No big deal, but it is a system—a system for putting it to people. That is what I hope to retain in legislation.

Now there are other questions and I really appreciate your testimony and your help, Mr. Sabatino. You have been enormously helpful. The question of portability really is an issue and I hope that you will continue to work with our staff on this particular subject. Maybe there is something that we can do on it.

The form of living will—we do not say anything about it—but clearly there are differences in quality of forms. I just anecdotally had a living will and I looked at it and I really wasn't satisfied. I could not understand what it meant.

The Journal of the American Medical Association, about a year ago, I think, had an article with a comprehensive form with boxes to check. I made out a new living will with the boxes checked. So I think that there is enormous room for trying to clarify how people think. You know, put it to people. If you are in this kind of situation, what would you like done? What kind of treatment would you like? I think that that is very fruitful.

And clearly, the power of attorney, because there are always going to be situations that nobody anticipated in detail before, and because we do not want something that is so legalistic that it is a matter of arguing almost as though we are arguing about a tax bill, you know, on the finicky detail of what was said or what wasn't said. So I think that the concept of a power of attorney is very, very important.

Those are really in the nature of closing comments. I want to express to each of you my appreciation for the time you have put into this and for your constructive approach to it and your willingness to work with us. I hope we can pass something and I hope we can do it with reasonable dispatch. But we certainly want it to be the wisest approach we can find and you are helping to make it so.

Mr. Chairman, this has really been a wonderful hearing and I appreciate your leadership and all of the witnesses who have added so much to it. I think that the more we talk about this subject the better off we are going to be as a people and this has been one forum where we have been allowed to do that. I appreciate your letting us have this opportunity.

Senator ROCKEFELLER. The hearing is adjourned.

[Whereupon, the hearing was adjourned at 12:49 p.m.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED

PREPARED STATEMENT OF KITTY C. ALLEN

Chairman Rockefeller, Senator Danforth and members of the Committee. My name is Kitty Allen. I am from Houston, Texas.

I am here to speak for my mother-in-law, who has Alzheimer's Disease, and for my family who cares for her. I am also here as cochair of the Public Policy Committee of the Alzheimer's Association and am submitting this statement on behalf of that organization.

I want to commend this Committee, and Senator Danforth particularly, for your leadership on this issue of patient self-determination.

This Committee, and especially you Chairman Rockefeller as head of the Pepper Commission, has been at the forefront of efforts to assure that all Americans have access to health care and to long term care services—to sustain and improve the quality of life.

It is appropriate that you should also be taking on the issue of how decisions are made about medical treatment, particularly as life nears its end.

The Alzheimer's Association is the national voluntary health agency organized to support families caring for loved ones with Alzheimer's disease and, through research, to find the cause, treatment and cure for this horrible affliction. We work through 210 chapters and over 1600 support groups throughout the country.

Alzheimer's disease is a degenerative disease that robs a person of memory, judgment, reasoning—everything that makes that person a unique human being. It is irreversible, untreatable, and always fatal.

One of the cruelest ironies of the disease is that the body often remains physically healthy long after the person inside has disappeared. Death is inevitable, but by the time the patient reaches the stage where decisions have to be made about life-sustaining treatment, he or she is no longer capable of participating in those decisions.

A TYPICAL STORY OF AN ALZHEIMER FAMILY

I want to tell you about Gran, my mother-in-law. My husband, Joe, is her only son. She and Papa have been married 55 years. He worked the docks for Exxon for 31 years. She was a homemaker.

Ten years ago, Gran was helping me take care of my babies. Today, at the age of 77, she lies in our house in a near fetal position.

When Gran was diagnosed with Alzheimer's disease in 1981, we did everything we thought we had to do to help her get her affairs in order, including updating her will. No one ever mentioned a living will, much less a durable power of attorney for health care.

Two years after her diagnosis, Gran and Papa sold their house and moved in with Joe and me and our two young children. She was still walking then, but she was gradually forgetting how to do even the most basic things. She was already wearing diapers and was forgetting how to eat. We went from feeding her table food, to junior foods, to strained baby food.

By 1985, she had shrunk from a 140 pound vital woman to an 80 pound shell of herself.

One Thursday afternoon, she finally forgot how to swallow. There was no way we could get any food or water into her body. By Saturday, it was clear even to me—and I'm no medical expert that she was becoming dehydrated. Her doctor was out of town. We called the emergency room, but they dismissed our concerns. "Honey, she'll eat when she's ready," they told me.

By Monday, when her doctor returned, we finally got someone to see Gran. They refused to listen to our explanation of what was happening and insisted that she probably had some kind of obstruction. Over our objections, they took her away from us to do something they called a "barium swallow."

But because Gran could not remember how to swallow, they ended up pouring the barium into her lungs and inducing pneumonia.

With that, they had to admit her to the hospital. The doctors told us that in order to treat the pneumonia, they would first have to insert a feeding tube to rehydrate her. They led us to believe it was a very temporary procedure. In any case, in the condition she was in, they estimated she had no more than 6 months to live.

We had agreed as a family, long before this incident, that there would be no extraordinary efforts to save Gran when it was time for her to go. Papa, Joe and I all knew that was what she wanted. We remembered Gran in tears, after her diagnosis, telling us, "I don't want to end up like Daddy"—the aging father for whom she had cared for years.

Had the doctors explained the implications of what they were doing to Gran—that they were introducing a life-support system that could never be disconnected—we never would have allowed the tube to be inserted.

It is now six years later. Gran has not been out of bed since the day they put in the tubes. The 80 pound woman we took to the hospital is now so heavy we have to use a hydraulic lift to move her. She lies at home in a near fetal position—alive, but not living.

Our lawyers tell us there is nothing we can do to remove the tubes and allow the natural process of dying to occur.

Papa, an 87 year old man in frail health himself, spends his days taking care of Gran. He now has an advanced directive. Even so, he lives in constant fear of being hooked up to a machine himself and constantly reminds us that we must never let this happen to him.

Our story is not fancy. It is not unusual. In fact, it is a fairly typical story of a family dealing with Alzheimer's disease—one that could be told by thousands of families around the country.

THE IMPORTANCE OF S. 1766 FOR ALZHEIMER PATIENTS

This is not a minor issue. *Four million people* in the United States today have Alzheimer's disease. Half of us in this room—if we live to be 85—will be stricken with the disease.

In every case, if some intercurrent illness does not end life sooner, the patient will reach the stage Gran is in today—unable to perform even the most basic function of daily life, certainly unable to communicate their wishes with regard to medical treatment.

This is why the Alzheimer's Association enthusiastically supports S. 1776 and Congressman Levin's companion bill, H.R. 4449.

The Association has adopted Guidelines for the Treatment of Patients with Advanced Dementia which includes family members as a critical part of the decision-making process. (A copy of these guidelines is attached.) The Supreme Court has now held, however, that the family does not have a constitutional right to make these decisions for a loved one. That ruling has underscored the importance of clear advance directives which not only specify a person's treatment wishes but authorize another to make sure those wishes are carried out if the person is not able to decide for himself or herself.

There is no doubt in our minds that Gran did not want to be kept alive the way she is today, that she would not want the feeding tube in her present condition. But because she had never written that down, and had never named a durable power of attorney for health care decisions, we cannot honor her wishes.

What a godsend it would have been if, when Gran entered the hospital for those diagnostic tests ten years ago, someone had talked to her, and to us, about her rights to execute an advanced directive and to make her wishes known.

This legislation encourages each of us to sit down with our loved ones and our doctors to work through these issues when we are competent to do so. A time of crisis is not a time for carefully considered rational decisions about medical treatment. Our family has learned the hard way the consequences of not making those decisions early, before tragedy strikes.

The best decision-making occurs when there is good and open communication among everyone involved—the doctor, the patient and the family. By making discussion of treatment wishes a routine part of health care, you are encouraging that communication. This bill recognizes that execution of a legal document does not end the process, but that providers have an affirmative obligation to continue to review treatment wishes.

The Association recommends one change in the bill, to assure that this obligation of communication continues even when the patient loses the capacity to participate in the discussion. The bill establishes a clear responsibility of the provider to the patient—to inform him or her of their rights, to inquire about the presence of an advanced directive, to honor the patient's wishes with regard to treatment, and to periodically review those wishes with the patient. We recommend that language be added to the bill to make clear that the provider has these same responsibilities to communicate with responsible family members or the patient's guardian. Without that protection, the bill would have little meaning for an Alzheimer patient, once that patient loses the ability to communicate about his or her wishes with regard to treatment.

In conclusion, let me express again the appreciation of the Association for your efforts to protect the rights of all of us to make our own decisions about medical treatment and to assure that those decisions are respected.

Enactment of S. 1766 will not do anything to change the cruel reality of Alzheimer's or to halt the inevitable progression of the disease. That will require an expanded commitment to medical research to find the answers to the disease and the development of a long term care system that provides help for its victims.

By encouraging early and clear decision-making with regard to medical treatment, however, you can at least help make it possible for patients and their families to come to the end of their ordeal with some final dignity and peace.

CHRISTIAN AFFIRMATION OF LIFE

Christians believe that in death life is transformed by the power of Christ's death and resurrection into eternal life. Because of this belief it is not always necessary to use every possible means to resist death. Persons who are dying should be given whatever support they desire to alleviate pain and to prepare for death, but they have no obligation to endure medical interventions that unduly prolong their dying without offering them reasonable benefit.

Persons who are terminally ill have the right and the primary responsibility to decide to what extent they will receive treatment. In order that they can exercise this responsibility, they should be fully advised of the diagnosis, the prognosis, the proposed treatment, other available treatment options, and the risks and benefits of each course of action.

When a person is unable to make decisions regarding treatment, others, usually the next of kin, will do so, but they must make these judgments in accordance with the person's legitimate wishes, if they are known. The "Christian Affirmation of Life" is provided as a means of indicating one's desires regarding treatment at the time of terminal illness. It is not intended as a legal document, but one of moral persuasion. However, it may have legal effect in some states, so the advice of an attorney is encouraged.

The Catholic Health Association of the United States
St. Louis, MO 63134

Directions For My Treatment

To my family, friends, pastor, physician, and attorney:

Because of my Christian belief in the dignity of the human person and my eternal destiny in God, I ask that if I become terminally ill I be fully informed of the fact so that I can prepare myself emotionally and spiritually to die.

I have a right to make my own decisions concerning treatments that might unduly prolong the dying process. If I become unable to make these decisions and have no reasonable expectation of recovery, then I request that no ethically extraordinary treatment be used to prolong my life but that my pain be alleviated if it becomes unbearable, even if this results in shortening my life. ("Ethically extraordinary treatment" is treatment that does not offer a reasonable hope of benefit to me or that cannot be accomplished without excessive expense, pain, or other grave burden.) However, no treatment should be used with the intention of shortening my life.

I request that my family, my friends, and the Christian community join me in prayer as I prepare for death. I request that after my death others continue to pray for me so that I will, with God's grace, enjoy eternal life.

Signed: ____________________

Date: ____________________

Witnessed: ____________________

Date: ____________________

Witnessed: ____________________

Date: ____________________

SUBMITTED BY SENATOR JOHN C. DANFORTH

Choices for the Journey

Durable Power of Attorney and Healthcare Decision Making for Religious

Brother Peter Campbell, CFX, JD

The Catholic Health Association of the United States
St. Louis, MO

ISBN 0-87125-163-9

4455 Woodson Road
St. Louis, MO 63134-0889

3

CONTENTS

[redacted]

DEATH: PHILOSOPHICAL AND PRACTICAL ISSUES

All members of Roman Catholic religious institutes (e.g. orders, congregations, monasteries, hermitages, and even society at large) must at some point discuss the topic of death. Whether the discussion occurs after a member dies, during a retreat, or in the course of the Church's liturgical year, it challenges every member to think about death which each of us must someday confront.

Such discussions often do not consider the practical issues relating to death and healthcare, however, these issues must be addressed. All that religious learn about being spiritually prepared for death remains important, but decisions may be required concerning the use of artificial or extraordinary means to prolong life. Each person, whether religious or lay, should decide beforehand what kind of life-prolonging means he or she would accept. Because an individual may not be able to make these critical decisions in an emergency, others will need to carry out the directives made in advance or act as the individual would likely act if competent to decide.

Naming a decision maker is especially critical. If none is named, American society usually looks to the natural family. Yet, if religious life has any special value and its usual decision-making process any relevance, the religious must make clear that usual presumptions about family responsibilities in healthcare decision making are inappropriate for religious. On the other hand, the family of a religious must not be excluded from playing a part in their loved one's dying. A religious should attempt to make clear, however, that religious life, especially when of long duration, has a validity that should not be ignored during healthcare decision making. The best way to ensure that the religious' values will be recognized is for the religious to make known beforehand by legal means the more important details to his or her religious institute, family, and physician(s) and to the general public.

Others may have the right to act on a religious' behalf, but today in the United States a religious is obligated to help in that process. The courts do not allow critical healthcare decisions to be made without attempting to determine the patient's wishes. In all critical healthcare choices the individual, therefore, whether competent or not, is always key to the decision-making process. Yet if a religious has not made a decision concerning a healthcare issue, such as use of a life-support system, someone else, perhaps not the person of choice, will be required to make the decision. The United States is in the process of developing procedures on critical healthcare decision making for patients who do not make their wishes known beforehand and who are no longer competent to decide. Unfortunately, this decision process is very complex. For a religious, it can involve the religious institute's leadership, the family, medical professionals, and the court.

Since different people may propose conflicting courses of action for an incompetent patient, the court often must decide what is in the patient's best interest. The court tries to protect all parties rights, but especially the patient's.

A court decision on a healthcare issue is usually slow and awkward, and the patient may die before a decision is made. Court procedures invade the patient's sphere of privacy and intimacy with family and friends at a time when the patient should be able to preserve the greatest personal dignity. Even in the best of court-resolved healthcare decisions, all the parties involved are frequently distracted by untimely needs to present their cases within ongoing, adversarial proceedings. A neutral party — the court — makes the final decision. Throughout the lengthy process the primary attempt is to decide what the patient would want if competent to decide.

Given the persistent American attempt to honor individual freedom, it therefore seems logical and sensible for religious to be more fully prepared for death. To be prepared today, a religious must take legal steps to clarify his or her healthcare decisions on *artificial* or *extraordinary* means for prolonging life and to name who makes such decisions if he or she is no longer competent.

Good planning for critical healthcare decisions will ensure that the religious receives the full dignity that should surround the dying process and will incorporate the basic values that characterize a religious' life. Once the

---

religious has identified which procedures to permit and which to exclude, he or she must create legal instruments like a living will or a durable power of attorney (see appendices). These legal instruments, discussed more fully below, permit a religious' wishes to be honored in the event he or she is incompetent.

Sample instruments should be studied to guide in the preparation of these legal documents. Care is needed, however, to observe and insert any relevant local law. All documents should be reviewed periodically to ensure that they continue to meet the individual's wishes, are still legal, and are not so outdated as to arouse suspicion whether they still express valid wishes.

ISSUES IN HEALTHCARE DECISION MAKING

There is no question that U.S. law protects an individual's right to make critical decisions on healthcare issues, including prolonging or terminating life. This right, however, is not absolute. When an individual acts in a reasonable manner that does not infringe on others' rights, the American legal system allows that person some degree of freedom in decision making. U.S. law is quite tolerant of the individual's right to make unusual healthcare decisions, provided they do not affect others' rights.

Although constraints on individuals' actions exist in certain areas of life, personal freedom to decide many areas of one's life is fiercely protected. In legal terms, these rights include especially a person's right to privacy.

Religious, as members of American society, have the same civil rights and obligations as any other persons. Entering religious life does not reduce an individual's civil freedoms. The religious, through vows, freely adopts a new style of life and agrees to some limitations on personal freedom. These limitations are free choices among religious, religious institutes, and the Church. The individual religious' free choice of living the religious life does not reduce basic civil freedoms. The individual religious has the same civil rights and obligations after vows as before vows.

Society always looks to the individual, even one who is a religious, to make informed decisions, including those on healthcare. Just as persons in every walk of life are influenced in their decision making by their life choices, so also a religious is influenced in his or her decisions by the choice to enter religious life. In the final analysis, however, the individual religious is still the best one to decide about his or her own healthcare, as about many other decisions.

A basic principle in the American legal system recognizes that a competent adult has the legal and moral right to refuse medical treatment. The legal right is qualified by the state's interest in preserving life, in protecting innocent third parties, in preventing suicide, and in maintaining the medical profession's ethical integrity. A companion principle is that the incompetent person has the same rights as the competent person regarding the legal right to refuse medical treatment. In this latter situation, other people must make the decisions the incompetent person should, but cannot, make.

A basic tenet in healthcare is that modern medical care works to heal and to prolong life. For many patients, recovery from an illness is short but the process of dying is long. Modern medicine can artificially prolong life even if it cannot ultimately prevent death. Death comes to everyone, but to very few is it sudden and unexpected.

Once an individual enters a healthcare facility, the emphasis is on sustaining life. Healthcare providers keep the patient informed and elicit decisions from the patient or from a surrogate about healthcare procedures they will or will not use. If healing is not likely, typically physician's desires and training will motivate them to prolong life. At some point healthcare providers' desires may not mesh with the patient's or surrogate's desires regarding a course of treatment. When this occurs and a patient is no longer competent, and his or her wishes are unknown or unclear, matters worsen. The players in the decision-making process on the patient's behalf, or on the healthcare providers' or the public's behalf, will have competing interests and liabilities. Possibly a hospital ethics committee will help the parties find a solution in the patient's best interests. If not, and as a last resort, recourse will be made to the court to work out conflicts and liabilities. The ideal course of events is to avoid going to court. To understand why this area can be so complicated, it is necessary to review some of the critical facets of healthcare decision making.

Informed Consent

Today in healthcare there is great emphasis on making sure that the patient understands the diagnosis and the various courses of treatment. Generally choices must be made in treatment decisions. The patient should understand that in the American system of law he or she must make those decisions. This understanding does not mean that the patient ignores healthcare professionals' knowledge, experience, and skill. It does mean that the patient must be informed of and understand what is happening and agree to some course of treatment. This agreement is known as informed consent, which derives from the patient's inherent dignity.

Informed consent is not an absolute term. Instead, it is a concept that considers many factors that can influence any decision. For healthcare, informed consent means that the patient understands what is wrong, what will be done, and what the consequences of both the illness and the course of treatment or nontreatment are. Fundamental to informed consent is that the patient must know the risks to his or her life and health in either accepting or refusing treatment.

A religious, when a patient, has the same right to make informed decisions as anyone else. A religious also has the right and opportunity to have others make informed decisions for him or her in a manner that makes sense for religious life and that is also acceptable to society. For a religious who has lived under vows and has frequently and freely ratified that choice, there will be no difficulty in satisfying society's concerns and spelling out any healthcare means to be used or avoided at death. The basic Christian values of respect for life, death, dying, and eternal life that are fundamental to religious life easily surmount any limitation society would impose on critical healthcare decisions.

5

Surrogates

When a patient cannot make healthcare decisions, and when no clear process exists for others to make those decisions, the situation becomes complex. It is possible that the interests of the parties involved will take precedence over the patient's right to die with dignity, especially in the context of Christian life. In theory this should not happen, but some cases that have moved through different courts suggest that the patient's best interests were lost in the time it took to wage an adversarial court case to guard against liability and make a decision.

Before the 1970s there was not much need for surrogate decision making. Families for their own members, and members of religious institutes for their own members, in cooperation with their physicians, made the critical decisions about healthcare procedures when the patient could not decide. This situation has changed in many ways.

One major change is the tremendous increase in available life-prolonging procedures. Another is the growth of lawsuits for medical malpractice against healthcare institutions and professionals. The healthcare provider is being challenged by the courts on behalf of patients and their survivors. Sometimes the standard of care is found wanting and the healthcare provider must pay monetary damages to the patient or to others on the patient's behalf.

The prominence that a potential lawsuit plays in the healthcare provider's mind cannot be denied, even if others may criticize the fear of a lawsuit as exaggerated. Fear of a lawsuit causes the healthcare provider to be more careful in making sure that informed consent has been obtained. Where the patient cannot provide the informed consent, healthcare providers want to be sure the law will protect them for actions taken at others' direction. This has led to the development of several ways through which the patient can still exercise control, or at least can influence healthcare decision making, when he or she is no longer competent to decide.

Another issue of note in regard to healthcare decision making is the type of decision that the Christian can or should make to be faithful to Christian traditions. Active destruction of one's own life or the leaving of directions for others to end one's life is contrary to the values of Christian tradition. Harming human life even in the guise of mercy is unacceptable and no one has a right to do so or to request such. Suicide or euthanasia are both actions that are wrong in the Christian tradition, and neither is in any way the proper subject of plans for healthcare decision making by a religious.

Suffering is a fact of human life and has special significance for the Christian as an opportunity to share in Christ's redemption. Nevertheless, there is nothing wrong in trying to relieve suffering. Besides making choices for different healthcare procedures, any planning for surrogate decision making should include the patient's wishes regarding relief of suffering, especially in certain types of painful terminal illness.

The religious must make sure that the traditions and values that guide religious life find their way into any plans for surrogate decision making. It is not enough to appoint someone to decide when one is no longer competent; it is important to provide the surrogate decision maker with examples of the types of decisions a religious would make and the underlying principles. First and foremost, Church teaching does not hold that life is an absolute value, but it is seen as a basic one that is a source and an indispensable condition of every human activity and all society. Therefore the religious should clearly state that life, although basic and fundamental, is not to be preserved and prolonged at all costs.

Every individual has a duty to care for his or her own body and to seek necessary medical care, but this does not mean that all remedies must be used in all circumstances. Traditional Church teaching holds that one is not obliged to use "extraordinary means" to prolong life when such means offer no reasonable hope or benefit or when they involve great hardship. Unfortunately, decisions in this regard are very complex. As medical science advances, the effectiveness of procedures on patients changes. No patient, even the religious patient, can or should make such decisions without discussing them with members of his or her own religious institute, with the family if possible, and with medical care providers.

LIVING WILL

One of the common ways a person can address the possibility of not being able to make healthcare decisions personally is by providing direction to others. In their simplest form, these directions may be no more than advice to physicians and others to follow in critical healthcare decision making. A popular name for these directions is a living will. In its short history it has evolved from a simple statement of nonbinding advice to a document that in some states must be followed.

In some ways the term living will is a curiosity and even a contradiction. It is obvious that whoever invented the phrase wanted to convey the idea that someone not yet dead was spelling out personal choices, in this case about healthcare decision making. The key word in the phrase living will is will, a term with a long history. Many people are advised to write a will in order to make their intentions known regarding their affairs after they are dead. Church law directs all religious to make a civilly valid will at the time they profess vows.

English common law has built up a vast body of law regarding wills, but the law deals with the content of a will only after the person making it is dead. A will has no use or effect over a person or his or her property during life. A will has relevance only after death. For example, a person can make a will leaving all his or her property to one person. Even though that will is ready to be used and is validly executed, the person may give the property to another so at the time of death there is no property to distribute. People may question such a person's good sense but no law was broken. At the time of death the will is valid, but regarding the property bequest, it will be ineffective. The will can control only what the person owns at the time of death.

For the lawyer trained in common law traditions, therefore the term living will was difficult to accept or appreciate. Today this is no longer such a problem because different state legislatures have defined the concept in ways to give it special effects.

The original intent of the living will concept was to borrow from the law an idea about a statement that expressed a person's wishes when he or she would be unable to do so. Whereas the true will is a binding document after death, the usual living will *has no binding effect*. It provides only advice. Yet it remains a useful tool for allowing one's decisions to be preserved.

Good living will statements exist in several forms and a religious can consider their use. On page 18 is a sample living will called a *A Christian Affirmation of Life: Directions For My Treatment*, published by The Catholic Health Association. The fact that the *Christian Affirmation of Life* is in its third edition indicates that it is still evolving to keep up with developments.

Many people in America have used different types of living will documents whether or not they were or are called living wills. The use of a living will is still a helpful way to make known one's wishes beforehand, but there has also been much activity around the country to address the fundamental defects in the living will. Merely providing advice is not enough, especially if it is not binding or if healthcare providers believe that following the advice does not protect them from liability.

To address the defects in the living will, different states have by statute defined the living will (sometimes under different names) as being more than advice. Some states have advanced the concept to where the living will amounts to a durable power of attorney (see below). Where state action has occurred, the trend is to make sure a citizen retains the right to make binding critical healthcare decisions or to have others make them when he or she is unable to act. The laws usually state that when healthcare providers rely on a living will document drafted to conform to the law, they are not liable for actions performed in good faith. In some places living will laws have made it mandatory that a medical provider honor a patient's wishes or withdraw from a particular case.

Most likely, generally acceptable living will documents, under various names, will emerge for use throughout the United States. Until that time comes, it is necessary to ensure that any document used conforms to local law and is checked periodically for continued validity. Religious have an additional problem not yet effectively treated in many living will statutes — the choice of a surrogate decision maker.

Some living will statutes require the physician to honor the patient's wishes and generally state that the physician should consult with the patient's family if he or she needs help in making decisions. The law presumes that the patient's family decides in place of the incompetent patient. This may not be an acceptable solution for a religious, nor one sensitive to the values of religious life. Few states provide in their living will statutes for nonfamily surrogates, but none demands that surrogates only be natural or legal family members. A religious, therefore, can choose to name surrogate decision makers, and a durable power of attorney, not a living will, is the better way to make that choice.

Power of attorney law has always recognized a person's ability to select an unrelated agent to act on his or her behalf. This area of law has some problems, but it is more developed. The durable power of attorney is a better choice for a religious to consider than a living will, since it is binding.

DURABLE POWER OF ATTORNEY

The concept of durable power of attorney has roots in the ancient English common law concept of power of attorney. Its growth into the longer phrase — durable power of attorney — is recent history. Yet it is an older concept than a living will. The difficulty with the durable power of attorney concept is that only very recently has it been considered for use in healthcare decision making. For years the plain power of attorney or durable power of attorney was never associated with healthcare matters. That situation is changing; in many states a well-drafted durable power of attorney can offer a religious an excellent means to express his or her wishes on critical healthcare decisions that others may have to enforce. It combines in one document control over one's healthcare wishes and the legal means to make sure one's wishes are carried out.

In English common law many of the legal structures found today developed in response to society's needs to act in an orderly manner. Corporations and trusts, for instance, are old concepts that are still developing to meet current needs. The power of attorney had similar roots as a response to society's needs to function in an age of limited communications. A businessperson could not be everywhere at once, and a person engaged in one place had no way to conduct affairs elsewhere. To address that problem, which was a real constraint on commerce, the person (the principal) was able to name an agent to act on the principal's behalf. Over time many formalities developed around this process, and it became known as granting a power of attorney. This does not mean that the agent must be an attorney.

One holding a power of attorney has a written instrument that delegates the principal's power to the agent in different ways and varying degrees depending on the principal and the business at hand. As the power of attorney developed, and for many years, it was effective only as long as the principal granting it could act at the very same time the agent acted if only the principal were present. If the principal could not act, the agent could not validly act. This concept makes sense if one considers that the power of attorney developed as a response to the inability to communicate or travel easily. No thought was given to what would happen if the principal could not act. The power of attorney thus was not valid if the principal became incapacitated.

In time a type of power of attorney evolved that could survive the incapacity of the principal granting it. This became known as a durable power of attorney. The change addressed the business reasons that usually surrounded the power of attorney when communication and travel improved to existing levels. When a person selects the durable power of attorney, he or she does not want business damaged just because the principal happens to be unable to act. Also, the durable power of attorney ensures that an individual's wealth, or business affairs, receive proper care even if the person is unable to conduct the affairs personally. In this latter sense the durable power of attorney provides a good response to healthcare decisions and a patient's inability to act, but it was not developed to grant powers about healthcare decisions. It was confined to business matters. Today all 50 states and the District of Columbia provide for a durable power of attorney in various matters. All cover business uses, but not all provide for healthcare decision making.

Some states specifically provide that a durable power of attorney can be used for healthcare, and many more do not prohibit healthcare purposes even if they are not specifically provided for in legislation. The durable power of attorney concept will no doubt evolve so that it will be recognized to cover not only business matters but healthcare matters as well.

Statements by a 1983 presidential commission and various governors' commissions that have looked at the whole process of healthcare decision making are clearly urging that the law move to recognize the need for knowing a patient's healthcare wishes and having a surrogate in place to carry out those wishes when the patient is unable to act. Not all the devices that are found in state law that address this problem are called a durable power of attorney, but more and more states are addressing these issues in both appropriate and legal ways. In time, common instruments will emerge nationwide.

Thus, a religious wishing to articulate his or her wishes for healthcare decision making and name a surrogate to act on his or her behalf can draft a legal instrument to that effect in most states. Even where the law is still evolving, or where it has been slow to address this concern, a durable power of attorney dealing with an individual's healthcare wishes and naming a surrogate decision maker can provide knowledge about the individual's desires. Even if the durable power of attorney is technically defective or is not recognized for healthcare uses, it can have value as a statement of the individual's wishes, since no court has ever denied the paramount importance of following a patient's clearly stated wishes regarding healthcare matters.

A religious using a durable power of attorney must make clear in the document that he or she is a religious. This ensures that the usual presumption of favoring family decision makers will not be used to preclude participation by members of one's religious institute in healthcare decisions.

Selection of one sample document over another for the durable power of attorney depends on a particular jurisdiction's legal concerns. For example, California has a specific form that has legal recognition and effect. In that state there should be no reason to deviate from the prescribed form. In most other states, one has some choice in how much to include in the document beyond stating one's religious life affiliation.

The religious must decide between a durable power of attorney restricted only to healthcare decision making or one that combines healthcare and business matters. Covering both healthcare and business matters may be important in some cases, but generally religious, who do not own property, do not need to include business powers in a durable power of attorney. On the other hand, when a religious institute in consultation with its attorney begins drafting a durable power of attorney for use by its members, it must be aware of how the durable power of attorney concept is understood in its own jurisdiction. If there is support for a durable power of attorney containing only healthcare powers, business powers can be omitted. If a jurisdiction has not developed its law on the durable power of attorney to consider healthcare powers, adding business powers, even if they are never needed, will strengthen the durable power of attorney document, ensuring its effectiveness. Business powers can thus become the bridge to give recognition to the health powers. One should not conclude that business powers should be excluded from a durable power of attorney just because they do not seem relevant. Legal advice concerning their inclusion or exclusion is crucial.

In the final analysis, a durable power of attorney is a legal instrument that must stand or fall on review by the legal system. One's own preferences regarding the form of the document are important but are secondary to the primary concern of ensuring the durable power of attorney's effectiveness.

While a religious institute and its attorney are drafting a durable power of attorney, the attorney most likely will play a key part, but this should not preclude the religious institute from making sure that the attorney gives proper place to statements in a durable power of attorney that explain that the religious made a free choice of entering religious life, has reaffirmed that choice in many ways through the years, and that life's values deserve recognition in any consideration or review by the users of the durable power of attorney document. These statements need not be long but should be clear. They should also address any potential questions on why family members are not holders of the power or why they are not looked to for critical healthcare decisions.

To cover fully the family issue, the durable power of attorney should include statements that the religious loves his or her family, but, because of the personal life choices made, expects the public to look to the religious institute through its lawful superiors for decision making when the religious cannot personally act. The document must clarify the religious' choice of life and that this choice counts for something. A durable power of attorney should not be suspect because the family is left out of the decision-making process. Even if the family wishes to interfere, as may happen, the durable power of attorney document should effectively notify all involved regarding the religious' intentions. Society easily recognizes that a husband will usually act on his wife's behalf, or vice-versa, and that blood relatives do not take precedence over a spouse. Society can be expected to do the same for religious and recognize the religious institute over the family.

Society recognizes legally the free choice of two people to marry and become a new family unit. Given this, society should and will, if notified, grant similar recognition to a religious' free choice of his or her religious "family." Society and its laws do protect an individual's rights to make known certain actions. If the contents of a durable power of attorney are ever questioned, and if the document is found defective, it at least can provide evidence on what course of action the religious expected to be followed.

Much has been said about drafting a good durable power of attorney, but the discussion has not covered one critical aspect of the document. Usually the person signing a durable power of attorney for healthcare decisions does not need it at the time of signing. If it were needed right away, serious questions would arise about the signer's competency to execute a legal instrument. How does a durable power of attorney become effective when it is needed?

Putting a durable power of attorney into effect usually is done by invoking the "springing power" (a statement that indicates how and when the durable power becomes effective) that should be in the document. The exact contents of the "springing power" can vary, but its purpose is to make the existence of the durable power of attorney known and to allow the agent holding the power to act. It is possible to grant the "springing power" to one party and the rest of the powers in the durable power of attorney to another. Usually the one obligated to carry out the individual's wishes will also have the "springing power."

Once a religious institute has a durable power of attorney it wishes to offer to its members, the members must understand its contents and its purpose. This is on the whole an easy and expected condition, but it is also vital to observe any legal formalities that will ensure that the document, if it ever is needed, will be effective. The law establishes minimum standards by which society recognizes legal instruments when the party who made them is unable to certify that the instrument belongs to him or her. Thus, certain formalities must be observed. In most states, a notary's certification to the durable power of attorney is advisable. The local attorney will know when to suggest that additional step. If it is suggested, it further validates the document.

Finally, the durable power of attorney, like the living will is still evolving. Care should be taken to ensure that a document once established for a religious institute (more than one document may be needed by some institutes in multiple jurisdictions) retain its validity. It may be necessary to revise it periodically. Also, any policy in effect should encourage members of the religious institute to redo the durable power of attorney periodically to ensure that their intentions regarding healthcare have not changed. An additional reason for redoing the durable power of attorney is to allow for the steady advance of technology. Basic Christian values applied to healthcare will require the religious to reevaluate continually the medical means that will or will not be used in his or her case.

In conclusion, legal means are now available to help religious make responsible decisions about their healthcare at the time of death. Not to use these means automatically shifts control of decision making to the religious' family or to society at large and places at risk the value a religious gives to death with dignity through being fully prepared as a Christian. To take this risk is both irresponsible and unnecessary.

APPENDICES

The following sample is the *Christian Affirmation of Life*, published in 1987 by The Catholic Health Association of the United States. It offers an introduction on the decision-making process surrounding healthcare issues and includes the actual form expressing one's wishes for decision making.

The sample General Durable Power of Attorney describes the full range of business, personal, and healthcare powers that a religious could delegate to another person, such as the major superior of the religious institute or even a major part of the institute. The document also allows for the major superior to decide when the "power" becomes effective and if another should act in the major superior's place. State law will influence under what form and title the concepts discussed in the text can be made effective. State law forms and practice must be followed carefully.

The sample Durable Power of Attorney for Healthcare is similar to the General Durable Power of Attorney but is confined to healthcare decision making. Note that the document that will be effective to accomplish the principal's wishes and will be effective within a particular state's legal system is the better choice. Possibly a General Durable Power of Attorney that includes healthcare issues will be more effective in some states than the more limited Durable Power of Attorney for Healthcare. Legal advice is needed to allow a religious or religious institute to make the best choice.

The durable power of attorney samples suggest that the agent for a religious be the Major Superior (e.g., Superior General, Provincial), but religious can select any agent. If the agent is other than the Major Superior, the religious institute must decide whether it can cooperate in decisions the agent makes. A religious institute has rights and cannot be bound to the consequences of decisions made by agents of its members who have no authority or responsibility for the institute's leadership and welfare.

CHRISTIAN AFFIRMATION OF LIFE

Christians believe that in death life is transformed by the power of Christ's death and resurrection into eternal life. Because of this belief it is not always necessary to use every possible means to resist death. Persons who are dying should be given whatever support they desire to alleviate pain and to prepare for death, but they have no obligation to endure medical interventions that unduly prolong their dying without offering them reasonable benefit.

Persons who are terminally ill have the right and the primary responsibility to decide to what extent they will receive treatment. In order that they can exercise this responsibility, they should be fully advised of the diagnosis, the prognosis, the proposed treatment, other available treatment options, and the risks and benefits of each course of action.

When a person is unable to make decisions regarding treatment, others, usually the next of kin, will do so, but they must make these judgments in accordance with the person's legitimate wishes, if they are known. The "Christian Affirmation of Life" is provided as a means of indicating one's desires regarding treatment at the time of terminal illness. It is not intended as a legal document, but one of moral persuasion. However, it may have legal effect in some states, so the advice of an attorney is encouraged.

Directions For My Treatment

To my family, friends, pastor, physician, and attorney:

Because of my Christian belief in the dignity of the human person and my eternal destiny in God, I ask that if I become terminally ill I be fully informed of the fact so that I can prepare myself emotionally and spiritually to die.

I have a right to make my own decisions concerning treatments that might unduly prolong the dying process. If I become unable to make these decisions and have no reasonable expectation of recovery, then I request that no ethically extraordinary treatment be used to prolong my life but that my pain be alleviated if it becomes unbearable, even if this results in shortening my life. ("Ethically extraordinary treatment" is treatment that does not offer a reasonable hope of benefit to me or that cannot be accomplished without excessive expense, pain, or other grave burden.) However, no treatment should be used with the intention of shortening my life.

I request that my family, my friends, and the Christian community join me in prayer as I prepare for death. I request that after my death others continue to pray for me so that I will, with God's grace, enjoy eternal life.

Signed: ____________________
Date: ____________________
Witnessed: ____________________
Witnessed: ____________________

[redacted]

GENERAL DURABLE POWER OF ATTORNEY

I (full legal name and if applicable add religious name) presently of (city and state) hereby appoint Sister/ Brother/Father, (title – provincial, general superior or president, etc.) of the (full title of the religious institute or religious title of the province of a named religious institute; titles should be Church names and not corporate titles) and (her/his) successor in this same office as my attorney-in-fact (herein called agent). I further grant the same status as my attorney-in-fact (agent) to any other member of the (restate the name of the religious institute) designated in writing by the (restate the title of the superior) or other designated agent may act alone or in cooperation with each other. Mention of agent, agent(s) or agents shall not require joint action by my agents. Once this power is declared effective, each agent alone may act validly. Who acts shall be controlled by the (restate the title of the superior).

EFFECTIVE DATE OF DURABLE POWER OF ATTORNEY. This durable power of attorney shall become effective on my disability or incapacity and shall thereafter not be affected by such disability or incapacity. The effective date shall be determined by the (restate the title of the superior) in writing attached to this durable power and (his/her) decision shall not be questioned by any third party.

I expect that the (restate the title of the superior) may declare all or part of this power of attorney effective depending on the circumstances and (he/she) shall be guided in this decision by consultations with appropriate healthcare professionals. Once the power is invoked, any agent given authority to act on my behalf may do so. Further, this durable power of attorney is intended to be effective in and conform to the laws of my state of residence indicated above.

MY LIFE AS A MEMBER OF (name of the religious institute and of province if applicable). It is my firm conviction that my life as a member of this religious institute has meaning and value in any circumstance that occurs once this durable power of attorney is declared effective. My decision to join the (repeat the name of the religious institute) was a free choice and is one that has been constantly reaffirmed over the years by my free choice to live the life of religious in this religious community. I do not wish any third party to look to anyone else for decisions regarding me except those acting as my agent(s).

I especially expect healthcare providers to act on my behalf as directed by my agent(s) and not to look to my family for decisions about my care. Also, I expect my family to honor my wishes and not interfere in decisions about my life or care. This desire in no way manifests a lack of love for my family, but it does recognize that I am a member of (named religious institute) and the proper one to decide about my care is the major superior of my religious institute acting personally or through other members as my agent(s). My agent(s), however, may consult with my family regarding my affairs or healthcare, and I encourage such consultation. If, against my wishes, this power of attorney, or decisions made because of it, is referred to a court of law, I expect the usual presumptions found in law to look to family especially for healthcare decisions to be put aside. I made a free choice in life to be a member of (name of religious institute and province if applicable) and to execute this durable power of attorney; I expect those choices to be honored and the decisions made by my agent(s) to be upheld.

GRANT OF POWERS. I grant to my agent(s) the following general business and healthcare powers to be exercised in my name and for my benefit:

1. *General Grant of Power.* To exercise or perform any act, power, duty, right, or obligation whatsoever that I now have or may hereafter acquire, relating to any person, matter, transaction, or property, real or personal, tangible or intangible, now owned or hereafter acquired by me, including, without limitation, the following specifically enumerated everything necessary in exercising any of the powers herein granted as fully as I might or could do if personally present, with full power of substitution or revocation, hereby ratifying and confirming all that my agent(s) shall lawfully do or cause to be done by virtue of this power of attorney and the powers herein granted;

2. *Collection Powers.* To forgive, request, demand, sue for, recover, collect, receive, hold all such sums of money, debts, dues, commercial paper, checks, drafts, accounts, securities, retirement or insurance benefits, all documents of title, all property of any type, now or hereafter owned by, or

due, owing payable or belonging to me or in which I have or may hereafter acquire an interest; to have, use, and take all lawful means and equitable and legal remedies and proceedings in my name for the collection and recovery thereof, and to adjust, sell, compromise, and agree for the same, and to execute and deliver for me on my behalf, and in my name, all endorsements, releases, receipts, or other sufficient discharges for the same;

3. *Real and Personal Property Powers.* To agree for, contract, purchase or sell, receive or exchange, and maintain any type of property in any form of ownership upon such terms and conditions as my agent(s) shall determine;

4. *Contract Powers.* To make, do, and transact every kind of business of whatever nature, and also for me and in my name, and as my act and deed, to sign, seal, execute, deliver, and acknowledge any and all documents resulting from such business;

5. *Banking Powers.* To make, draw, sign in my name, deliver, and accept all banking instruments for deposit or withdrawal from any commercial or savings account;

6. *Tax Returns.* To prepare, execute and file reports, returns, declarations, forms, and statements for any and all tax purposes, to pay such taxes and any interest or penalty thereon or additions thereto; to make and file objections, protests, claims for abatement, refund or credit in relation to any such tax proposed, levied, or paid;

7. *Restrictions on Agents' Powers.*
   a. No power exists to execute a will, trust, or codicil on my behalf by my agent(s) but my agent(s) can enter into custodial arrangements with a bank with trust powers.
   b. No assets of mine can be directed to my agent(s) unless after my death my will so directs.

8. *Interpretations and Governing Laws.* This instrument is to be construed and interpreted as a general durable power of attorney subject to the laws of the state of my residence. The enumeration of some specific powers herein is not intended, nor does it limit or restrict, the general powers herein granted to my agent(s) or those powers provided by statute. No grant of power contrary to law should negate the

effect of the remaining lawful powers or the general intent of this durable power of attorney.

9. *Personal and Medical Care.* My agent(s) are to make each and every judgment necessary for the proper and adequate care and custody of me including to fire, employ, pay for, and discharge such domestic help, nursing services, and practical and/or registered nurses as my agent(s) may determine to be in the best interests of my health, and the power to give an informed consent or any informed refusal on my behalf with respect to my physical or mental healthcare and comfort, including specifically by way of illustration only and not by way of limitation:

a. Any medical care, diagnosis, surgical procedure, therapeutic procedure and/or other treatment of any type or nature;
b. Any physical rehabilitation program;
c. Any dental procedure;
d. Any psychiatric or psychological care or treatment;
e. The admission to any hospital, medical center, nursing home, or mental institution;
f. The use of any drugs, medication, therapeutic devices, or other medicines or items related to my health;
g. The execution of waivers, medical authorizations, and such other approval as may be required to permit or authorize care which I may need;
h. The waiver of any doctor-patient privilege; and the power in general to take and authorize all acts with respect to my health and well-being, and to expend all amounts in connection therewith to the same extent as I could if mentally competent to do so. The prices, costs, expenses, and compensation incurred in furtherance of the foregoing are all to be within the sole and absolute discretion of my agent(s);
i. The access to any and all medical information from past or present.

10. *Terminate Life Support Systems.* I wish to live as long as possible, but I do not wish to receive futile medical

treatment, which I define as treatment that will provide no benefit to me and will only prolong my inevitable death or irreversible coma. Therefore, my agent(s) are to request that aggressive medical therapy not be instituted or, if instituted, be discontinued, including (but not limited to) cardiopulmonary resuscitation, the implantation of a cardiac pacemaker, renal dialysis, parenteral feeding, the use of respirators or ventilators, blood transfusions, nasogastric tube use, intravenous feedings, endotracheal tube use, antibiotics, and organ transplants. They should try to discuss the specifics of any such decision with me if I am able to communicate with them in any manner, even by blinking my eyes. If I am unconscious, comatose, senile, or otherwise unreachable by such communication, my agent(s) should make the decision guided primarily by any preferences that I may have previously expressed and secondarily by the information given by the physicians treating me as to my medical diagnosis and prognosis. My agent(s) may specifically request and concur with the writing of a "no-code" (DO NOT RESUSCITATE) order by the attending treating physician.

CERTIFICATION FOR ARTICLES 9 AND 10

I certify that I have read Articles 9 and 10 authorizing my agent(s) to refuse medical treatment for me under the circumstances specified in these articles, that I understand such provisions, and that such provisions state my wishes and desires under the circumstances described.

____

(Signature)

11. *Provide Me Relief from Pain.* My agent(s) are to consent to and arrange for the administration of pain-relieving drugs of any type, or other surgical or medical procedures calculated to relieve my pain even though their use may lead to permanent physical damage, addiction, or even hasten the moment of (but not intentionally cause) my death.

12. *Protect My Right of Privacy.* My agent(s) are to exercise my right of privacy to make decisions regarding my medical treatment and my right to be left alone even though

the exercise of my right might hasten death or be against conventional medical advice. They may take appropriate legal action, if necessary in their judgment, to enforce my right in this regard.

13. *Make Anatomical Gifts.* My agent(s) have the power to make anatomical gifts to such persons and organizations as deemed appropriate.

14. *Funeral Arrangements.* My agent(s) shall make any arrangements for my funeral and burial.

15. *Power to Nominate Conservator or Guardian.* If required by law or by a court order, my agent(s) should nominate and/or petition for the appointment of one agent named herein to be a guardian, conservator, or serve in any fiduciary office representing me or any interest of mine. Also, I waive any bond requirement such office may require.

16. *Third Party Reliance.* For the purpose of inducing any medical care provider, bank, broker, custodian, insurer, lender, transfer agent, taxing authority, governmental agency, or other party to act in accordance with the powers granted in this document, I hereby represent, warrant, and agree that:

a. If this document is revoked or amended for any reason, I, my estate, my heirs, successors, and assigns will hold such party or parties harmless from any loss suffered, or liability incurred, by such party or parties in acting in accordance with this document prior to that party's receipt of written notice of any such termination or amendment.

b. The powers conferred on my agent(s) by this document may be exercised by them alone, and a signature or act under the authority granted in this document may be accepted by third parties as fully authorized by me and with the same force and effect as if I were personally present, competent, and acting on my own behalf.

c. No person who acts in reliance on any representation made as to the scope of authority granted under this document shall incur any liability to me, my estate, my heirs, successors, or assigns for permitting the exercise of any such power, nor shall any person who deals with my agent(s) be responsible to determine or insure the proper applications of funds or property.

d. All third parties from whom my agent(s) may request information regarding my health or personal affairs are hereby authorized and directed to provide such information to them without limitation and are released from any legal liability whatsoever to me, my estate, my heirs, successors, or assigns for complying with their requests. With specific reference to medical information, including information about my mental condition, I hereby authorize in advance all physicians and psychiatrists who have treated me and all other providers of healthcare, including hospitals, to release to my agent(s) all information and photocopies of any records that my agent(s) may request.

17. *Photographic Copies.* Photographic or other facsimile reproductions of this executed power may be made and delivered by my agent(s) and may be relied on by any person to the same extent as though the copy were an original. Anyone who acts in reliance on any representation or certificate of my agent(s) or on a reproduction of this power shall not be liable for permitting my agent(s) to perform any act pursuant to this power.

I have signed and delivered this General Durable Power of Attorney this _____ day of ____________, ______.

____
Signature

WITNESSED: ______________________________
Signature

____
Signature

State of ______________________________
County of ______________________________

On this _____ day of ____________, _____, personally appeared ______________________ before me, a Notary Public, who executed the above General Durable Power of Attorney, and acknowledged the same to be his/her free act and deed.

Subscribed and sworn to before me, this _____ day of ____________, _____.

____
Notary Public

My Commission expires

____

DURABLE POWER OF ATTORNEY FOR HEALTHCARE

I (full legal name and if applicable add religious name) presently of (city and state) hereby appoint Sister/ Brother/Father, (title-provincial, general superior or president, etc.) of the (full title of the religious institute or religious title of the province of a named religious institute; titles should be Church names and not corporate titles) and (her/his) successor in this same office as my attorney-in-fact (herein called agent). I further grant the same status as my attorney-in-fact (agent) to any other member of the (restate the name of the religious institute) designated in writing by the (restate the title of the superior) or other designated agent may act alone or in cooperation with each other. Mention of agent, agent(s) or agents shall not require joint action by my agents. Once this power is declared effective, each agent alone may act validly. Who acts shall be controlled by the (restate the title of the superior).

EFFECTIVE DATE OF DURABLE POWER OF ATTORNEY FOR HEALTHCARE. This durable power of attorney for healthcare shall become effective on my disability or incapacity and shall thereafter not be affected by such disability or incapacity. The effective date shall be determined by the (restate the title of the superior) in writing attached to this durable power, and (his/her) decision third party.

I expect that the (restate the title of the superior) may declare all or part of this power of attorney effective depending on the circumstances, and (he/she) shall be guided in this decision by consultations with appropriate healthcare professionals. Once the power is invoked, any agent given authority to act on my behalf may do so. Further, this Durable Power of Attorney is intended to be effective in and conform to the laws of my state of residence indicated above.

MY LIFE AS A MEMBER OF (name of the religious institute and of province if applicable) It is my firm conviction that my life as a member of this religious institute has meaning and value in any circumstance that occurs once this durable power of attorney is declared effective. My decision to join the (repeat the name of the religious institute) was a free choice and is one that has been constantly reaffirmed over the years by my free choice to live the life of religious in this religious community. I do not wish any third party to look to anyone else for decisions regarding me except those acting as my agent(s).

I especially expect healthcare providers to act on my behalf as directed by my agent(s) and not to look to my family for decisions about my care. Also, I expect my family to honor my wishes and not interfere in decisions about my life or care. This desire in no way manifests a lack of love for my family, but it does recognize that I am a member of (named religious institute), and the proper one to decide about my care is the major superior of my religious institute acting personally or through other members as my agent(s). My agent(s), however, may consult with my family regarding my affairs or healthcare, and I encourage such consultation. If, against my wishes, this power of attorney, or decisions made because of it, is referred to a court of law, I expect the usual presumptions found in law to look to family, especially for healthcare decisions, to be put aside. I made a free choice in life to be a member of (name of religious institute and province if applicable) and to execute this durable power of attorney; I expect those choices to be honored and the decisions made by my agent(s) to be upheld.

GRANT OF POWERS. I grant to my agent(s) the following healthcare and related powers to be exercised in my name and for my benefit:

1. *Personal and Medical Care.* My agent(s) are to make each and every judgment necessary for the proper and adequate care and custody of me including to hire, employ, pay for, and discharge such domestic help, nursing services, and practical and/or registered nurses as my agent(s) may determine to be in the best interests of my health, and the power to give an informed consent or any informed refusal on my behalf with respect to my physical or mental healthcare and comfort, including specifically by way of illustration only and not by way of limitation:

   a. Any medical care, diagnosis, surgical procedure, therapeutic procedure, and/or other treatment of any type or nature;
   b. Any physical rehabilitation program;
   c. Any dental procedure;
   d. Any psychiatric or psychological care or treatment;

e. The admission to any hospital, medical center, nursing home, or mental institution;
f. The use of any drugs, medication, therapeutic devices, or other medicines or items related to my health;
g. The execution of waivers, medical authorizations, and such other approval as may be required to permit or authorize care that I may need;
h. The waiver of any doctor-patient privilege; and the power in general to take and authorize all acts with respect to my health and well-being, and to expend all amounts in connection therewith to the same extent as I could if mentally competent to do so. The prices, costs, expenses, and compensation incurred in furtherance of the foregoing are all to be within the sole and absolute discretion of my agent(s);
i. The access to any and all medical information from past or present.

2. *Terminate Life Support Systems.* I wish to live as long as possible, but I do not wish to receive futile medical treatment, which I define as treatment that will provide no benefit to me and will only prolong my inevitable death or irreversible coma. Therefore, my agent(s) are to request that aggressive medical therapy not be instituted or, if instituted, be discontinued, including (but not limited to) cardiopulmonary resuscitation, the implantation of a cardiac pacemaker, renal dialysis, parenteral feeding, the use of respirators or ventilators, blood transfusions, nasogastric tube use, intravenous feedings, endotracheal tube use, antibiotics, and organ transplants. They should try to discuss the specifics of any such decision with me if I am able to communicate with them in any manner, even by blinking my eyes. If I am unconscious, comatose, senile, or otherwise unreachable by such communication, my agent(s) should make the decision guided primarily by any preferences that I may have previously expressed and secondarily by the information given by the physicians treating me as to my medical diagnosis and prognosis. My agent(s) may specifically request and concur with the writing of a "no-code" (DO NOT RESUSCITATE) order by the attending treating physician.

3. *Provide Me Relief from Pain.* My agent(s) are to consent to and arrange for the administration of pain-relieving drugs of any type or other surgical or medical procedures calculated to relieve my pain even though their use may lead to permanent physical damage, addiction or even hasten the moment of (but not intentionally cause) my death.

4. *Protect My Right of Privacy.* My agent(s) are to exercise my right of privacy to make decision regarding my medical treatment and my right to be left alone even though the exercise of my right might hasten death or be against conventional medical advice. They may take appropriate legal action, if necessary in their judgment, to enforce my right in this regard.

5. *Make Anatomical Gifts.* My agent(s) have the power to make anatomical gifts to such persons and organizations as deemed appropriate.

6. *Funeral Arrangements.* My agent(s) shall make any arrangements for my funeral and burial.

7. *Power to Nominate Conservator or Guardian.* If required by law or by a court order, my agent(s) should nominate and/or petition for the appointment of one agent named herein to be a guardian, conservator, or serve in any fiduciary office representing me or any interest of mine. Also, I waive any bond requirement such office may require.

8. *Interpretations and Governing Laws.* This instrument is to be construed and interpreted as a durable power of attorney for healthcare subject to the laws of the state of my residence. The enumeration of some specific powers herein is not intended, nor does it limit or restrict the powers herein granted to my agent(s). No grant of power contrary to law should negate the effect of the remaining lawful powers or the general intent of this durable power of attorney for healthcare.

9. *Third Party Reliance.* For the purpose of inducing any medical care provider, governmental agency, or other party to act in accordance with the powers granted in this document, I hereby represent, warrant, and agree that:

a. If this document is revoked or amended for any reason, I, my estate, my heirs, successors, and assigns will hold such party or parties harmless from any loss suffered, or liability incurred, by such party or parties in acting in accordance with this document prior to that party's receipt of written notice of any such termination or amendment.

b. The powers conferred on my agent(s) by this document may be exercised by them alone, and a signature or act under the authority granted in this document may be accepted by third parties as fully authorized by me and with the same force and effect as if I were personally present, competent, and acting on my own behalf.

c. No person who acts in reliance on any representation made as to the scope of authority granted under this document shall incur any liability to me, my estate, my heirs, successors, or assigns for permitting the exercise of any such power, nor shall any person who deals with my agent(s) be responsible to determine or ensure the proper applications of funds or property.

d. All third parties from whom my agent(s) may request information regarding my health or personal affairs are hereby authorized and directed to provide such information to them without limitation and are released from any legal liability whatsoever to me, my estate, my heirs, successors, or assigns for complying with their requests. With specific reference to medical information, including information about my mental condition, I hereby authorize in advance all physicians and psychiatrists who have treated me and all other providers of healthcare, including hospitals, to release to my agent(s) all information and photocopies of any records that my agent(s) may request.

10. *Photographic Copies.* Photographic or other facsimile reproductions of this executed power may be made and delivered by my agent(s) and may be relied on by any person to the same extent as though the copy were an original. Anyone who acts in reliance on any representation or certificate of my agent(s), or on a reproduction of this power,

shall not be liable for permitting my agent(s) to perform any act pursuant to this power.

I have signed and delivered this Durable Power of Attorney Attorney this _____ day of ___________, _____.

____
Signature

WITNESSED: ______________________________
Signature

____
Signature

State of ______________________________
County of ______________________________

On this _____ day of ___________, _____, personally appeared ____________________ before me, a Notary Public, who executed the above Durable Power of Attorney for Healthcare, and acknowledged the same to be his/her free act and deed.

Subscribed and sworn to before me, this _____ day of ___________, _____.

____
Notary Public

My Commission expires

____

The Catholic Health Association of the United States is the national organization of Catholic hospitals and long term care facilities, their sponsoring organizations and systems, and other health and related agencies and services operated as Catholic. It is an ecclesial community participating in the mission of the Catholic Church through its members' ministry of healing. CHA witnesses this ministry by providing leadership both within the Church and within the broader society and through its programs of education, facilitation, and advocacy.

This document represents one more service of The Catholic Health Association of the United States, 4455 Woodson Road, St. Louis, MO 63134-0889, 314-427-2500.

About the Author

Brother Peter Campbell, CFX, JD, a member of the Brothers of St. Francis Xavier, is Senior Attorney for The Catholic Health Association of the United States. He received a JD, from The Catholic University of America. He was formerly the Director of the Office of Legal Services, a project of the Conference of Major Superiors of Men, the Leadership Conference of Women Religious, and the National Association of Religious Institutes.

Brother Peter has been a member of the board of directors of several healthcare corporations and systems, and the Lawyer Advisory Committee to the Board of Directors of The Catholic Health Association. He has consulted with religious institutes in financial crisis.

PREPARED STATEMENT OF JULIANNE DELIO

My name is Julie Delio. I am from New York and I would like to tell you of some of my experiences pertinent to this Patient Self Determination Act.

In 1986, my husband, Daniel Delio, underwent a minor operation to repair a rectal fistula. During the operation due to an act of negligence by the anesthesiologist , his brain was destroyed rendering him permanently unconscious. Danny suffered not only cortical brain death but also the misfortune of having his heart revived even though his human essence had been destroyed. His EEG was flatline; he had brainstem function only. He was 33 years old. He was a PhD in exercise physiology ,an expert in cardiac rehabilitation and exercise rehabilitation for hypertensives and diabetics as well as a marathon runner. His life was essentially over. He had been thrown into a persistent vegetative state.

At this point medicine was able only to offer him an existence in oblivion. He was being kept "alive" by artificial nutrition and hydration forced through a jeujunostomy tube into his intestines. He was entirely defenseless against medical technology that forced upon him an existence which he found abominable. He was prepared to accept a natural death.

Danny believed the death of the cortex to be synonymous with death of the person. This belief stemmed from his extensive scientific understanding of the body and all its integrated functions as well as from his philosophy of life.

Danny and I had had extensive, detailed discussions on vegetative states and artificial life support measures. He had made me promise never to let him live even one day in such a state. His mother and I were the only ones left to speak for him. I requested termination of all life support including artificial nutrition and hydration so that his death , begun by the doctors who operated on him could finally conclude.

At that time I was employed as an Assistant Professor of Medicine at NY Medical College which is affiliated with Westchester County Medical Center (WCMC), the facility to which Danny had been transferred for treatment. The Chairman of the Department of Medicine to whom I reported at NY Medical College was also the Chief of Medicine and Chairman of the Medical Board of Directors at WCMC. Despite the fact that WCMC doctors privately agreed with my request to terminate life support measures, the hospital officially ignored my request and forced me to resort to litigation. After filing the necessary lawsuit, I was fired.

My termination was a clear message to WCMC physicians. Among other fears, the MDs were afraid of losing their jobs as I had lost mine. The Hospital administration was making all decisions from a "risk management" viewpoint. The medical staff who knew and understood the medical issues and Danny's family who knew and understood his desires were shut out.

All of the physicians sympathized with me, but none had the courage to do anything about it. They all told me how brave

I was for going to court. They said it was the only way, and that I would help them as physicians and so many other patients like Danny. They said it was desperately needed. The hypocrisy was sickening. Our family had to pay the price for the doctor's inability to resolve this situation.

Taking my case to court alienated me from the medical community. No physician ever called me after I filed my law suit. They continued treating him aggressively without informing me and without my consent until I threatened them with criminal assault charges. Then they made me sign refusal to consent to treatment forms each time they felt he required some form of treatment. They made me feel like I was signing a death warrant each time.

The judicial process was devastating to me and my mother-in-law. The loss of my husband was tragic enough, yet I was then forced to plead publicly to strangers for his death. You cannot imagine the psychological trauma involved in pleading for the death of the person you love most in this entire world. I could barely concentrate in court. I was so afraid.

After 13 harrowing months in the court system, the NY State Appellate Division upheld Danny's right to refuse treatment even though he was no longer able to speak for himself.

After the NY State Appellate Court ruled in our favor giving me the right to remove all unwanted treatment for my husband, the hospital still refused to terminate treatment. The day after the court order came down, the feeding tube fell out as had so often happened throughout the year. I begged them not to reinsert it, citing the Appellate Court Decision on our right to refuse this treatment. A Doctor promised that the tube would not be put back in. I left the hospital late that night only to return early the next day to find they had not only reinserted this tube into my unconscious defenseless husband but they also stitched it in! I will never forget the fresh blood on his emaciated stomach. There was no record of who reinserted the tube, who gave the order and no MD would face me to explain. The administration had ordered this to be done against my husband's wishes and against my wishes as his court appointed conservator.

The hospital was ordered to terminate treatment or transfer Danny to another facility that would agree to abide by his wishes. WCMC said they would not appeal the decision as long as we agreed to transfer him. They simply wanted to wash their hands of this whole affair. Their inhumanity added enormously to our private tragedy. Families should not be stigmatized by County or public facilities and further traumatized by forced transfer as my family was simply for requesting their legal rights. Why should a County hospital be able to refuse a patient's legal Court sanctioned rights when Danny's physicians in that hospital were willing to comply with the court order?

After a heart wrenching search Danny was transferred to Beth Isreal Hospital in Manhattan so that his death which began 13 months earlier would be allowed to conclude. Ten days later he died quietly in my arms, surrounded by his mother and uncle. We thought it was finally over for him.

But not even death gave him release from the bureaucracy of our medical and legal communities. Two hours before his funeral I was informed that the NYC Coroner's office refused to issue a cremation certificate. They demanded an autopsy on Danny's body. No one could tell me why. After his funeral they took his body to the city morgue and autopsied him. Two days later I was called to identify his body.

When Danny died, I donated all of his organs according to his wishes. I was told his year in a vegetative state had left all of his organs except for his corneas useless to the living. Artificial nutrition was not even minimally able to keep him in an acceptable state for organ donation. The power of medicine was only to further destroy his body.

Had my husband been allowed to die a natural death when his brain was first destroyed at least five others could have lived. Had the doctors been empowered to honor his wishes in a timely fashion, without me going to court, his heart, liver, kidneys, bones and skin could have been used to give back to others the joy of life which had been taken from my husband. Danny's tragedy was a tragedy for many other lives.

Danny did not have a will. He never put his wishes in writing. I did not even have power of attorney for him even though we were a well educated couple and knew these things were important. We were young and enjoying a happy life.

Who would have known what was to happen to us? That Danny and I talked so extensively about vegetative states was amazing to most people. Most people are not like him. They have not and will not speak of these issues in the kind of depth our courts and laws seem to be requiring of our American families. These people will still be at risk for all the things that happened to Danny and me.

Even though the court system eventually worked for us, we were brutalized by it. Emotionally , our family paid dearly by fighting for his rights. I believe no one should ever have to go to court under these circumstances. Court is the last place a family belongs when they are facing their darkest hours.

We were not a typical family - both of us had PhD's, had extensive scientific training, and had worked in a medical setting for years. We were able to offer clear and convincing evidence of my husband's wishes. What has happened to the Cruzan family is far more typical. The system failed them. Their case is a more typical and more horrifying example of how most American families will fare in our present system.

For us it is too late, but perhaps somehow we can lessen the devastation to others in the future.

Julie Delio

ADDENDUM

49-04 Annandale Lane
Little Neck, New York 11362

February 3, 1987

Ms. Tracy Miller,
Executive Director
New York State Task Force
on Life and the Law
33 West 34th Street, 3rd Floor
New York, New York 10001-3071

Dear Members of the N.Y.S. Task Force on Life and the Law:

I understand that you are currently discussing Living Will legislation and intend to propose such legislation for New York State. Tracy Miller has urged me to write to you in an effort to inform you of some of my experiences since my husband, Daniel Delio, was tragically thrown into a vegetative state. I am not simply theorizing or philosophizing about termination of treatment for the permanently comatose; I am living it. You have a responsibility and an obligation to consider my experiences. The psychological and physical trauma of my experience cannot possibly be conveyed in a letter of this sort but I must tell you of some of the events that have occurred since the beginning of this tragedy.

My husband has been vegetative for eight months. He suffered cortical brain death during minor surgery on a rectal fistula last May. He has brain stem function only. All indications are that there was induced cerebral hypoxia, due to physician error. My husband is 33 years old. He was a marathon runner and was in prime physical condition. He had a Ph. D. in Exercise Physiology. I am 32 years old. I also have a Ph. D. in Exercise Physiology and until last September, I was an Assistant Professor of Medicine at New York Medical College. I was terminated from employment at New York Medical College after I filed my petition to terminate all medical care for my husband at Westchester County Medical Center (WCMC). When I asked why I was terminated, the Department of Medicine Administrator told me they didn't need a reason to terminate anyone. He said they were an "at will" employer. It is of interest to note that New York Medical College and WCMC are closely allied.

I requested termination of all medical treatment including nutrition and hydration because these were Danny's wishes under such circumstances. I am currently waiting for my appeal to be heard by the Appellate level of the New York State Supreme Court.

The loss of my husband's life is a tragedy and continuing nightmare in and of itself. What has happened to his family is a horror story worthy of note.

First, you must understand that Danny and I both believed that the death of the cortex is synonymous with death of the person. Please realize this belief stems from our extensive scientific understanding of the body and all its integrated functions as well as from our philosophy of life.

When my husband's diagnosis was clear to me I requested termination of all medical treatment. The attending physician refused. The reasons given were:

> "You have a medical malpractice suit pending against St. Agnes Hospital. The doctors at St. Agnes are going to point a finger at me and say 'We didn't kill him, you did.'"

"There is a 'hot shot' D.A. in Westchester County who charged a physician with manslaughter under similar circumstances. I can be charged with manslaughter if I terminate treatment. (The D.A. later sent a statement to all parties saying he felt this was essentially a private matter for the family and the physicians. The doctors still felt threatened)."
"If I terminate care, any of the nurses or any other right to life group can make charges against me."

"That's a societal decision. I can't make that decision."

Danny and his medical condition was not considered even once in these comments. Not a single reason had anything to do with Danny's wishes or the medical facts. The M.D.'s were only fearful of what might happen to themselves without regard for what would happen to Danny and his family.

The M.D.'s seemed to be ignorant of the President's Commission and its findings on termination of care for the permanently comatose. They were unaware of their own society's recent statement, the AMA's March 1986 statement on withdrawal of life support for the hopelessly ill. They did not seem to care.

A whisper campaign began. I was told informally and unofficially by many different hospital personnel to consider taking my husband home. I was told "He'll die faster at home."; "We won't let him die, but you can at home."; "He'll get a plug faster at home.", etc. It was clear to me they simply wanted to wash their hands of this responsibility. They all believed to let him die was the right thing to do but none had the courage to stand up for their convictions.

I heard comments from most of the M.D.'s involved in my husband's care such as: "He is a dead man."; "Your husband was a dead man that first night."; "I'm afraid your husband is dead."

All of the M.D.'s sympathized with me but none had the courage to do anything about it. They all told me how brave and courageous I was for going to Court. They said it was the only way and that I would help them (as physicians) and so many other families and patients like Danny. They said it was desperately needed. The hypocrisy was sickening. Our family had to pay the price for their inability to resolve this situation.

Only one M.D. stepped forward on our behalf. He wrote an affidavit on medical facts on my husband for me to submit to the Court when I filed my petition in New York State Supreme Court for termination of all care. The WCMC Administration immediately refused to let this doctor sign his affidavit. They blocked and delayed my attempt to get my case into Court. The doctor told me he felt he could lose his job if he signed the affidavit against their orders.

Taking my case to Court alienated me from the medical community. No physician has ever called me since I filed my petition. No M.D. even kept me informed of changes in my husband's condition. They did not inform me when they started him on antibiotics, whenever he had fevers, whenever he had projectile vomiting or whenever his feeding tube was blocked. I learned these things only when I visited him and only after I specifically asked the nurses about complications.

I finally had a confrontation with one M.D., I demanded to be informed when they treated my husband without my consent. My Court petition had made things worse at the hospital. After the judge denied my petition, the doctors thought they were now under strict Court orders to treat Danny as aggressively as possible on all levels. They even mentioned exploratory surgery to find out the cause of the projectile vomiting Danny had for over a month each time they put him back on the tube feedings.

It was finally determined that the vomiting was caused by the feeding tube itself - it was in the wrong position inside of him. Let this stand as evidence that this artifical feeding is not a simple passive procedure. Since the start, the tube has become clogged recurrently. This necessitated constant changing of his tube. The vomiting caused by the tube also caused harrowing changes in Danny. He had lost a great deal more of weight and looked terrible. It's hard to believe anyone can continue to exist in the state he's in.

The judicial process was devastating to me and my Mother-in-Law. The loss of my husband was tragic enough yet I was then forced to publicly plead to strangers for his death. You cannot imagine the psychological trauma involved in pleading for the death of the person you love most in the entire world. I could barely concentrate in Court. I was distracted by everything that I had been hit with over the past months. I was so afraid.

The Guardian ad Litem was another source of distress to me and my Mother-in-Law. We feared and resented a stranger who had power over my husband's fate. The fact that an outsider had to be appointed to watch over my husband's interests when no one could be more concerned about his interests than my Mother-in-Law and myself was terrifying. It was his family who were so intimately involved medically and personally. It should be a family decision, not an outsiders', however well meaning that outsider may be. How could he possibly protect my husband's rights unless he personally understood everything about my husband's philosophy and knowledge of life? Who was this man to have such power over us? Who were all these people to intrude on our life on so personal an issue?

When our story and the judge's decision made headlines in Westchester and was carried on New York City radio stations, Danny's mother was devastated. She felt violated that her most private words could be quoted from Court transcripts and printed to expose her to the world like that. Since the newspaper and radio accounts, I have received obscene and crank phone calls.

Meanwhile, I had been informed by the hospital in August that Blue Cross/Blue Shield (BC/BS) would no longer pay for my husband's hospitalization even though he had 365 days of coverage. He was no longer considered in need of an acute level of care, therefore BC/BS would not pay. I owe the hospital $631.00 per day. My bill is over $157,000.00 so far.

Every nursing home rejected my husband. They claimed he required too much care because of the tracheostomy and jujostomy. They also did not want him because of my Court action. Even though the hospital could find no facility to take Danny, BC/BS would still not pay for his hospitalization. It is a "Catch-22" situation.

The hospital made it clear to me that they would hold me directly responsible for the hospital bill. I told them I would not pay for care that neither Danny nor I consented to. They told me the hospital would press me for payment. I am terrified of loosing everything Danny and I ever worked together for.

The psychological trauma of knowing the hospital wants to get rid of Danny and no one else will take him is incredible.

The hospital lawyer at one point in Court said she'd put my husband in the parking lot if she could, to get him out of the hospital. At another point in Court the hospital said they would not appeal a favorable decision if the Court did not direct them to comply with the order to terminate care but would allow them to transfer him to a facility that would comply with the Court's decision. The judge said "Are you telling me this family is going to have to shop around?" The hospital gave no reason for their position. They were treating Danny like a piece of fish.

I cannot believe that complying with a Court order to terminate treatment would be more traumatic for the hospital staff than having to watch Danny and his loved ones be violated and tortured every day. In fact, nurses taking care of my husband have told me "This is a crime. No one should be left like this."; "If that were my husband I'd stuff cotton balls down his trachea."; Another has said she hoped she was on duty when Danny developed a potentially fatal complication. She said she would let it happen while a more inexperienced nurse may try to save him not fully understanding his condition.

. have no nursing home coverage for custodial care. My insurance policies pay only for convalescent long term care.

I dread a transfer: the paperwork, the bills, the trauma of becoming familiar with new staff and new surroundings. For what purpose? Danny's life is over. There is no sense to any of this. The burden on me and my family is enormous.

The thought of taking him home is even a greater nightmare to me. Our home was the happiest of homes. I have only good memories of him in our home. He refurbished every wall and ceiling in our home. He was so proud of his flawless craftsmanship. How can I bring his body into our home in the horrid state he is in? Indeed, he is dead already, by our own belief. If he had even an infinitesimal' awareness or cognition of any kind, I would have had him home in an instant. If any level of comfort could be given to him I would have taken him home immediately. Now it would be worse than taking a dead body into our house. What is left of him is not even his essence.

How can I watch him die in his own home, surrounded by all the creative, beautiful things he made with his own hands, knowing how his brain was destroyed, knowing how careful he had been with every task he took on, knowing how he was killed because those doctors did not take care to do their job as conscientiously as he would have?

I imagine his body in my bedroom and wonder if I will ever be able to live in this house again. Seeing his twisted emaciated body with horrific grimaces on his once handsome face in our own home would be unbearable. I already have nightmares of these scenes. How can I bring it into our own home? And yet the thought of transfer to another facility drains me. Why can't this be ended at WCMC? My spirit is almost broken. I loved him so much.

We have been forced to sit by my husband's side for eight months. Danny hated wakes and he made me promise never to have a wake for him. He had also requested not to be left in this kind of state even one day. I feel as if I have failed him.

Some people bury their dead in a day. We have been forced to watch him be subjected to indignities beyond belief. We have had to watch his beautiful strong body disintegrate and atrophy in the worst way imaginable. The nurses called his body awesome when he first arrived in the hospital. Now, the contrast is numbing. No one should have to watch the things we have seen happen to their most loved, especially when they know what he wanted for himself. The disregard for his carefully thought out wishes is torturous to me.

Many people do not understand what it looks like when one is in a vegetative state. Most think the person lies quietly, motionless and unresponsive. If you saw what we see you would have nightmares, as we do.

Recently, during one visit, my husband started foaming at the mouth, his teeth were clenched so tightly, clamped down on his lower lip so hard that it was cut open and bleeding. His mother and I leaned over him to try to release his lip from his grinding teeth. Suddenly, he vomited with great force green fluid all over me, his mother, the nurse, himself. Projectile vomit flew everywhere. It hit the walls, the floor, the curtains. This scene was worse than any horror film you may have ever seen. I was gagging, his mother was in my arms crying hysterically, trembling uncontrollably and pleading for them to let her baby die. I was dazed. I can't believe what they have done to him, to us. This is only one example of the frightful and shocking events we have been tortured with.

I personally have had to seek professional counseling to handle this entire trauma. My Mother-in-Law is in need of counseling but feels she cannot afford it. She wants to spend every penny of her widow's pension on traveling to see her son. It costs her about $200-$250 per week to travel to Westchester and takes her 2-3 hours each way. She just wants to die. She does not want to see anymore of this life.

Lastly, I must comment on two often made points regarding my request o terminate all treatment for my husband. One, that he is so young, nd two, that he is not terminally ill.

become frantic when some suggest because Danny is so young he should e kept "alive" waiting for some medical breakthrough. This is science iction in his case. How dare they keep him "alive" for a scientific periment that has not yet even been conceived of, let alone one that s not been approved by a Human Subjects Committee. More importantly, would not consent to being part of this fictitious procedure.

th respect to terminal illness, remember that I believe Danny is ad already. But for those who do not understand this concept, at ast realize that to me on a scale of one to ten, if death is a 10, er neocortical brain death is a 9.999. Terminal illness would be a life can still be experienced with a terminal illness. Nothing be experienced with cortical brain death. It is oblivion.

id not know where to start or end this letter. There is so much e to say. This letter has drained me, but I sincerely hope it can p you to formulate a good law for people in our position. I just t peace for my husband, for his mother and for me.

s whole affair has wrecked violence on me and my family. My personal edy has been compounded and exacerbated by the medical and legal unities.

task force must propose laws that can offer relief to families as mine. I hope this letter can be of use to you as you develop aft on living will legislation. For me and my husband it is ntially too late, but perhaps we can lessen the devastation to rs in the future.

With Unrelenting Sorrow,

Sincerely yours,

Julie Delio

Julie Delio

PREPARED STATEMENT OF NANCY W. DICKEY

Mr. Chairman and Members of the Subcommittee: My name is Nancy W. Dickey, M.D. I am a family practitioner in Richmond, Texas and a member of the American Medical Association's Board of Trustees. I am also the former chair of the AMA's Council on Ethical and Judicial Affairs. With me is Michael Zarski, Senior Legislative Attorney for the AMA. We appreciate this opportunity to appear before the Subcommittee to discuss advance medical directives,such as "living wills."

The right of a competent adult to control medical decisions affecting his or her body is deeply rooted in our laws and is grounded in the importance our society has traditionally accorded the autonomy of the individual. The right to refuse treatment, however effective that treatment may be or however grave the consequences of refusal may be, is an essential element of individual autonomy.

Invoking the right to refuse medical treatment is a course of action which at one time would have been unthinkable for the vast majority of the citizens of our nation. But recent developments in the technology of life-sustaining medical care means that, for some, medical treatment may merely prolong the dying process.

The AMA, many ethicists, and a presidential commission all have sanctioned—under proper circumstances—the withdrawal of artificial life supports from a terminally ill or permanently unconscious patient. Moreover, most Americans believe that a person's wishes regarding the use of life support in the event of terminal illness or permanent unconsciousness should be honored.

While the right of patients to determine their own treatment has been recognized, problems arise when it comes to invoking that right under some circumstances. This is because the issue of determining for the patient whether artificial life support should be utilized or withdrawn generally does not arise until the patient has become unconscious or otherwise mentally incompetent. At that point, of course, the patient will be unable to indicate his or her wishes. In addition, the patient might not have indicated before becoming incompetent whether life-sustaining care should be used in the event of terminal illness or permanent unconsciousness. In short, a person's right to decline artificial life support can be frustrated by a failure of the individual to leave sufficiently clear advance directives.

This problem was highlighted recently in the *Cruzan* case. The United States Supreme Court recognized a competent person's constitutional right to refuse medical treatment. At the same time, the state's interest in preserving human life entitled it to require clear and convincing evidence of a person's wishes regarding withdrawal or refusal of life-sustaining treatment.

Unfortunately for Nancy Cruzan, and the concerned members of her family, the evidence of her wishes to avoid prolonging the situation she is now in was not "clear and convincing" in the opinion of a state court. Therefore, she remains in a persistent vegetative state with no chance of regaining significant cognitive function. She may remain in this condition for 30 years, maintained by a gastrostomy tube which delivers hydration and a nutritional solution.

There are two mechanisms by which an individual can avoid the controversy and the outcome of the *Cruzan* case, namely, through written directives or the appointment of a proxy to make health care decisions in the event of incompetency.

The AMA's Committee on Medicolegal Problems has studied the available mechanisms for indicating decisions regarding life-sustaining treatment. The advantages and disadvantages of each of these mechanisms are described in a communication published in the May 2, 1990 Journal of the American Medical Association. This communication expanded on the report of the Committee on Medicolegal Problems. A copy of this publication is attached to our testimony.

The AMA also has reviewed Federal legislation on this subject, including S. 1766, the Patient Self-Determination Act. This bill would require that hospitals and other institutional providers enter into agreements assuring that Medicaid and Medicare beneficiaries receiving institutional services have an opportunity to participate in and direct health care decisions affecting them. Specifically, S. 1766 would require hospitals and nursing homes to maintain written policies and procedures to determine whether Medicaid and Medicare beneficiaries, at the time of admission, have prepared an "advance directive" such as a living will, durable power of attorney or similar document.

Under S. 1766, written policies would be required of institutions to inform patients (Medicare/Medicaid) of their rights to make decisions concerning medical care, including: the right to accept or refuse medical or surgical treatment; the right to execute a written power of attorney to make health care decisions; and the right to provide written instructions concerning health care. Institutions would also be required to inquire whether or not these patients had prepared a living will or durable power of attorney, to document the treatment wishes of the patient and periodically review such wishes with the patient. The institutions would be required to ensure that legally valid "advance directives" be implemented to the maximum extent possible under the relevant state law; arrange for the prompt and orderly transfer of a patient to the care of others when as a matter of conscience the hospital cannot implement the wishes of the patient; and create an institutional ethics committee to initiate educational programs for staff, patients, residents, and the community. In addition, within six months of the date of enactment, the Secretary would be required to develop and implement a national campaign to inform the public of the option to execute "advance directives."

There is strong support among physicians for the use of advance directives. We believe that it is extremely important that the wishes of the patient be known to the medical treatment team and that voluntary use of advance directives should be strongly supported and encouraged by physicians. The AMA therefore strongly supports the goal of S. 1766, to increase the use of advance directives, and the educational program proposed. We are, however, concerned with many of the specifics within the bill, including the major focus on institutions in pursuing advance directives at the time of admission and continued follow-up throughout the patient's stay. The AMA does not believe that the hospital or nursing home is the most appropriate place, nor admission to a facility the most appropriate time, for a patient to consider initially the issues of advance directives. These are issues that need careful thought and advice from family, clergy, physicians and others whom the patient wants to consult. These discussions should take place outside of the emotionally difficult time that immediately precedes or is concurrent with admission to a health care facility

The AMA believes that there are appropriate roles for both health care providers and the government to encourage the use of advance directives and we have developed the following principles as the basis for reviewing legislative initiatives in this area:

- Support the use of advance directives including "living wills" or durable powers of attorney for patients who wish to make known their desires about treatment.
- Support educational programs to better inform the public about advance directives, their benefits and uses.
- Government, both Federal and state, should be encouraged to financially support educational programs concerning advance directives.
- The Social Security Administration should be required to inform beneficiaries, at the time they enroll for benefits, about advance directives, their benefits and uses.
- The Social Security Administration should be required to notify beneficiaries at least once every 24 months, in the same envelope as the Social Security check or other regular mailings, about advance directives, their benefits and uses.
- Hospitals and nursing homes, as a condition of participation in the Medicare program, should be required to have procedures to determine, at admission, whether a patient has executed a valid advance directive. If such directive has been executed, a procedure should be required to note that fact on the patient's chart. Hospitals and nursing homes should have available information and forms for patients who want to execute advance directives.

These principles reflect an appropriate approach towards greater use of advance directives in medical care.

We understand that Senator Danforth, the sponsor of S. 1766, is developing some modifications to the bill. One proposed modification would specifically require that HHS develop informational materials on advance directives to be made available to Medicare and Medicaid providers and possible mailings of information to Social Security recipients.

The AMA believes that the proposed modifications would improve S. 1766 and make the bill more consistent with the principles we have adopted.

Even without a legislative impetus, the Association is committed to increasing awareness among physicians and the patient population of advance medical directives and health care powers of attorney.

To this end, our Office of General Counsel is developing two brochures—one directed at physicians and one intended for distribution to pie: well as a model "medical directive" form. We also are exploring the possibility of offering our patient material, to HCFA for distribution to Medicare and Medicaid beneficiaries.

In the meantime, we continue to refer those who call or write the AMA requesting an advance directives form to a variety of sample advance medical directives including a form published on June 9, 1989 in JAMA, which also is attached to this statement.

CONCLUSION

In conclusion Mr. Chairman, we commend you for holding a hearing on this important matter. Although there may be different ideas regarding the responsibilities and logistics for promoting the development and use of advance directives, there is no doubt that the patient, the patient's family, the physician, providers and government programs all benefit from the existence of a clear expression of the individual's preferences regarding the provision of life-sustaining medical treatment technology in the event that the patient's medical condition is such that he or she can no longer express this intent directly. The AMA is eager to incorporate the information and ideas developed by this Committee into our own projects and to work with the Department of Health and Human Services to promote the use of mechanisms for advance medical directives. Thank you, and I would be happy to answer any questions you may have.

Attachment.

The Medical Directive

A New Comprehensive Advance Care Document

Linda L. Emanuel, MD, PhD, Ezekiel J. Emanuel, MD, PhD

Living wills have been strongly endorsed in principle. Unfortunately, existing living wills are rarely used in clinical practice because they are vague and difficult to apply. To remedy this, we propose a new advance care document: the Medical Directive. The Medical Directive delineates four paradigmatic scenarios, defined by prognosis and disability of incompetent patients. In each scenario, patients are to indicate their preferences regarding specific life-sustaining interventions. The Medical Directive also provides for the designation of a proxy to make decisions in circumstances where the patient's preferences are uncertain. Finally, there is a section for a statement of wishes regarding organ donation. The Medical Directive provides an opportunity for significant improvement in the documentation of patients' preferences regarding life-sustaining care in states of incompetence. As an expression of a patient's wishes, the Medical Directive should be honored by courts and should facilitate physician-patient discussions of critical and terminal care options.

(*JAMA*. 1989;261:3288-3293)

OVER the last decade, living wills have been strongly endorsed by courts, lawyers, physicians, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and special public interest groups. Despite this, the use of living wills is not widespread. We offer some reasons and propose a new advance care document that physicians can recommend to their patients to promote the inclusion of personal directives in medical decisions. We propose it as a model that courts, state legislatures, and Congress may wish to adopt. The Medical Directive covers preferred treatment goals and specific treatment preferences in several scenarios of incompetence. It also includes the option to designate a proxy decision maker or power of attorney for the event of incompetence, the option to record a personal statement, and a place to designate wishes for organ donation.

ENDORSEMENT OF LIVING WILLS

Approval of living wills (advance care documents should a person become unable to communicate his or her desires about medical care) had been urged, with little success, since the 1960s. In 1976 the case of Karen Quinlan,[1] the first case involving withdrawal of life-sustaining technology from a permanently incompetent adult, alerted the country to the dilemmas of terminating unwanted medical care. This case became a nidus around which the debate concerning living wills crystallized, fostering a strong consensus in their favor.

On January 1, 1977, California's Natural Death Act became the first law to give legal force to living wills. In the subsequent decade, more than three fourths of the states passed similar "natural death" acts.[2] There has also been growing approval by physicians for advance care documents.[3,4] One survey of physicians found 89.7% endorsed the legal recognition of living wills.[5] Generally, physicians view them as promoting patient-physician communication, protecting patients' rights, and affording legal security for physicians.[6,7] Since living wills provide patients with an extension of their self-determination, many ethicists have also supported their use.[8,9] Similarly, they have been endorsed by many religious authorities.[10,11] Finally, as a recent opinion poll showed, there is strong public support for the patient's right to terminate life-sustaining care.[12]

DESUETUDE OF LIVING WILLS

In the face of this wide and strong endorsement, it is striking how rarely living wills are actually used in medical practice. Nine percent of Americans have made a living will.[13] However, these documents are apparently not reaching physicians' offices or hospitals. Empirical data on the use of living wills are not abundant. One of the few studies surveyed California physicians specifically involved in the care of terminally ill adults, and found that more than a third had no patients with a living will and more than 70% had fewer than five pa-

---

From the General Internal Medicine Unit, Massachusetts General Hospital, Boston (Dr L. Emanuel), and the Program in Ethics and the Professions, Harvard University, Cambridge, Mass, and the Department of Medicine, Beth Israel Hospital, Boston, Mass (Dr E. Emanuel).

Reprint requests to General Internal Medicine Unit, Massachusetts General Hospital, 32 Fruit Street, Boston, MA 02114 (Dr L. Emanuel).

tients in their practice with living wills.[7] In addition, a review of the medical records in a Massachusetts teaching hospital of 113 consecutive patients with do not resuscitate orders during a 3-month period, and all 73 cases seen by an ethics committee during a 10-year period, revealed no mention of a living will or advance care document.[illegible] Despite a broad social acceptance for living wills in principle, there appears to be little use of them in clinical practice.[illegible]

LIMITATIONS OF LIVING WILLS

Part of the explanation for this divergence between principle and practice may inhere in the historical origins of living wills. Since living wills arose out of a concern that people might have their lives needlessly prolonged by medical interventions, almost all existing living wills focus on the patient's desire to have medical treatments terminated. To many people, including physicians,[7] living wills seem to be for the rejection of care—possibly even for accelerating death—rather than an opportunity for the patient to outline in advance a full range of preferences about medical care, including desires to have specific types of treatments administered.[illegible]

Another part of the explanation for the lack of use of living wills may inhere in their current format and design. Standardized living wills use vague terminology, inviting problems of interpretation. One level of this linguistic vagueness concerns the patient's condition. Thus, most living wills request cessation of life sustaining care when "there is no reasonable expectation of recovery from extreme physical or mental disability."[illegible] A second level of this linguistic vagueness concerns the types of interventions to be terminated. For example, the Concern for Dying living will[illegible] directs physicians to forego "artificial means and heroic measures." Others request the termination of "life prolonging procedures." Later living wills have included some specific guidelines, for instance, requesting the termination of surgery, ventilation, antibiotics, blood products, and intensive care unit services.[illegible] Nevertheless, the most important operational terms—"no reasonable expectation of recovery," "heroic measures," "life prolonging procedures," etc—are open to multiple interpretations on when to act and on what interventions the patient would desire.[illegible]

Third, by not taking account of a range of possible clinical circumstances, living wills seem too inflexible for the individualized direction of care.[illegible] For example, many living will laws permit the foregoing of interventions only if the patient is terminally ill. In some cases, terminal illness is defined very restrictively, that is, that the patient will die with or without medical care within 1 year.[illegible] Ironically, restricting living wills to terminal illness does not sanction the removal of respirators from patients, such as Karen Quinlan, who suffer from no terminal disease process but are being sustained by medical technology.[illegible]

Finally, people often sign living wills without discussing its terms and their wishes with their physicians. This limits the living will's efficacy, because it often leaves the patient's physician ignorant of the existence of the living will and its provisions, and because it does not provide physicians and patients the opportunity to communicate and clarify the physician's understanding of the patient's wishes and the patient's understanding of how his or her wishes may best be translated into medical decisions during critical or terminal illness.

PROXY DECISION MAKERS

Such limitations of written living wills have prompted many to advocate that patients designate proxy decision makers through durable power of attorney laws.[illegible] All states have general durable power of attorney laws. The New Jersey Supreme Court recently upheld the use of such a general durable power of attorney law to appoint a proxy with authority to make decisions regarding the cessation of life sustaining treatments.[illegible] In addition, the legislatures of 13 states have explicitly authorized the use of durable powers of attorney for termination of life sustaining treatments.[illegible]

However, proxy decision makers present a limited solution. In particular, while the proxy may be a relative or close friend of the patient, he or she may not have had an opportunity to discuss the patient's preferences for critical or terminal care. Even when proxy decision makers have had such discussions they are likely to have made use of vague terms and are therefore unlikely to overcome the ambiguities that plague advance care documents. Under such circumstances, proxy decision making is less an exercise of the patient's autonomous decision and more the proxy's decision for the patient.[illegible] Such proxy guessing is limited; a recent survey[illegible] of elderly patients, their physicians, and their spouses revealed a strikingly poor ability of either the spouse or the physician to guess correctly the patient's wishes about resuscitation. Furthermore, the proxy's ethical and psychological burden may be overwhelming. Willingness to withdraw life-sustaining treatments decreases from 70% to 46% when the decision is not for oneself but rather for a relative.[illegible] Finally, at least in the case of patients with acquired immunodeficiency syndrome, the choice of a proxy appears to be less durable over time than wishes specified in a living will.[illegible]

THE MEDICAL DIRECTIVE: A REMEDY

The problems of existing living wills—lack of accommodation for positive requests for treatment, linguistic vagueness, inflexibility, and poor communication—can all be substantially relieved by the use of the Medical Directive (Figure). The Medical Directive is a specific and comprehensive advance care document for care at the end of life. It is divided into five parts: (1) an introduction, (2) a section containing four paradigmatic scenarios of illness in which preferences for medical care are given, (3) a section for the designation of a proxy decision maker, (4) a section for organ donation, and (5) a personal statement.

The Introduction

This section provides an explanation of advance care documents. It emphasizes that the decisions in it are often of a personal, philosophical, and spiritual nature and that the person may wish to talk with his or her family, friends, or religious mentor prior to completing the Medical Directive. It suggests that consideration of personal values and goals of treatment may be used initially to clarify, in discussion with the physician, the patient's wishes and medical values. It also points out that advance care documents should be given to the patient's physician and family or friend so that they will be available when needed. The emphasis on prior discussion and description of key questions around which to articulate a patient's set of medical values are essential parts of the introduction.

Four Paradigmatic Scenarios

In this part, patients (1) consider actual illness circumstances, chosen for their paradigmatic nature, that can involve their mental incompetence, (2) evaluate types of life sustaining medical interventions commonly employed, and (3) designate their preferences with respect to specific treatments. The presentation of illness scenarios and types of intervention provides a context for an extensive exploration of a patient's wishes and how they reflect a particular view of life and the process of dying. It provides a unique opportunity for a phy

THE MEDICAL DIRECTIVE: AN INTRODUCTION

As part of a person's right to self-determination every adult has the freedom to accept or refuse any recommended medical treatment. This is relatively easy when people are well and can communicate. Unfortunately, during serious illness people are often unable to communicate their wishes at the very time that many critical decisions about medical interventions need to be made.

The Medical Directive states a person's wishes for or against types of medical interventions in several key situations, so that the person's wishes can be respected even when he or she cannot communicate.

A Medical Directive only comes into effect if a person becomes incompetent or unable to make decisions or to express his or her wishes. It can be changed at any time up until then. Decisions not involving incompetence should be discussed directly with the physician.

The Medical Directive also allows for appointment of someone to make medical decisions for a person should he or she become unable to make them; this is a proxy or durable power of attorney. The Medical Directive also allows for a statement of wishes concerning organ donation.

A copy of the completed Medical Directive should be given to a person's regular physician and to his or her family or friend to ensure that it is available when necessary.

Medical Directives should be seen not only as legal protection for personal rights but also as a guide to a person's physician. The use of Medical Directives with the physician can help in making plans for health care that suit a person's values.

• •

A person's directive to others may be affected by personal philosophies and religious views; such people may wish to discuss the issue with family, friends, and religious mentors as well.

[illegible]

[illegible]

DURABLE POWER OF ATTORNEY

I understand that my wishes expressed in these four cases may not cover all possible aspects of my care if I become incompetent. I also may be undecided about whether I want a particular treatment or not. Consequently there may be a need for someone to accept or refuse medical interventions for me in consultation with my physicians. I authorize

____

____

as my proxy(s) to make the decision for me whenever my wishes expressed in this document are insufficient or undecided.

Should there be any disagreement between the wishes I have indicated in this document and the decisions favored by my above named proxy(s), I wish my proxy(s) to have authority over my medical directive / I wish my medical directive to have authority over my proxy(s). (Please delete as necessary.)

Should there be any disagreement between the wishes of my proxies

____

shall have final authority.

ORGAN DONATION

I hereby make this anatomical gift, to take effect upon my death.

I give ___ my body ___ any needed organs or parts ___ the following organs or parts ____________________

to the following person or institution ___ the physician in attendance at my death ___ the hospital in which I die ___ the following named physician, hospital, storage bank or other medical institution ________

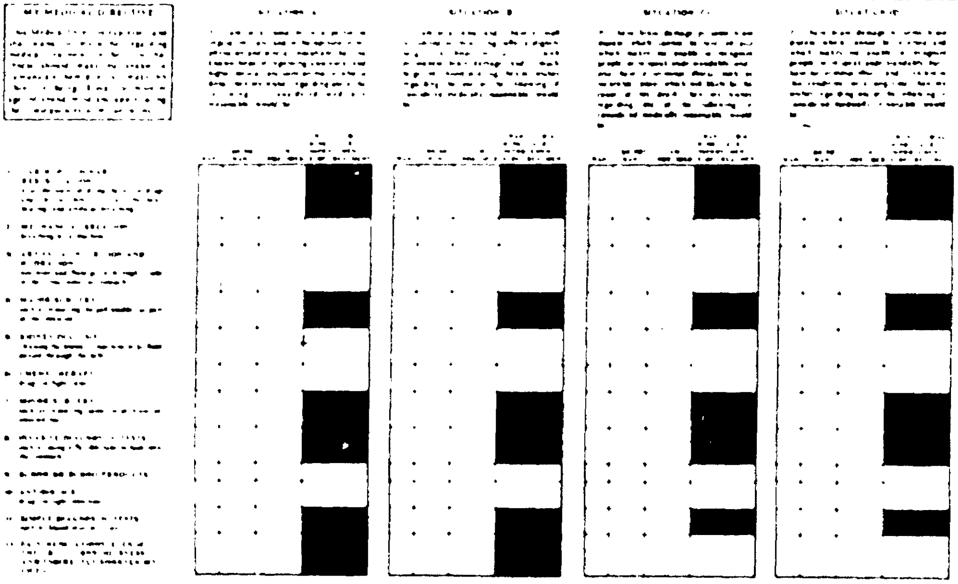
for the following purposes ___ any purpose authorized by law ___ transplantation ___ therapy ___ research ___ medical education

MY PERSONAL STATEMENT (use another page if necessary)

Signed ________________ Date ______

Witness ________________ Date ______

Witness ________________ Date ______



MY MEDICAL DIRECTIVE

SITUATION A

SITUATION B

SITUATION C

SITUATION D

The Medical Directive

sician to educate the patient on life-sustaining technology and how it can fit with the patient's wishes. The use of illness scenarios and specified interventions makes the directives both very informative and flexible.

The four illness scenarios are as follows: when the patient is in an irreversible coma or a persistent vegetative state but with no terminal illness (situation A); when the patient is in a coma with a small and uncertain chance of recovery (situation B), when the patient has some brain damage causing mental incompetence and is terminally ill (situation C), and when the patient has some brain damage causing mental incompetence without any terminal illness (situation D).

It is important that the scenarios are defined by disability and prognosis. Several diagnoses may be used for illustrative purposes, but are not part of the definition. Preserving the definition free from individual diagnoses allows for generality without loss of specificity.

These four illness scenarios are paradigmatic in two ways. First, they encompass the spectrum of types of mental incompetence. Second, they represent the principle circumstances arising in medical practice that have prompted legal cases.[4] For instance, the first scenario (situation A) has arisen in many legal cases such as *Quinlan*,[5] *Brophy*,[6] and *Jobes*[7]; the third scenario (situation C) has arisen in the case of *Dinnerstein*[8]; and the fourth scenario (situation D) is common for patients with Alzheimer's dementia and organic brain syndrome and has arisen in the *Spring*[9] and *Conroy*[10] cases.

In each of these paradigmatic scenarios the patient is to indicate whether he or she would want or not want interventions in 12 treatment categories, ranging from resuscitation and ventilation to artificial feeding and simple diagnostic procedures. These categories encompass the typical range of diagnostic and therapeutic interventions for incompetent patients.

The designated options permit not only refusal of care but also affirmative requests that certain interventions be definitely administered if clinical indications warrant them. In addition, the options do not force patients to accept or refuse each treatment, but recognize that patients might be unsure about their preferences for some interventions or may definitely desire some interventions, albeit with specific limits on how long these treatments should be continued. In this way, the specificity of interventions should help reflect the nuances of patient preferences.

Thus, the scenarios provide patients the opportunity to indicate how their own values apply to medical care in the event of their incompetence. In particular, they permit patients to inform physicians if and when they believe termination or limitation of their medical interventions is justified. In this way, the specificity of the scenarios will permit more informed generalization to related situations.

Left to their own efforts, many people will be unable to imagine, delineate, and articulate in precise terms the possible clinical circumstances and range of medical interventions in which an advance care document might be useful. Detailing for patients specific illness scenarios and treatment options ensures they have the opportunity to express their wishes as precisely as possible, regardless of their intellectual abilities.[4]

Proxy Decision Maker

The objective of this part of the Medical Directive is to provide the patient with a chance to designate a proxy decision maker or durable power of attorney. The proxy would be called on for directives in circumstances not delineated in the four paradigmatic scenarios or where the patient expressed uncertainty. It is expected that, in the former case, the patient's responses to the four paradigmatic scenarios will provide substantial guidance to the proxy.

To provide for the possibility of a difference in interpretation of the Medical Directive by concerned parties or a disagreement between the patient's wishes and the proxy's decision or between proxies where more than one has been designated, the Medical Directive allows the patient to designate which party should have the final say.

In the Medical Directive, the choice of a proxy decision maker is not a substitute for the patient's own advance care document. Both are necessary and therefore linked in the same document.[4] Preferences specified in the four scenarios and the personal statement are an expression of the patient's views, while the proxy is to cover the uncertain and unexpected circumstances arising in individual cases. Thus, a proxy supplements but is not expected to supplant the patient's stated preferences elicited in the four illness scenarios.

Organ Donation

There is a short section dealing with the patient's preferences on organ donation. Including organ donation in an advance care document should increase patient consideration of this matter. This form will not substitute for the federal law of 1986 (the Omnibus Reconciliation Act) and state-required request laws, which require that next of kin be approached regardless of the patient's expressed wishes. However, the organ donation section of the Medical Directive will (1) spur communication of organ donation preferences within a family and with a physician before actual decisions have to be made, (2) provide substantive indication of the patient's preferences, and (3) reduce the occasions when organs were not donated simply because it was forgotten or the patient's wishes were unknown.

Personal Statements

At the end of the document, provision is made for a personal statement. In the introductory section of the Medical Directive, it is indicated to the patient that personal values concerning the limits of life and goals of treatment in various scenarios are the important guiding principles in making the Medical Directive. Since personal goals and values cannot be accurately translated into specific decisions by anyone as well as they can by the patient, these personal statements should not stand in isolation, but with the specific selections in the scenarios.

Together, these five parts make the Medical Directive a comprehensive declaration, permitting patients to express their views on medical care during critical illness and at the end of life.

PHYSICIANS AND THE MEDICAL DIRECTIVE

It is important to emphasize several areas of classical physician responsibility that would continue to fall desirably so on the shoulders of physicians. In addition to performing the tasks of diagnosis, only the physician can assess the risks and benefits of possible interventions, recommend one or a few, and judge prognosis. Transmitting the information to and discussing it with the deciding parties is the responsibility of the physician.

Some early acquaintance with a patient's outlook is often part of a physician's agenda. Focussing this attention on a discussion of the Medical Directive would be beneficial. If such discussions reveal that the patient's wishes seem incompatible with the physician's principles, it might be advantageous to alert the patient to the possibility of seeking alternative medical care.

OBJECTIONS

First, it may be objected that the Medical Directive does not eliminate the vagueness of other advance care documents. It is necessary to make a distinction between medical vagueness and linguistic vagueness. Medical vagueness refers to the inherent and irreducible uncertainty that occurs when clinical knowledge is applied to specific patients. Medical knowledge does not permit precise extrapolation from clinical knowledge, which is often probabilistic, to predications about the course of an individual patient. Estimation of prognosis and level of human interaction will always be subject to limited certainty. Often the physician can tell a competent patient or a proxy no more than the fact that the patient has a "small and uncertain chance" of recovery and cannot be more specific about a patient's duration of life than the fact that the patient is terminally ill. While this uncertainty is frustrating, it is irreducible and forms the circumstances in which many medical decisions—including life-and-death ones—must be made. The Medical Directive makes use of scenarios in which prognosis and level of human interaction are defined as accurately as any real clinical situations would permit.

Conversely, linguistic vagueness refers to the limitations of verbal expression. Here the Medical Directive avoids most of the vagueness of current living wills, substituting 12 specific interventions for "heroic measures" and four scenarios from persistent vegetative state to reversible coma for "extreme physical and mental disability." Similarly, in situations C and D, the Medical Directive suggests certain simple tests for mental capacities that many believe constitutive of a meaningful human life: Can the patient correctly recognize family members or friends? Can the patient communicate in meaningful language? While even in the best of circumstances language will also be subject to uncertainty, the use of multiple treatment options in a defined scenario restricts the need for and scope of interpretation of the patient's meaning, while providing a tangible expression of the patient's wishes.

Thus, both medical vagueness and linguistic vagueness are pushed, within the limits of practical reality, virtually to their limit. Clinical knowledge and personal choices cannot be completely transparent, ever. The use of scenarios with types of intervention provides a qualitative and quantitative improvement in physicians' ability to approximate the ideal of complete definition of a patient's particular judgment in circumstances when we are otherwise far removed from them.

Second, it might be objected that too much medical knowledge, time, or intellectual concentration is required to complete the Medical Directive. The four scenarios do not require trained medical knowledge to understand them. They are descriptions similar to ones a physician might normally use to explain situations to patients or a patient's family. Some knowledge of the types of interventions listed is required, but each term is briefly described and examples are given. Most patients are exposed to education afforded by the media and by personal experience, and few people are unable to provide the concentration needed to consider life-and-death matters such as these. In addition, if it became necessary to explain anything in the Medical Directive, this would also provide an opportunity for the physician to discharge his or her responsibility to discuss terminal care issues.[illegible]

Third, it might be objected that the provision for requesting treatments will force physicians to provide useless care. The request for treatments derives from the fact that the Medical Directive does not deal only with terminal illness but also critical and chronic illness. However, the patient's right to refuse treatment does not imply a right to demand any intervention. In particular, a patient does not have the right to demand interventions that the physician considers futile.[illegible] Recognizing this important point, the Medical Directive makes all requests for treatments conditional, stating in each scenario that requests apply only "if considered medically reasonable."

Fourth, it might be more generally objected that the Medical Directive lacks legal recognition, lacks standing in court, and might expose physicians to lawsuits. While there are legal differences between statutory and nonstatutory forms, there should not be undue cause for concern over litigation. A patient's right to self-determination is a basic principle of American law. Consequently, some state courts have recognized living wills as an expression of self-determination in the absence of state statutes recognizing them.[illegible] Furthermore, courts have recognized verbal statements as binding expressions of patients' self-determination.[illegible] The Medical Directive would be far stronger evidence of the patient's wishes than this. While complete insulation from liability cannot occur, it would seem unlikely that physicians would face successful litigation if they respected the Medical Directive, and possible for them to face litigation if they did not respect it.[illegible] Hospital attorneys will be able to advise individuals on statutory and case laws of particular states.

It is also important to note that some of the ambiguities that have undermined the use of living wills are of greater legal than medical concern. The medical profession's ability to promote a patient's choice of medical care so that it is in concert with his or her particular life outlook is likely to be much improved by use of the Medical Directive. Legal concerns, while valid in themselves, should not undermine and distract physicians' attempts to further their patients' medical interests by discussions of terminal and critical care decisions.

Fifth, it might be objected that organ donation preferences are a separate consideration that should not be included in the document or perhaps even discussed with the physician ahead of time. In response, it should be noted that in addition to stimulating advance consideration and discussion of the issue with next of kin, inclusion of the topic in an advance care document makes more palatable, and could in some cases obviate the need for, the current legal requirement that physicians initiate discussion of organ donation with the next of kin of all potential donors. Use of an advance care document would reduce the stress of facing the decision at the time of newly discovered death.

Finally, it might be objected that the Medical Directive would not be widely used. This is open to physician initiative. Medical Directives available in office waiting rooms or introduced in a routine fashion to all patients during office visits would rapidly alter the situation. It is also open to third-party payer initiative. For example, the third-party payer might provide a one-time reimbursement to physicians for each patient with whom they discussed the Medical Directive. This would be one way to shift from reimbursement for procedures toward reimbursement for better physician-patient communication regarding medical decision making, a change which is already being urged by others.[illegible] It might reduce the need for statutes such as those in Alaska and Texas, which use financial disincentives for ignoring patient preferences.

CONCLUSION

We suggest that routine availability of the Medical Directive in physicians' offices and routine discussion of treatment options in the various scenarios (emphasizing that advance care documents are not limited to the refusal of treatments) would prevent the most serious drawbacks of living wills. Linguistic vagueness would be limited; interpretation would be well guided by stated patient views; and applicability would be extended and clarified. Proxy decisions would be available when no preferred sources were possible and would be aided by the Medical Directive. A minimum of information comprehension by the patient would be necessary to assess patient preferences well and much of that information would be available in the Medical Directive itself. The special skills and judgment of the physician would be as necessary as ever, and their use would be enhanced.

We thank John Stoeckle, MD, for his continuing insights and support and Daniel Federman, MD, Troyen Brennan, MD, JD, MPH, and George Annas, JD, MPH, for their critical reviews of the manuscript.

References

1. *In re Quinlan*, 70 NJ 10 (1976).
2. *Handbook of Living Will Laws 1987 Edition.* New York, NY: Society for the Right to Die; 1987.
3. Miles SH. Advanced directives to limit treatment: the need for portability. *J Am Geriatr Soc* 1987;35:74-76.
4. Relman AS. Michigan's sensible 'living will.' *N Engl J Med* 1979;300:1270-1272.
5. Uhlmann RF, Clark H, Pearlman RA, Downs Addison JH, Haining RG. Medical management decisions in nursing home patients. *Ann Intern Med* 1987;106:879-885.
6. Shapiro RS, Tavill F, Raskin G, Gruchow H. Living will in Wisconsin. *Wisc Med J.* October 1986;85:17-23.
7. Redleaf DL, Schmitt SB, Thompson WC. The California natural death act: an empirical study of physicians' practices. *Stanford Law Rev* 1979;31:913-945.
8. Bok S. Personal directions for care at the end of life. *N Engl J Med* 1976;295:367-369.
9. *Deciding to Forego Life-Sustaining Treatment.* Washington, DC: President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; 1983.
10. Schneiderman LJ, Arras JD. Counseling patients to counsel physicians on future care in the event of patient incompetence. *Ann Intern Med* 1985;102:693-698.
11. Paris JJ, McCormick RA. Living-will legislation, reconsidered. *America.* September 5, 1981;145:86-89.
12. Ramsey P. *Ethics at the Edges of Life.* New Haven, Conn: Yale University Press; 1978: chap 9.
13. Steiber SR. Right to die: public balks at deciding for others. *Hospitals.* March 5, 1987;61:72.
14. Brennan TA. Ethics committees and decisions to limit care: the experience at the Massachusetts General Hospital. *JAMA* 1988;260:803-807.
15. Caplan AL. Living wills and the lessons of organ donations. *New Physician.* September 1985;34:7, 19.
16. Kapp MB. Response to the living will furor: directives for maximum care. *Am J Med* 1982;72:855-859.
17. *A Living Will.* New York, NY: Concern for Dying; 1984.
18. Annas GJ, Glantz LH. The right of elderly patients to refuse life-sustaining treatment. *Milbank Quarterly* 1986;64(suppl 2):95-162.
19. Emanuel EJ. A review of the ethical and legal aspects of terminating medical care. *Am J Med* 1988;84:291-301.
20. Fox EKW. Nurse living will. *West J Med* 1987;146:118.
21. Steinbrook R, Lo B. Decision making for incompetent patients by designated proxy: California's new law. *N Engl J Med* 1984;310:1598-1601.
22. *Life-Sustaining Treatments: Making Decisions and Appointing a Health Care Agent.* New York: New York State Task Force on Life and the Law; 1987.
23. *In re Peter*, 108 NJ 365 (1987).
24. Emanuel EJ. Should physicians withhold life-sustaining care from patients who are not terminally ill? *Lancet* 1988;1:106-108.
25. Uhlmann RF, Pearlman RA, Cain KC. Physicians and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontology* 1988;43:M115-M121.
26. Steinbrook R, Lo B, Moulton J, Saika G, Hollander H, Volberding PA. Preferences of homosexual men with AIDS for life-sustaining treatment. *N Engl J Med* 1986;314:457-460.
27. *Brophy v New England Sinai Hospital*, 398 Mass 417 (1986).
28. *In re Jobes*, 108 NJ 394 (1987).
29. *In re Dinnerstein*, 380 NE2d 134 (1978).
30. *In re Spring*, 399 NE2d 433 (1979).
31. *In re Conroy*, 98 NJ 321 (1985).
32. *In re O'Connor* No 312 (NY Court of Appeals October 14, 1988).
33. *In re Gardner* 534 A2d 947 (1987).
34. *Leach v Shapiro* 469 NE2d 1047 (1984).
35. Emanuel EJ. Physician liability and taking rights seriously. *South Med J* 1987;80:1416-1417.
36. Hsiao WC, Braun P, Dunn D, Becker ER, DeNicola M, Ketcham TR. Results and policy implications of the resource-based relative-value study. *N Engl J Med* 1988;319:881-888.

From the Office of the General Counsel

Advance Medical Directives

SOCIETY has increasingly recognized the right of patients to refuse life-sustaining care that merely prolongs the dying process The American Medical Association,[1] ethicists,[2] and a presidential commission[illegible] all have sanctioned the withdrawal of artificial life supports from a terminally ill or permanently unconscious patient if the patient had expressed the desire that such treatments not be used Moreover, the vast majority of Americans believes that a person's wishes regarding the use of life support in the event of terminal illness or permanent unconsciousness should be honored (*New York Times* March 17, 1985, sect 1:38).

While the right of patients to determine their own treatment clearly has been recognized, problems arise when it comes to invoking that right This is because the issue of either utilizing or withdrawing artificial life support generally does not arise until the patient has become unconscious or otherwise mentally incompetent At that point, of course, the patient will be unable to indicate his wishes Moreover, the patient might not have indicated before becoming incompetent whether life-sustaining care should be used in the event of terminal illness or permanent unconsciousness Even if the patient did discuss the use of artificial life supports, the prior statements will often be discounted by the courts if they were made in general terms, in casual circumstances, as a spontaneous reaction to another person's medical treatment, or while the patient was young and in excellent health[illegible] In short, a person's right to decline artificial life support can be frustrated by a failure to leave sufficiently clear advance directives

There are two important mechanisms by which an individual can clearly indicate in advance how treatment decisions will be made regarding the use of artificial life supports, namely, through written directions (ie, a living will) or appointment of a proxy to make health care decisions in the event of incompetence An individual may also choose to utilize both of these mechanisms in a complementary fashion. For example, a patient may provide a proxy with written directions regarding treatment in certain situations, while depending on the proxy to make all additional medical decisions.[illegible]

In a recent report prepared by the Committee on Medicolegal Problems, the American Medical Association discussed the advantages and disadvantages of the different approaches to advance medical directives.[illegible] This article presents an expanded version of the report.

Living Wills

Forty-one states have passed living will statutes These statutes provide that a person's written, advance directives regarding the use of artificial life supports will be honored Living wills are executed while the individual is still competent to make medical decisions, and they become effective when the individual loses that competence[illegible] The individual may draft the directions in her own language or use a model will that is printed in the statute[illegible]

Through a living will, a person can specifically dictate the kinds of life supports that should be used and the conditions under which they should be used For example, a person might decline a ventilator but not medications if terminally ill Or a person might refuse a feeding tube if permanently unconscious but not if terminally ill

Living wills have significant drawbacks, however First, a will drafted in specific language cannot provide guidance for circumstances that were not anticipated when the will was written If, on the other hand, the will is written in general language to cover a broad range of possible circumstances, then its terms may be ambiguous in particular situations In addition, many statutes restrict the kinds of directions that may be given in a living will For example, living will statutes often apply only in the setting of a "terminal condition," which is generally defined as an irreversible condition that makes death imminent."[illegible] A living will statute, then, may not apply if the patient suffers from a persistent vegetative state Moreover, in some states, the living will statute may not apply to the withdrawal of a feeding tube[illegible]

Most of the courts that have addressed the issue of the withdrawal of artificial life supports have recognized that individuals have a common law or constitutional right to refuse treatments in settings other than those covered by a living will statute[illegible] Consequently, if a patient expressed treatment preferences in a living will for circumstances that went beyond the scope of the living will statute, the preferences would likely be upheld under common or constitutional law However, the limitations in a state's living will statute may influence patients when they compose their wills Many patients are likely to use the model living will form that is published as part of the state's living will statute In addition, courts may be influenced by the scope of the living will statute in deciding the scope of a patient's common law or constitutional right to refuse artificial life supports.[illegible]

The problems with a living will can often be addressed by designation of a proxy to make health care decisions.

Appointment of a Proxy Decision Maker

The second mechanism for a person to indicate in advance whether artificial life supports should be used is by appointing a family member, friend, or other person as a "proxy" or "agent" for making health care decisions. The proxy decision maker has the authority to make any medical decisions for the patient that the patient would be entitled to make if he were mentally competent. The proxy reaches a decision by applying the patient's prior statements and personal values to determine what the patient would want to have done under the circumstances.

There are two ways to appoint a proxy. In approximately 12 states, the living will statute includes a provision for the appointment of a health care proxy.[illegible] By appointing a proxy under a living will statute, an individual can avoid both the rigidity of specific directions and the ambiguity of general directions. However, because the proxy's authority extends no further than the patient's authority, if the living will statute limits the kinds of directions that the patient may give, then a proxy appointed in accordance with the provisions of a state's living will statute is limited in the same way. Thus, if the living will statute applies only to terminal conditions, the proxy can make health care decisions only in the setting of a terminal condition. While some courts may recognize a living will that grants a proxy more authority than is permitted under the state's living will statute, others may limit the proxy's authority to the limits expressly delineated by law.

A method of appointing a proxy with more flexible authority is the creation of a "durable power of attorney," which is a specific type of power of attorney. A power of attorney is a means by which one person (the "principal") can authorize another person (the "agent") to take legally binding action on the principal's behalf.[illegible] The agent need not be a lawyer, but may be a family member, friend, employee, or any other legally competent adult.

Ordinary powers of attorney are usually inadequate in the setting of health care decisions for the hopelessly ill. This is because the ordinary power of attorney creates a proxy authority that is limited in the same way as the principal's authority. Hence, when the principal becomes legally incompetent, the proxy is incompetent to act on her behalf. In response to this deficiency of the ordinary power of attorney, every state has adopted a durable power of attorney statute. Under a durable power of attorney, the agent's authority remains in effect (or, in some cases, takes effect) when the principal becomes incompetent.[illegible]

It is unclear whether durable powers of attorney can be used to grant authority to an agent to make health care decisions. Traditionally, durable powers of attorney have been used in connection with actions that involve the principal's property or financial affairs. Consequently, a court might find that the legislature did not enact the durable power of attorney statute with the intent to permit its use for health care decisions. The New Jersey Supreme Court, on the other hand, has interpreted the state's durable power of attorney statute to encompass health care decisions.[illegible]

To avoid any uncertainty whether durable powers of attorney can be used for health care, at least 11 states have enacted durable powers of attorney for health care.[illegible] A durable power of attorney for health care explicitly permits an individual to delegate to an agent his right to accept or refuse health care. The delegation may be a broad one, permitting the agent to make any medical decision that the principal could have made if legally competent. Alternatively, the principal may choose to delegate only the power to make certain medical decisions.[illegible] Moreover, the principal can include in the delegation of power statements regarding her treatment preferences for specific situations.[illegible] For example, the principal may indicate that no life-sustaining measures, including a feeding tube, should be used in the event of permanent unconsciousness. In any event, the agent is obligated to act in accordance with the principal's desires and intents, whether expressed in the delegation of power or in other ways by the principal before the principal became incompetent.[illegible]

Durable powers of attorney for health care have important advantages over living wills. While living wills are often limited to treatments in the setting of a terminal illness where death is imminent, durable powers of attorney for health care can generally be used to delegate authority for health care decisions in all cases of patient incompetence. Further, because the agent has legal authority to make health care decisions, physicians are able to rely on the agent's decisions even when the patient's desires were not clearly expressed or did not take into account unforeseen developments. (Indeed, the durable power statutes generally provide immunity from suit for physicians who act on an agent's decision if the physician believes in good faith that the decision is not contrary to the patient's desires.[illegible]) In other words, the agent is able to resolve ambiguities or inconsistencies in the patient's prior written and oral statements when deciding what the patient would want under the circumstances. In contrast, there is no one with legal authority, other than a judge, to interpret the terms of a living will in cases of disagreement or ambiguity regarding the patient's wishes. Consequently, with durable powers of attorney for health care, there should be less of a need or tendency to seek judicial intervention. A living will also suffers from the possibility that it may get lost or that the physician who treats the patient may not be made aware of its existence.[illegible] There is less of a likelihood that a proxy decision maker would be lost or overlooked.

There are important disadvantages to the durable power of attorney for health care. For many people, there is no person that they would be comfortable with as an agent to make all health care decisions. In addition, if family members disagree about the patient's desires, decisions by the agent are subject to challenge as not consistent with those desires. Some commentators have argued that decisions of a proxy are less representative of a patient's wishes than treatment preferences expressed in a living will.[illegible] However, when a patient designates another individual as the proxy decision maker, the patient is choosing to accept the proxy's understanding of the patient's preferences and to accept the proxy's treatment choices based on that understanding.

Incorporating directions for certain treatment decisions into durable power of attorney documents may be the optimal method for ensuring that a patient's wishes will be implemented. A patient would be able to provide specific instructions for the course of treatment in many circumstances while maintaining control over the decision-making process in unanticipated circumstances. In addition, when making treatment decisions in unanticipated circumstances, the proxy would have a greater sense of the patient's general preferences for treatment from the specific instructions included in the document.

The Physician's Role in Implementing Treatment Preferences

In a 1988 public opinion survey conducted by the the American Medical Association, 66% of adults reported that they had discussed with family members their treatment preferences in the event of a coma from which doctors believe that recovery is not possible.[28] However, only 15% of the patients in the study had filled out a living will. Other polling data yield similar results; many more patients have treatment preferences regarding artificial life supports than have expressed those preferences through a living will or appointment of a proxy decision maker.[29]

Physicians can serve a primary role in ensuring that patients give appropriate consideration to the issue of artificial life support and that the treatment preferences of their patients are adequately documented.[30] Physicians can initiate discussion and advise patients of possible treatment decisions that might have to be made once the patient is no longer competent and can supply the patient with pertinent medical information regarding terminal illnesses and permanently unconscious conditions. In addition, physicians can document the patient's wishes in the patient's medical record, thereby ensuring that there is sufficient evidence of the patient's preferences even if the patient does not write a living will or appoint a proxy decision maker.

Physicians should not wait until the onset of an illness or disease to begin exploring a patient's treatment preferences. As the Karen Quinlan[31] and Nancy Cruzan[4] cases demonstrate, even relatively young and healthy patients should be encouraged to think about the issues that surround treatment decisions in the event of terminal illness or permanent unconsciousness. Because a patient's wishes may change with the passage of time or with the progression of illness, a patient's treatment preferences should be periodically revisited. A patient's wishes may also change upon the occurrence of a significant life event, such as having children or becoming widowed.

While it is often difficult for people to discuss their own death in a concrete way, it is becoming increasingly important for individuals to express their preferences regarding the use of artificial life supports. For perhaps 70% of Americans, a decision will be made whether to provide life-sustaining medical care when devastating illness becomes terminal or irreversible.[illegible] Making these decisions in advance will ensure not only that the patient's wishes are carried out but also that family members and friends can act on the patient's behalf with the confidence that they are acting in the patient's best interests.

David Orentlicher, MD, JD
Ethics and Health Policy Counsel

Kristen Halkola made important contributions to the research and writing of this article.

1. *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association.* Chicago, Ill: American Medical Association, 1989; sect 2 20.
2. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* Briarcliff Manor, NY: The Hastings Center; 1987:26-29.
3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life Sustaining Treatment.* Washington, DC: US Government Printing Office, 1983.
4. *Cruzan v Harmon*, 760 SW2d 408 (Mo 1988).
5. *In re Jobes*, 108 NJ 394, 529 A2d 434 (NJ 1987).
6. *In re Colyer*, 660 P2d 738, 748 (Wash, 1983).
7. Emanuel LL, Emanuel EJ. The medical directive: a new comprehensive care document. *JAMA.* 1989;261:3288-3293.
8. Report of the Board of Trustees of the American Medical Association. *Living Wills, Durable Powers of Attorney, and Durable Powers of Attorney for Health Care.* Chicago, Ill: American Medical Association, 1989.
9. *Appointing a Proxy for Health Care Decisions: Analysis and Chart of State Laws.* New York, NY: Society for the Right to Die, 1989.
10. Ill Stat Ann ch 110 1/2, ¶703(e).
11. Fla Stat Ann §765.03(6).
12. Ill Ann Stat ch 110 1/2, ¶702(h).
13. Ind Code Ann §16-8-11-9.
14. Ill Ann Stat ch 110 1/2, ¶702(d).
15. Ind Code Ann §16-8-11-4.
16. *Couture v Couture*, 48 Ohio App 3d 208 (Ohio Ct App 1989).
17. Fla Stat Ann §765.06(2).
18. Tex Rev Civ Stat Ann art 4590h(3)(e).
19. Ind Stat Ann §30-2-11-1.
20. *In re Peter*, 108 NJ 365, 529 A2d 419, 426 (1987).
21. *What You Should Know About Medical Durable Power of Attorney, Proxy Appointments, Health Care Agents*, New York, NY: Society for the Right to Die, 1990.
22. Ill Stat Ann ch 110 1/2, §804-810.
23. Cal Civ Code §2434(b).
24. RI Gen Laws §23-4.10-2.
25. Ill Stat Ann ch 110 1/2, §804-808.
26. Cal Civ Code §2438(a).
27. Van McCrary S, Botkin JR. Hospital policy on advance directives: do institutions ask patients about living wills? *JAMA.* 1989;262:2411-2414.
28. *Physician and Public Attitudes on Health Care Issues.* Chicago, Ill: American Medical Association, 1989:113.
29. Steiber SR. Right to die: public balks at deciding for others. *Hospitals.* 1987;61:72.
30. Emanuel LL. Does the DNR order need life sustaining intervention? *Am J Med.* 1989;86:87-90.
31. *In re Quinlan*, 70 NJ 10, 355 A2d 647 (1976).
32. Miles S, Gomez C. *Protocols for Elective Use of Life Sustaining Treatments.* New York, NY: Springer Publishing Co Inc, 1989.

PREPARED STATEMENT OF SENATOR JOHN HEINZ

Mr. Chairman, along with the miracles of modern medicine come weighty decisions on when to prolong life. The recent Supreme Court decision on the case of Nancy Cruzan underscored the importance of having an advance directive to assure that such decisions are not made haphazardly or without respect for the patient's wishes.

I applaud the efforts of Senator Danforth and Congressman Levin to assure that all adult patients of hospitals, nursing homes, clinics and health maintenance organizations are provided with information about their rights under the applicable State law to have a living will and/or assign a family member or other person durable power of attorney. Requiring institutional providers and HMOs to have written policies and procedures concerning advance directives as a condition of participation will encourage and assist individuals to make decisions now, while they are of sound mind and body, for future health care events.

Patient education, however, is just one aspect of what is needed to assure that the rights of individuals are respected in decisions to continue or terminate treatment. A complimentary and equally important measure is required as well: institutional protocols to direct professional staff in their actions when a patient is not able to participate in decision making about their care. I am referring in particular to protocols regarding when to resuscitate a dying patient.

Institutional resuscitation policies and guidelines were strongly advocated in 1983 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and the Joint Commission on the Accreditation of Healthcare Organizations requires all accredited health care facilities to develop resuscitation guidelines. Nonetheless, a report by the Office of Technology Assessment that I commissioned a few years ago during my tenure as the Chairman of the Special Committee on Aging found that hundreds of hospitals and thousands of nursing homes still have not developed or implemented such protocols. Of those that have, only a small percentage include reference to other types of life sustaining technologies, or to living wills and other advance directives.

When health care facilities do not have clear guidelines for their professional staff to follow when the need for resuscitation arises, the results can be truly unacceptable, as was demonstrated by our committee's examination of specific case histories. For example, in one case, that of Ms. Stevens, the lack of a policy led to her being kept alive against her wishes. When Ms. Stevens was admitted to a nursing home in Florida, in 1986, she and her son agreed that if she had a heart attack or stroke, she did not want to be resuscitated. The nursing home, however, had no policy or procedure for documenting or responding to Ms. Steven's request. Several months later, when she suffered permanent and severe brain damage from a stroke, she was put on a ventilator, despite her original request. Her son was forced to go to court to ensure that his mother's original wishes were respected.

In another case, a decision was made not to resuscitate an 83-year-old woman in New York, without any attempt to determine her wishes. This patient had been in the hospital for several months battling pneumonia when she suffered a heart attack. Because there was no written agreement between the patient, family or doctor, no one knew whether or not this patient wanted to be resuscitated, so she was not.

The OTA report, which I referenced earlier, recommended the adoption of formal institutional guidelines for making decisions on whether to use or withdraw life sustaining treatment. The phrase "use or withdraw" is particularly important because discussions regarding advance directives often presume that patient will choose to have treatment withdrawn or withheld should they become medically incompetent, when in fact there are patients that want to fight for life under any circumstance. In developing public policy regarding advance directives, the right of individuals to sustain their life must be respected as much as their right to die.

Last year, in response to the findings of OTA, I developed "The Life Sustaining Treatments Act," which was discussed in the Finance Committee during the budget reconciliation, but not included as part of the final package. My proposal, which I believe could be married to that of Senator Danforth quite readily, is to require Medicare and Medicaid participating hospitals and skilled nursing homes to provide 24-hour staffing of at least one individual currently certified as competent to perform Basic Life Support Cardiopulmonary Resuscitation and to develop a written protocol for resuscitative services. Such a protocol would assist each hospital patient, nursing home resident, and persons authorized under State law to act on their behalf should they become incapacitated, in making decisions about whether and when to withhold resuscitative services.

The requirement that nursing homes have the capability to provide CPR at all times is long overdue. Only 30 percent now have a staff person certified in CPR available around the clock, and only half require their nurse to hold present certifications. Unless all nursing homes have staff capable of providing CPR 24 hours a day, a resident's wish to be resuscitated is a hollow one.

Institutional protocols would be a significant step forward in helping patients exercise greater control of the end of their lives. These protocols also would provide hospitals, nursing homes and their staffs with important protections by reducing the risk of litigation and helping to settle disputes, should they occur. In addition, protocols can protect the civil liberties of professional staff by allowing them to withdraw from a case if they have moral objections to the requested treatment plan.

As envisioned by my proposal, each written protocol would be developed with medical staff, nursing staff and other appropriate personnel and be approved and adopted by the governing body of the facility. Among other things, the protocol would describe the procedures by which an individual decision of whether or not to withhold resuscitative services is to be reached and the procedures to be used in resolving potential family or other conflicts which may occur in the decision making process. The protocol would require that appropriate orders be written by the physician primarily responsible for the patient, and that documentation of the orders is included in the patient's medical record, if resuscitative services are to be withheld.

Mr. Chairman, the development and application of life-sustaining medical technologies has rapidly outpaced the development of any consensus by our society regarding the moral, ethical, legal and financial ramifications of the use or non-use of these technologies. What is clear from a growing compilation of case law is that patients have a right to control their destiny. We must support that right to the fullest extent possible. I am convinced that if each prospective patient were provided with a copy of the institution's resuscitation protocol and information about their rights concerning advance directives, and the presence of any such directive was documented in the medical record, much of the confusion and trauma that currently surrounds decisions regarding the application of life sustaining technology could be prevented.

PREPARED STATEMENT OF SENATOR SANDER M. LEVIN

Mr. Chairman, I want to thank you for the opportunity to testify at this hearing. I also want to commend Sen. Danforth and Sen. Moynihan for their leadership on this important legislation.

Later today you will be hearing from several witnesses who will surely address many of the technical issues relevant to the Self Determination Act, and, perhaps, many issues that are not relevant to the bill. What I'd like to do this morning is to make sure we don't lose the forest for the trees in our deliberations. The context for these discussion can be summed up in three interests that underlie this legislation: personal decision-making, clarity, and knowledge.

Last month's Supreme Court decision in the *Cruzan* case has brought the issue of personal decision-making into sharp focus. Eight of the nine justices recognized that we have a right to accept or refuse medical treatment. This right to determine the medical treatments we prefer is rooted in the ethical principle of autonomy, and in constitutional liberty interests. This is not to say that people may choose medical care that is inappropriate, or that they should make these decisions in the absence of consultation from family, health care professionals, religious advisors, or others. But respect for the integrity of the individual within society is part of our American tradition.

The Supreme Court reiterated a point that courts have been making for many years, that the right to make decisions regarding one's own welfare choose does not end should people become unable to communicate their preferences. Our second major interest, clarity, comes into play at this point. The Court ruled that states have the power to set standards for how clear the prior wishes of an incapacitated person must be in order to be honored. Although there was disagreement about whether Missouri's standard was appropriate, the justices overwhelmingly agreed on the validity and importance of advance directives—living wills and durable powers of attorney—in providing the clarity that is necessary in such difficult situations.

In the week or so following the *Cruzan* decision, it seemed that copies of living wills were published in every newspaper in the country. But advance directives did not spring up overnight. They have evolved over the last 15 years, and contain numerous safeguards to assure appropriate use of the directives, worked out after extensive negotiations with various provider, patient, and religious groups at the state level. Advance directives can help people implement their desire to have life-sustaining treatments withdrawn or withheld when these treatments only serve to prolong death. They can also articulate treatments that are *desired;* clarifying for providers what the patient feels is acceptable or preferable.

Booklets and pamphlets about advance directives, designed for the general public, are currently being developed and distributed by many groups, including the American Bar Association, the Catholic Health Association, and various state medical associations, such as those in Illinois and California. In fact, a booklet entitled "A Matter of Choice: Planning Ahead for Health Care Decisions," was produced several years ago at the request of the Senate Special Committee on Aging, and distributed by the American Association of Retired Persons.

Advance directives can significantly increase the clarity of all parties concerned when dealing with stressful, traumatic situations in which difficult decisions need to be made. People need not wait until it's too late, but can provide evidence of their wishes in advance, when there is time to deliberate and plan. The fact is, however, that only about 10% of the public have formulated advance directives. In addition, studies show that physicians are not well-informed about the opportunities for advance directives provided by the state. And thus, our third major interest: knowledge.

The major point of the bill is that better medical decisions can be made if parties involved in those decisions are well informed as to the options open to them. In all of our discussions, nobody has seriously argued that it is desirable to withhold information from people. Forty-seven states have passed advance directive legislation. They did not pass this legislation hoping that nobody would find out. Our bill's purpose is to educate people, including health care professionals, about advance directives.

Let us be very clear about what our bill does NOT do. It does not preempt state law. It is clear that the power to make substantive policy regarding advance directives resides with the states. Many of the concerns that are expressed in relation to the Self Determination Act are relevant to already crafted state law, such as provisions regarding, witness constraints, pregnant women, and others. Our bill maintains the state's jurisdiction to define the details of implementing advance directives. What we are doing is attempting to enhance people's knowledge of the opportunities the states have already provided them. I believe that such personal and important medical decisions should be made by individuals, families, and physicians. They should not be made by judges, except in exceptional cases. The knowledge and clarity produced by this bill will facilitate the achievement of that goal.

We take no position on what choices people make about their health care, nor do we require that anybody choose to fill out an advance directive. Part of the principle of respect for autonomy is to respect a person's decision NOT to formulate an advance directive. Indeed, our bill specifically prohibits providers from conditioning the provision of care on the presence or absence of advance directives.

We are not seeking to penalize providers. We have made the requirements of our bill a condition of participation for Medicare with the intent of demonstrating the importance of the issues involved and the actions that need to be taken. But we certainly do not intend that providers will be expelled from Medicare simply because they have forgotten to provide a brochure to a couple patients. We are well aware of the reality that providers need to be "substantially out of compliance" with the conditions of participation before action to exclude them will be taken.

I think it is important to note that the public is way ahead of us on this issue. As we hold endless discussions about whether people will be frightened by being told of their options to plan for their future, surveys public opinion show that the vast majority of Americans favor the concept of advance directives, and want to be told about them. A recent survey in Michigan, done by Wayne State University, found that 94% of the public feels that people "should be allowed to decide in advance what means will or will not be used to keep them alive" in the event of a coma. Another survey found that over two-thirds of a sample of elderly patients welcomes the opportunity to discuss the question of life-sustaining treatments with their physicians, and 53% felt that the physician should raise the subject. In hearings in May in the Health Subcommittee of Ways and Means, we heard testimony from a researcher at Harvard who has found that both physicians and patients respond positively to discussions of advance directives.

One writer, commenting in an August 1989 issue of *Hospital Practice,* put the issue quite well: "Physician-patient communication should be more open, more frequent, and better taught than it has been in this era of intensive life-support technology." Our bill is only a small step—the step of having patients and those caring for them have information available to them—that will facilitate the trend toward better communication and, as a result, better health care.

Prepared Statement of Richard A. McCormick, S.J.

I am Richard A. McCormick a Jesuit priest and John A. O'Brien Professor of Christian Ethics at the University of Notre Dame. I have been teaching Christian ethics and writing in the field for 35 years. A subspeciality has been bioethics. In that capacity I have been a member of the following committees: the Ethics Advisory Board of the former Department of Health, Education, and Welfare; the Ethics Committee of the Catholic Health Association; the Ethics Committee of the American Hospital Association; the Ethics Committee of the American Fertility Society. I speak for myself not for the Cathclic Church though my convictions are deeply informed by the moral perspectives of that church. I do not speak for the Catholic Health Association though I share virtually all of its sentiments pertaining to S. 1766. I agree with the Catholic Health Association's endorsement of S. 1766. I should like to explain why.

There is a basic human right of self-determination with regard to acceptance or rejection of medical treatment. This is an implication of human dignity. If there is a right to accept or reject medical treatment (self-determination), it seems to follow that there is a corresponding obligation on someone to make the exercise of that right practically operable and exercisable. This obligation has two overlapping facets: (1) negative: not placing obstacles, removing obstacles; (2) positive: providing facilitating measures. obviously these two facets overlap very extensively.

One of the greatest obstacles to the exercise of the right of self-determination in this context is ignorance about the right itself and about the ways to exercise it. This ignorance causes families great suffering at the time of crisis when they are faced with treatment decisions. This ignorance also promotes the fear of malpractice for physicians because they have no clear knowledge of the patient's wishes. Similarly, lack of knowledge and discussion about this right and its implementation through advance directives leads to cases like Nancy Cruzan where the state has refused to allow treatment to be terminated.

I can personally testify through my own work that ignorance about this right and its implementation is widespread. Over and over again when I address the public on care of the dying, people approach me to inquire about advance directives and the durable power of attorney. In general I would say that the vast majority do not know where to turn or what to do to state their personal preferences. S. 1766 is basically aimed at this serious lack of knowledge regarding the tools available to patients to express their views of life-sustaining treatment. In Section 2 of S. 1766 we find a listing of the reasons for this legislation Here I want to add two more reasons which can strongly impede the exercise of self-determination.

The first dimension of health care that can support ignorance about self-determination is the increasing depersonalization of such care. When health care is depersonalized things are done to patients. This can easily be an institutionalized form of an older paternalism.

The depersonalization I refer to is by and large traceable to three factors:

Technology. Everything from diagnosis through acute care to billing is done these days by computer. That is but a symbol of the massive presence of technology in modern medicine. In saying that, I mean in no way to knock technology. Technology quite simply makes possible the otherwise impossible. No one who has fought an uneven battle with kidney stones will take careless shots at the lithotriptor. No one who has been spared a stroke by carotid endoarterectomy will criticize the sonography and arteriograms that clinched the diagnosis. No one whose lesion was pinpointed by magnetic resonance imaging will belittle that wonderful technology.

Even after technology has been given its due, it remains true that the price of efficiency can be a measure of depersonalization. This must give pause to a profession whose self-description is that of a healing ministry on a person-to-person level.

Cost containment. The cost of health care in the United States hovers around eleven percent of the GNP. It has become routine to encounter descriptive phrases such as "out of control" and "skyrocketing" to paint the picture. The factors contributing to the enormity of the health bill are well known: sophistication of services, higher wages, more personnel, inflation, cost pass-along systems, the malpractice system, unnecessary care, etc.

But there is a cost-containment revolution afoot. Diagnostic related groups (DRG) are a symbol of this. Joseph A. Califano, Jr., former Secretary of Health, Education, and Welfare (1977-79), puts it as follows:

> The spirited air of competition is for the first time swirling through the health industry. Fed up with years of waste, the big buyers of care—governments, corporations and unions—are demanding the facts, changing the way doctors, hospitals and other providers are used and paid, and reshaping financial incentives that have encouraged patients to seek unnecessary care. And a host of new health care providers is scrambling to get their business.

Califano points out some interesting facts that form the background for new cost-containment efforts. Item. Some 20-25% of hospital admissions are unnecessary. Item. There are erratic geographical variations in medical practice. For instance, the rate of major cardiovascular surgery is twice as high in Des Moines as in Iowa City for patients with the same symptoms. Item. Patients of fee-for-service physicians are twice as likely to have bypass surgery as those in health maintenance organizations. Item. A small number of patients accounts for a disproportionately large proportion of health costs. For instance, more than 30% of Medicare's expenditures goes to patients with less than a year to live. In 1984, 3.4% of Chrysler's insured accounted for 43.5% of the company's health care payments.

Obviously, the new concern with cost containment will spawn many ethical problems. I will not attempt to detail them here since I am chiefly concerned with the emergence of the cost-containment factor itself and its impact on the depersonalization of health care.

Public entities. I use this term to refer to the increasing presence of legislation (e.g., Baby Doe rules), the courts and the legal profession in medical decision making. The symbols of this presence: legislated living wills, Wade-Bolton, Quinlan, Fox, Storar, Dinnerstein, Conroy, Brophy, Chad Green, Nancy Cruzan, and a host of others.

It is my thesis that these three factors (technology, cost containment, public entities) can affect the very matrix of the healing profession. This matrix is constituted by the conviction that medical decision making best serves the interests of patients when it is located within the triad of patient-physician-family. (By "physician" here I mean to include all members of the health care team, e.g., nurses.) Decisions must be tailor-made to the individual patient. They are like a glove fitting an individual hand. They are personal decisions.

The three factors I have listed are impersonal factors. They can easily have the effect of preprogramming our treatment. And clearly this can result in depersonalized treatment, a subtle form of oppression of the weak and dependent by the powerful and healthy. This growing depersonalization of treatment has led George Caldwell, former president of the Lutheran General Health Care System, to note that what goes on in hospitals too often is "fixing" and not "healing." Whatever the case, in a depersonalized atmosphere patient self-determination easily gets submerged.

The second dimension of health care that can reinforce ignorance about self-determination is death as the ultimate enemy. The medical profession is committed to curing disease and preserving life. That we take for granted. But this commitment must be implemented within a healthy and realistic acknowledgment that we are mortal. The point seems so obvious as to be trivial. In a sense it is.

But living it out is not. The attempt to walk a balanced middle path between medico-moral optimism (which preserves life at any cost, with all means, regardless of diagnosis, prognosis, family history, patient preferences, etc.) and medico-moral pessimism (which takes life when it becomes onerous, boring, dysfunctional and "hopeless") is not easy, especially in a highly litigious atmosphere. Symptoms of this abound in the inflated statements we encounter on life-preservation. Let a few suffice here. Worcester Hahnemann Hospital issued this policy directive. "No one, patient, family or physician, may consent to, direct or initiate the removal or withdrawal of care or treatment which may be considered in any way to be life sustaining to any patient, except as provided below." The "provision below" was that the patient be dead according to the so-called Harvard Criteria of Death and be declared so by the attending physician. In other words, no withdrawal of any life-sustaining technology unless the patient is dead!

Carol A. Smith, Assistant Attorney General of the State of Washington, gave this opinion (1977) regarding the law with respect to withdrawing or withholding life support from a dying patient: "Under the present law, an attempt to bring about death by the removal of a life sustaining mechanism would constitute homicide, first degree."

Such attitudes also pervade the medical profession. In testimony before the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Dr. Marshall Brummer, a pulmonary specialist, was asked: "Is it the duty of the physician to do everything for that patient until that patient is called to his or her reward?" The answer: "Yes."

Behind such assertions lies a kind of medical idolatry, the absolutization of physical existence. This idolatry takes concrete form in the conviction that the inability to cure or prevent death is medical failure. The disturbing corollary of this: everything that can be done must be done. When this attitude pervades the hospital setting self-determination is crushed.

In combination the two dimensions of health care that I have mentioned act as powerful obstacles to the notion of self-determination and of the tools of its implementation.

It has been my experience that most decisional problems touching acceptance or rejection of treatment can be traced to lack of communication. For this reason I believe that the notion of advance directives can relieve this problem. Advance directives such as durable power of attorney and living wills encourage discussion and documentation of views on sustaining treatment in advance. Thus the pain and burden on families can be eased at the time of dying.

Like the Catholic Health Association, I strongly support proposed changes in the language of the bill that require the Secretary of the Department of Health and Human Services to conduct a public information campaign that includes development or approval of materials that will be made available to Medicare and Medicaid providers to help them comply with the provisions of this bill. It is far better to learn about health care decision making rights and advance directives prior to entering the hospital.

I also support S. 1766's provision that the provider determine the existence of a previously executed advance directive.

I should like to underline an aspect of S. 1766 that can easily be missed: staff education. I would support alternate language in the bill that would allow facilities to collaborate with each other on their educational efforts for both staff and community. I much prefer this to requiring facilities to create institutional ethics committees as the vehicle for education. An ethics committee should arise spontaneously from a felt need.

Finally, I agree with those who request that explicit language be added to the bill that would exempt hospitals from applying the provisions of S. 1766 to emergency room admissions until the patients are medically stabilized.

(Citations in this testimony may be found in my book *The Critical Calling*, Georgetown University Press, 1989.)

PREPARED STATEMENT OF SENATOR DAVID PRYOR

Mr. Chairman, I appreciate your holding today's hearing on S. 1766, the patient self-determination act. You, by chairing this hearing, and Senator Danforth, by introducing S. 1766, are providing a great public service by focusing needed additional public attention on the sensitive issue of the right of individuals to maintain control over decisions about their personal health care treatment.

I recall Jack Danforth expressing his concern about this issue on numerous occasions during last year's Finance Committee deliberations on the repeal of the Medicare Catastrophic Coverage Act. He deserves a great deal of credit for acting on his concerns by introducing his bill and I am pleased to be a cosponsor of S. 1766.

Most of us here today are aware of the recent Supreme Court decision in the case of Nancy Cruzan. While the Supreme Court did not grant the family of Ms. Cruzan their wish to withdraw medical treatment from their permanently comatose daughter, it has put the spotlight on the importance of advance decision-making about our own health care treatment. One of the most important messages to be drawn from the *Cruzan* decision is that if we do not wish to continue our existence in a permanent comatose state or to be the subject of a legal drama excruciatingly painful to our loved ones, as the Cruzans have experienced, then it is best that we express clearly in advance our specific wishes.

Fortunately, most of the States have taken steps to make it possible for individuals to do just that. Nearly all States have addressed the individual's ability to control their autonomy in health care decision-making by enacting laws establishing various forms of so-called advance directives. Most typically, these laws are known as living wills and durable powers of attorney. while Nancy Cruzan did not have an advance directive, most of us have the opportunity to do just that if we wish to maintain control over our health care treatment in the event we should become terminally ill or otherwise severely incapacitated. Unfortunately, however, it seems that far too many Americans remain unaware of their right to make these choices.

Moreover, even when we execute an advance directive valid under State law, we have no guarantee that our wishes will be honored by the hospital, nursing home, other health care setting, or a physician, entrusted with our care.

I believe that legislation governing the enactment and provisions of these advance directives is appropriately a matter for State jurisdiction. With few exceptions, the States have exercised their responsibility on this matter. However, there is an appropriate Federal role here. The Danforth legislation specifically addresses the responsibilities of health care providers who are the recipients of Federal funds.

In sum, the patient self-determination act requires that health care providers who receive Medicare and Medicaid funds inform patients about advance directives, document whether or not a patient has executed an advance directive, and honor the wishes of the patient who has executed a legally valid advance directive. If the provider cannot, as a matter of conscience, honor the patient's wishes, then the provider would be obligated to "arrange for the prompt and orderly transfer" of the patient to another health care provider.

The Danforth bill is a responsible attempt to help individuals and their families to avoid the tragedy that the Cruzan family, and others, such as the family of Karen Anne Quinlan, experienced. It does it in a way that fully preserves the responsibility of the States in this area.

Today's hearing will enable us to take a look at the full implications of the legislation, particularly upon health care providers and the States. We have an excellent array of witnesses beginning with Representative Levin, who has offered a similar bill in the house, and Dr. Wilensky, Administrator of the Health Care Financing administration.

I look forward to a full discussion today on this important matter so that we can ensure that decisions concerning our health care are handled with the utmost dignity, are consistent with our personal wishes, and are not burdensome to the health care providers entrusted with our care.

PREPARED STATEMENT OF PAUL C. RETTIG

INTRODUCTION

I am Paul C. Rettig, Executive Vice-President of the American Hospital Association (AHA). On behalf of AHA's nearly 5,500 member hospitals and almost 48,000 individual members, I welcome this opportunity to present AHA's views on S. 1766, The Patient Self Determination Act of 1989.

We applaud the Subcommittee for exploring the issue of advance directives and living wills, and we commend Senator Danforth and Senator Moynihan for introducing this legislation. The bill addresses two major issues of primary concern to hospitals: first, the development of a national educational campaign to educate the public regarding the importance of self determination and the use of advance directives; and second, the use of both living wills and durable powers of attorney as mechanisms for expressing patient treatment wishes. The more knowledgeable the public becomes in the use of advance directives, the more frequently informed medical decisions will be reached through collaboration between patients, families, physicians and institutions. Senators Danforth and Moynihan propose, and hospitals wholeheartedly agree, that competent adults should have the right to accept or decline medical or surgical treatment, or appoint surrogates to make such decisions, in advance of the time they may be rendered incompetent by illness or accident. For years AHA has played a leadership role in the ongoing debate concerning biomedical ethical issues. Through its Special Committee on Biomedical Ethics, the AHA has published policies and positions addressing the role of patients, families, guardians, physicians and hospitals involving the withholding and withdrawal of medical treatment. Further, the AHAs bimonthly publication, "Hospital Ethics," offers a forum for learned discussion of biomedical ethical issues. Most recently, the AHA filed an amicus curiae brief before the United States Supreme Court in support of the Cruzan family. The importance of advance directives to hospitals in effectively rendering care cannot be overstated, as we confront the issue every day. Indeed, of the 1,300,000 Americans who die each year in hospitals, seventy percent are involved in a decision to forego life sustaining treatment.

NATIONAL EDUCATIONAL CAMPAIGN

The proposed legislation mandates that the Secretary of Health and Human Services develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient's right to participate and direct health care decisions. We believe that this educational campaign is important and necessary to achieving the legislation's goal because if living wills and durable powers of attorney are to be executed before the need for them arises, individuals must be educated prior to being admitted to a hospital. Hospitals fully accept their role in educating patients concerning advance directives. In this regard, AHA recognizes also the importance of the physician role in sharing advance directive information with patients, and commends the American Medical Association and other physician groups for their efforts to that end.

ONGOING ISSUES

The proposed legislation requires the Secretary of Health and Human Services to conduct a study and report to Congress with respect to the experience of providers, practitioners, and regulators in complying with the Act, as well as the methods for communicating treatment wishes when patients are transferred or discharged to other health care settings. In addition, the Secretary must make recommendations for further legislative efforts to carry out the purposes of the legislation.

Hospitals strongly support a Federal effort to gather evidence of the effects of the legislation. All issues surrounding the use of advance directives will not be resolved by the Patient Self Determination Act, although the legislation is an excellent first step in addressing the issue. For example, the bill does not deal with one of the biggest problems hospitals face—that of incompetent or unconscious patients. Providers need direction on how best to handle such patients where clear written advance directives do not exist, or where a patient arrives in an incompetent or unconscious state and the hospital cannot determine whether directives exist.

We note that the recent Supreme Court decision in *Cruzan v. Director, Missouri Department of Health* left to the states the question of incompetent patients who have not executed advance directives. Unfortunately, there is a lack of consistency between state laws. For example, states may limit the use of advance directives to terminally ill patients, thereby offering no guidance for treatment of patients in a persistent vegetative state, such as Nancy Cruzan. Or, states may define medical treatment to exclude nutrition and hydration, so that even where advance directives exist, they may be enforceable in some states, but not in others. The *Cruzan* decision affirmed states' rights to establish laws and procedures for executing and implementing advance directives and honoring a patient's wish to refuse treatment. However, to the extent that states define an individual's right to refuse treatment differently, the *Cruzan* decision raises questions as to the extent of that right and may make the task of educating individuals more complicated.

The requirement that HHS conduct a study on the effects of the Patient Self Determination Act acknowledges that the discussion on advance directives needs to continue. AHA offers its support and assistance to ensure that the study will lead to the clarification of these ongoing issues.

KEY PROVISIONS OF LEGISLATION

The Patient Self Determination Act requires providers to maintain policies and procedures recognizing the ability of competent adults to make decisions to accept or refuse medical or surgical treatment, and to designate an agent or surrogate through a durable power of attorney to make health care decisions, should the individual be unable to do so. The legislation sets forth provisions which must be included in providers' advance directive policies.

INFORM PATIENTS OF THEIR RIGHTS

Under this legislation, a health care institution must "inform" patients of their right to make decisions about their own medical care, including the acceptance or refusal of such treatment, and of their right under state law to execute a living will or designate a durable power of attorney for health care decisions.

Requiring hospitals to notify patients of their rights to make treatment choices and to ask patients whether they have an advance directive seems reasonable and can easily be incorporated into existing procedures for admitting and history-taking. Making this inquiry during the taking of the patient's history would assure that the information is documented in the medical record, since hospitals routinely comply with existing laws and accreditation standards requiring that a comprehensive physician assessment be completed within the first 24 hours of admission.

Hospitals believe it is appropriate to play an active role in informing patients of their rights concerning advance directives, although the requirement as stated in the legislation raises a concern. A general requirement to inform patients of their rights under state law could inappropriately place hospitals in the position of legal counsel, in that they would be required to interpret and communicate state statutory and common law. This information would typically be transmitted upon admission to the hospital, thus placing the burden upon hospital staff who may not be qualified to advise patients concerning the law. Furthermore, hospitals are concerned that this general obligation would expose them to liability risk based on their transmission of information to patients.

AHA understands that Senator Danforth intends to revise the Patient Self Determination Act to address hospitals' concerns about the informational requirement. Specifically, we understand that the Secretary of Health and Human Services will develop informational materials on individuals' rights to refuse medical treatment, and will make the materials available to providers. Each state would be required to supplement the HHS materials to reflect state law on the use of advance directives. Hospitals, nursing homes, and other providers would be responsible for distributing the materials to 'patients upon admission. This approach to hospitals' obligation to inform patients of their rights would alleviate hospitals' concerns about communicating the law. All individuals will receive accurate and uniform information on advance directives. AHA, on behalf of its members, acknowledges and appreciates Senator Danforth's response to this issue. Hospitals, as part of our commitment to the community, accept the responsibility to join with others in a collaborative effort to educate the public on advance directives.

Finally, we note that the legislation does not address the issue of comatose or incompetent patients who have not executed living wills or durable powers of attorney. Therefore, we suggest that the written information prepared by the Department of Health and Human Services and the states address this issue. Not only providers, but family and friends, need to be informed as to how to make treatment decisions where no written advance directive exists and the patient is incapable of making such decisions. Specific state information is essential, as state laws on surrogate decision making vary.

DOCUMENTATION OF PATIENT TREATMENT WISHES

The legislation requires hospitals to document patients' treatment wishes and periodically review those wishes with the patient. This broad requirement may be problematic. Hospitals would be charged with interpreting the oral expressions of treatment wishes, which could make accurate documentation difficult and give rise to confusion when the wishes need to be implemented. In addition, an individual's wishes could change frequently depending on the circumstances, requiring constant revision of the documentation.

We understand that Senator Danforth intends to address this concern and clarify the intent of the legislation. Hospitals would be required to inquire upon admission whether a written advance directive exists, and document the response in the patient's medical record. The status of the patient's advance directive documentation would be reviewed if the patient is readmitted to the hospital at a later date. Hospitals appreciate clarification of the documentation requirement, and believe the revision would best accomplish the goal of this provision.

TRANSFERS WHERE WISHES CANNOT BE IMPLEMENTED AS A MATTER OF CONSCIENCE

Hospitals commend Senator Danforth for recognizing that providers for religious or ethical reasons may not, in good conscience, be able to carry out a patient's advance directive or treatment wishes. In this case, the legislation requires that the hospital or provider transfer a patient to a provider who will carry out the patient's treatment wishes, as state law permits.

ETHICS COMMITTEES

The Patient Self Determination Act requires that, as a condition of participation in the Medicare program, hospitals establish an institutional ethics committee to initiate educational programs for staff, patients, residents, and the entire community on ethical issues in health care. In addition, the committee would be required to advise on particular ethical cases and serve as a forum for such issues. Hospitals have two concerns regarding this requirement. First, AHA sees ethics committees as one option for resolving biomedical ethics dilemmas, but believes that the decision to establish such a body should be left to the discretion of each institution based upon its needs. In its "Guidelines" on hospital biomedical ethics committees and in *Values in Conflict*, the report of the AHA Committee on Biomedical Ethics, AHA acknowledges the potential usefulness of ethics committees but does not endorse their use in all hospitals. While hospitals believe that some form of an advisory forum is needed, an ethics committee may not be the appropriate forum for all hospitals, particularly small and rural hospitals.

Second, the scope of functions suggested by the Act exceeds what is appropriate for an ethics committee. Hospitals recognize ethics committees as one option for advising on individual cases, but not for achieving the Act's educational goals. In practice, ethics committees are most often used as internal forums for debate on ethical issues raised by institutional policies or individual cases. They are typically used primarily to advise patients and practitioners in working through difficult treatment decisions. Ethics committees generally are not the proper instrument for initiating public, or even staff and patient, education.

AHA understands that Senator Danforth intends to revise the legislation to permit flexibility in the manner hospitals employ to address ethical issues and educate staff and patients on advance directives. The legislation will allow hospitals to join with other institutions to fulfill their educational obligation, and will permit each hospital to decide the most appropriate mechanism for advising on ethical treatment decisions. We acknowledge and appreciate this response to hospitals' concerns.

MEDICARE CONDITIONS OF PARTICIPATION

While AHA strongly supports the goals of the Patient Self Determination Act and believes that the legislation will accomplish those goals, we do not support its tie to the Medicare Conditions of Participation. The requirements for participation in the Medicare program are meant to provide Medicare beneficiaries with access to high quality health care. Providers should not be at risk of termination from the Medicare program due to a requirement not related to fundamental delivery of care.

CONCLUSION

In summary, AHA strongly supports the goals of the Patient Self Determination Act, and is especially pleased that the revised legislation is expected to address many of our concerns. We will continue to work with the sponsors to resolve the remaining issues so that the goals of the act may be fully realized. Thank you for the opportunity to share our views on the proposed legislation.

PREPARED STATEMENT OF CHARLES P. SABATINO

Mr. Chairman and Members of the Subcommittee: I am Charles P. Sabatino, Assistant Director of the American Bar Association's Commission on Legal Problems of the Elderly. I submit these remarks as the designee of our President, L. Stanley Chauvin, Jr., and at the request of the Chair of our Commission on Legal Problems of the Elderly, John H. Pickering, who could not be here today because of a prior commitment. I want to thank the Subcommittee for the opportunity to appear today to express the American Bar Association's support of the proposed Patient Self-Determination Act of 1990.

I would like to accomplish three tasks in my testimony today. First, I will explain the nature of the ABA's support of the "Patient Self-Determination Act of 1990." Second, I will relate the relevance of this Act to the current state of the law. And finally, I will offer some observations about the challenges and pitfalls we ought to be aware of in the development of public policy in this sensitive area of health care decision-making.

A. AMERICAN BAR ASSOCIATION'S SUPPORT OF PATIENT SELF-DETERMINATION

The ABA has addressed patient self determination in health care through three policy enactments. First, in 1986, the ABA House of Delegates endorsed the "Uniform Rights of the Terminally Ill Act," promulgated by the National Conference of Commissioners on Uniform State Laws. The Uniform Act is intended to promote uniform legislation for authorizing and implementing so-called "Living Wills."

Second, because of the limitations inherent in living wills, the ABA in 1989 adopted a policy statement encouraging the use and recognition of a broader and more flexible form of advance directive, the health care power of attorney.

Finally, in February of this year, the ABA endorsed a resolution supporting the principle that individuals have the right to consent to and to refuse suggested health care interventions, and that appropriate surrogates may exercise this right on behalf of individuals who are incapable of making such decisions.

During the last three years, the ABA, particularly through the Commission on Legal Problems of the Elderly, has exerted considerable effort to educate both the public and the legal community about the nature and availability of advance directives, especially health care powers of attorney. The response to our efforts has unequivocally confirmed our belief that people want and need information and guidance in planning ahead for lifetime events in a way that ensures respect for their personal autonomy. Our first educational effort consisted of a short video on the topic of planning ahead for incapacity. Featuring actress Helen Hayes, this video has been shown to community groups all over the country by bar associations, offices on aging, private attorneys, public television, civic and church groups, health care facilities, and others to introduce individuals to the legal planning tools for preserving personal autonomy.

An outgrowth of this project was the development of a recently released booklet on health care powers of attorney, containing a plainly written explanation about Health Care Powers of Attorney—what they are, why they are useful, what to consider in establishing one, and, most importantly, a do-it-yourself form and instructions to enable readers to establish a health care power of attorney on their own. The booklet also addresses when to seek individual counsel and the necessity of consulting state law. Through the generosity of the American Association of Retired Persons and other contributors, single copies of this booklet are available free from AARP.

The proposed Patient Self-Determination Act addresses a major aspect of health care decision-making needs by requiring Medicare and Medicaid providers to take some elementary but critical steps to inform patients of their decision-making rights, to inquire and document whether patients have executed an advance directive, and to respect patients' advance directives to the maximum extent permissible under state law.

These steps are important for at least three reasons. First, most health care providers either do not have or do not communicate their policies concerning treatment decision-making. Second, health care providers as well as patients and their families too often fail to appreciate the importance of ascertaining patient wishes and preferences until it is too late to do so. And third, too few people are sufficiently aware of the legal tools available to assure that one's wishes and values are respected. The recent Supreme Court decision in the case of Nancy Cruzan poignantly underscores the point that our right to control health care decisions may depend on our documenting our wishes while still alive. This legislation appropriately addresses these needs through Medicare and Medicaid provider agreements.

The bill's additional requirements that the Secretary of Health and Human Services evaluate the use of advance directives in health care decision-making and develop a public education effort are especially important parts of this legislation. State law and practice is developing in varied and fragmented ways, and serious national research needs to be accomplished in order to provide better guidance for state and national policy. For all these reasons, the ABA supports the aim and basic elements of this proposed legislation.

B. CURRENT STATE OF THE LAW

The statutory law concerning advance directives has developed in two distinct waves—the first being the development of living will legislation from the mid-1970's to the mid 1980's, and the second being the development of special health care power of attorney legislation, starting with California in 1983 and continuing through the present. Some 41 states plus the District of Columbia have enacted living will legislation. A growing awareness of the limitations of living will legislation has been one of the key factors spurring on a current surge in health care power of attorney statutes. As of July, 1990, the following 32 jurisdictions had enacted health care power of attorney legislation:

HEALTH CARE POWER OF ATTORNEY LEGISLATION AS OF JULY 1990

Alaska (1988)
California (1983)
Colorado (1983)
Connecticut (1990)
District of Columbia (1989)
Florida (1990)
Georgia (1990)
Idaho (1988)

Louisiana (1990)
New York (1990) [1]
Ohio (1989)
Oregon (1989)
Pennsylvania (1982)
Rhode Island (1986)
South Carolina (1990)
South Dakota (1990)

HEALTH CARE POWER OF ATTORNEY LEGISLATION AS OF JULY 1990—Continued

---

Illinois (1987)
Indiana (1987)
Kansas (1989)
Kentucky (1989)
Maine (1985)
Mississippi (1990)
Nevada (1987)
New Mexico (1989)
Tennessee (1990)
Texas (1989)
Utah (1985)
Vermont(1988)
Virginia (1989)
Washington (1989)
West Virginia (1990)
Wisconsin (1990)

---

[1] Awaiting governor's signature as of 7 10 90

Twenty of these acts came into existence in just the last 18 months. Clearly, this is an area of intense state legislative and public interest.

Absent special legislation creating DPAs for health care, other sources of state law may directly or indirectly acknowledge their validity, at least in certain contexts. In six states without specific health care DPA legislation, "Natural Death" or "Living Will" statutes either authorize or at least make reference to proxy decision-makers. Unfortunately, the purview of proxy decision-making under these statutes may be limited to the same extent that statutory living wills are limited. These states are:

Arkansas, Delaware, Hawaii, Iowa, Minnesota, and Wyoming

Court cases in two other states—Arizona, and New Jersey—look favorably upon the use of durable powers of attorney for health care. Finally, in the state of Maryland, an Attorney General's opinion states that durable powers of attorney specifically delegating medical decision-making authority are legally effective in that state.

Thus, in the aggregate, at least 40 states and the District of Columbia have some affirmative legislative, executive, or judicial recognition of durable powers for health care as of today. In the other 10 states, express authority pro or con is lacking Nevertheless, most authorities who have looked at the issue believe that existing durable power of attorney statutes are broad enough in principle to include health care decision-making powers within their scope (including the power to permit withdrawal or withholding of life-sustaining treatment). States have moved ahead with legislation primarily in order to clarify the law, incorporate patient protections, and grant provider immunity.

C. CHALLENGES TO ADDRESS AND PITFALLS TO AVOID

In our testimony on this same legislation before the House Ways and Means Subcommittee on Health on May 22, 1990, we highlighted certain challenges faced in implementing this kind of legislation and some of the pitfalls that we hoped it would avoid. The challenges concerned the need to overcome the increasing substantive and procedural variability and confusion evident in state law, and the need to pursue public education on this topic seriously. The main pitfall addressed was the danger of allowing implementation of the act to descend to the level of mere paper compliance. Those comments still reflect major concerns of the ABA, but instead of repeating them here, we wish to focus on two concerns that have arisen in the course of public discussion of this proposed act.

- *Portability of Advance Directives*

At the time this particular bill was conceived, a major concern was the lack of legislation authorizing advance directives in many states. The legislative avalanche in the last year and a half has greatly vitiated this concern. Consequently, the provision in the original version of this bill requiring states to enact advance directive legislation is of minimal value. In its place has arisen concern over state law variability which raises doubt about whether a validly executed instrument from one state will be recognized in another. Just this past Monday my office received a typical letter from an individual with this question. The gentleman wrote:

> "I am retired and spend half each year in Lake Luzerne, N.Y. and half in Palm Springs, CA. I can't, naturally, be sure where I will be when and if I need someone to act for me. So, do I need to appoint power of attorney to two different people; one in NY and one in Calif.?"

There may indeed be some pragmatic reasons for having different surrogates in different geographic areas, but our concern here is the legal necessity to execute two documents one in compliance with New York law and one in compliance with California law.

Of the 32 existing health care power of attorney statutes, only six expressly grant recognition to out-of-state Instruments that comply with the law of the other state (D.C., Kansas, New York, Texas, Vermont, and West Virginia). This is the one area that Federal action could make a dramatic difference in ensuring the rights of patients who by choice or by fate happen to cross state lines. Without advocating a particular position on the proper extent of Federal involvement in setting a state standard, let me suggest that the Congress could consider a range of possible options for Federal leadership in promoting what we lawyers call comity among state statutes. At the high end of intervention, this legislation could preempt state law by requiring states to grant recognition to instruments executed in other states as a condition of receiving Federal Medicare/Medicaid funding. A less forceful version of this approach would be to impose the requirement but allow states to override it by legislative action. This would effectively introduce a standard, and put the burden on states to act if they want to change the standard.

Another alternative would be to require states at least to make clear their policy on recognition of out-of-state advance directives through legislative or administrative action. A clearly stated Federal policy in favor of the interstate portability of advance directives would enhance this effort, and certainly have exhortatory value in itself even in the absence of other Federal action. Our previous testimony also suggested the option of creating a Federal model advance directive form. While such a model could be directly binding only in Federal facilities, it would nevertheless exert considerable influence on the development of state law. The ABA Commission is willing and available to work with the Congress and the Secretary to refine and implement any of these approaches.

- *Impact of Advance Directives on the Poor and Isolated*

The practical problem before us today is how to translate the individual's right to control health care decisions into policies and practices that ensure the effectuation of this right in the face of incapacity. Clearly, both the public and providers need to alter fundamentally both their thinking and practices regarding the use of advance directives. It is roughly estimated that only about 15 percent of the adult population have executed any kind of written medical directive, and many health care facilities have no policies or procedures recognizing their validity. Thus, initiatives such as the Patient Self-Determination Act are especially propitious.

Looking ahead down the road, however, it is not hard to see some risk in pushing the pendulum too far in the other direction. This could happen if hospitals and nursing homes and other facilities become inappropriately involved in advising patients to execute advance directives that call for terminating treatments. Those with loving family members, friends, and advisors will undoubtedly still make personally authentic choices. However, indigent, poorly educated, and isolated individuals will be vulnerable to facile execution of documents urged upon them by caretakers. The inherent incentives for facilities do not always work in favor of the best interests of these patients.

Consequently, it is important to confine the role of facilities to providing information and education without presuming to undertake advocacy or individual counseling. The source of counsel and advice should be the family, attending physician, and other confidants, counselors, or lawyers independent of the facility. We applaud suggested changes in the bill which clarify this boundary of facilities' role and which prohibit discrimination based on the presence or absence of an advance directive. Additionally, the obligation of the Department of Health and Human Services to develop informational materials further ensures an objective presentation of options.

In closing, let me again emphasize the American Bar Association's basic support for this legislation and offer our resources to assist both in fine-tuning the Act's provisions and ultimately in implementing the Act when it becomes law. Thank you.

PREPARED STATEMENT OF THOMAS J. SCULLY

Mr. Chairman and Members of the Subcommittee, I am Doctor Thomas Scully of Reno, Nevada, Co-Director of the Bioethics Program at the University of Nevada School of Medicine.

I appreciate the opportunity to speak in support of *Senate Bill S 1766—"The Patient Self Determination Act of 1990"* and thank the Subcommittee for its invitation.

Although I am a member of several organizations endorsing and/or supporting this bill, I speak as a private citizen.

I speak . . .

- as a *physician* who has cared for mentally incompetent and permanently unconscious patients who never made known their wishes concerning medical treatment.
- as a *bioethicist* who has frequently consulted with families, both privately and in the context of a hospital ethics committee, concerning decisions that had to be made for loved ones who never made known their wishes concerning medical treatment.
- as a *teacher* and *medical educator* who realizes how difficult it is to persuade people, young and old, to acknowledge their vulnerability and mortality, to confront their denial of death, and to write down their wishes concerning medical treatment.
- as an *author,* who, with my wife, has interviewed hundreds of patients about medical decision making (or more often lack of it) in their families, telling their stories, some tragic, some hopeful, and some joyful in our book *"Making Medical Decisions."*
- and I speak as a *patient* who has undergone major surgery four times (including a kidney transplant) has survived a myocardial infarction and has gratefully experienced the benefits of "high tech" medicine provided by a multitude of knowledgeable, skillful, caring physicians and nurses, most of whom were total strangers to me, knowing little or nothing of my life's goals, aspirations, hopes, fears or anxiety—(not to mention religious beliefs) or what I would wish to have happen to me should I be unable to make medical decisions for myself.

Prior to undergoing the first of those surgeries, I executed a Durable Power of Attorney for Health Care in order to spare my family the additional anguish and heartache attendant to making difficult decisions to withhold or withdraw medical treatment from me if, as a result of those surgeries or illnesses I had become permanently unconscious or unable to make decisions for myself.

From all these perspectives, I see the urgent need for a Patient Self Determination Act, such as S. 1766, that will not only mandate all states to enact Advance Directive Legislation, but foster a highly visible and aggressive public education program which stresses the importance of all adult citizens making their wishes concerning medical treatment known, and (in light of the recent Supreme Court decision in the *Nancy Cruzan Case*) making those wishes known in writing in the most "clear and convincing" terms.

I will not elaborate on the present status of Advance Directive Legislation as others will do that before this Committee or have already done so before the Ways and Means Committee of the House on H.R. 4449.

Suffice to say that:

- 41 states and the District of Columbia have Living Will laws,
- 29 states have Durable Power of Attorney for Health Care laws, and
- another 11 states have case law or special legislation which indirectly acknowledges the designation of a proxy for medical decision making.

With the exception of a few states, great advances have been made on the legislative front concerning Advance Directive Statutes. One could only wish that all states adopted a uniform statute thereby assuring portability from state to state.

Practical problems in effecting the changes envisioned in S. 1766 arise in the areas of education and implementation.

Public and professional education, two sides of the same coin, are, in my view, the most important parts of this Act.

A. Public Education:

"A national campaign to inform the public" (Section 6) will hopefully increase public awareness and create a demand to execute Advance Directives. But if the implementation awaits the admission of mostly Medicare or Medicaid patients to hospitals or nursing homes, then it will be too late for many, young and old, already rendered decisionally incapacitated by either the injury or disease that brought them to the institution in the first place.

Public education should be directed to every citizen who

- subscribes to a Health Maintenance Organization or joins a Group Health Insurance Program
- is enrolled as a Medicare or Medicaid recipient
- is employed by the Federal Government
- is enrolled as a public employee in a public retirement program

- enlists in any Federal Service or is discharged and becomes eligible for Veterans' Benefits
- registers to vote in a national election or completes a U.S. Census form.

But most importantly, public education should begin early:

- when every teenager takes a driver's education course or obtains a driver's license to drive on a *federally funded highway*. (Remember that a large number of those in the persistent vegetative state and permanently unconscious are teenagers and young adults who survived serious automobile accidents which they never anticipated and which occurred prior to their ever having made their wishes known in a "clear and convincing" manner.)
- public education, regarding the need for Advance Directives should continue each time a citizen renews his or her driver's license or registers an automobile.

B. Professional Education:

As public awareness concerning Advance Directives increases, health professionals must be ready, willing and able through prior education and training to inquire about Advance Directives in a sensitive and caring way, facilitate the resultant communication on the most sensitive of issues, namely death and disability and help negotiate the execution of such directives.

The education and training of physicians, nurses, social workers, pastoral counselors and others working in hospitals and health care facilities are essential to the successful implementation of this Act. If communication with patients is perfunctory, hurried, callous, ending up in legal formalities and paper pushing, then more harm than good will result.

In this process, patients must be free to sign or not sign an Advance Directive, free of coercion. They must also be reassured concerning the quality and type of care to be provided so that the Advance Directives will not be misinterpreted as cutting them off from *beneficial* care that they may want and should receive. Patients must understand that, as their wishes to minimize, withhold or withdraw active treatment are respected, they will still be cared for and not be abandoned.

C. Ethical Foundations:

Modern medical ethics is based on four principles; namely:

- Nonmaleficence; the duty or obligation *not* to cause harm to patients,
- Beneficence; the duty or obligation to do good and benefit others, that is, to help patients further their own legitimate interests,
- Autonomy; the duty or obligation to respect persons and promote self determination of patients; and
- Justice; the duty or obligation to allocate social burdens and benefits fairly among all persons.

In implementing this Act, the physician is essential. The doctor-patient relationship is based on trust and it is the physician's responsibility not only to foster trust, but, under the principles of autonomy and beneficence, to help patients further their own legitimate ends.

Rooted in the principle of autonomy, Advance Directives serve to preserve a competent person's expression of health care preferences at a time when the person is unable to make decisions. In fostering communication, discussion and dialogue with patients, the physician should engage the patient in a process of shared decision making, so appropriately called for by the President's Commission. In my view, physicians and appropriately trained hospital personnel should routinely ask all adult patients at the time of admission about the existence of Advance Directives as called for in the Act. But most important is the inquiry about a surrogate decision maker, proxy or Attorney in Fact.

A single page Living Will can easily be lost, misplaced or overlooked in the fast paced, complex world of high tech, intensive care hospital medicine with its teams of health care professionals. If a Living Will gets from the patient's safe deposit box or the physician's office record to the hospital chart it may never be seen in a hospital chart which expands exponentially with reports, consultations and progress notes.

It is far more important, in my view, for each person to designate, *in writing*, a surrogate decision maker, either as a proxy or Attorney in Fact in a Durable Power. This should be done in addition to the Living Will. The surrogate can monitor the progress of the patient's care and be available to speak for the patient and interpret what the patient had previously written down as his or her wishes. Such a surrogate should be able to assist the patient meaningfully in maintaining both dignity and autonomy. Such a surrogate can help the patient review his or her records, obtain a physician qualified to give a second opinion, delay procedures when informed consent is in doubt, delay undesired discharge, and forbid any experimental or teaching use of the patient without the patient's permission or knowledge.

Such a person should be someone not likely to be intimidated in the health care setting, someone well known to the patient, aware of the patient's values, and not afraid to speak up and be assertive for the sake of the patient. The proxy or surrogate decision maker must be comfortable abiding by the patient's wishes, not their own—particularly when there are issues concerning foregoing life-sustaining treatment. Such a surrogate should be prepared to carry out the patient's wishes and not impose his or her views on the patient.

I served as a surrogate for my 86 year old mentally incompetent mother during the last few years of her life I sat with her when she died quietly and peacefully, as she wished, without any futile last minute attempts at resuscitation, or attached to machines or tubes.

Physicians' attitudes toward Advance Directives have changed significantly in the last 10 years as indicated in a recent study from the University of Arkansas where 80% of all primary care physician respondents expressed a positive attitude and fewer than 2% expressed a negative attitude toward Advance Directives. More than 80% of the physicians in this study indicated that Advance Directives were an effective way for patients to influence their medical care should they lose competence, help to reduce family discord and relieve patient worry about unwanted treatment should they lose mental competency to make decisions for themselves. (It should be noted out that Arkansas was one of the first states to pass Advance Directive legislation in 1977 and now, following the model Bill of the National Conference of Commissioners of Uniform States, recognizes "proxy" directives, the inclusion of permanently unconscious as well as terminally ill and the authorization of surrogates to speak for patients who have no advance directives.) From this study, one of the few of its kind reported in the medical literature, it can be concluded that "most of the benefits claimed for Advance Directives—improved communication and trust, easier and more confident treatment decisions, less stress and guilt, and promotion of patient autonomy"—are true.

Another study from the Johns Hopkin University School of Hygiene and Public Health indicated that although 67% of hospitals had a formal policy regarding Advance Directives, only 4% actively inquired about these documents, and, although 46% of the hospitals reported having an ethics committee, the presence of an ethics committee was not significantly associated with the presence of a formal policy. S. 1766 calls for the establishment of institutional ethics committees with educational responsibilities. It is not clear what the make up of these committees would be and what would be their duties in terms of establishing policies for hospitals and seeing that they are implemented. This portion of the Act needs to be strengthened if the Johns Hopkin's Study is an indication of what actually happens in hospitals—and I believe it is! One suggestion is to assure that at least a few members of such committees are from the community and are not employees of the institution or members of its governing board or medical staff.

In conclusion, it is clear that competent adults have the absolute right to accept or reject any and all medical treatment, consistent with their private values and preferences; and that this right should continue through the mechanism of an Advance Directive to the time when they are decisionally incapacitated. It is equally clear from the recent Supreme Court decision in the *Nancy Cruzan case* that there is a need for every adult to write down his or her wishes and preferences in advance of decisional incapacity; and, that they, as syndicated columnist Ellen Goodman wrote in her July 1, 1990 Travelers' Advisory—"Don't leave home without it."

Thank you very much.

PREPARED STATEMENT OF GAIL R. WILENSKY

Mr. Chairman and Members of the Subcommittee: I am pleased to be here today to discuss advance directives, such as "living wills," and their role in making personal health care decisions. The recent, highly publicized *Cruzan* decision by the United States Supreme Court has elevated the importance of living wills in the public mind.

As we move into the 1990s, medical science and technology are performing life saving and sustaining treatments that were unthinkable a few decades ago. Decisions not necessary twenty years ago have now become commonplace in the hallways of our hospitals and nursing homes. These health care decisions affect our entire population, not just the elderly.

The growing use of sophisticated medical services increases the likelihood that individuals will have to make difficult decisions about whether to prolong care. Providers of health care recognize that these decisions may place them in a troubling position from an ethical and legal standpoint. In this health care environment, living wills and other advance directives assume an even greater importance.

BACKGROUND

Before the recent Supreme Court decision, the importance of living wills was slowly being acknowledged across the nation. Most States recognize living wills, durable powers of attorney and other forms of advance directives as valid written documents expressing an individual's fundamental right to make choices about health care. A living will is a written document that instructs physicians to withhold or withdraw care that would prolong the dying process. A durable power of attorney gives another person the authority to make health care decisions if an individual is unable to do so. Over 40 states have laws or court rulings that acknowledge advance directives and define parameters for refusing treatment.

I commend Senator Danforth and the Subcommittee for raising this complex issue for discussion. Decisions regarding the quality of life and death are not easy to deal with. A recent Harvard study revealed that only 15 percent of the patients surveyed had made formal planning arrangements and only 9 percent possess an advance directive. The study also found that when patients are informed of advance directives by their doctor or other health professional they generally receive the material favorably and initiate formal planning.

PROPOSED LEGISLATION

Senate Bill 1766, the "Patient Self Determination Act of 1989," represents an ambitious effort to highlight the importance of advance directives, and to inform and educate the public about such directives. We share these goals.

I follow a guiding principle: the more knowledge people have about their health care options, the better able they will be to make informed choices.

Your goal of educating health care consumers about living wills is entirely consistent with this principle. Even so, we need to ask questions:

- How can we best advance your goal of informing the public, and
- What role should the Federal Government play in promoting public awareness of living wills?

S. 1766 would rely on the Medicare Conditions of Participation for health care providers to achieve these goals. We are concerned that this would manipulate the conditions to a purpose significantly removed from their primary objective of ensuring that quality care is rendered in a safe environment. We also have serious concerns about the adequacy of patient protections and the role of States and State laws regarding living wills. Let me provide a little more detail about our concerns.

MEDICARE CONDITIONS OF PARTICIPATION

The Medicare Conditions of Participation serve the primary purpose of ensuring that health care facilities provide care that meets professionally recognized quality standards. The health and safety requirements embodied in the Conditions require providers to meet prescribed standards for the health care services they furnish and for the physical environment where they are delivered.

The bill would accomplish its objectives by imposing additional Federal regulation and oversight of Medicare and Medicaid providers of health care. Specifically, to enforce the bill's requirements, we would have to publish regulations amending the Conditions of Participation for providers of care. The new Conditions would describe the procedures and documentation necessary to assure that facilities are in compliance with the requirements relating to advance directives.

Enforcing these Conditions would place the Federal Government in a position of *judging* how adequately providers inform and educate patients about advance directives and their right to make treatment decisions; whether providers properly implement advance directives within the limits of State law; and whether providers appropriately advise patients and staff on ethical issues.

Under this scenario, the Medicare and Medicaid Conditions of Participation would be used to regulate an activity which does *not* directly relate to the Conditions' immediate goal of assuring quality care. Our enforcement of the Conditions would also be diminished by turning the focus away from the actual care furnished to paperwork documentation. This would be a risky precedent and could encourage further use of Medicare's Conditions to accomplish other unrelated objectives.

Let's be clear about this. The living will issue is too important to do otherwise. If the Congress believes that society will be better served by knowing about living wills, then let's find a way to provide that information directly. We should not obscure the issue by including it in a regulatory process that deliberately stays at arm's length from medical decision-making.

PATIENT PROTECTIONS

Our most important concern is for patients. The bill would require providers of care to inform patients of their rights to have advance directives and to document their treatment wishes. We are concerned that the bill does not provide adequate safeguards for poor and vulnerable patients. Providers should not be given incentives to limit possible financial losses by pressuring indigent patients into making hasty decisions about living wills, or by implementing these wills too quickly.

A sick person may be unable to properly consider information about living wills while in a hospital or other facility, at a time of physical and psychological stress. Indeed, a patient could believe that his care might be compromised *unless* he gives specific treatment instructions. The bill's requirements place an unnecessary burden not only on the patient, but also on the health facility that is required to provide the information.

Conventional record-keeping requirements and Federal survey processes cannot effectively ensure that patient rights are protected under these circumstances.

A living will or other advance directive needs to be considered calmly and logically. A person needs time to think through the implications of such a decision and to obtain any necessary advice and assistance. A discussion of living wills at a time when medical treatment is being sought may only serve to confuse patients or to create anxiety.

There must be better ways to inform people about living wills than through providers of health care. We should look at other avenues to provide information.

THE STATE ROLE

The bill would also require States to enact legislation regarding living wills as a condition for Medicaid funding. If a State does not does not comply, financial assistance critical to the medical care of the poor could be jeopardized.

Further, the bill would require the Secretary to conduct a national, public information campaign. It is true that a general campaign could increase the public's awareness of the value of living wills. However, such a campaign could not be fully effective without describing the varying legal requirements in each State. But I don't think the States would want the Secretary to interpret their laws. And, because of the diversity of State laws, the Secretary could not assure that an accurate and consistent message on living wills would be delivered from State to State.

States are better equipped than the Federal Government to effectively inform their citizens about advance directives. States know the scope of their laws; they can best interpret these laws, and they can provide better oversight of the laws' implementation.

Unless potentially more effective means of educating the public about living wills have been exhausted, we do not think the intrusive, cumbersome Federal regulatory role the bill would require is appropriate. Other options could better advance the objective.

OTHER OPTIONS

Improved public awareness about living wills could be better accomplished without linking it to a Federal requirement. The government, at the Federal, State, and local levels, funds other educational programs that are not tied to a regulatory enforcement scheme. Why should education about living wills be singled out as a compliance issue?

We need to develop a coordinated package of informational activities that will effectively inform the public about living wills, outside of a forced or coercive atmosphere.

For example, we could consider establishing a national 800 number where people could get answers to general questions and be directed to more specific State information.

States could provide information at various points of contact with their citizens. One that comes immediately to mind is when people apply for drivers' licenses, similar to what is being done for the organ donor program. Such a program could also refer individuals to the 800 number for more explanation.

In fact, States that want to elevate the importance of living wills could mandate that providers conduct information and educational activities as a requirement for State licensure.

We could also work with professional groups like the American Hospital Association and the American Medical Association to encourage voluntary efforts by hospitals and physicians. Informational material could be made available in waiting rooms, again, with a reference to the 800 number. Physicians could participate in continuing medical education seminars to encourage informed discussion of advance directives with their patients.

Community and advocacy groups can be enlisted to spread the word on living wills. These groups, along with trade associations, union organizations, professional associations, and senior groups publish regular newsletters which can target specific information to their constituencies.

Since the Supreme Court decision, we have seen many such organizations distributing information and providing assistance on living wills. We would hope these voluntary efforts would continue and would certainly lend our support and assistance wherever possible.

I intend to see that HCFA does its part by providing informational materials to our beneficiaries. The next update of the *Medicare Handbook* will contain information on advance directives. I will also see that our new beneficiary education campaign addresses this important issue. Further, we will consider other informational tactics, such as "check stuffers," which we often include in Social Security checks to provide important information to our beneficiaries.

We can also work with other Federal agencies such as the Administration on Aging and the Department of Veterans Affairs, to tap into their routine lines of communication with the people they serve.

The options are endless. It will take a mutual commitment to develop an informational strategy that works, and HCFA will contribute its share to the effort.

CONCLUSION

I want to reiterate my strong support for making the public more aware of the importance of advance directives.

However, given the sensitivity of the life and death decisions made through advance directives, action by the Federal Government regarding their use should be carefully and cautiously considered. Any Federal requirement to advise and inform should not result in a tension or pressure that is inappropriate in personal treatment decisions. We can, however, work together to fashion cooperative programs that educate the public about living wills.

I thank you for the opportunity to discuss this important issue and would be happy to answer any questions you may have.

COMMUNICATIONS

STATEMENT OF THE AMERICAN ASSOCIATION OF CRITICAL-CARE NURSES AND AMERICAN NURSES ASSOCIATION

On behalf of the American Association of Critical-Care Nurses (AACN) and its 70,000 members and the American Nurses Association (ANA) and the 200,000 members of its 53 constituent state and territorial associations, we would like to present our views on S. 1766 the, "Patient Self-Determination Act of 1900." The ANA commends the sponsors and this committee's timely discussion of this issue. The AACN and ANA have long supported patient autonomy and self-determination in health care decisions. We also support the ethical standards of the nursing profession.

Recently, the American Association of Critical-Care Nurses and the American Nurses Association joined The American Association of Nurse Attorneys (TAANA) in an amicus brief before the Supreme Court in support of the petitioners, Mr. and Mrs. Cruzan. They were joined by the New Jersey State Nurses Association, the Missouri State Nurses Association, and the Emergency Nurses Association. The amicus brief focused on the right of an individual to accept or refuse medical treatment and the nurses role as a patient advocate. Finally, the amicus brief stated that the nurse will be required to violate his/her role as the patient advocate if instead of respecting the patient's right to self-determination, the nurse is required to continue treatment no matter what the patient would have wanted so that they could end their life with dignity.

ANA's Social Policy Statement establishes that nurses have the highest regard for self-determination, independence and choice in decision-making in matters of health. Nursing is committed to the respect of individuals unaltered by the social, educational, economic, cultural, racial, religious, or other specific attributes of those receiving care, including the nature and duration of disease and illness. Our *Code for Nurses* (Addendum No. 1) reiterates those principles.

The American Association of Critical-Care Nurses adopted a position statement on the Role of the Critical-Care Nurse as Patient Advocate in August 1989. (Addendum No. 2) It defines advocacy as respecting and supporting the basic values, rights, and beliefs of critically ill patient. The critical-care nurse is obligated to support the decisions of the patient or the patient's designated surrogate or transfer care to an equally qualified critical-care nurse.

A recent survey of approximately 5000 critical-care nurses was conducted by AACN and will be published soon as the "1990 Critical Choices Survey." The respondents indicated that 70 percent of critical-care nurses are involved in withdrawal or withholding of life support decisions several times a month. Another 25 percent participate in such decision making several times a week. Our findings show 90 percent of all critical-care nurses deal with such health care/ethical issues daily and are comfortable with their involvement and level of knowledge.

We believe that a competent patient has the right to refuse treatment. A competent patient is someone who can make an informed decision. This includes the right to accept or to refuse health. An individual should have the freedom to make decisions with respect to his/her own life as long as that decision does not interfere with the self-determination of others. We recognize the role of the nurse as a patient advocate. (See Addendum #2). The nurse advocate assists the patient so that a knowledgeable decision can be made. The level of understanding needs to be ascertained to determine whether the patient comprehends exactly what his/her decision includes.

However, when a patient is incompetent, he cannot participate in such decisions. Living wills and durable power of attorney have been legislated to assist with resolving this problem. The living will and durable power of attorney for health care

are vital to ensure the rights and patient care wishes of those who are incapacitated.

Unfortunately, in general, people do not anticipate a situation arising that will render them unable to make decisions. When such an incident occurs and no advance directive exists, a dilemma results related to what the patient would have wanted.

When an incompetent patient has not executed an advanced directive, the nurse as the patient advocate may be placed in the middle, between what is best for the patient and what the family or physician may want. Too many times nurses are caught between the patient's wishes, the family's desires and the provider facility's policies Nurses must implement physicians' prescriptions and nursing care based on the goals set by the patient and the health care team including the family. The nurse's duty is to provide quality care to his/her patients and to promote the quality of their life.

A dilemma exists whenever a person is in an incapacitated state due to illness. If certain care is terminated or refused a person with a potentially curable disease may die. If certain life sustaining measures are taken, there is the risk of prolonging the provision of care to someone who wished otherwise or who would have opposed existence in a vegetative state. Keeping someone alive by artificial means can be viewed as prolonging life or the dying process. Death is inevitable for everyone. The quality of the dying process itself is the issue.

We believe that an individual given the opportunity to make an informed decision should have his/her wishes carried out. A physician, family member or even the nurse's own wishes should not be substituted in the place of the patients. ANA and AACN have adopted position statements on the Withholding and/or Withdrawing or Life Sustaining Treatment (addendum 113 and 4) because of the nurses significant role in these decisions and their implementation.

These other interested parties may be motivated by personal feelings to support their values or beliefs for the patient's decision. The patient's family members may not want to let go or may not understand the long-term effects on the patient. Providers may not feel comfortable discussing death or may not believe in withholding treatment regardless of whether the patient wants it or not. The incapacitated patient is unable to protect his or her self.

We believe that the patient's establishment of a living will and/or durable power of attorney for health will ensure the implementation of the patient's wishes for treatment or termination of treatment. It may also facilitate the family and health care provider's acceptance of the patient's goals. Ideally, it will also prevent the superimposing of another's morals or values regarding health decisions.

As Justice Sandra O'Connor stated in her concurring opinion in the *Nancy Cruzan* case, "The liberty guaranteed by the due process clause must protect, if it protects anything, an individual deeply personal decision to reject medical treatment, including the artificial delivery of food and water . . . "Whether a state must also give the effect to the decisions of a surrogate decision-maker . . . may well be constitutionally required to protect the patients liberty interest in refusing medical treatment."

The Patient Self-Determination Act addresses the issue by placing the decision in the individual's control. It also encourages individuals to create advance directives.

The American Nurses Association and the American Association of Critical-Care Nurses make the following observations and recommendations on S. 1766 based on our past experience in the education of the public, health care providers and patients regarding organ donations and the subsequent state and Federal legislation to implement required request programs in hospitals. We believe S. 1766 must address these implementation and efficacy concerns to be beneficial in the health care setting.

Public education is necessary before requiring organizations to comply with the requirements of the Act. We believe that Section 6, Public Education Demonstration Project must be implemented broadly and initially to ensure success. Facilities would be placed at a disadvantage if they were required to comply with Section 3(b) by the effective dates in the bill, if public education has not been initiated. Facilities cannot bear the burden of initial public education. Utilization of brochures and pamphlets could be available for patients and families. However, people must be educated before they enter a hospital. Such decisions require thought and discussions with family and legal and spiritual advisers without the emotional pressure of hospitalization.

We agree that public education be required to be implemented no later than six months after the effective date. However, we recommend that facility programs be phased in for design and implementation no later than six months after that; and that health care staff be required to be educated to the concepts of advanced directives and their professional and legal responsibilities before facilities initiate such programs. Additionally, mechanisms must be put into place to ensure consistency and minimize duplication of efforts regarding inquiries about advanced directives. ANA believes that an educated public, as well as oriented and committed health care providers and clear facility policies will ensure acceptance of the programs.

The public needs to be educated about advance directives; before they are asked if they have one. Inquiry about advanced directives is beneficial if the patient is competent. It will not assist patients like Nancy Cruzan who are incapacitated at their initial contact with the health care system Surrogate decision-makers therefore are important to guarantee the patient's wishes in such instances During such health care incidents, families are often in crisis and may lack full understanding of the care or intervention options to be discussed Individuals need to be instructed on what life support measures include and what happens when a person is resuscitated. A Do Not Resuscitate Order does not mean do not treat It means do not resuscitate.

Additionally, we must stress that authorization language must include an adequate appropriation level for the operation of the public education project and the assessment study Existing health care programs cannot afford to finance this endeavor, notwithstanding its value

ANA and AACN urge the consideration of a provision to require states to enact recognition of advance directives laws as prescribed in other states The bill does not address recognition of such directives from one state to another We believe that an institutional commitment must be demonstrated to address sues such as advanced directives, one way is the establishment or utilization of an institutional ethics committee including representatives of the multidisciplinary health team including nurses and consumers Hopefully, this will minimize conflicts with patients health care providers and institutions regarding the acceptance and implementation of the patient's wishes. In addition, in the absence of state mandates, S. 1766 does not specify how to enforce institutional and physician compliance with the advance directives. The patient's family or provider may not recognize their validity. This is especially true when the next of kin is opposed to the patient's wishes. Patients may have to consider transfer to a different health care facility or change to different physicians This could prove disruptive for someone already in a stressful position. The patient's care may be compromised when faced with a choice between a physician or institution and the right to refuse certain types of medical treatment.

Society may have misconceptions of what an advance directive entails. A terminal illness does not have to exist for a person to have an advance directive Its existence is merely a way for a person to let his/her health care decisions be known. A person may believe that by signing an advance directive they will be forgoing treatment or that they will get less care. Patients must be assured that they will receive quality care notwithstanding their health care decision-making.

Nurses as care givers, patient advocates, and health educators must be involved in this public education process; only then do we have a chance of ensuring that our right to self-determination survives even though we may become incapable of directly expressing decisions about our health care.

The experience of many of our members reflect the effect of advanced directives and living wills or their absence can have on patient care. A recent experience of a nurse in a skilled nursing facility during one eight hour shift is such an illustration.

A newly admitted elderly nursing home resident who was alert and oriented became congested and exhibited symptoms of respiratory distress. The physician was contacted and the lack of a Do Not Resuscitate order was noted. The emergency response system (911) was called and the emergency response team proceeded with cardiopulmonary resuscitation and intubation and other emergency care when the resident arrested. Ironically, the person appointed as power of attorney arrived during the procedure and indicated that the resident did not want heroic measures. The nurse indicated that this was not documented on the resident's chart. The daughter stated that he had made a living will but the wife would not honor it. The resident subsequently died after admission to the emergency room.

The nurses' and physicians' actions were determined by the absence of an advanced directive. The family of the nursing home resident underwent the additional psychological distress of seeing unwanted treatment inflicted upon someone for whom they cared because his wishes were not documented and honored. There are thousands of other examples like these. When nurses meet their discussions eventually turn to recounting such episodes. The issues are complex and frustrating to those who care. A critical-care nurse has shared the following description of her frustration.

> In many situations it seems that medical intervention only prolongs the death of the patient. Sometimes it seems that therapy is instituted because it is technically feasible but without much attention directed to the appropriateness of the outcome. The process of treatment selection seems to be a response to a pre-programmed decision tree from which there is little or no deviation.
>
> In moments of crisis when decisions must be made about therapy, families seem sadly willing to abdicate their responsibility with respect to the choice of intervention to others. They seem unable to ask the necessary questions and unwilling to make decisions. It has been a source of conflict to us when families do not understand that a condition is irreversible. Families often indicate what they want done but may not understand the scope of that directive.
>
> The financial costs of these decisions to the health care industry have to be staggering, the emotional costs to the patients and families must be beyond measure; and for the nurses who are caught in this emotional whirlpool the stresses have to lead to indifference, frustration, conflict and/or resignation.

Another patient incident involved a 65 year old married male with two adult children who was admitted to a cardiac critical care unit. He was placed on life support after a severe heart attack. He experienced multiple body system failures requiring him to be placed on hemodialysis and a respirator. He remained unresponsive and respirator dependent in the critical-care unit for two-and-a-half months, receiving many transfusions and one-to-one care.

> After another cardiac arrest and resuscitation the family indicated its care decisions. The wife wanted her husband to be well again and one son wanted his father to live. After an explanation regarding the intervention options the wife remembered that her husband had said he did not ever want to be useless. A Do Not Resuscitate order was requested.

In light of such experiences we have therefore endorsed The "Patient Self-Determination Act of 1990."

We hope that discussions around the passage of this bill and subsequent passage of S. 1766 and H.R. 4449 will ensure the participation of patients at every level of their health care treatment plan. We look forward to our continued work with you to accomplish the right of self-determination of health care consumers. Thank you for the opportunity to provide testimony on this important issue.

#1

CODE FOR NURSES

with Interpretive Statements

American Nurses' Association

CODE FOR NURSES

1 The nurse provides services with respect for human dignity and the uniqueness of the client, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.

2 The nurse safeguards the client's right to privacy by judiciously protecting information of a confidential nature.

3 The nurse acts to safeguard the client and the public when health care and safety are affected by the incompetent, unethical, or illegal practice of any person.

4 The nurse assumes responsibility and accountability for individual nursing judgments and actions.

5 The nurse maintains competence in nursing.

6 The nurse exercises informed judgment and uses individual competence and qualifications as criteria in seeking consultation, accepting responsibilities, and delegating nursing activities to others.

7 The nurse participates in activities that contribute to the ongoing development of the profession's body of knowledge.

8 The nurse participates in the profession's efforts to implement and improve standards of nursing.

9 The nurse participates in the profession's efforts to establish and maintain conditions of employment conducive to high quality nursing care.

10 The nurse participates in the profession's effort to protect the public from misinformation and misrepresentation and to maintain the integrity of nursing.

11 The nurse collaborates with members of the health professions and other citizens in promoting community and national efforts to meet the health needs of the public.

POSITION STATEMENT

AACN

#2

Role of the Critical Care Nurse as Patient Advocate

THE AMERICAN ASSOCIATION of Critical-Care Nurses believes that patient advocacy is an integral component of critical care nursing practice. Therefore, definitions of advocacy and the behaviors that typify advocacy are essential.

WHEREAS, the *Code for Nurses* (American Nurses' Association, 1985) requires that nurses safeguard the patient and the public when health care and safety are affected by the incompetent, unethical, or illegal practice of any person, and

WHEREAS, many definitions of advocacy exist, and

WHEREAS, critical care nurses are confronted with situations that require them to act immediately on the patient's behalf, and

WHEREAS, personal and professional risks are associated with being a patient advocate, and

WHEREAS, state nurse practice acts may require the nurse to be a patient advocate, and

WHEREAS, the process of informed consent mandates that the patient or the patient's surrogate be informed fully and give consent freely, and

WHEREAS, the continuum of advocacy is not limited to the individual but may extend to societal concerns,

THEREFORE, BE IT RESOLVED THAT the American Association of Critical-Care Nurses believes the critical care nurse is a patient advocate,

AND THAT the American Association of Critical-Care Nurses defines advocacy as respecting and supporting the basic values, rights, and beliefs of the critically ill patient.

BE IT FURTHER RESOLVED THAT the American Association of Critical-Care Nurses believes that as a patient advocate, the critical care nurse shall do the following:

1. Respect and support the right of the patient or the patient's designated surrogate to autonomous informed decision making.
2. Intervene when the best interest of the patient is in question.
3. Help the patient obtain necessary care.
4. Respect the values, beliefs, and rights of the patient
5. Provide education and support to help the patient or the patient's designated surrogate make decisions.
6. Represent the patient in accordance with the patient's choices.
7. Support the decisions of the patient or the patient's designated surrogate or transfer care to an equally qualified critical care nurse.
8. Intercede for patients who cannot speak for themselves in situations that require immediate action
9. Monitor and safeguard the quality of care the patient receives.
10. Act as liaison between the patient, the patient's family, and health care professionals.

BE IT RESOLVED THAT the American Association of Critical-Care Nurses recognizes that health care institutions are instrumental in providing an environment in which patient advocacy is expected and supported

ALSO, BE IT FURTHER RESOLVED THAT as patient advocate, critical care nurses initiate and promote actions to improve the health care of the critically ill through social change.

REFERENCE

American Nurses' Association (1985) Code for nurses with interpretive statements. Kansas City, MO: Author.

Adopted by AACN Board of Directors, August, 1989

AMERICAN ASSOCIATION
OF CRITICAL-CARE NURSES
ONE CIVIC PLAZA · NEWPORT BEACH, CA 92660
714 644 9310 · FAX 714 640 6903 / TLX [illegible]

BEST AVAILABLE COPY

POSITION STATEMENT

AACN

#3

Withholding and/or Withdrawing Life-Sustaining Treatment

ADVANCES IN HEALTHCARE technology have dramatically increased the ability to prolong life. Because of these advances, ethical and legal dilemmas arise when complex therapy is instituted to sustain vital functions, even when there is no hope of reversing the disease processes.

The American Association of Critical-Care Nurses recognizes that critical care nurses have a significant role in supporting a patient's preferences and beliefs about ending treatments of this type.

THEREFORE, AACN resolves that when choices about withholding and/or withdrawing life-sustaining treatments are being considered, critical care nurses should collaborate with individual patients or their surrogates, physicians and other healthcare providers. This should happen in an atmosphere that promotes reasoned deliberation and communication of a patient's preferences and best interests.

To support this resolution, AACN believes that the following elements are essential for nursing practice:

- Critical care nurses will participate in ongoing assessment of a patient's ability to make decisions about their own healthcare.
- Critical care nurses will participate in discussions exploring the patient's beliefs about end of life care at the earliest appropriate time. The best time for discussions and decision-making about withholding and/or withdrawal of life sustaining treatment is before entry into the healthcare system.
- When patients cannot make decisions for themselves, their preferences may be determined from advanced directives (such as living wills or durable power of attorney for health care), previous spoken or written information and personal lifestyle.
- Critical care nurses, as patient advocates, will initiate and promote the decision-making process and assure that nursing care goals are consistent with patient preferences or best interests.
- In the event that life-sustaining treatment is withheld or withdrawn, critical care nurses will participate in planning, implementing, and evaluating supportive care. Supportive care includes providing comfort, hygiene, safe surroundings and emotional support for patients and the family.

Thus AACN believes that healthcare institutions must have policies that direct a process to withhold and/or withdraw life-sustaining treatment. These policies should include:

- A process for ongoing review of treatment goals and interventions. The scope of the care the patient will receive should be specified in writing.
- A process for designating a surrogate when the patient does not have decision-making capacity.
- A process for dispute resolution among patients, surrogates, and health care team members when there is disagreement about the decision-making process.
- A process for transferring care of a patient to another qualified critical care nurse, when a decision to withhold and/or withdraw life-sustaining treatment conflicts with the nurse's personal beliefs and values.

This position on withholding and/or withdrawing life-sustaining treatment is based on these beliefs and ethical principles:

1. Individuals have a moral and legal right and responsibility to make decisions about their healthcare and the use of life-sustaining treatment.
2. There is no moral or legal difference between withholding and withdrawing treatment. Considerations that justify not initiating treatment also justify withdrawing treatment.

(Continued)

AMERICAN ASSOCIATION
OF CRITICAL-CARE NURSES
ONE CIVIC PLAZA NEWPORT BEACH, CA 92660
714·644·9110 / FAX 714 640 4903 / TLX 294957

3. A person's capacity to make decisions is shown by their ability to: understand relevant information, reason, and deliberate about choices, reflect on information according to their individual values and preferences, and communicate their decision to healthcare providers.
4. The process for decision-making on behalf of incapacitated patients should be directed by the established standards of substituted judgment or best interests.

Definitions

Advance Directives: A document in which a person gives advance directions about medical care or designates who should make medical decisions on their behalf if they should lose decision-making capacity. There are two types of advance directives: treatment directives, such as living wills, and proxy directives, such as durable power of attorney for health care.

Best Interest Standard: This standard gives priority to the protection of the patient's welfare. In these cases the designated surrogate tries to make a choice on the patient's behalf that seeks to implement what is in the patient's best interests by reference to more objective, societally shared criteria.

Substituted Judgment: The doctrine of substituted judgment requires that the surrogate attempt to reach the decision that the incapacitated person would make if he/she were able to choose. This standard preserves the patient's interest in self-determination.

Bibliography

American Association of Critical-Care Nurses (1989). *Role of the critical care nurse as a patient advocate.* Newport Beach, CA: Author.

American Nurses' Association (1985). *Code for nurses with interpretive statements.* Kansas City, MO: Author.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (March 1983). Washington, DC: Government Printing Office.

The Hastings Center (1987). *Guidelines on the termination of life-sustaining treatment and the care of the dying.* Briarcliff Manor, NY. Author.

Adopted by AACN Board of Directors, February 1990

#4

AMERICAN NURSES' ASSOCIATION

Committee on Ethics
Guidelines on Withdrawing or Withholding Food and Fluid

Is it morally permissible to withhold or withdraw food or fluid from sick patients—and should nurses ever be involved in doing so? The answer to these two related questions is No, under most circumstances, and Yes, in a few instances. The focus of these guidelines, therefore, is upon the *circumstances* under which it is morally permissible to withhold food and fluid.

The starting point for our understanding of what nurses ought to do is based on the general moral consensus of civilized societies, religions, and generations regarding the usual obligation to provide food and fluid to the needy, sick, and dependent who can be helped by it. Such an obligation is central to the common understanding of nurses' professional and moral duties.

An aspect of nursing care, as carried out regularly and routinely by all bedside nurses, is the provision of some form of food and fluid. Patients need food and fluid in order to feel better, physically, and emotionally. The benefits of life and health from receiving food and fluid are so clear that, especially for those in the health professions (and perhaps most especially for nurses), there is a generally unambiguous moral duty to provide them. Thus, under most circumstances, it is *not* morally permissible to withhold or withdraw food or fluid from persons in their care, and nurses should not do so.

The most frequent instance when it is morally permissible, indeed obligatory, for nurses to withhold feedings are those occasions when patients would clearly be more harmed by receiving than by withholding feeding. Clinical examples include patients preparing for or just recovering from surgery, infants with such conditions as tracheo-esophageal fistula or anal atresia, and certain overeating disorders. These circumstances are temporary and usually involve subsitute provision of specified nutrients. The goal is to provide proper nutrition later, when it is safe and beneficial. *Harm*, as used in this moral reasoning, is not simply synonymous with hurt, pain, or discomfort, though it may involve each. It refers rather to serious damage, often irreparable, and involving the loss of valued capacities or pleasures. There are occasions when the provision of food and fluid is both painful and beneficial and the justification for the temporary imposition of some short-term discomfort from hunger and thirst.

Thus far, we have identified the two most ethically clearcut and common instances. First, nurses should almost always provide food and fluid because it is almost always an essential, life-preserving, health-giving benefit. Second, nurses should temporarily withhold food and fluid when their very provision clearly causes harm.

Ethical difficulties arise when it is unclear whether food and fluid are more beneficial or harmful. Since they are essential for life, this uncertainty ultimately leads to questions about whether life, under certain conditions, might be a greater harm than death. Determination of benefit and harm are further complicated by questions about whose evaluation of benefit and harm should be decisive. Should the evaluation by the patient, the family, the professional caregiver, a religious advisor, or that of society, through the court, predominate? There are also questions about whether possible harms and benefits to others, in addition to the patient, should be considered.

Since competent, reflective adults are generally in the best position to evaluate various harms and benefits to themselves in the context of their own values, life projects, and tolerance of pain, their acceptance or refusal of food and fluid should usually be respected. This ethical judgment is now well established legally[1,2] through various cases affirming the right of competent patients to refuse treatment, including food and fluid. It is morally, as well as legally, permissible for nurses to honor the refusal of food and fluid by competent patients in their care. The Code for Nurses[3], the historical evolution of nurses' professional responsibilities as patient advocates, and the general moral principle of respect for persons, sometimes referred to as the principle of autonomy, supports this view.

It is important, however, to guard against the possibility that respect for a competent patient's right to refuse food and fluid could lead to indifference or a misplaced respect for patient autonomy. The danger, in this instance, results in nurses' failure to interest themselves in a patient's reason for exercising the presumed right. It is the patient's *reasons* which established the right and which, therefore, are pivotal in determining what the nurse should do. Moreover, because such serious harms to the patient are associated with the refusal of food and fluid (initial discomfort from hunger and thirst, illness, physical wasting, and ultimately, death), it is not enough simply to fulfill the obligation to respect the wishes of competent persons. Obligations to prevent harm and bring benefit also require that nurses seek to understand the patient's reasons for refusal.

First, it is important to establish clearly the patient's ability to understand her or his situation, the alternatives, and the associated harms and benefits. The refusal of food and fluid, however, is not itself evidence of incompetence. Patients who refuse based on their evaluation of life with severe physical constraints, or with intractable pain, or as a choice about way and time to die in the face of an eventually fatal illness, or as a last resort to draw attention to important social causes[4] will usually have weighed carefully the various harms and benefits associated with their refusal, in the light of their own values and capacities. Such reasoned reflection should be respected by nurses. Thus, in the case of competent patients with good reasons, "the patient" is the answer to questions about whose evaluation of benefit and harm should be decisive.

This answer should not, however, be taken automatically to apply to all circumstances of competent refusal. Competent patients can refuse for incongruous reasons. They may not have an accurate picture of the facts or they despair for reasons that are reversible, though they may not presently think this is true. These patients should receive special, sympathetic attention from nurses. Nurses should make every effort to correct inaccurate views, to modify superficially held beliefs and overly dramatic gestures, and to restore hope where there is reason to hope.

In certain instances, when a patient is no longer competent but it is possible to establish with certainty the patient's projected refusal, the same respect for a patient's values is indicated. Documents such as a living will, or other written or well-established verbal Advance Directives, or the legal assignment of a Durable Power of Attorney[5] for healthcare, can be taken as aids in discerning the patient's view. The application of a previously stated refusal will, of necessity, require the judgment – both clinical and moral – of nurses and other caregivers as to whether the current situation is one to which the patient intended her or his refusal to apply. In general, Advance Directives, even those involving the withholding or withdrawing of food and fluid should carry great weight in caregivers' discussions with the patient's family or surrogate. It is imperative, in this process, that nurses not substitute their own views about which lives are worth saving and living for the views of their competent or formerly competent patients.

In circumstances where the patient never has been competent (including infants, children, many mentally retarded persons, and the never competent mentally ill), nurses along with others have the moral and professional responsibility to decide whether provision of food and fluid is in the patient's best interest. The same moral and professional responsibility falls to caregivers in the situation of a patient who is not now competent, and where the patient's views, while competent, cannot be discovered. Patients who are incompetent make an *exceedingly vulnerable* population dependent upon caregivers for careful thought and compassionate action, including the provision of nutrition.

The withholding of food and fluid might be indicated only when feeding is futile because of underlying, incorrectable absorption problems; when it is itself severely burdensome to the patient or sustains life only long enough to die of other more painful causes. Only under very special circumstances is it morally permissible to withhold feeding or give less than adequate feeding to those who cannot speak for themselves. In such circumstances, the nurse's responsibility for care continues and special attention should be given to mouth and skin care, and other forms of compassionate touch.

If withholding food and fluid appears more harmful than expected, or if the patient's condition changes and hydration or nutrition appears potentially beneficial, the giving of food and fluid should be reinstituted. The views and moral sensibilities of caregiving family members should be influential in decisions for such patients unless there is clear indication that the family does not wish to be involved in decision-making or is not competent, or substitutes their own interests for those of the patient.

In almost all cases the provision of food and fluid is in the patient's best interest. For some, it is one of life's central pleasures. Rarely is feeding more burdensome than beneficial. In addition, the nurse's obligation to fulfill the duties of her office or profession and remain faithful to her patients includes the general role promise that the nurse will engage in activities that are nurturative, even when such care is not clearly beneficial so long as it is not harmful.[6]

Central to the benefit of life itself is the benefit of nourishment which sustains physical being and provides psychological or emotional comfort. Thus, even in circumstances where food and fluid does not provide adequate nourishment, it should be continued if it provides comfort. For example, infants with irreversible absorption problems still enjoy sucking and mouthing food, or older adults who have refused further renal dialysis may still derive pleasure from sips of fluid or bits of food despite their impending death. Feeding should not be continued or forced, however, when it is futile and when it inflicts suffering or harm that is not outweighed by an important long-term benefit.

The nursing profession believes that the social and economic responsibilities which result from this position should be shared by all citizens, not solely those with a family member in need of nursing. We further believe that the good conscience, security, and sense of well-being among citizens rests in part on the knowledge that the vulnerable will be nourished and that carefully considered refusals of food and fluid will be respected.

---

[1] Nelson, Lawrence J., "The Law, Professional Responsibility and Decisions to Forego Treatment," *Quality Review Bulletin*, Joint Commission on Accreditation of Hospitals, January, 1986, p. 8.

[2] Grant, Edward R. and Forsythe, Clark, "A Plight of the Last Friend: Legal Issues for Physicians and Nurses in Providing Nutrition and Hydration," *Issues in Law and Medicine*, Vol. 2, No. 4, January 1987, p. 279-299.

[3] American Nurses' Association. *Code for Nurses with Interpretive Statements*. Kansas City, Mo.: The Association, 1985.

[4] Suicide attempts as a prima facie refusal of life itself should not be taken as unquestionably entailing a refusal of food and fluid. Intervention to halt or reverse suicide rightly includes the emergency provision of food and fluid until the patient's reasons for the suicide attempt can be ascertained.

[5] A durable power of attorney is an individual's written designation of another person to act on his or her behalf, when the designation is authorized by a state's durable power of attorney statute. Under state law, a power of attorney terminates when the designating individual loses decision making capacity, whereas a durable power of attorney does not.

[6] The Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*, New York: The Hastings Center, 1987, p. 57.

Issued by 1985-1987 American Nurses' Association Committee on Ethics.

Mila A. Aroskar, Ed.D., R.N., F.A.A.N., chairperson
Sister Karin Dufault, Ph.D., R.N.
Marsha Fowler, Ph.D., R.N.
Christine Mitchell, M.S., R.N., F.A.A.N.
Marilyn Whipple, M.S., R.N.,C.S.

American Nurses's Association
2420 Pershing Road
Kansas City, Missouri 64108
(816) 474-5720

January 1988

BEST AVAILABLE COPY

ADDENDUM #5

We strongly recommend that people take one or more of the following actions. Only then do we have a chance of ensuring that our right to self-determination survives even though we may become incapable of directly expressing decisions about our health care.

1. Contact an attorney or health care advocacy group to discuss whether a "Durable Power of Attorney for Health Care" is available. Through such a document, you can appoint someone to make health care decisions for you in the event you become unable to express your own wishes. You can also state specifically what those decisions should be in given circumstances.

2. Check your state's Living Wills laws. Different states have different restrictions on the power of these documents. A Living Will must be made while a person is competent.

3. Talk to your health care providers--nurses and physicians. Make your treatment wishes known to them in advance of the need for treatment <u>and</u> ask them to document the wishes in your medical records.

4. Communicate your viewpoint to your state lawmakers. The Supreme Court has said it is up to the states to develop procedures for recognizing and implementing a person's directives about health care, so they need to hear from their constituents.

5. Communicate your viewpoint on this issue to your U.S. Senators and Representatives. A national uniform effort is needed to educate people about exercising their right to determine their own health care.

6. Tell those close to you--family, friends, spiritual advisers how you feel about life-sustaining treatment in various situations. There are some jurisdictions where, in specific circumstances, families may still act as substitute decision-makers for an incompetent patient, and may consent or refuse health care on behalf of the patient.

ADDENDUM #6

The following scenarios appeared in an article written by Gerri Kobren for The Sunday Baltimore Sun on July 8, 1990 about the scope of living wills. The incidents were intended to educate readers about the effect of such documents.

> Linda, 32, like Nancy Cruzan, has been unconscious for seven years. She breathes on her own, but she cannot eat or drink. Food and fluids drip through a tube inserted in her stomach.
>
> Her parents believe she would not want to live this way and have asked that the tube be removed so she can die naturally.
>
> Linda, like Ms. Cruzan, had never made known what she would want in such a circumstance.
>
> No case like Linda's--which, like other scenarios in this article, is hypothetical--has been argued in Maryland courts, local legal experts say. Theoretically, however, the family of any person in a vegetative state would have to go through the same process as the Cruzan family, according to Mr. Schwartz:
>
> - They would have to go to court to have someone declared Linda's guardian.
> - The court would appoint a lawyer to act on Linda's behalf.
> - The guardian would have to get a lawyer.
> - Physicians would have to determine Linda's condition.
> - The guardian would then have to petition for withdrawal of life-sustaining measures and artificial feeding and hydration The case would be argued by the two lawyers and perhaps even a third representing a hospital or nursing home
> - The court would either accept or deny the petition.
>
> "The only way a person can be sure their wishes will be carried out...is to prepare a durable power of attorney form," Mr. Schwartz said. "A living will would not do it."
>
> When Bill was in his 20s, he sat down and wrote: "I do not want to be kept alive by artificial means. If I am ever in a persistent vegetative state and unable to communicate my wishes, I want my wife to children or doctor to end artificial life support for me." He signed and dated it.
>
> Then one day when Bill was 45, a car accident left him comatose. His wife found the paper he had signed 20 years earlier and presented it to Bill's doctors.

Documentation that is less formal and less specific may not be as effective, Maryland lawyers say.

Even with a statement written years before, family members are "not going to walk into a nursing home with it and have them say, "Fine," said attorney Jack Tranter, former chairman of the Maryland Bar Association's health care law division.

"The family would have to go to court to have a guardian appointed, who would then go to the nursing home and make decisions based on the fact that you had clearly expressed what you wanted. It's better than nothing, but you are clearly better off if you have the durable power of attorney for health care."

A regular durable power of attorney for legal and financial matters is not sufficient. A Baltimore woman discovered this when she objected to insertion of a naso-gastric feeding tube for her husband, an institutionalized Alzheimer's disease patient.

Although she had a power of attorney form that empowered her to make decisions if her husband were terminally ill, nursing home authorities told her that did not give them the authority to allow him to starve to death.

"I was given the alternatives of making a court case or transferring him out of the home," said the woman, who asked that her name not be used. Even though she agreed to allow use of the tube, her husband died three days later.

Joseph, 85, was in the hospital being kept alive by machines. He had a massive stroke and multiple organ failure.

He was alive, but he was unconscious and worsening. His family thought it was time to let him go. He had not completed a living will, nor did he have a durable power of attorney.

For terminal patients, a decision by family and doctors to stop treatment mat indeed by "legally appropriate", Mr. Schwartz said.

"If a person is dying and hasn't done a living will or durable power of attorney, and the family is in agreement that the proper course...is to stop the life-sustaining treatment, and if the treating physicians and the [hospital] ethics committee agree, that is a proper way for a decision to be made."

The article ended with this observation, "But whether this kind of decision-making works in all terminal cases remains doubtful."

STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ATTORNEYS, INC.

"The Patient Self-Determination Act of 1989," S. 1766 and "The Patient Self-Determination Act of 1990," H.R. 4449 seek to ensure that a person's right to determine his or her own health care future is respected. The proposed bills address those situations in which competent individuals specify in advance what kind of treatment they do or do not want—or who should make those decisions—should they become unable to do so. The legislation is intended to help individuals establish advance directives by educating health care providers as well as patients' and by requiring that health care institutions have written policies and procedures to ensure their use.

Until recently, Federal oversight on decisions to withhold or withdraw medical treatment from adults was relatively nonexistent. The development of the law has been a function of statutes and case law at the state level. These state laws and decisions vary greatly from state to state. Defining a proper role for Federal Government intervention in this very emotionally charged area of health care decision-making involves at a minimum balancing individual rights, provider responsibilities, ethical standards and societal norms (as expressed in the state statutory scheme and precedents). In this controversial area, preservation of the right of individual self-determination appears to be emerging as the dominant consideration. The established Federal position of 'no role' in health care decision-making for adults may be altered in the near future if pending legislation which supports greater use of advance directive mechanisms in health care institutions becomes enacted into law.

SUMMARY OF THE LEGISLATION

"The Patient Self-Determination Act of 1989," S. 1766 was introduced on October 17, 1989, by Senators John Danforth (R-MO) and Daniel Moynihan (D-NY). A companion bill, "The Patient Self-Determination Act of 1990," H.R. 4449 was introduced in the House of Representatives on April 3, 1990, by Representative Sander Levin (D-MI). The proposed legislation is based on the principle that competent adults have a right to control the medical decisions that affect their lives. The bills were motivated by concerns that patients, in the absence of clear directives regarding their views of life-sustaining treatment, do not have their preferences respected when they become incapacitated. Under current standings, the bills would seek to enhance patient participation in health care decision-making by educating people about the options of executing a living will and for appointing a proxy through a durable power of attorney to represent their wishes should they become unable to do so themselves.

Both S. 1766 and H.R. 4449 affect all certified Medicare and Medicaid providers through amendments to the Social Security Act. These amendments add new requirements to Medicare provider agreements and Medicaid state plan requirements. The House bill goes further to explicitly include health maintenance organizations which operate under a deficient authorizing section of the Medicare statute. Other health care providers over which the Federal Government has jurisdiction such as the Veterans Administration, Department of Defense and other Federal institutions are not within the scope of the legislation.

Under the proposed legislation, providers must establish written policies to ensure that patients are informed of their rights to direct medical treatment decisions, to advise patients of documents they can execute to make sure their wishes are carried out, and to record and periodically review preferences for intensity of medical care with the patient. There is no explicit requirement mandating that Medicare and Medicaid certified providers honor patients' wishes.

The legislation shifts the burden of production for advance directives from the patient to the provider. Under current law, Medicare and Medicaid providers are under no obligation to ask if a person has executed any advance directives. The burden is on the patient or his surrogate to produce information about the existence of any directives and bring it to the attention of the providers of care. "The Patient Self-Determination Act" requires Medicare and Medicaid certified providers to inquire as to the existence of these directives, ideally upon admission. However, under no circumstances can admission (initial treatment) be denied based on the existence or lack of advance directives.

Legally valid advance directives are to be implemented under the proposed bills to the maximum extent permissible under state law. Where the provider is unable to implement the patient's wishes as a matter of conscience, arrangements for prompt and orderly transfer must be made. The Senate bill would also require the creation of an institutional ethics committee to provide education and to advise on particular cases.

S. 1766 further requires that as a condition of Medicaid state plan approval, states enact legislation authorizing the use of advance directives if they have not already done so. According to the Senate bill's sponsors, six states would be required to enact legislation to comply with the law. Failure to do so within a reasonable time would lead to temporary loss of Medicaid funds. The House bill contains no such requirement.

ANALYSIS [1]

The introduction of Federal legislation which would seek to enhance patient participation in health care decisions through greater use of advance directives raises at least the following issues:

1. Whether Federal legislation is necessary and/or appropriate to protect and promote an individual's right of self-determination in matters of medical decision-making.
2. Whether the provisions of the proposed legislation will affect the stated purposes.
3. Whether the legislative process of public attention, debate and enactment will satisfactorily address the substantive and procedural issues raised in the proposed bills.

The assumption underlying S. 1766 is that a patient's right to self-determination and right to refuse treatment is of little value if not supported in clinical practice. Therefore, the bill attempts to address the problem by mandating procedural aspects of the use of advance directives for health care decision-making. The proposals are limited to specified providers under the Medicare and Medicaid programs. The legislation does not affect other Federal medical providers such as the Veterans Administration or the Department of Defense.

By requiring written policies and procedures to inform all patients of their rights to make decisions, accept or refuse treatment, appoint a surrogate and/or provide written instructions to the provider, S. 1776 and H.R. 4449 appear to endorse the use of advance directives but do not explicitly require that they be honored by the provider. Both on an individual provider basis and institutionally, there are no methods to monitor compliance and no meaningful enforcement provisions. In theory, Medicare certification or Medicaid state plan approval could be at stake for a potential "violation."

The use of the term "provider" may cause unintended conflicts where multiple providers are involved. This is particularly true in the case of an individual attending physician and an institutional provider such as a nursing home where policies, personal ethics or interpretation of state law may differ.

In addition, the Act places the responsibility for determination and implementation of the patient's wishes upon the "provider" and the "entity." This is contrary to the current common law which places the responsibility for obtaining a patient's informed consent for treatment decisions upon the physician, not the health facility.

The lack of national standards in the development of state legislation regarding living wills and durable powers of attorney, and inconsistencies in case law and precedent in this area of the law make determinations of patients' rights and the validity of an express wish or a written document purporting to be an advance directive subject to question. Providers may see the requirement of informing patients of their rights under state law as burdensome and inappropriate because of their lack of knowledge of the law and the inconsistencies that exist in the law.

Very few state statutes recognize the validity of an advance directive executed in another state. This lack of portability and the lack of minimum national standards may be a source of confusion and uncertainty to patient and provider alike. The provider is not capable of opining on the legal validity of a document purporting to be a living will. The law does not provide guidance to resolve conflicts among family members and the patient and does not address the difficult clinical and ethical question of decisionally incompetent patients who have never executed an advance directive.

Many state laws contain ambiguities in definition or restrictions in application that may in fact restrict a patient's right to self-determination in matters of medical decision-making. Definitions of terminal illness, statutory requirements that death

---

[1] The foregoing analysis was benefited by the research done by the Office of Technology Assessment and Alan Meisel in his book *Right To Die*.

be imminent, and the issue of artificially supplied nutrition and hydration are some of the most problematic areas. Therefore, deferral to state law may not always enhance individual rights. Most state courts have not had occasion to interpret their state statutes authorizing living wills. Furthermore, the case law, where it has developed, has tended to be very fact-specific and generally unpredictable as courts themselves struggle with these decisions. The purposes of the law might be more easily realized if the Congress considered the alternative of mandating Federal minimum standards for state legislation authorizing advance directives. However, opponents of such a requirement would likely see such a mandate as an infringement of states' rights to legislate under their *parens patriae* power.

Providers may also feel the recordkeeping and policy generating requirements are more burdensome than beneficial. Neither bill requires providers to honor the patient's directives. Rather, merely having policies and procedures in place will satisfy the statute. Thus, there is no meaningful enforcement or compliance action possible. Furthermore, those who believe in supporting life at any cost, or who are skeptical of Federal involvement in medical decision-making, may see the bills as unwarranted intrusion on the physician's prerogative and infringement on the confidentiality of the doctor-patient relationship.

Interjecting institutional providers between the doctor and the patient may also cause confusion and conflict with state laws. Confusion may be the result of multiple persons, including the attending physician inquiring as to the existence of advance directives. Someone may try to influence the substance of a patient's decision by lobbying for or against a particular objective. By assigning responsibility to all providers, in addition to the attending physician, these provisions may also be in direct conflict with state law provisions that assign responsibility for advance directives solely to the attending physician, and those that place the burden of production on the patient rather than the provider.

Mandatory transfer provisions raise potential issues in areas where there are limited alternative placements or where the patients change their minds about treatment preferences after the provider undertakes to care for them. The legislation does not otherwise take the ethical positions of the provider into account except in the transfer requirement.

There is at most only an implicit requirement for informed decision-making by the patient, but no express procedural safeguards to ensure that the patient is informed, or that he or she evaluates and/or understands the implication of his or her choices to forego further treatment. Requiring providers to solicit this information may result in the transmission of the provider's biases to the patient under stressful circumstances such as admission to a hospital emergency room or nursing home. Raising the issue of preferences regarding intensity of medical treatment with a patient also leaves open the opportunity to request all manner of extraordinary treatment. Does the legislation, which implies the right to refuse treatment also carry an implied right to any and all medical treatment? Could a chronic alcoholic, for example, request a liver transplant as an exercise of his right of self-determination? If not, why not? From a cynical perspective, the specter of rationing and the high cost of dying may cause opponents of this legislation to claim that it is purely budget driven.

Methods are needed to educate people who want to document their treatment preferences in advance of future incapacity. In fact, just the process of debate and legislative consideration leading to enactment may encourage more competent adults to consider and document their treatment preferences. Additional consideration of the legal, ethical and practical issues associated with decisions to withhold or withdraw medical treatment is warranted. Both the Senate and the House versions of the proposed legislation give some consideration to this objective by requiring studies and demonstration projects to be conducted by the Department of Health and Human Services. More analysis would appear to be indicated in areas where serious legal uncertainties exist because there is no relevant jurisdiction, because laws differ greatly in the different jurisdictions and because the law is changing rapidly. Existing legal precedent does not offer clear guidance to providers; therefore, research, demonstration projects and public education aspects of the legislation may be more appropriate for enactment at this time.

STATEMENT OF THE AMERICAN JEWISH CONGRESS

The American Jewish Congress welcomes this opportunity to present testimony in support of the patient Self-Determination Act of 1990 (S. 1766).

For over 70 years. the AJCongress, a membership organization of 50,000 American Jews nationwide, has fought to defend the individual rights of Jews and all Americans, particularly those rights of free exercise of religion and separation of church and state enshrined in the First Amendment to the United States Constitution.

Because the complex ethical legal and public policy issues created by advancements in medical technology have profound significance both for religious observance and cultural pluralism, matters of particular concern to the organization, the American Jewish congress in 1988 created a Bio-Ethics Task Force. The mandate of this Task Force is to make recommendations to the governing bodies of the AJCongress on the position it should take with respect to legislative initiatives and court decisions involving bio-ethical issues. This Task Force, composed of prominent bioethicists, medical doctors, patients, Rabbis, and other individuals learned in this field, in turn, created a subcommittee which evaluated the issues involved in decisionmaking with respect to life-sustaining treatment. This subcommittee after more than a year of study submitted a report which in May 1989 was approved by the Governing Council of the AJCongress. That report entitled *Decisions to Forgo Life-Sustaining Treatment,* unreservedly supported the general right of patients to determine for themselves whether to forgo life-sustaining treatment, and also supported the right of patients to write advance directives or appoint health care agents to implement their wishes about what type of treatment they would want in their last days.

The Report concluded that providing individuals with the opportunity to determine their medical future when they still retain decisionmaking capacity would "reduce suffering, bring comfort and restore dignity to patients and their families." Further, the report noted, this policy of preserving the autonomy of the individual through use of such devices as the advance directive or health care agent "simultaneously respects the diversity of religious and ethical views within the American community and contributes to the protection of freedom of conscience[1] and religion and the pluralism which has for so long been a source of our society's strength."

As an arm of a Jewish organization, the American Jewish Congress Bio-Ethics Task Force in its report recognized that there might be differences among the three branches of Judaism on issues relating to refusal of treatment. For example, it noted that some representatives of the Orthodox Jewish tradition teach that preservation of life is a paramount value and that virtually all other values are rendered subservient to this overriding concern. However, it pointed out that other Jewish religious theologians and writers take a less absolutist approach to preservation of life.

The AJCongress Task Force concluded, however, that since legislation authorizing use of advance directives did not command any particular course of conduct with respect to the use of medical technology, and left it to the individual to determine the issue for him or herself according to his own religious or ethical tradition, such legislation because it advanced free exercise of religion and religious values should be supported.

In the light of this firm and carefully considered commitment to the importance of a patient's decision-making, AJCongress welcomes the introduction of S. 1766. S. 1766 requires that as a condition of participation in Medicare and Medicaid, health care institutions must inform adult patients of their rights under state law with respect to specifying their treatment wishes as well as about the institution's own policy with respect to withdrawal of treatment. It requires hospitals and nursing homes to maintain written policies and procedures to determine whether Medicare and Medicaid beneficiaries, at the time of admission, have prepared an advance directive and to document the treatment wishes of the patient and periodically review such wishes with the patient. The institutions would be required to ensure that legally valid advance directives be implemented to the maximum extent possible under the relevant state law; arrange for the prompt transfer of a patient to the care of others when, as a matter of conscience, the hospital cannot implement the patient's wishes; and create an institutional ethics committee to initiate educational programs on ethical issues in health care for staff, patients, residents and the community. Also, within 6 months of the date of enactment, the Secretary of the Department of Health and Human Services would be required to develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient's right to participate in and direct health care decisions.

---

[1] The AJCongress Report recognized that the religious moral views of a health care agency may be opposed to such decision and in these circumstances took the position that the institution should be given an opportunity to transfer the patient. We are happy to note that S. 1766 also respects the institutional conscience in this way.

We believe S. 1766 will go far to increase knowledge about and use of advance directives and health care proxies. This bill becomes of even greater importance in the light of the *Cruzan* case. In that case, the United States Supreme Court recognized a competent person's constitutional liberty interest in refusing medical treatment. However, at the same time, the Court held that a state could require a very high standard of proof concerning the patient's wishes regarding withdrawal or refusal of life-sustaining treatment and could reject efforts by third parties to take action on the patient's behalf in the absence of such proof. The Missouri Supreme Court in that case did not specifically define what kind of evidence would suffice. However, as a dissenting Justice of the United States Supreme Court noted, "its general discussion suggests that only a living will or equivalently formal directive from the patient when competent would meet this standard." [2]

However, surveys show that the overwhelming majority of Americans have not executed such written instructions.[3] On the other hand, surveys also reveal that most Americans would not want, for example, to have their lives maintained with artificial nutrition and hydration if they were in Nancy Cruzan's situation.[4]

These two facts that an overwhelming majority of Americans would want to have treatment withdrawn under certain circumstances, and that few individuals have provided the formal directives which the Supreme Court has held a state could demand before it would honor an individual's wishes suggest that any measures to educate patients about advance directives fill a serious need, S. 1766 by giving individuals an opportunity to learn about advice directives, discuss their treatment wishes with health professionals and to execute such directives while they are still competent, goes far to meet that need and increase patient autonomy and self determination. While taking no position in what decisions individuals should make or even whether they should execute an advance directive at all, S 1766 by increasing knowledge enhances patient participation in health care, a requirement of ethical decision-making.

Turning to the particulars of the bill itself, AJCongress supports the requirement that a durable power of attorney for health care or a living will, be made part of the patient's medical record for the treatment care team and suggests further that the bill require that copies of the document also be filed in the health cars institution's central files We would also join those who urge that the public information campaign to be developed by the secretary include preparation or approval of materials that will be made available to Medicare and Medicaid providers to help them comply with the provisions of this bill and that such education not await the admission of Medicare or Medicaid patients to hospitals or nursing homes

As Thomas J Scully, M D of the Program in Bio-Ethics, University of Nevada, pointed out:

> If the implementation awaits the admission of mostly Medicare or Medicaid patients to hospitals or nursing homes, then it will be too late for many, young and old, already rendered decisional incapacitated by either the injury or disease that brought them to the institution in the first place.
>
> Public Education should be directed to every citizen who subscribes to a Health Maintenance Organization or joins a Group Health Insurance Program, is enrolled as a Medicare or Medicaid recipient, is employed by the Federal Government, is enrolled as a public employee in a public retirement program, enlists in any Federal Service or is discharged and becomes eligible for Veterans' Benefits, registers to vote in a national election or completes a U.S. Census form.
>
> But most importantly, public education should begin early when every teenager takes a diver's education course or obtains a driver's license to drive on a *federally funded highway*. (Remember that a large number of those in the persistent vegetative state and permanently unconscious are teenagers and young adults who survived serious automobile accidents which they never anticipated and which occurred prior to their ever having made their wishes known in a "clear and convincing" manner), public education, regarding the need for Advance Directives should continue each time a citizen renews his or her driver's license or registers an automobile.

---

[2] Opinion of Justice Brennan, dissenting in *Cruzan* v. *Missouri Dept. of Health*, 58 U.S.L.W. 4916, 4932 (June 25, 1990).

[3] *Id.* at n.21, pointing to various surveys indicating only 9% to 23% of those questioned said that they had executed advance directives or living wills or put their treatment instructions in writing.

[4] *Id.* at 4929.

We also join with the American Bar Association in urging the Committee to study the problem of portability from state to state of advance directives. The variability and complexity of the various state living will and durable power of attorney statutes suggest that some measures are necessary to ensure that patients who happen to fall ill in states other than the state in which they have executed an advance directive will have their interests protected.

Finally, we wholly reject the view of Gail Wilensky, Administrator of the Health Care Financing Administration, that the Medicare and Medicaid Conditions of Participation should not be used to regulate concerning advance directives an activity which she argues "does not directly relate to the Conditions' immediate goal of assuring quality care."

We at the American Jewish Congress believe that the shared decision-making between the patient, his family, and his health care provider which would be encouraged by S. 1766 is an essential aspect of "quality medical care" and, in fact, such care cannot be delivered without it.

Passage of S. 1766 will go far to eliminate the depersonalization and tyranny of technology from which patient care has long suffered and which deprives many patients of the dignity and autonomy they wish and need in their last days. We urge its enactment.

STATEMENT OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

The Catholic Health Association of the United States (CHA) is the national service organization comprising Catholic hospitals and long term care facilities, their sponsoring organizations and systems, and other health and related agencies and services operated as Catholic. For 75 years, the Catholic healthcare ministry has responded to the call to participate in the healing mission of Christ.

S. 1766, The Patient Self Determination Act, sponsored by Senators John C. Danforth (R-MO) and Daniel P. Moynihan (D-NY), would require providers of services under Medicare and Medicaid to ensure that individuals who receive their services be given information about their rights to participate in healthcare decisions that affect them. The bill also would require that providers be educators on issues concerning advance directives for their own staff and communities.

Respect for human dignity requires that any healthcare system nurture the autonomy of individuals by building in as much opportunity for personal choice as possible. One of the central themes of Catholic social teaching is that human dignity is manifest in our ability to reason and understand, in our freedom to shape our own lives and the life of our communities. Within the ministry, we have assumed the responsibility to help the sick, the elderly, the indigent, and the dying give concrete expression to their personal dignity by developing and offering them ways to exercise self-determination.

The recent interest in living will legislation and proxy healthcare decision making reflects, in part, the worry many persons have about not being given the opportunity to participate in healthcare decisions being made about them. Many fear being kept alive on life-support systems without their consent. Many are just as concerned that healthcare professionals may assume unjustifiably and without consulting them that they are "too old" or "too sick" to receive a certain treatment.

These legislative initiatives and the set of moral issues that such legislation attempts to address are of particular interest to the Church. The Catholic tradition looks on life as a gift of God that human beings hold in trust. It motivates us to support laws that protect persons' rights to participate in their treatment decisions and that provide a way for them to make their wishes known in advance should they become incompetent or permanently comatose at the end of life. Likewise, our tradition inclines us to actively oppose legislation that would legalize euthanasia or assisted suicide.

The concept of advance directives is one that CHA believes can enhance better communication among patients, families, physicians and care givers. Advance directives such as durable power of attorney for healthcare and living wills encourage discussion and documentation of views on life-sustaining treatment *in advance*. The pain and burden placed upon families of patients can be eased at the time of dying when the patient's own wishes are known in advance. In that way, the patient's participation in his own healthcare decision making is not lost if the patient becomes unable to make decisions.

With S. 1766, the protection of a person's right to self-determination in healthcare decisions is taken one step further. The bill would require hospitals, long term care facilities and other healthcare providers to provide information to individuals about their rights under State law to make healthcare decisions and document in the medical record whether or not a patient has executed an advance directive.

Some hospital personnel worry that patients will be frightened if they are asked about advance directives on admission. The specific concern is that patients will see this request as an indication that there are additional, unexplained risks involved in the hospital stay. We are aware of no evidence of this sensitivity from hospital personnel who routinely ask all or some specific groups of patients about whether they had completed an advance directive.

Consistent with our belief in a person's right to self-determination in healthcare decisions, CHA supports S. 1766 which would ensure that the existence of previously expressed wishes of a patient, as written in a durable power of attorney for healthcare or a living will, would be made part of the medical record for the treatment care team.

CHA strongly supports proposed changes in the language of the bill that require the Secretary of the Department of Health and Human Services to conduct a public information campaign that includes development or approval of materials that will be made available to Medicare and Medicaid providers to help them comply with the provisions of this bill. Since it is better to learn about healthcare decision making rights and advance directives prior to entering the hospital, the public education campaign will be able to target persons who are now healthy and not under the stress of an impending hospital or other facility admission. The informational materials are vital to providers so they can ensure consistency and accuracy of information being provided to patients on the sensitive subjects of the right to accept or refuse medical or surgical treatment and the existence of advance directives. Likewise, CHA also supports the bill's requirement for states to develop or approve state-specific informational materials regarding advance directives.

This proposed legislation is not a "right to die" bill, or a "living will" law. The legislation takes no stand on what particular decisions individuals should make, nor does it require individuals to execute advance directives. The Federal and state informational materials to be developed must give equal importance to the patient's right to choose to sustain, as well as to terminate, treatment. Because of the serious lack of knowledge regarding the tools available to patients to formally express their views of life-sustaining treatment, this legislation attempts to enhance patient participation in healthcare decisions, which is a requirement for sound ethical decision-making.

In support of respect for patients' preferences, CHA is in agreement with S. 1766's provision that the provider determine the existence of a previously executed advance directive. Hospitals and other healthcare providers have a moral obligation to act in their patients' best interest by inquiring about a valid document that not only is expressly drafted to be used and known in such a situation, but which facilitates difficult treatment decisions. The hospital or other healthcare provider may also benefit from patients' having or being asked about advance directives. Healthcare professionals can often accept decisions with which they disagree if they are assured that the decision represents the patient's preferences. The advance directive can provide that reassuring information.

If healthcare facilities are to be the providers of information about advance directives, first they will have to be sure that they themselves understand both the legal and ethical import of the advance directive. S. 1766 requires that staff education be conducted to accomplish that understanding. CHA supports new language in the bill that would allow facilities to collaborate with each other on their educational efforts for both staff and community. This approach is much preferred over requiring facilities to implement institutional ethics committees and to use the committees as the conduit for education. While there is increasing recognition of the role and value of such committees, there is a serious question as to whether they should be mandated. If the committee does not arise from a felt need of the institution, it is doubtful that it will be effective.

While CHA agrees that the patient's right to make healthcare decisions can be asserted without the execution of legal documents, in the present legal and healthcare climate there exists a need for public education on the issue of advance directives, and good legislation could be helpful in that process. The public education campaign that is required as a part of this bill will be an important tool. The study to assess implementation of directed healthcare decisions to be undertaken by the Secretary of the Department of Health and Human Services will evaluate the experience of practitioners, providers, and government regulators in complying with provisions of the act. CHA suggests that the experience of those for whom the act is most dedicated—patients and residents—be included in the evaluation.

CHA also requests that explicit language be added to the bill that would exempt hospitals from applying the provisions S. 1766 to emergency room admissions until the patients are medically stabilized.

The Patient Self-Determination Act is an important piece of legislation to which The Catholic Health Association is pleased to lend its support. Community service and education are a vital part of the healthcare ministry for Catholic providers. Through such efforts, the right of patients to control medical decisions that affect their lives can be protected.

CENTRAL CONFERENCE OF AMERICAN RABBIS,
Youngstown, OH, July 12, 1990.

To: Senate Finance Subcommittee on Health

Re: The Moynihan-Danforth Patient Self-Determination Act

From: Committee on Judaism and Health, Central Conference of American Rabbis

As chairperson of the CCAR Committee on Judaism and Health, I want to share with you our committee's support for the earliest possible passage of the Patient Self-Determination Act. At our meeting held in Seattle on June 26, 1990, we subscribed to the following:

(1) Whereas the morning's newspapers reported the decision of the United States Supreme Court in the case of Nancy Cruzan of Missouri;

(2) And whereas the Court appears to instruct lower courts to attend carefully to the clearly expressed wishes of each individual regarding his/her own treatment or non-treatment;

(3) And whereas the purpose and effect of the Moynihan-Danforth Patient Self-Determination Act is to enable patients to make their wishes known in a clear form, if they wish to do so and have not previously done so in a currently accessible form;

Therefore, be it resolved that this committee endorses and repeats the support expressed on our behalf at the press conference held by Senators Moynihan and Danforth at the Russell Office Building in October, 1989, and recorded in the *Congressional Record*,

And be it further resolved that this committee urges the passage of this Act with all deliberate speed, to address to some extent the concerns of the United States Supreme Court, expressed in the decision in the Cruzan case.

Respectfully,

RABBI JONATHAN M. BROWN,
Chairperson, CCAR Committee,
Judaism and Health.

PREPARED STATEMENT OF JOAN BRIDGERS DINAPOLI

EDUCATION AND DIALOGUE ARE IMPERATIVE TO PATIENT SELF-DETERMINATION

Individuals have a right to make their own healthcare decisions and a right to designate, in advance, someone to make these decisions in the event they are ever judged incompetent or cannot communicate their own decisions. These rights are not new. But, as the emotional and financial cost of healthcare rise, the impact of ignorance of these rights becomes critical.

Recently, the United States Supreme Court reaffirmed these individual rights. In the *Cruzan* Case, the Court affirmed the constitutional right of a competent person to refuse life-sustaining treatment, including artificially administered nutrition and hydration. However, the Justices upheld the state's right to require clear and convincing evidence of the patient's desire to refuse treatment when that patient cannot communicate a decision or has been judged incompetent.

This ruling underscores the importance for people of all ages to consider and make their healthcare choices known before they are no longer able to make their own decisions. Yet, estimates given to Congress during hearing testimony and floor proceedings reveal how few people have *living wills* and *durable power of attorneys* or even recognize the importance of these legal tools. When there are no *living wills and durable power of attorneys* that document the patients' desires, families, healthcare providers, healthcare institutions and attorneys face the potential of unnecessary conflicts, dilemmas and costs.

Recognizing these problems and the need to prevent them, The Duke Endowment and the National Endowment for the Humanities, through the Medicine and Society Program of the North Carolina Humanities Committee, joined in coalition with the following North Carolina organizations to support and fund the development of a tool to educate and facilitate dialogue about difficult healthcare decisions among individuals, families and healthcare providers: North Carolina Association For Home Care, North Carolina Association of Long Term Care Providers, North Carolina Division of Aging, North Carolina Health Care Facilities Association, North Carolina Homes for the Aging Foundation, Wake Area Health Education Center, an affiliate of Wake Medical Center and the University of North Carolina at Chapel Hill Area Health Education Centers.

The project was initiated and guided by a steering committee that represented the sponsoring organizations. The author and co-author, in consultation with an interdisciplinary committee and review panel, evolved the format and content of *A Practical Guide to Life & Death Decisions: Questions to Ask . . . Actions to Take . . . .** The process of making healthcare decisions is viewed from the vantage points of the individual, family and healthcare provider.

The contents of this tool highlight the unique interdisciplinary perspectives that medicine, nursing, health administration, ethics, psychology, education, religion, law and the consumer bring to these complex healthcare decisions. Although the samples of a living will and a durable power of attorney at the end of the text are based on North Carolina law, the contents address issues, processes and legal rights that reflect Federal statutes and United States Supreme Court holdings.

This guide focuses attention on the medical-legal-ethical factors surrounding the right to make healthcare decisions and discusses the use of a *durable power of attorney* and a *living will to* clarify personal decisions. Rarely do perfect choices exist or the situation demand only one difficult decision. Usually a series of complex healthcare decisions are required. Hence, the guide focuses on a process individuals can use to work their way through possible choices to reach their own personal decisions. It informs them that a *living will* and a *durable power of attorney* are two legal tools to clarify personal choices.

The proposed *Patient Self-Determination Act* appears to be a positive and important step toward enhancing patient involvement in their healthcare decisions, affirming the principle of informed consent and extending patient self-determination through *living wills* and *durable powers of attorney*. But, it should not be viewed as complete solution to patient involvement in their own healthcare. Being informed that they have the right to consent to or refuse diagnostic and treatment regimes does not automatically equate with knowing how to sort through confusing choices to make these very personal decisions.

The public can be misled by what appears to be a simple solution. There may be the tendency to consent to treatment without really understanding they have the right to refuse. They may complete *living will* and *durable power of attorney* forms without knowing their purpose, limits, implications and consequences. Important healthcare decisions merit more attention than just filling in the blanks of standardized forms of a *living will* and a *durable power of attorney*. First, there are questions to ask yourself, your family, doctors, attorney and others. Then, actions you can to take to clarify and document your decisions.

Therefore, the educational and accountability requirements in the *Patient Self-Determination Act* are essential elements of this legislation. Through the education provisions, consumers and healthcare providers can become aware of medical-legal-ethical issues they need to consider, identify questions to ask about risks, benefits, limits and consequences of their options, and recognize actions they should take to inform others of their decisions. Then, the balancing healthcare provider accountability provisions, which reinforce their current legal responsibilities, increase the probability that only wanted healthcare will be delivered.

Healthcare decisions are some of the most important decisions many people will have to make for themselves or others. Interdisciplinary tools, such as *A Practical Guide to Life & Death Decisions: Questions to Ask . . . Actions to Take . . . ,** can assist patients and healthcare providers to clarify these complex issues while facilitating the imperative dialogue among individuals, families and healthcare providers.

Information and ongoing dialogue are essential prerequisites to informed consent and the subsequent ability of an individual to maintain control of their increasingly

---

* For information on availability and cost of *A Practical Guide to Life & Death Decisions: Questions to Ask . . . Actions to Take . . .*, send inquiries to Consultation & Research, Inc., PO Box 3202, Durham, NC 27715, Fax # 1-919-383-3934.

complicated healthcare. The *Patient Self-Determination Act's* requirement that patients be informed of their right to consent to and refuse medical procedures and treatments reinforce the legal mandate that individual and institutional healthcare providers now have to obtain informed consent prior to intervention.

The proposed *Patient Self-Determination Act* can be giant step toward enhancing patient involvement in their healthcare decisions. By affirming the principle of informed consent and facilitating patient self-determination beyond competency and the ability to communicate, it can also assist individuals to control their emotional and financial healthcare cost by decreasing unwanted diagnostic and treatment procedures.

STATEMENT OF THE MINNESOTA COMMISSIONER OF HUMAN SERVICES

The State of Minnesota is pleased to provide testimony regarding Senator Danforth's proposal to require Medicare and Medicaid providers to make available to their patients information about living wills and to ask their patients whether they have executed living wills.

While the intent of the proposal—to encourage people to execute living wills—is commendable, it has the potential to exacerbate problems with Medicaid provider relations.

In order for a provider to obtain reimbursement from the Minnesota Medical Assistance Program (Medicaid), he/she must comply with a myriad of state and Federal rules, regulations and administrative policies. Although they are necessary for the administration of the Program and the health and well-being of Program recipients, these requirements can be quite burdensome.

In Minnesota, access to health care is becoming an increasingly significant problem in some areas. We are finding that some providers choose to end their participation in the Program simply because they are no longer willing to take on the administrative burden. In an effort to reduce this effect, we are attempting to keep new administrative requirements to a minimum.

This new proposal would impose a new administrative responsibility on a provider community that has fewer than ever incentives to participate in Medicaid. Also, there may be providers who are philosophically opposed to the concept of a living will and other advance directives, and who would be forced to discontinue their participation in the Program. Finally, this is a requirement that would be extremely difficult to enforce. Therefore, only the most conscientious providers would bear the burden.

Again, although advance planning for incapacitation should be encouraged, it should not be mandated at the expense of access to quality health care, nor should it be required only of those persons who use public funding for their health care needs. Perhaps the goal of this legislation could be better accomplished by promotion of living wills among the general population.

STATEMENT OF THE NATIONAL ASSOCIATION FOR HOME CARE

The National Association for Home Care (NAHC) is the nation's largest professional association representing the interests of nearly 6,000 home health care providers, homemaker-home health aide organizations and hospices, who care for millions of Medicare beneficiaries. As such, NAHC strongly supports the intent of the Patient Self-Determination Act (S. 1766). The recent Supreme Court ruling in the *Cruzan* case makes it particularly important for patients to be made aware of their rights under State law to issue advance directives.

It should be noted that home care providers have long been engaged in activities that echo the intent of this bill. For example, the Home Care Patient's Bill of Rights (see attached) which is distributed to home care patients, stresses the importance of patient participation in the development of the care plan. The Bill of Rights states: "Clients have the right: to be fully informed in advance about the care and treatment to be provided by the agency, to be fully informed in advance of any changes in the care or treatment to be provided by the agency that may affect the individual's well-being, and (except with respect to an individual adjudged incompetent) *to participate in planning care and treatment or changes in care or treatment.*"

Furthermore, providers as a matter of course follow patients' wishes regarding "do not resuscitate" (DNR) orders—for example, orders that no efforts should be made to resuscitate the patient if he or she should go into cardiac arrest. In many instances, the patient's physician makes the patient's wishes known to the home care agency prior to admission into home care.

NAHC does, however, question whether it is appropriate to use home care agency staff to communicate information regarding advance directives to the patient. Although home care providers would not be responsible for actually drafting the materials that would be distributed, the bill would make the visiting staff responsible for giving patients these materials. If, as seems likely, patients would have questions about this information, nurses, homemaker-home health aides and therapists would be put in the position of trying to explain complex provisions of state law.

Moreover, the provision of these materials could be expected to raise questions in the patient's mind about the state of their health which would call for reassurance. In order to allay these concerns, the home care staff could be placed in the awkward position of trying to respond to questions about the patient's medical prognosis that should be properly handled by a physician.

Further, under the current provisions in the legislation, there is a strong possibility of patient confusion. By the time a patient reaches the home care setting, he or she will, in the majority of cases, already have been presented with the same information, but with varying explanations, at least once already as the result of previous stays in a hospital or skilled nursing facility. NAHC would recommend that one entity have central responsibility for disseminating advance directive information.

One option would be to make the patient's primary care physician responsible for providing the appropriate information. Primary care physicians typically have lifelong involvements with their patients. Advance directives should, of course, be issued at a relatively early age if the individual is to be covered when, without warning, he or she is incapacitated by some traumatic event—an auto accident, for example. The primary care physician could reach these people before they become incapacitated, for example by providing the necessary information as part of routine physical examinations.

NAHC would also suggest that states take the lead in conducting educational campaigns to inform people of their rights under their respective laws. In this regard, we strongly support the provision in this bill that requires all states to enact legislation on this issue. NAHC would further recommend that states develop model "living wills." State laws on this issue are enormously complex, and in constant flux because of the growing body of case law. Thus, it is appropriate for states to play an active role in explaining their statutes and disseminating accurate information. To assure that this information is brought to people's attention at an early age, states could provide it in conjunction with awarding driver's licenses, analogous to organ donor information.

Last, NAHC would urge that the Department of Health and Human Services be encouraged in its efforts to develop materials on this issue, and that the subject be covered by the handbook which is distributed to all Medicare beneficiaries.

NAHC applauds Senators Danforth and Moynihan for introducing this important legislation and stands ready to assist the Committee in its efforts to address this issue.

HOMECARE

BILL OF RIGHTS*

Home care consumers (clients) have a right to be notified in writing of their rights and obligations before treatment is begun. The client's family or guardian may exercise the client's rights when the client has been judged incompetent. Home care providers have an obligation to protect and promote the rights of their clients, including the following rights.

Clients and Providers Have a Right to Dignity and Respect

Home care clients and their formal caregivers have a right to mutual respect and dignity. Caregivers are prohibited from accepting personal gifts and borrowing from clients.

Clients have the right:

- to have relationships with home care providers that are based on honesty and ethical standards of conduct;
- to be informed of the procedure they can follow to lodge complaints with the home care provider about the care that is, or fails to be, furnished, and regarding a lack of respect for property (to lodge complaints with us call ____________________);
- to know about the disposition of such complaints;
- to voice their grievances without fear of discrimination or reprisal for having done so; and
- to be advised of the telephone number and hours of operation of the state's home health "hot line." The hours are ____________ and the number is ____________.

Decisionmaking

Clients have the right:

- to be notified in writing of the care that is to be furnished, the types (disciplines) of the caregivers who will furnish the care and the frequency of the visits that are proposed to be furnished;
- to be advised of any change in the plan of care before the change is made;
- to participate in the planning of the care and in planning changes in the care, and to be advised that they have the right to do so; and
- to refuse services or request a change in caregiver without fear of reprisal or discrimination.

The home care provider or the client's physician may be forced to refer the client to another source of care if the client's refusal to comply with the plan of care threatens to compromise the provider's commitment to quality care.

---

* In 1982, the National Association for Home Care adopted a comprehensive Code of Ethics to which all members subscribed. Among the elements in this Code was a clients' Bill of Rights similar to the rights outlined in this document. In 1987, Congress enacted a provision requiring home care agencies to inform clients of these rights.

Privacy

Clients have the right:

- to confidentiality with regard to information about their health, social and financial circumstances and about what takes place in the home; and
- to expect the home care provider to release information only as required by law or authorized by the client.

Financial Information

Clients have the right:

- to be informed of the extent to which payment may be expected from Medicare, Medicaid or any other payor known to the home care provider;
- to be informed of the charges that will not be covered by Medicare;
- to be informed of the charges for which the client may be liable;
- to receive this information, orally and in writing, within fifteen working days of the date the home care provider becomes aware of any changes in charges; and
- to have access, upon request, to all bills for service the client has received regardless of whether they are paid out-of-pocket or by another party.

Quality of Care

Clients have the right:

- to receive care of the highest quality;
- in general, to be admitted by a home care provider only if it has the resources needed to provide the care safely, and at the required level of intensity, as determined by a professional assessment; however, a provider with less than optimal resources may nevertheless admit the client if a more appropriate provider is not available, but only after fully informing the client of its limitations and the lack of suitable alternative arrangements; and
- to be told what to do in the case of an emergency.

Quality of Care

The home care provider shall assure that:

- all medically related home care is provided in accordance with physicians' orders and that a plan of care specifies the services to be provided and their frequency and duration; and
- all medically related personal care is provided by an appropriately trained homemaker-home health aide who is supervised by a nurse or other qualified home care professional.

STATEMENT OF THE NATIONAL LEGAL CENTER FOR THE MEDICALLY DEPENDENT & DISABLED, INC.

This testimony is made upon the request of Senator David Durenberger for the National Legal Center for the Medically Dependent and Disabled to comment on "advance directives" and on S. 1766, the "Patient Self Determination Act of 1989," proposed legislation now before this Committee.

The National Legal Center is funded as a support center by the Legal Services Corporation to provide legal assistance to attorneys representing indigent persons in need of life-sustaining treatment or care. As such, we have participated directly or indirectly in every major termination of treatment or "right to die" case since our inception. We are particularly concerned that persons with disabilities and others who may depend upon medical attention not be discriminatorily deprived of the care necessary to sustain their lives or well-being.

It is our understanding that S. 1766 will be amended to delete any requirement that states enact "living will" or durable power of attorney for health care legislation as a condition for receiving Federal health care funds. Three matters remain, however, that particularly concern us with regard to S. 1776: (1) general reservations over "living wills" and durable powers of attorney for health care, the use of which would inevitably be encouraged should S. 1776 become law; (2) specific reservations over the process by which states would be compelled to develop or to articulate their policies regarding the withholding or withdrawing of life-sustaining treatment or care; (3) concern over the conscience rights of patients and health care providers.

I. RESERVATIONS REGARDING ADVANCE DIRECTIVES

We presume that the concept of an "advance directive" includes both "living wills" and durable powers of attorney for health care. Forty-one states and the District of Columbia now have some form of living will legislation. Twenty-two have some form of legislation specifically authorizing execution of durable powers of attorney for health care. Four states have construed their general durable powers of attorney statutes to authorize appointment of surrogate health care decisionmakers. All 50 states have general durable power of attorney statutes.

There are certain difficulties in both the living will and durable power approaches that should inspire a degree of caution and skepticism toward either.

A. *"Living Wills"*

First, living wills may violate the usual requirement for "informed consent" that the affected person be specifically informed of the nature and consequences of medical treatment or care in the context of a specific disease or injury. "Living wills" are typically directed toward an abstract future set of general circumstances and therapies. They obviate the need to seek, and discourage the health care provider from seeking, consent to forego specific forms of life-sustaining treatment in specific circumstances. This may be particularly problematic because many may change their minds over time regarding the nature and scope of treatment they may desire.

Second, living wills are often so general in their terms that they simply grant health care providers immunity that blankets discretionary decisions made under the guise of honoring patient autonomy. Thus, the operative terms in living wills typically provide that "life-sustaining" or "heroic" treatment may be foregone if the patient has a "terminal condition." The health care provider will determine what these terms may mean—often with little or no specific guidance from the living will itself or from the legislation that authorizes execution of such a document.

Third, it is true that living will laws typically provide the opportunity to identify specific forms of treatment that the person may wish to forego in specific circumstances. But because most living wills are not executed in contemplation of a specific condition or specific circumstances, and because the multiplicity of possibilities cannot be fully anticipated in any case, specific instructions will often prove irrelevant or even perhaps defeat the true intent of the person.

Fourth, the living will laws of almost all the states and the living will forms that follow from them are almost all strongly ratcheted in favor of forgoing treatment—they certainly do not impartially suggest that the person may require treatment through the use of such a document, even if this is technically possible. Such an unbalanced approach belies the asserted purpose of such laws: to protect patient autonomy. It is especially troublesome because the presumption that used to be applied in the absence of an advance directive—that aggressive treatment should always be provided—has significantly eroded and, indeed, shifted toward a presumption *against* treatment for certain classes of people, especially older people and people with disabilities.

B. Durable Powers of Attorney for Health Care

Durable powers of attorney for health care permit an individual to appoint a surrogate health care decisionmaker. As such, their use avoids some of the difficulties associated with the use of "living wills"—in particular, the very real prospect that the living will might be overly general or overly specific.

On the other hand, this approach contemplates process even further removed from the informed consent of the affected person than does the living will. And the presence of a health care surrogate by no means guarantees that a decision will in fact be made for a person that the person would have made for himself or herself, as recent research shows. Diamond, *Decision-Making Ability and Advance Directive Preferences in Nursing Home Patients and Proxies,* 29 Gerontologist 622 (1989); Zweibel, *Treatment at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies,* 29 Gerontologist 615 (1989).

Most disturbing, durable power of attorney statutes place no substantial restrictions on the authority of the surrogate to make *any* health care decision for the appointing principal—they simply would impute or "trade off" to the surrogate the same authority over the treatment of the person that the person himself or herself would possess if competent. Since the patient may have the authority to refuse any and all kinds of treatment or care—no matter how beneficial or minimally burdensome, and irrespective of whether the patient has a terminal or any other condition—the authority bestowed upon the surrogate is broad indeed.

There is little or no assurance that the appointing principal will fully appreciate the scope of authority that he or she grants to another through use of a durable power of attorney for health care. Moreover, the fact that one individual is bestowed with the authority to withhold or withdraw even beneficial or minimally burdensome treatment or care from *another* individual should heighten social and, hence, legal concern. Thus, for example, suicide is in itself now nowhere in the United States a criminal act, although it is hardly a "right." But suicide cannot be safely *assisted* by another, and homicide by omission is universally punished by the criminal law.

II. DEVELOPMENT OF STATE LAW AND POLICY

Our stated general reservations over the use of "living wills" or durable powers of attorney for health care are underscored in the context of S. 1766.

S. 1766 would require both Medicare and Medicaid providers to maintain written policies and procedures to assure: (1) that the patient is informed of the patient's "right to make decisions concerning such patient's medical care, including the right to accept or refuse medical or surgical treatment, the right to appoint an agent or surrogate through a written power of attorney to make health care decisions on behalf of such individuals, and the right of such patient to provide to such provider written instructions concerning the patient's health care, including instructions for the disposition of patient's organs . . . ;" (2) that an inquiry is made whether or not the patient had executed an advance directive; (3) that the patient's "treatment wishes" are documented and periodically reviewed; and (4) that advance directives will be implemented "to the maximum extent permissible under State law." *See* S. 1776 at §3(a)(3) (p. 3, lines 21-25; p. 4, lines 1-21; §4(a)(2) (p. 6, lines 3-25).

The inevitable, no doubt intended consequence of these provisions would be to encourage patient medical treatment decisionmaking to the "maximum extent" under state law and policy. Assuming the preference for the near-absolute patient autonomy that underlies S. 1766 is correct and desirable, S. 1766 nevertheless does not address the *process* by which state law and policy is to be formulated and articulated.

Courts and legislatures have, over the past 15 years, begun to grapple with the difficult and conflicting legal, ethical, and medical issues that encompass decisions to forgo life-sustaining treatment or care. But no state has developed a comprehensive body of law to govern such decisions; only a few states have developed anything more than partial answers to the questions raised by such decisions; most states have little or no law on the matter.

S. 1766 would, however, require hasty and perhaps precipitous articulation and development of law and policy in this area in order to assure continued receipt of Federal funds—regardless of the degree to which law and policy is settled or clear in an individual state. What entity is to articulate state law and policy? Health care providers? State health bureaucracies? Attorney or medical associations? Legislatures? Courts? The U.S. Department of Health and Human Services?

Oversight to insure compliance with S. 1766 would require, at the very least, that Federal regulators be employed to judge whether the law and policy articulated by an individual state or health care provider reflects, for example, implementation of state living will statutes "to the maximum extent permissible under State law." Serious questions relating to the system of federalism are raised when states' interpretations of their own laws and policies may be so easily questioned by the Federal bureaucracy.

S. 1766 assumes, both in its expressed "Purpose" and in its substantive provisions, a "right" to refuse medical treatment or care unbalanced by any countervailing state interest in the preservation of human life, in prevention of suicide, in protection of innocent third parties, or in preservation of the ethical integrity of the medical professions—the state interests recognized by courts that have considered the matter. It seems to assume that patient "treatment wishes" should be honored, regardless of patient competence or irrationality. Yet those who are a "danger to themselves"—which is clearly the case when patients refuse care or treatment necessary to sustain life—may be subject to possible therapeutic evaluation for competence in all 50 states. *See. e.g.*, Mo. Ann. Stat. §§632.355(3), 632.005(9)(a) (Vernon Supp. 1985); Minn. Stat. Ann. §253.A.07 subd. 17(a)(1)(i) (West 1982).

S. 1766 thus neglects concerns and interests that may be balanced against any asserted right to refuse treatment or care. Yet because law and policy that governs foregoing treatment or care is underdeveloped in almost all the states, whatever statement of law or policy developed in order to comply with S. 1766 is likely to reflect the imbalance inherent in this proposed law in order to assure the continued flow of Federal funds.

We recommend, therefore, that S. 1766 be amended to:

(1) State specifically how the process by which the nature of state law and policy on foregoing and receiving life-sustaining treatment or care is to be formulated and articulated, with due regard for the limitations imposed by the Federal system;

(2) Recognize various state interests in the "Purpose" of S. 1766 that might be balanced against any asserted "right" or "liberty interest" in refusal of life-sustaining treatment or care, including the right and obligation of the state to inquire into whether or not decisions to refuse such treatment or care are competent and voluntary.

IV. "CONSCIENCE" PROVISIONS

Sections 3(a)(3) and 4(a)(3) (p. 4, lines 10-11, p. 6, lines 15-16) of S. 1766 both state that providers must ascertain from patients whether or not they have executed a "living will" or a durable power of attorney for health care, "while under no circumstances denying a patient admission based on presence or absence of such documents. . . ."

It is entirely conceivable, however, that forms of discrimination other than denial of admission may result from failure to execute such a document. Hence, we suggest amendments that would broaden the protective scope of these provisions:

> *Amend* §§3(a)(3) (p. 4, lines 11) and §4(a)(3) (p. 6, lines 15-16) by deleting "denying a patient admission" and replacing it with "*discriminating against a patient.*"

Sections 3(a)(3) and 4(a)(3) (p. 4, lines 22-24; p. 5, line 1; p. 7, lines 1-4) both state that the health care provider must "arrange for prompt and orderly transfer of a patient to the care of others when as a matter of conscience the provider cannot implement the wishes of such patient . . . ."

This is a necessary and desirable provision in view of the substantive requirements of S. 1766 and the unfortunate tendency of some courts to compel health care providers to act against their ethical principles. *See, e.g.*, *In re Requena*, 213 N.J. Super. 475 A.2d 886 (Ch. Div. 1986); *Gray* v. *Romero*, 697 F. Supp. 580 (D. R.I. 1988). Nevertheless, we believe that S. 1766 is unclear as to whether or not it would permit agents of providers (*e.g.*, nurses) to assert conscientious objections and on whether or not providers would be compelled to carry out objectionable patient wishes if they are unable to effect transfers. We thus suggest the following amendments:

> *Amend* §3(a)(3) (p. 4, lines 22-24; p. 5 line 1) and §4(a)(3) (p. 7, lines 1-4) as follows: ". . . arrange for the prompt and orderly transfer of a patient, if possible, to the care of others when, as a matter of conscience, the provider *or its agent* cannot implement the wishes of such patient *while under no circumstance requiring the provider or its agent to act against conscience by failing to provide necessary treatment or care to the patient;* . . . ."

We thank this Committee for providing us with the opportunity to aid in its deliberations on this important matter.

STATEMENT OF THE OLDER WOMEN'S LEAGUE

The Older Women's League, OWL is pleased to lend its support to S. 1766, the Patient Self-Determination Act. We commend Senator John Danforth's courageous leadership in sponsoring legislation on this very sensitive but timely issue.

Death and dying are very much older women's concerns and staying in control until the end of life has long been a vital concern of OWL. In 1985, our organization sponsored a forum in the Dirksen Auditorium entitled "Taking Charge of the End of Your Life: A Forum on Living Wills and Other Advance Directives." Tish Sommers, co-founder of OWL, and former Senator Jacob Javits, both of whom were terminally ill at the time, addressed the assembled group. This forum provided the opportunity to discuss the proper Federal role in assuring that a patient's wishes are carried out. A fundamental assumption at this session was that every individual has the right to make advance plans for his or her own health care that should be followed at the end of life, regardless of contrary wishes of health care professionals.

There is a tremendous disparity between how people would like to be treated when they are dying and what actually happens. The failure to communicate ones desire about dying all too often results in tragic consequences. This was sadly reinforced by the recent Supreme Court decision in *Cruzan* v. *Director, Missouri Department of Health* when the court refused family members the right to intervene in the treatment of their loved one because of the absence of "clear and convincing evidence of the patient's wishes."

The vast majority of Americans have not taken any affirmative action to express their wishes in advance concerning their desires about treatment in the event of incompetence at least in part because they are not aware of their rights in this regard and ignorant of the consequences of failing to do so. Too many surrender their rights to control their own destinies because they do not know that they may provide advance direction to family members and health care providers.

Two fundamental realities cause issues surrounding death and dying to be of crucial importance to women. First, because approximately 85% of surviving spouses and the majority of family caregivers are women, the burden and frustration of possibly not being able to carry out the wishes of a loved one falls primarily on them. Secondly, because women tend to outlive their spouses they are more likely to die in a nursing home or other institution where the probable absence of advance directives results in the possibility of institutional interference in matters of personal preference at the time near death or incapacitating illness.

The Patient Self-Determination Act will help to addresses these concerns by requiring Medicare and Medicaid providers to establish procedures which will provide information to program beneficiaries which will enable them to participate in the decisions affecting their own care.

The key concepts in S. 1766 are basic and straight forward: *information, self-determination and documentation.*

Information is empowering. There are huge gaps between what is currently legally permissible and what is generally known and understood by the public. It is noteworthy that the proposed bill does not establish new rights. It merely establishes structures and procedures which will assure that necessary information is disseminated to those who can act on it.

Self-determination means staying in control of one's own destiny. By requiring providers to make available information about living wills, durable powers of attorney, and organ donation, patients will have the opportunity to make their wishes known so that when the time comes to make treatment decisions there will be no doubt about what course of action the *patient* wants taken.

Documentation means accountability. The legislation would require providers to inquire about and document the existence of advance directives, as well as any treatment preferences and to review these periodically with the patient. Presumably, such documentation would be accessible to appropriate providers so that a patient's directions could be easily implemented.

The contemplation of one's own mortality is not easy. But we all eventually must face the inexorableness of death. To be able to do so in the context of staying in control and knowing that our personal desires will be followed allows us to face death with dignity and at least some degree of comfort. The Older Women's League has long supported the objectives contained in the Patients's Self-Determination Act and we look forward to its swift passage.

STATEMENT OF PROFESSOR GEORGE P. SMITH, II, CATHOLIC UNIVERSITY SCHOOL OF LAW

Mr. Chairman. As a teacher, research scholar,[1] international lecturer and Editor of The Journal of Contemporary Health Law and Policy, as well as an individual who has studied the field of Health Law for twenty-five years, I appreciate the opportunity to present my views regarding SENATE BILL 1766, *The Patient Self-Determination Act of 1989*. I support strongly this proposal and urge its adoption.

Norman Cousins observed recently that "no one gets out of this world alive, and few people come through life without at least one serious illness."[2] A recent poll conducted by the newspaper, USA TODAY, reflects the opinion that if and when fatal illness does occur, Americans should be allowed to conclude their lives and, further, that medical facilities should be made available to them in order to achieve that end.[3]

A poll sponsored by the American Medical Association, the results of which were released in November, 1986, showed that nearly 3 of 4 Americans or 73% of the 1,510 respondents in this survey, favor "with-drawing life support systems, including food and water, from hopelessly ill or irreversibly comatose patients if they or their family request it." Fifteen percent of the respondents opposed this option, and 12% expressed uncertainty. Interestingly, 75% of those younger than sixty-five favored the proposal, as did 64% of those sixty-five or older. Twenty percent of the older group said they were unsure—compared with 10% of the younger group. The withdrawal of life support systems was more likely to be favored by individual respondents having at least a high school education as well as by those respondents whose annual income was more than $10,000.[4]

When Americans died in 1950, the majority died at home with their families and local physicians in attendance. Today, death has become "medicalized," with the result that human interventions replace natural processes, thereby prolonging life in one form or other. With a growing array of high-powered life support techniques and so-called "miracle" drugs, death is simply another matter of human choice and one laden with ethical complexities. Presently, of the approximately 5,500 Americans who die each day, 80% do so wired and insulated in an institution where the expensive technology is arrayed and controlled by specialists who likely know little about the patient beyond the medical problem.[5]

In classical Greece, medicine had three roles: to alleviate the sufferings of the sick; to lessen the violence of diseases that afflicted them; or to refuse "to treat those who (were) overmastered by their diseases, realizing that in such cases medicine is powerless." Indeed, the most common duty of all Greco-Roman physicians was "to help, or at least to do no harm." Whether a hopeless case was taken by a physician was purely a matter of discretion. This prevailing sentiment of physicians in this period of civilization found strong precedent in Egyptian and Assyro-Babylonian medicine. As a medical sentiment, in fact, it continued in vitality throughout the Middle Ages. In the late sixteenth and early seventeenth centuries, Francis Bacon is commonly thought to have advanced the conclusion that medicine should seek to prolong life and expand longevity, and the notion has grown in an exaggerated the misdirected manner since that time.

Thus, while a physicians so-called duty to prolong life *qua* life has no classical roots, the idea of "respect for life" does have a rich tradition of observance. However, even though physicians did not actively seek to terminate a life either by abortion or euthanasia, they neither sought to actively prolong life, itself. With the rise of Christianity, abortion, suicide, and euthanasia became sins, even though the prolongation of life never became a virtue or a duty.[6]

In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that artificial feeding should be regarded as a treatment decision and not mandated except when the benefits of its use outweigh the burdens. In 1986, the American Medical Associations Council on Ethical and Judicial Affairs announced its conclusion that all means of life-prolonging treatment—including food as well as water—could be withdrawn from patients in an irreversible state or those in a terminal condition.[7]

A so-called "living will" is an instrument that indicates its maker's preference not to be started or maintained on a course of extraordinary treatment in the event of accidental or debilitating illness. The biggest uncertainty surrounding living wills and their subsequent administration is related to whether health care providers are required—under pain of civil or criminal sanction—to execute the terms of the will. An interlinking concern is whether those participants charged with fulfilling the will's terms will be assured of immunity from civil or criminal prosecution. Whether refusing life-sustaining therapies would constitute a suicide largely remains another vexatious and unresolved issue. Regardless of these great uncertainties, some thirty-eight states and the District of Columbia have passed living will legislation.[8]

Those jurisdictions recognizing living wills still address the types of medical techniques that are "extraordinary" and the type of circumstances that will "demonstrate that the person's previously expressed desire to forego treatment continued up to the time immediately prior to his or her medical disability." Without legislative decisions that tackle these issues with clarity, the courts will be faced with a case-by-case determination of the parameters of life.[9]

To correct some of the weaknesses and uncertainties of living will legislation, more and more states are enacting Natural Death Acts.[10] In actual practice, there is evidence to suggest that a patient's wish to be kept off life-sustaining treatment may be ignored in states where Natural Death legislation exists. If attending physicians and health care providers view such legislation as the sole means for both initiating and implementing a decision to forego treatment, and if they believe that the decision cannot be made by a surrogate on behalf of the patient but only in strict accordance with an advance directive that has been properly executed, dying patients may in fact be subject to treatment which is neither requested nor beneficial. As an additional fear, an improper inference may be drawn that a patient does not want life-sustaining treatment *ended* under any and all circumstances unless a directive has properly been executed. The truth of the matter might well reveal that a directive was not executed because of either ignorance of its legislative existence, an unawareness of its importance, or even uncertainty regarding how it should be composed.[11]

Generally, the right to die, or natural death acts, apply only to "competent adults," with children and mental incompetents being excluded. Yet, some jurisdictions have made provision for proxy consent. In North Carolina, the controlling statute allows proxy consent for an irreversibly comatose patient who has not previously executed a living will. Consent may be given by a spouse, legal guardian, or a majority of the relatives of the first degree. No reference is made in the statute to any other type of incompetent patient. Virginia does not expressly allude to the rights of patients with inadequate decision making capacity and refers only to competent adults. New Mexico provides for proxy consent for minors, although not for incompetent adults. Arkansas, however, covers both minors and incompetent adults.[12]

As a consequence of the numerous weaknesses encountered with living will legislation and Natural Death Acts, additional safeguards should be utilized for implementing advance directions on life-sustaining modalities of treatment. Specifically, adoption of proxy directives through durable powers of attorney statutes would go far toward assuring an individual's desires regarding treatment. A sizable majority of states authorize durable powers of attorney that enable the appointment of a proxy to act after a person becomes incompetent. The language of these statutes is usually broad enough to accommodate the appointment of a surrogate to facilitate problems which involve health care for the incompetent. However, the statutes were not enacted for remedying these specific problems of incompetence.[13]

Since the usual power of attorney ceases when the principal becomes incapacitated, some states have created specific durable powers of attorney whereby an agent's authority continues after a debilitating event happens to the principal. In this way, the power may create an "advance proxy directive" allowing an individual to nominate another to make all decisions regarding health care in the event the principal becomes incapacitated. This mechanism greatly advances the efficiency and fairness of the whole decision making process for incapacitated persons.[14]

As durable power of attorney statutes are adapted and applied to areas that they were not originally designed to accommodate, care and study must be undertaken to make certain that these original procedures—initially enacted to "avoid the expense of full guardianship or conservatorship proceedings when dealing with small property interests"—are not abused burdens of decision making and in allowing the courts to respect individual and familial privacy.[15]

In August, 1985, the National Conference of Commissioners of Uniform State Laws approved and recommended for enactment in all states a Uniform Rights of The Terminally Ill Act. This Act authorizes an adult to execute a declaration to his physicians and health care facilities directing the withholding or withdrawing of life-sustaining treatment in the event he is in a terminal condition of health and thereby unable to participate in decisions concerning medical treatment. The scope of the Act is quite narrow in that it provides only *one* way for the wishes of a terminally ill person to be fulfilled. It is designed to avoid inconsistency in approach to decision making, which has continued to plague living will statutes, by providing that the effectiveness of a patient's directive will be executed uniformly in all states.[16]

Section Three of *The Patient Self-Determination Act of 1989* is the crucial mechanism for assuring autonomy and self-determination in health care decisions. The provisions that mandate Medical Provider Agreements be executed and, as such, state in writing the policies and procedures concerning patient medical care—and the right to accept or to refuse medical or surgical treatment—are quite correct and, indeed, proper. Allowance for periodic review of the wishes of the patient as to his or her course of treatment is also very sound and commendable. All of these policies are, in turn, both advanced and strengthened by the provisions within this Section, that Living Wills and written Durable Powers of Attorney—when legally validated within each state--be implemented. This proposed legislation, which I support vigorously and urge its passage, tracks well with the initiative in this area of concern seen recently in New York and—as observed—in popular polls, throughout the country, itself, by a majority of Americans. On July 1, 1990, the New York state legislature approved legislation allowing incoming hospital patients the right to designate friends or relatives as proxy decision makers to order cessation of life-support systems (that, in turn, may or may not include artificial nutrition and hydration) should they become terminally ill.[17]

On June 25, 1989, the United States Supreme Court held in the case of *Cruzan v. Director of the Missouri Department of Health*, that it was proper for the state of Missouri to apply a clear and convincing standard of evidentiary proof in determining the extent of an incompetent patients right (here, a thirty-two-year-old-woman named Nancy Cruzan)—exercised through her parental guardians—to discontinue nutrition and hydration when "living" in a persistent vegetative state.[18] Ms. Cruzan has, since a 1983 automobile collision, been surviving in a coma provided artificially with food and water. Capable of living, with artificial assistance, for some thirty or more years, the state of Missouri is paying presently $130,000.00 a month to maintain her tragic existence. Perhaps the only option open presently for Ms. Cruzan's guardians to effect her death with dignity is to move her to another state where the right to refuse food and water, as medical treatment, is recognized.[19]

The practical effect of this "sad" and "devastating" decision by the High Court is that it may prompt very ill people to consider suicide before they lose physical and mental control of their faculties.[20] A salutary effect of the decision, however, on the ninety-five percent of those Americans who do not have living wills will be to force them to deal with the eventuality of their own death and to think through very carefully the manner in which they wish to die under controlled medical conditions. Hopefully, such thoughtful re-evaluations will in turn prompt more citizens to execute living wills and, when appropriate, durable powers of attorney authorizing surrogate decision makers to implement final life-threatening medical decisions for them. *The Patient Self-Determination Act of 1989* would go a long way toward advancing and guaranteeing such a re-evaluation; a re-evaluation needed desperately on both an individual and a societal basis if death with dignity is to be common place in America.[21]

ENDNOTES

1. Bibliography of Writings, 6 J. CONTEMP. HEALTH L. & POL'Y 483 (1990).
2. Cousins, A Nation of Hypochondriacs, TIME, June 18, 1990, at 88. See generally, N. COUSINS, ANATOMY OF AN ILLNESS (1980).
3. The poll of 724 Americans was conducted in June, 1990, and found two-thirds of those polled subscribing to the opinion that terminally ill individuals should be allowed to end their lives.
4. Smith, All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?, 22 CAL. DAVIS L. REV. 275, 367 at n. 656 (1989). A 1985 Louis Harris poll of 1,254 adults disclosed 85% of them believed that a terminally ill patient ought to be able to tell his doctor to let him die-with 82% supporting the notion of withdrawing nasogastric (feeding) tubes if the at-risk patient directs such action. Id. at 655.
5. Id. at 367. See Smith, Death Be Not Proud: Medical, Ethical and Legal Dilemmas in Resource. Allocation, 3 J. CONTEMP. HEALTH L. & POL'Y 47 (1987).
6. Smith, All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?, 22 CAL. DAVIS L. REV. 275, at n. 288 (1989).

7. Supra note 4 at 373. See G. SMITH, THE NEW BIOLOGY: LAW, ETHICS AND BIOTECHNOLOGY (1989); D. CALLAHAN, SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY (1987).

8. Supra note 6 at 84, f.n. 39.

9. Id.

10. Id. at 84, 85, f.n. 42.

11. Id.

12. Id.

13. Id. at 85, 86, f.n. 56.

14. Id.

15. Id.

16. Id. at 76, 77.

17. N.Y. Passes Law to Allow Care Decisions by proxy, WASH. POST, July 2, 1990, at A8, col. 1.

18. 58 U.S.L. WEEK 4916 (June 26, 1990).

19. Okie, Medical Groups Criticize Court Interferring In Life-or-Death Designs, WASH. POST, June 26, 1990, at A8, col. 1.

20. Id.

21. See Smith, Recognizing Personhood and the Right to Die with Dignity, 6 J. PALLIATIVE CARE 24 (1990); Hastings Center, GUIDELINES ON THE TERMINATION OF LIFE SUSTAINING TREATMENT AND THE CARE OF THE DYING (1987).

STATEMENT OF THE SOCIETY OF CRITICAL CARE MEDICINE

The Society of Critical Care Medicine supports legislation sponsored by Senator John C. Danforth, S. 1766, the "Patient Self Determination Act of 1990" (the "Act"), which would ensure that people are informed of their rights under State law to control decisions about their own health care through the use of advance directives. This bill is particularly important to practitioners of critical care medicine who too often encounter situations where the patient is unable to voice his or her wishes. The Supreme Court's recent decision in the case of *Cruzan* v. *Director,* where a majority of the Court indicated that the Constitution protects an individual's right to refuse life-sustaining medical treatment but held that states may restrict that right by requiring "clear and convincing" evidence of the patient's own wishes to be presented before life-sustaining therapies are withdrawn, emphasizes the need for families and their physicians to discuss issues related to death and dying *and express them in writing* so that a patient's wishes are known before a crisis occurs. Requiring Medicare and Medicaid providers to inform their patients of advance medical directives allows individuals to exercise their freedom of choice as to the treatment they wish to receive in the event they subsequently become unable to express their preferences to the health care professional caring for them.

The Society is a 20-year old, multi-disciplinary organization formed by specialists from anesthesiology, internal medicine, pediatrics and surgery. The more than 4,000 members of the Society blend the knowledge, skill and technology from the four medical specialties, nursing, and allied health professions into a coordinated effort to achieve an optimal outcome for critically ill or injured patients. The goals of the Society include promoting and developing optimal facilities in which critical care medicine may be practiced, assuring high educational standards in critical care medicine, and improving humane care for patients with acute life-threatening illness and injuries.

This last goal is that also of the Act. Just as good medical practice seeks the consent of patients before any medical intervention, people clearly have the indisputable right to refuse that treatment. A patient should not lose that right if he or she becomes unconscious or otherwise unable to make decisions. Too often, though, patients are unaware of the options available to them, and their families or personal medical provider lack the legal resources of advance medical directives which clearly spell out the spoken wishes of the individual. As more than 80 percent of people today die in hospitals, medical centers and nursing homes, these institutions are likely outlets to inform individuals of their right to determine the course of their medical care.

More than forty states and the District of Columbia have statutes recognizing "living wills" which dictate an individual's wishes for medical treatment in cases where life could be sustained but at great compromise to the quality of that life; more than half of the states recognize durable powers of attorney for the same purpose. However, there is great variation in these state laws. Recognizing that this variation is due in some degree as a reflection of local beliefs regarding advance directives, the variations nonetheless complicate the ability of individuals to ensure that their advance directives would be valid in another state in the event of travel or relocation. *Provisions regarding comity of other states' provisions for advance directives ought to be included in the legislation to prevent the likelihood of these situations. Moreover, a single, uniform model of advance directives would ensure that variances in state interpretation do not require treatment diametrically opposed to a patient's stated wishes.*

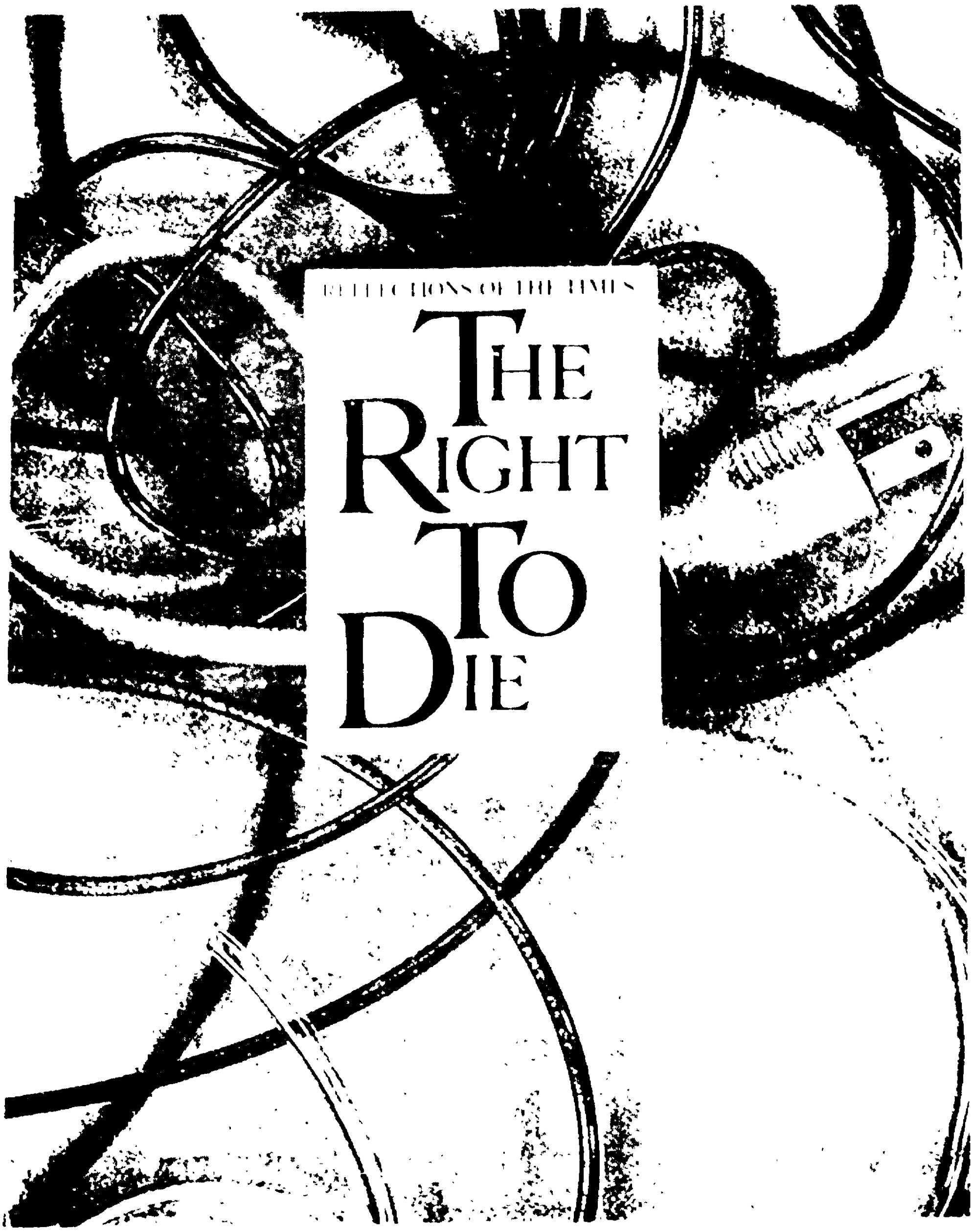
Even with the great availability today of these medical directives, though, comparatively few people take advantage of this freedom of choice. Here, too, S. 1766 would ensure that all people admitted to hospitals and nursing homes which receive Medicare and Medicaid funding are aware of the extent to which State law allows them to dictate their medical care, providing an important, though perhaps not the most ideal, educational outlet for these tools.

Advance medical directives allow an opportunity for communication between the patient and his or her doctor and family to discuss and document the patient's views of life-sustaining treatment which may ease the burden on families and providers when it comes time to decide whether or not to pursue all possible treatment options. *In the view of the Society, it is important that S. 1766, and related legislation sponsored by Congressman Sander Levin, include provisions to encourage involvement by the patient's personal physician in an initial counseling session determining the patient's personal medical directive, and that they consult with critical care specialists in updating the directive as the course of the patient's care necessitates.*

Without these directives, doctors often just do not know the patient's exact wishes in these situations, and though the family feels that their loved one would prefer to die peacefully, providers in the critical care setting are obligated to do all in their power to resuscitate the life of the patient. The "Patient Self Determination Act" would greatly reduce the incidence of second guessing the patient's wishes, which can come at great emotional—and financial—expense to the family.

Today's medical technology enables doctors to take extraordinary heroic measures to save patients' lives in instances where they might have once died; after the crisis has passed, though, the doctor must wrestle with moral conscience of the consequences of his actions. Timely enactment of S. 1766 into law will improve the ability of practitioners of critical care medicine to treat their patients in the most appropriate and ideal manner possible: according to the informed decision of the patient as determined with specific knowledge of his or her medical condition and framed by personal ethics.

TIMES MIRROR CENTER FOR THE PEOPLE AND THE PRESS



REFLECTIONS OF THE TIMES

THE RIGHT TO DIE

Introduction

The Times Mirror Center for the People and the Press is pleased to publish this report of its first *Reflections of the Times* survey, an in-depth examination of Americans' attitudes toward various ways to deal with terminal illness and disability.

We intend to continue to sponsor *Reflections of the Times* surveys periodically, along with our ongoing *People & the Press* studies of public attitudes toward the news media.

Our objective is to continue to provide timely information that policymakers, journalists, educators and opinion leaders across the country will find relevant and useful.

Finally, we wish to acknowledge the work of Diane Colasanto and Andrew Kohut, of Princeton Survey Research Associates, who designed and conducted this investigation.

Donald S. Kellermann, Director

Times Mirror Center for the People and the Press

Table of Contents

The Right to Die

It's estimated that some 70 percent of all Americans will have to make a decision someday regarding whether or not to continue to use life support systems to keep a family member alive. Hence, it is critical to define clearly the laws that affect these decisions.

The United States Supreme Court took a significant step in this direction on June 25, when it ruled 5 to 4 in *Cruzan v. Missouri* that states have the right to insist on clear evidence of what the victim would want before a family member is granted the right to discontinue life-sustaining medical treatment.

This ruling runs counter to a broad consensus among Americans that close family members should be allowed to make decisions about life-sustaining medical treatment if the patient is unable to make his or her own wishes known. Americans also support the right of patients to make their own decisions about receiving life-sustaining medical treatment.

All segments of the public, including members of all major religious groups, support right-to-die policies. People who have helped to make medical treatment decisions for a dying loved one think about these issues in just the same way that people who have not been through this painful process think about them. Experiencing the difficulties of making medical treatment decisions in terminal cases leads people to think more and talk more about these issues, but it does not lead to different attitudes on the subject.

Support for various right-to-die policies stems from the widely held belief that physicians should sometimes allow a patient to die, rather than use the full range of medical procedures and treatments available. Furthermore, the views that Americans express about right-to-die policies reflect their feelings about how they would want their *own* medical treatment to be handled, and what they can imagine about the wishes of their parents in such painful or debilitating circumstances. Most Americans would want life-sustaining treatment withdrawn if they were suffering a great deal of pain from a terminal disease, or if they became totally dependent on another person for daily care.

Underlying the public's attitudes on the right-to-die and patient choice is a recent trend toward greater acceptance of suicide in the face of suffering from a terminal disease.

These are among the findings of a new *Reflections of the Times* poll of 1,213 adults nationwide. The poll, conducted for the Times Mirror Center for the People and the Press in Washington D.C., examined in depth the public's views about dealing with terminal illness and disability.

Several studies during the 1970s and 1980s showed high support for patient choice and the use of proxies as decision makers. While each poll addressed these issues in a slightly different way, taken all together, the results of the earlier polls and the *Reflections of the Times* poll indicate that support for these policies has been steadily increasing during the past two decades. However, the *Reflections of the Times* investigation is unique among the public polls in demonstrating the broad consensus generated by right-to-die policies, in analyzing how attitudes change depending on the circumstances involved, and in revealing how Americans imagine their own behavior in situations where the right to die becomes an issue.

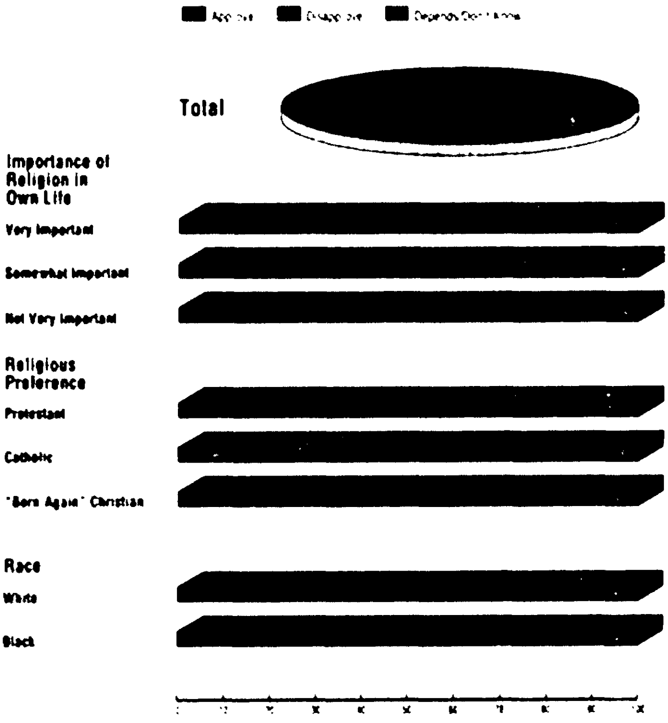
Right-to-Die Policies

Eight in ten Americans think there are sometimes circumstances where a patient should be allowed to die, whereas only 15 percent think doctors and nurses should *always* do everything possible to save the life of a patient. Blacks, born-again Christians, people who are very religious, people over age 65 and people who are not college graduates are slightly more likely to think that a patient's life should always be saved. However, even among these groups a clear majority believes that, in some circumstances, a patient should *not* receive life-sustaining treatment.

The public's feelings about right-to-die legislation are driven by its belief in the need for discretion in administering life-sustaining medical treatment. Eight in ten adults approve of state laws that allow medical treatment for a terminally ill patient to be withdrawn or withheld if that is what the patient wishes. (*See Figure 1.*) Only 13 percent of the public disapprove of laws that let patients decide about being kept alive through medical treatment, and 5 percent approve of these laws only in certain situations. Again, blacks, people age 65 and older, people who have not gone to college, and people who are very religious are less likely to express approval for right-to-die legislation. However, no less than a two-thirds majority in all population subgroups approves of right-to-die legislation in at least some circumstances.

Figure 1

"In some states, it is legal to stop medical treatment that is keeping a terminally ill patient alive, or never start the treatment in the first place, if that's what the patient wants. Do you approve or disapprove of laws that let patients decide about being kept alive through medical treatment?"

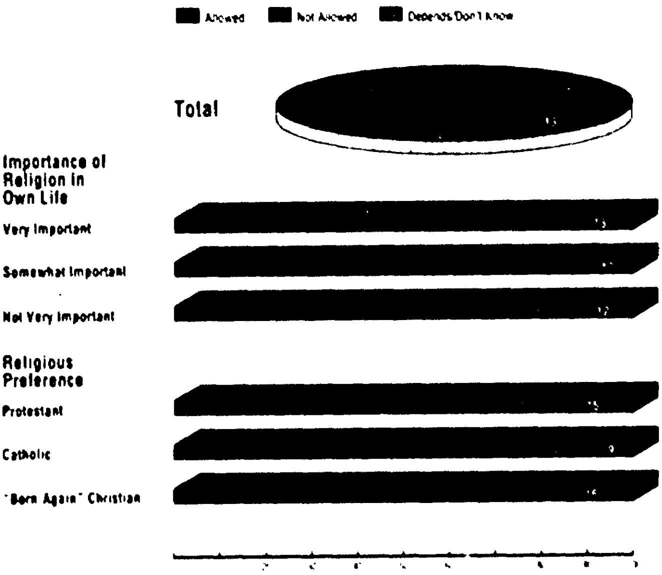


Most states have some form of right-to-die legislation, but the issue remains controversial. For the first time in its history, the U.S. Supreme Court considered whether there is a constitutional right to discontinue life-sustaining medical treatment in the case of *Cruzan v. Missouri*. In New Jersey, right-to-die legislation recently approved by the state Senate is drawing criticism from several members of the State Bioethics Commission that produced the proposal for the legislation and from some religious and right-to-life groups in the state. It's uncertain whether the bill, approved in April by the New Jersey Senate, will be approved by the Assembly and signed into law by Governor Florio.

Fewer than half (18) of the states that have enacted right-to-die legislation to date have also included provisions for patients to specify a health care spokes

Figure 2

"If a patient with a terminal disease is unable to communicate and has not made his or her wishes known in advance, should the closest family member be allowed to decide whether to continue medical treatment, or should a family member not be allowed to make this decision?"



person, or proxy, to authorize withholding or withdrawal of their life support. However, the public clearly supports the use of proxy decision makers.

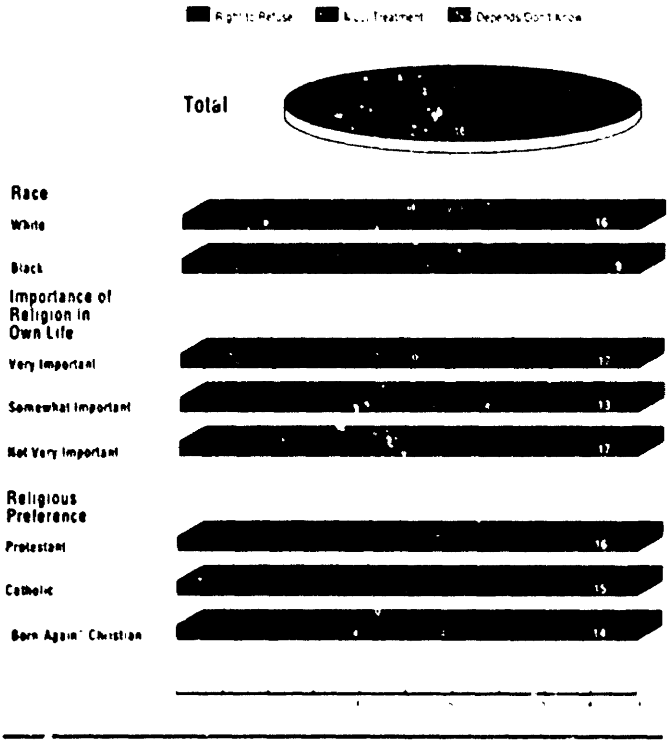
In the view of most Americans, close family members ought to be able to serve as proxies for terminal patients who are unable to communicate and have not made their wishes known in advance. (*See Figure 2.*) Seven in ten think family members should be allowed to make decisions about medical treatment on behalf of the patient, while another 5 percent think this is appropriate only in some circumstances. Only about one in six adults overall, and a slightly greater proportion of blacks, thinks such proxy decision making should *not* be allowed. People over the age of 50 express somewhat more uncertainty, with just under one in five unsure about whether proxy decision making should always be allowed.

The public, in particular those with strong religious feelings, makes an important distinction between how decisions about medical treatment should be made for adults and how they should be made for infants. Half of the public *reject* the notion that parents can refuse life-sustaining treatment on behalf of their severely handicapped infant, asserting instead that such infants should receive as much treatment as possible. (*See Figure 3.*) A third accept the idea that parents should be able to refuse medical treatment for their severely handicapped infant, while 8 percent would agree only under certain circumstances. Women, whites, and college graduates are more likely than others to think that parents should be able to refuse treatment, with over four in ten in these groups saying this right exists at least in certain circumstances.

The public's distinct ideas about right to die issues with respect to infants are not

Figure 3

"When a severaly handicapped child is born, do you think the parents have the right to refuse medical treatment that might save the infant's life? Or, do you think the infant, no matter how handicapped, should receive as much treatment as possible?"



motivated by a general rejection of "proxy" decision making, since the overwhelming majority favors letting close relatives make treatment decisions where the patient is unable to express his or her wishes. Experts point to several other reasons that opinions about infant patients differ from opinions about adult patients.

Susan M. Wolf is a lawyer with The Hastings Center, a research institute in New York that studies medical ethics. She notes that medical decision making for handicapped infants has become quite different from that for adults because "it's difficult to agree on what the patient's best interests are in the case of a newborn, and there's no way to extrapolate what the patient would want from knowledge of his or her life." She also remarks that cases of decision making involving infants have been influenced by the direct involvement of the federal government in passing legislation that recognizes withholding life-sustaining medical treatment as a new category of child abuse.

Religion profoundly affects views about the proper treatment of severely handicapped infants, with born-again Christians and those who are very religious most opposed to parental decision making in these cases. In fact, majority support for the right of parents to refuse medical treatment only occurs among those who say religion is not important in their lives (51 percent). Whites, women and adults age 30 and older are also more likely to favor the rights of parents to decide about medical treatment.

There is no difference, however, in the views of Protestants and Catholics about parental decision making. In fact, in all areas of this investigation, Protestants and Catholics disclose similar opinions. It is the importance of religion to a person's day-to-day life that affects opinions on right-to-die issues, rather than one's adherence to a specific set of religious beliefs.

Feelings About Aging

In today's rapidly aging society, Americans have profoundly mixed feelings about growing old. Only four in ten (39 percent) adults would like to live to be 100 years old, and half (49 percent) would emphatically not want to live to be that old. Women, in particular, do not look forward to reaching the milestone of their 100th birthday, which is ironic, since this accomplishment is more likely for a woman than a man. Only 31 percent of women, compared with almost half (48 percent) of men, admit that they would like to be 100 years old.

Dr Arnold Goldstein, a statistician at the US Census Bureau, notes that the population of centenarians quadrupled between 1980 and 1989 from about 15,000 to 61,000. He predicts that "by the year 2000 there will be another 60 percent increase in this part of the population and the US will then have about 100,000 centenarians." He adds that "women now make up almost 80 percent of the over-100 population," and he expects women's share to increase to 83 percent in 10 years.

Americans express a wide variety of feelings when they imagine what will face them in old age. But, the range of concerns and worries they articulate is far greater than the joys and rewards they expect. When asked in an unstructured way to talk about what they most look forward to about getting old, almost everyone (85 percent) can name something. Most people mention not having to work, or having less stress and pressure in their lives (54 percent). Some people mention other specific expectations like the joy of sharing in the lives of their children and grandchildren (14 percent), travel (7 percent) and experiencing broad social changes (3 percent). A few (2 percent) even say that they most look forward to death and eternal life with God. But, most focus their positive feelings about aging on the reduction of their responsibilities in the world.

When the public is asked about their greatest worries, a wide range of specific concerns about old age emerges. Three in ten (31 percent) mention worries about health, and another 5 percent name a specific disease that they fear. One quarter worry about what their financial situation will be like when they're old (24 percent). Over one in six (17 percent) fears having activities restricted or losing the ability to be independent, and another 4 percent worry about senility. Five percent, including 13 percent of those younger than 30 now, worry about death itself. Four percent worry about the world situation. Optimistically, almost one in five (19 percent) of those 50 or older (compared with only 6 percent of younger adults) claims to worry about nothing when anticipating old age.

The Implementation of Patient Wishes

One section of the New Jersey legislation grants immunity from civil, criminal and professional liability to physicians who carry out their patients' instructions for treatment. Many states have such legislative provisions. Yet, many observers have noted that physicians often do not carry out their patients' wishes with regard to life-sustaining medical treatment because they lack such explicit legislative protection and because they have an inherent tendency to seek *treatment* solutions for their patients' conditions.

A special panel of a dozen physicians, writing last year in *The New England Journal of Medicine*, noted that a patient's written instructions, or directives, regarding treatment "do not exert enough influence on either the patient's ability to control medical decision making at the end of life or the physician's behavior with respect to such issues in hospitals, emergency rooms, and nursing homes. There remains a considerable gap between the acceptance of the directive and its implementation."

In fact, few people think doctors and nurses pay a lot of attention to instructions from patients about whether they want treatment to keep them alive. Only one in five (20 percent) says that medical professionals pay a lot of attention to patients' wishes, although this view is slightly more prevalent (28 percent) among people who actually have helped to make medical treatment decisions for a loved one who suffered a prolonged or painful death. For the public as a whole, 37 percent think medical professionals pay "some" attention to patient wishes, 28 percent think little or no attention is paid, and 15 percent have no view about how medical professionals consider patient wishes in making treatment decisions.

Americans are split in their opinions about how to handle cases where patient wishes have been ignored. Asked to consider a situation where a patient does not want treatment to be kept alive, but receives it nonetheless and survives in a severely disabled condition, four in ten (42 percent) think the doctor or hospital should be held *legally* responsible for the patient's disabled condition. However, almost as many (35 percent) think the hospital staff is justified in trying to save the patient's life.

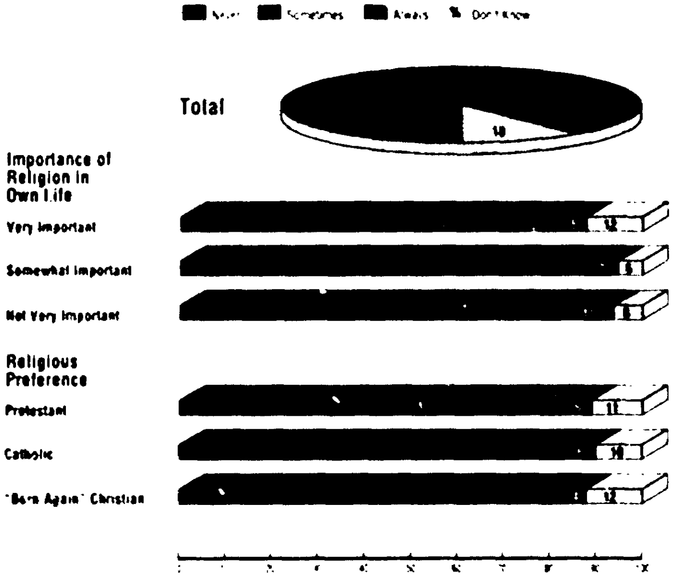
Susan Wolf of The Hastings Center noted that "there have been a handful of cases in the country where a patient or family member has sued for damages, and there is a well-established idea in the case law that makes it appropriate for the courts to consider these cases." She went on to cite the opinion of Justice Cardozo in the 1914 *Schloendorff* case in New York that expresses this basic idea: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."

Suicide and Mercy Killing

Most Americans are willing to go much further than simply supporting right-to-die policies when considering cases of *adults* who are suffering with a terminal disease or disability. Six in ten adults think it is justified at least some of the time for a person to kill his or her spouse if the spouse is suffering terrible pain from a terminal illness. *(See Figure 4.)* Only one in five thinks this is never justified. Blacks register the most objection to mercy killing, with over one-third (36 percent) saying such acts are never justified.

Figure 4

"We sometimes hear of cases where a person has killed a spouse because the husband or wife was suffering terrible pain from a terminal disease. Do you think the actions of these people are never justified, sometimes justified, or always justified?"



About half of the public think a person has a moral right to commit suicide if suffering from an incurable disease or suffering great pain with no hope of improvement. *(See Figure 5.)* Acceptance of suicide in such cases has been increasing gradually over the fifteen-year period since 1975 when these attitudes were first measured by the Gallup Poll. Forty-eight percent of the public now think a moral right to suicide exists if a person has an incurable disease, compared to 40 percent in 1975. Over half (55 percent) now think a person suffering great pain with no hope of improvement has a moral right to suicide, compared to only four in ten (41 percent) 15 years ago.

The increasing acceptance of suicide is largely due to the aging of the population, as revealed by an analysis of the change in attitudes over time within age subgroups of the population. The older people who overwhelmingly rejected suicide as a response to terminal illness 15 years ago have died and been replaced in the population by younger people with more moderate views about the acceptability of suicide in these circumstances. Today's older people have views about suicide that resemble those of middle-aged adults 15 years ago, while today's middle-aged adults resemble the young adults of the '70s.

Attitudes toward suicide remain patterned by age today, with more acceptance of suicide expressed by younger people in the cases of incurable disease or great suffering. For example, two-thirds (67 percent) of adults under age 30 and 58 percent of those age 30 to 49 think a person has a moral right to suicide if suffering great pain from a disease with no hope of improvement. Fewer older people agree — just under half (47 percent) of those age 50 to 64 and 39 percent of those 65 and older. In part, this is because older people are more uncertain of their views on suicide than younger people.

Attitudes about suicide also are different for men and women. In three of the four situations investigated (all but the case where "living has become a burden") men are more likely to say that a right to suicide exists.

The public makes clear distinctions about the acceptability of suicide between cases involving terminal disease and suffering and those where the patient has become a burden on his or her family, or daily life has become a burden to the patient. Majorities of Americans *reject* a moral right to suicide, with 57 percent opposed if the burden on the family is extremely heavy and 59 percent opposed if life is a burden for the individual. However, even these attitudes represent an increase in acceptance of suicide over 15 years ago, when almost three in four (72 percent) Americans rejected a right to suicide in cases where a patient has become an extremely heavy burden on his or her family.

The role of religion in determining views about ending the life of a suffering person through these more extreme non-medical means is surprising. Attitudes about suicide and killing a husband or wife differ *greatly* depending on the strength of one's religious views, but do not differ based on religious beliefs. The attitudes of Protestants and Catholics on these issues are very similar. Despite the fact that Catholic doctrine labels the taking of a life, including one's own, as a sin, half of Catholics think a person suffering great pain has a moral right to suicide. And, only 17 percent of Catholics think the mercy killing of a husband or wife is never justified.

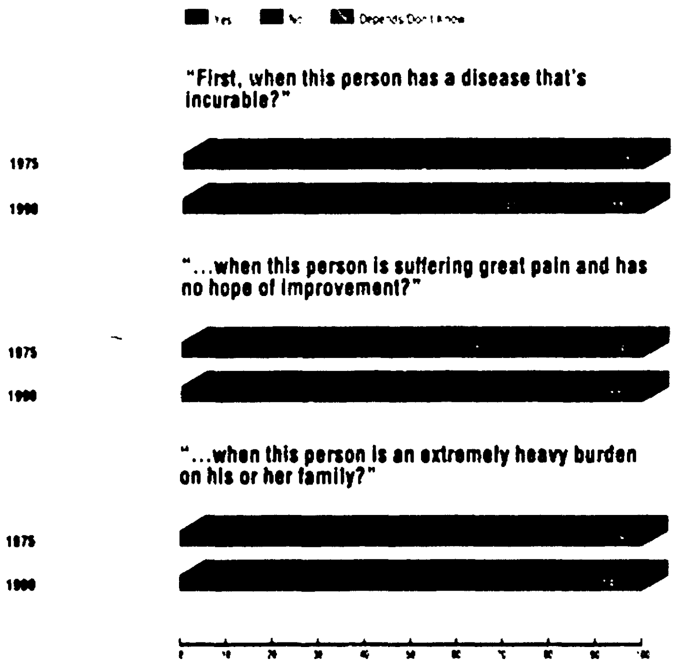
Most born-again Christians and very religious people reject a right to suicide even in the case of a terminal illness, and are fairly evenly divided in their attitudes about suicide when the patient is suffering great pain. Yet, paradoxically, a majority of born-again Christians and the very religious think acts of so-called "mercy killing" by husbands or wives are sometimes justified.

It appears that some Americans, particularly those who are very religious, make an important distinction between what is "justified" and what is a "right." This implies that the difficult decision to end a person's life is perhaps justified, understandable and acceptable, yet not *endorsed*.

The ambivalent feelings of the public about mercy killing and suicide are reflected in the impassioned debate that surrounds consideration of active euthanasia and assisted suicide. The recent actions of Dr. Jack Kevorkian in Michigan, who helped to bring about the death of Janet Adkins, an Oregon Alzheimer's patient, have fueled this debate. However, as Susan Wolf notes, "although ethicists, physicians and others debate active euthanasia and assisted suicide, these concepts have been clearly rejected in the law."

Figure 5

"Do you think a person has a moral right to end his or her own life under any of the following circumstances?"

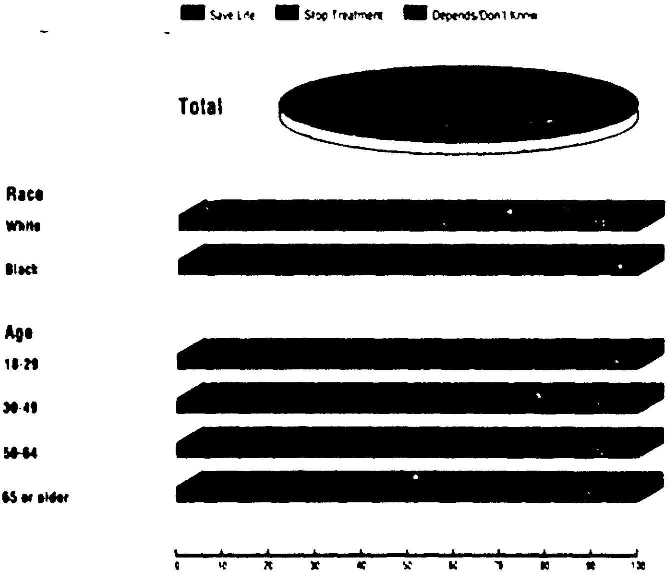


Personal Wishes

The views that Americans express about right-to-die policies reflect their personal feelings about how they would want their own medical treatment handled in various situations, and what they know or can imagine about the wishes of their parents. People's feelings about whether they would choose to receive or continue life-sustaining medical treatment change depending on the medical circumstances of the case.

Figure 6

"If you had a disease with no hope of improvement and you were suffering a great deal of physical pain, would you tell your doctor to do everything possible to save your life, or would you tell your doctor to stop treatment so you could die?"



More than half of all Americans would want their doctors to stop administering life-sustaining treatment if they had a terminal disease and were suffering a great deal of physical pain (59 percent), or if they had an illness that made them totally dependent on another family member for all daily care (51 percent). *(See Figures 6 and 7.)* Fewer than a third are certain of their desire to have their physicians pursue every possible treatment in these two situations (28 percent and 31 percent, respectively).

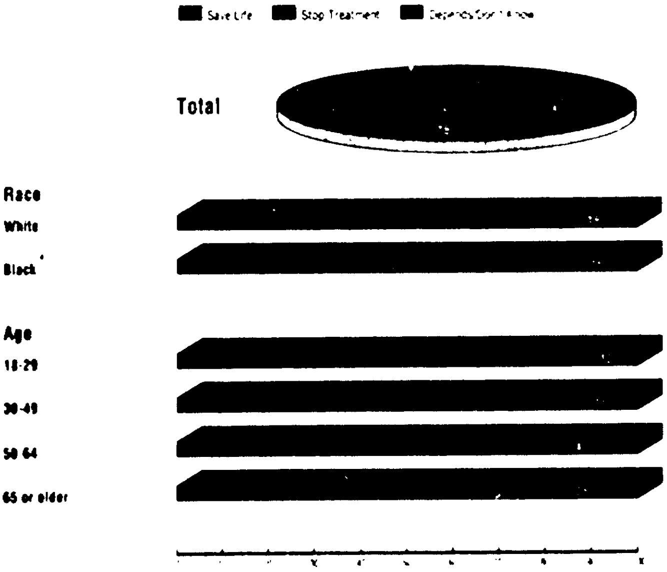
Over four in ten (44 percent) would want medical treatment stopped even in the case where a terminal disease made it difficult to function in day-to-day activities, whereas 40 percent would want all possible life saving medical treatments and procedures used. *(See Figure 8.)*

Personal choices about medical treatment in these three situations are shaped by the importance of religion in one's life. In all cases, the wish to have life-sustaining medical treatment withdrawn decreases as the importance of religion increases. However, a majority (52 percent) of even the very religious would want their own treatment stopped if they were suffering a great deal of physical pain.

Personal choices also vary by race and age. Blacks are less likely than whites to think they would opt to have treatment stopped in all three situations investigated. Young adults, under age 30, do not make distinctions about how they would want their own treatment handled depending on the nature of the situation, while older adults make such distinctions. For example, more people over the age of 65 would want their treatment stopped if they were suffering great pain (60 percent) than if they were dependent on a family member (50 percent) or had difficulty with daily living (47 percent). Young adults do not distinguish among these situations in judging how they would react (49 percent, 50 percent and 44 percent would want treatment stopped in these three situations, respectively).

Figure 7

"How about if you had an illness that made you totally dependent on a family member or other person for all of your care?"



Most people think their parents' wishes for medical treatment in these circumstances are similar to their own wishes. About half of those with living parents think their mothers and fathers would want medical treatment stopped if they were suffering a great deal of pain in a terminal disease (54 percent for mothers and 50 percent for fathers), or if they became totally dependent on a family member (49 percent for mothers and 48 percent for fathers). Four in ten think their parents would want medical treatment stopped if daily activities became a burden (43 percent for mothers and 42 percent for fathers).

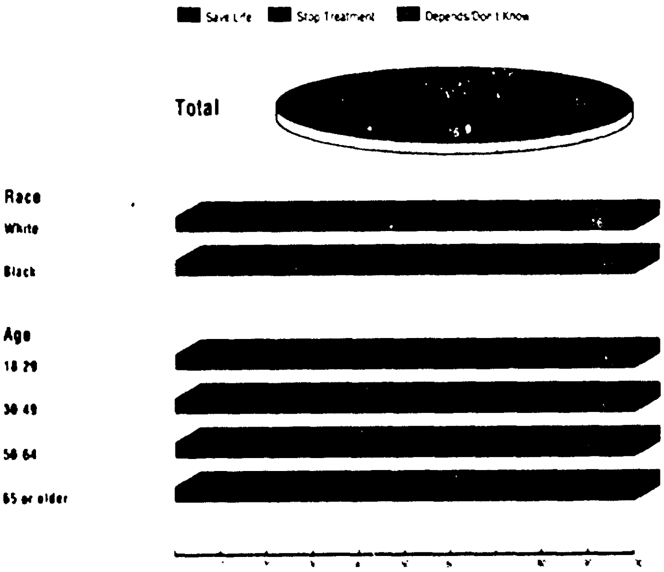
Although religion plays a role in shaping an individual's own wishes about medical treatment, it does not influence perceptions about the amount of treatment one's parents would wish.

There are some important group differences in perceptions of mothers', but not fathers', wishes. Daughters' and sons' perceptions of their mothers' wishes for medical treatment are different, as are the perceptions of those whose mothers are under age 60 and those whose mothers are 60 or older. Daughters are more likely than sons to think that their mothers would want treatment stopped in all three situations considered. Those whose mothers are over 60 are more likely to think their mothers would want treatment stopped if suffering great pain.

In large part, these differences arise because daughters are more likely than sons to have explicitly *discussed* a mother's wishes with her, and because these discussions are more frequent between mothers and their children when the mother is older. Often, mother and child have experienced the death of the child's father together, where these medical treatment issues may have become relevant. In fact, people who have participated in medical treatment decisions for a loved one (15 percent of all American adults) are more likely to think their mothers would want their

Figure 8

"How about if you had a disease with no hope of improvement that made it hard for you to function in your day-to-day activities?"



own medical treatment stopped, especially in the case where totally dependent on another family member.

Over four in ten (43 percent) adults have talked to their mothers about their mothers' wishes for medical treatment, including 37 percent of men, 49 percent of women, 58 percent of those whose mothers are 70 or older, and 68 percent of people who have participated in medical treatment decisions for a deceased loved one. Fewer adults (28 percent) have had such discussions with their fathers. Sixteen percent are aware of written instructions that exist for their mothers, and 16 percent also know that their fathers have written instructions regarding wishes for medical treatment.

A third of all adults can imagine *themselves* taking the life of a loved one who was suffering terribly from an illness that was terminal (28 percent can imagine this unequivocally, and 5 percent can only imagine it under certain circumstances). (*See Figure 9.*) Almost six in ten (59 percent) cannot imagine such an action, and 8 percent are unsure. The ability to imagine the mercy killing of a husband or wife or other loved one is greater for men, and it decreases significantly with age, presumably as the possibility of actually facing such a choice becomes more likely. For example, four in ten (40 percent) young adults (under age 30) can imagine a mercy killing under some circumstances, compared with only half as many (20 percent) people age 65 and older.

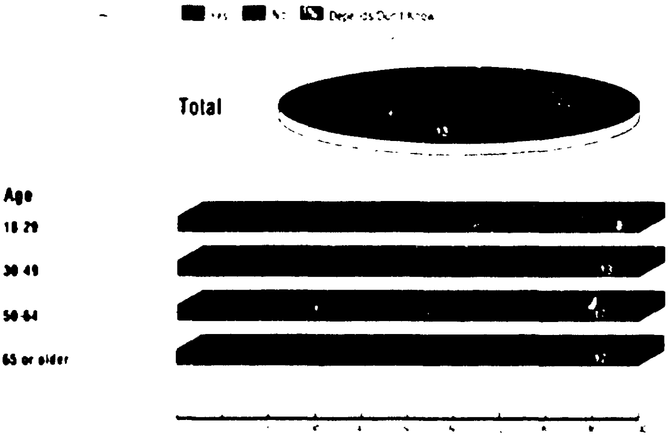
Strength of religious feeling also affects how people imagine their own behavior if their partner were suffering great pain from a terminal disease. Those for whom religion is very important are much less likely than others to be able to imagine taking the life of a loved one who is suffering (25 percent if religion is very important, compared with 40 percent if religion is somewhat important and 52 percent if religion is not important).

Half the married people (51 percent) have talked to their mates about his or her wishes for medical treatment, and one in ten (11 percent) has written instructions regarding these wishes. People who have not attended college discuss their spouses' wishes less than those who have attended college.

Blacks are much less likely than whites to have had any family discussions about medical treatment wishes, whether with a spouse, mother or father. Even though blacks have different beliefs about right-to-die issues than whites, these differences do not explain why blacks talk less often about these issues with family members. There are large racial differences in reports about family discussions even among blacks and whites who hold the *same* beliefs about the appropriateness of ending treatment in certain medical situations. Other differences between blacks and whites (on strength of religion, level of education and age of parents) also cannot account for the lower frequency of family discussions among blacks.

Figure 9

"We sometimes hear of cases where a person has killed a spouse because the husband or wife was suffering terrible pain from a terminal disease. Can you imagine you, yourself, taking action like this if someone you loved was suffering terribly from an illness that was terminal?"



Americans, particularly women and older Americans, have thought about their own wishes for life-sustaining medical treatment. *(See Figure 10.)* Almost three in ten (28 percent) say they had already given these issues a great deal of thought before they were interviewed for this study, 36 percent had given some thought, 22 percent not very much thought, and only 13 percent had given no thought at all to decisions about medical treatment in these severe cases.

Over a third (35 percent) of those age 50 or older have given a great deal of thought to their own wishes for medical treatment. Most strikingly, half (47 percent) of the people who have experienced the difficulty of making treatment decisions for a dying loved one have given careful consideration to how they would want their own situation handled.

Almost two-thirds (64 percent) of the people who have considered these issues have also discussed their feelings about medical treatment with a spouse (34 percent), child (15 percent), parent (15 percent), other relative (14 percent), medical or legal professional (5 percent), or with another person (10 percent). Affluent individuals (those with $50,000 or more in annual household income) have these conversations more often than those who are less well off.

Women discuss their feelings about medical treatment more than men. Women also talk to more different types of people about these issues than men, and women more often discuss these issues with a child. Age and experience with a painful or prolonged death are also related to having had conversations with others about wishes for medical treatment. And, almost three-fourths (72 percent) of the people who helped make treatment decisions for a dying loved one have talked to a family member, friend or professional about the treatment they would want for themselves.

A living will is a document that provides a patient's instructions to his or her doctor about when life-sustaining medical treatment should be withdrawn or withheld. Almost one in seven (14 percent) American adults has a living will or has put his or her wishes for medical treatment in cases of terminal disease or disability in writing, including almost one quarter (24 percent) of adults over age 64 and almost one quarter (24 percent) of those who have helped make medical treatment decisions for a loved one.

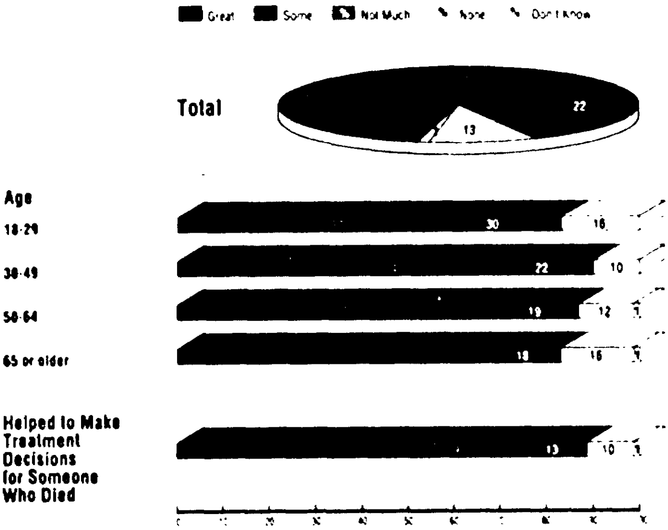
Seven in ten Americans (71 percent) have heard of living wills, with high awareness among college graduates (83 percent), affluent individuals (85 percent), and women (75 percent), and lower awareness among young adults (56 percent) and blacks (49 percent).

Fenella Rouse, the Executive Director of the Society for the Right to Die, which is in New York, says that even though her organization distributes thousands of examples of living wills to interested individuals each year, "most of the inquiries we get are from people who are already in a difficult situation involving medical treatment for themselves or a family member and they want to know what their options are and how they can get help."

One likely consequence of the US Supreme Court's decision in *Cruzan v Missouri* is that more people will avail themselves of living wills and durable powers of attorney (granting to a family member or friend the right to make life-sustaining decisions) because they provide what the Court saw as essential — "clear evidence of what the victim would want."

Figure 10

"Before today, how much had you thought about your own wishes for medical treatment if you were in the kind of circumstances like those we've been talking about? Had you given this a great deal of thought, some thought, not very much thought, or no thought at all?"



BEST AVAILABLE COPY

Methodology

This survey is based on telephone interviews with a representative sample of 1,213 adults, age 18 and older, living in the continental United States. Interviews were conducted during the period May 1 to May 5, 1990. For results based on the total sample, one can say with 95 percent confidence that the error attributable to sampling and other random effects is plus or minus three percentage points. In addition to sampling error, question wording and practical difficulties in conducting surveys can introduce error or bias into the findings of opinion polls.

STATEMENT OF VOLUNTARY HOSPITALS OF AMERICA, INC.

Voluntary Hospitals of America, Inc. ("VHA") is a national alliance of 651 not-for-profit hospitals and their 184 affiliates. VHA very much appreciates the opportunity to comment on the proposed legislation that would mandate a systematic role to be played by hospitals in educating the public about advance medical directives.

VHA strongly supports the goals of the Patient Self-Determination Act (S. 1766) which emphasize the importance of educating the public about their rights to make medical treatment decisions and to execute medical directives stating their treatment preferences. As not-for-profit, community-based organizations, hospitals have a significant role to play in this educational process. VHA believes hospitals should both inform individuals of their rights to draft medical directives and also make certain that these written directives are followed.

NEED FOR INFORMATION ABOUT MEDICAL DIRECTIVES

VHA recognizes that technological advancements in life-sustaining procedures have complicated the difficult decisions individuals and their family members must make regarding medical treatment. While these decisions may place significant stress upon the individual, the family, and the community, it is evident that decisions about medical treatment should ultimately be made by the person who is to receive the treatment after consultation with family and physician.

Unfortunately, there are often times when individuals are unable to communicate their treatment preferences due to either unconsciousness or incompetency. VHA believes it is important to ensure that all individuals maintain control over medical treatment decisions and that this control should extend to such times of incapacity.

In an effort to facilitate an individual's control over medical care decisions, a vast majority of states have enacted laws that allow individuals to execute medical directives. These medical directives commonly take two forms: "living wills" and durable powers of attorney for health care decisions. "Living wills" are legal documents that state in advance the medical treatment preferences of an individual who may become terminally ill. Durable powers of attorney permit an individual to designate a health care proxy to make decisions for that individual during periods of incapacity.

While medical directives may be very useful tools for ascertaining and carrying out an individual's wishes regarding medical treatment, less than 10% of Americans have drafted such documents. Studies have indicated that as many as 95% of Americans believe their wishes regarding medical treatment should be known in advance. These statistics as well as other studies indicate that the public is not well informed about their rights to draft medical directives. Moreover, the United States Supreme Court in *Cruzan* v. *Director, Missouri Department of Health* recently held that states may require clear and convincing evidence of an incompetent's wishes as to the withdrawal of the life-sustaining treatment prior to allowing such treatment to end. The decision highlights the importance of clearly stating in writing one's wishes regarding life-sustaining treatment. It is evident that the public should be better informed about medical directives.

EDUCATIONAL ROLE OF HOSPITALS

As community-based institutions concerned about the quality of health care and protecting the dignity of their patients, hospitals certainly have a role to play in educating the community about medical directives. While the proposed legislation focuses on the distribution of informational materials about medical directives by hospitals at the time a patient is admitted to a hospital, hospital efforts to educate the public should not stop here. Hospitals can voluntarily work to distribute such information to their communities through numerous community-based activities. For example, hospitals can use existing outreach programs and seniors access programs as opportunities to assist communities in learning more about medical directives.

VHA recognizes that the best time for the discussion of medical directives is well before an individual is admitted to a hospital. Ideally, patients entering a hospital with the potential need for life-sustaining treatment will already have thought carefully about and discussed such issues with their family, physician, and attorney prior to hospitalization. Unfortunately, many people are not aware of their prerogative to draft medical directives and thus do not take advantage of them.

THE PATIENT SELF-DETERMINATION ACT

Senator Danforth's Patient Self-Determination Act is an important step toward making sure that the public receives information about medical directives. Ideally, individual communities and public institutions should be moving voluntarily to provide the public with such information. However, because of the increasing need for education about medical directives, a Federal initiative highlighting the importance of such education is appropriate.

It is important to note that hospitals confront the issues surrounding decisions about life-prolonging treatment on a daily basis. Hospital personnel are often in consultation with patients and their family members about decisions to either initiate or end life-sustaining treatment. Thus, hospitals already deal intimately with the issues surrounding medical directives.

The proposed legislation requires hospitals to inform adult patients at the time of admission about their rights to make decisions concerning medical care and to execute medical directives. In addition, the bill provides that hospitals ask patients if they have medical directives and document whether or not they do have them in the patient's medical records. The proposed legislation takes a systematic approach to solving the educational problem surrounding medical directives by utilizing an existing administrative process to disseminate information. While the specific details of an individual's own medical directive should be discussed outside of the hospital admissions environment, the point of admission could serve as an appropriate place to provide pertinent information on medical directives.

VHA supports a provision requiring the Department of Health and Human Services and the individual states to develop the specific materials to be distributed by hospitals. VHA believes that it is essential that these materials are developed by HHS and the states in order to ensure that different hospitals provide uniform information regarding an individual's rights under state law to execute medical directives. Requiring state governments to develop these materials also would absolve hospitals from having to interpret state statutory intent.

Moreover, Senator Danforth's legislation requires that hospitals ensure that these medical directives are implemented to the extent permissible under state law. VHA believes these provisions constitute sound hospital policy and are effective means for ensuring that individuals receive medical treatment consistent with their wishes. We also support a provision requiring hospitals to maintain written policies concerning the implementation of medical directives.

Representative Levin's companion legislation in the House, H.R. 5067, requires that hospitals must give adult patients information about such written policies. VHA does not believe that it is necessary to provide every patient with this additional information. However, it would be appropriate to provide such information to those patients who have executed medical directives. A hospital could inform patients who do not have medical directives that the hospital maintains written policies regarding the implementation of such instruments and that the patient could review these policies upon request.

In addition, S. 1766 requires a hospital to arrange for the transfer of a patient if as a matter of conscience the hospital cannot implement the wishes of the patient. VHA appreciates the inclusion of this provision since it recognizes there may be instances when a hospital would not feel comfortable carrying out a patient's treatment wishes for either religious or ethical reasons.

The Senate legislation further requires that hospitals establish institutional ethics committees which would initiate educational programs for staff, patients, and the community on ethical issues. VHA recommends deleting the ethics committee requirement and supports changing this provision to require that providers, either individually or with other institutions, educate the staff and community about advance directives and other ethical issues in health care.

VHA believes this is an important revision. The majority of hospitals already have ethics committees, but many smaller institutions would be burdened by such a requirement. Hospital ethics committees usually serve as forums for physicians and patients to discuss bioethical questions that are frequently case specific. In general, these committees are not informational resources but are rather forums for discussion and debate. The structure and purpose of such a function should not be mandated by the Federal government but should be left to the individual hospital.

Using the Medicare Conditions of Participation for enforcement of this legislation is a rather stringent measure; however, there is precedent for such provisions. For example, hospitals are already required to provide Medicare patients with information concerning their rights to benefits at the time of admission. VHA believes that both informing patients about their rights to execute medical directives and ensuring that these directives are followed are as important as providing patients with information about rights to benefits. We believe the requirements of the legislation are directly related to assuring quality of care in that they make certain that patients receive care consistent with their treatment wishes.

Finally, VHA would support a provision such as the one in H.R. 5067 that explicitly requires health maintenance organizations and other prepaid organizations to also provide information regarding medical directives at time of enrollment. VHA is also aware of the proliferation of managed care and the significant role managed care could play in the educational process as well. It would be most beneficial to educate individuals about medical directives when they are not in the acute stages of illness. Thus, the time at which an individual enrolls in an HMO or a prepaid insurance plan would be an appropriate opportunity for informing that person about medical directives.

CONCLUSION

In conclusion, VHA recognizes the importance of educating the public about their rights to make medical treatment decisions and to utilize medical directives that state their treatment preferences. As community-based organizations concerned about responding to the emotional as well as the physical needs of their patients, hospitals have an important role to play in informing individuals of their rights to execute medical directives and in ensuring that their patients' wishes are followed.

VHA supports the goals and many of the provisions of the Patient Self-Determination Act and commends both Senator Danforth for introducing this legislation and Senator Rockefeller for holding this hearing. VHA intends to encourage its member hospitals to accomplish the objectives of this legislation while it is under consideration by the Congress.

○