

GAO

Report to the Ranking Minority Member,
Subcommittee on Health,
Committee on Ways and Means,
House of Representatives

August 1995

PATIENT SELF- DETERMINATION ACT

Providers Offer
Information on Advance
Directives but
Effectiveness Uncertain





United States
General Accounting Office
Washington, D.C. 20548

**Health, Education, and
Human Services Division**

B-257739

August 28, 1995

The Honorable Fortney (Pete) Stark
Ranking Minority Member
Subcommittee on Health
Committee on Ways and Means
House of Representatives

Dear Mr. Stark:

In 1990, the Congress passed legislation commonly referred to as the Patient Self-Determination Act (PSDA) to reinforce individuals' constitutional right to determine their final health care.¹ The act requires health care providers to increase public awareness about the use of "advance directives"—a living will or health care power of attorney. An advance directive specifies how life-support decisions should be carried out should the patient become terminally ill and unable to communicate his or her wishes.²

As you requested, this report provides information on PSDA implementation and the effectiveness of advance directives in ensuring patient self-determination. Specifically, we looked at the extent to which (1) institutional health care providers and the federal government are complying with the act's provisions, (2) the public uses advance directives to express their end-of-life treatment wishes, and (3) an advance directive effects a patient's desired care.

In preparing this report, we interviewed federal officials, representatives of health care provider associations including hospitals, physicians, and nursing home associations), interest groups, and medical ethicists. We reviewed federal regulations as well as written comments submitted by interested parties. We also reviewed the literature and surveys conducted by public and private entities and met with researchers conducting studies on advance directives. We did not attempt to systematically measure either the number of people with advance directives or institutional compliance with PSDA. We conducted our review from July 1994 to

¹Omnibus Budget Reconciliation Act of 1990, P. L. 101-508, sec. 4206 and 4751, 104 Stat. 1388, 1388-115, and 1388-204 (classified respectively at 42 U.S.C. 1395cc(f) (Medicare) and 1396a(w) (Medicaid) (1994)).

²In current medical practice, it is presumed that the patient wants all possible care to be provided, unless otherwise stated. PSDA further assumes that the treatment preferences expressed by people when they are competent are also desired by them when they become incompetent. This issue is being addressed in several court cases.

July 1995 in accordance with generally accepted government auditing standards.

Results in Brief

Health care institutions and the Department of Health and Human Services (HHS) generally appear to comply with most PSDA requirements. Surveys, facility inspections, and industry officials indicated that nearly all providers inform patients about their right to have an advance directive, but fewer consistently document in the medical record whether a patient has one. HHS has incorporated PSDA provisions into Medicare and Medicaid provider requirements, expanded the Medicare handbook, and engaged in a limited public education campaign. However, the agency has not conducted a mailing to Social Security recipients about advance directives—a specific requirement of the act.

We also found that advance directives have been advocated more than they have been used. Surveys indicated that, in general, only 10 to 25 percent of Americans have documented their end-of-life choices or appointed a health care agent. Lack of communication between patients and physicians and misunderstandings about the appropriateness and purpose of advance directives may explain why completion rates remain low.

The provider groups we spoke with generally support advance directives. Yet, advance directives may not always be implemented as patients intend. A variety of factors affects whether an advance directive actually controls end-of-life care decisions, including the availability or specificity of a living will, family wishes, physicians' attitudes, and legal issues.

Background

The controversy over patients' rights escalated in the 1970s, coinciding with dramatic advances in medical technology. The early legal cases concerned the "right to die," testing what medical treatment can be administered in the face of a patient's desire to die naturally, without artificial, life-prolonging equipment. In the Quinlan case, for example, the court held that the Constitution guarantees individuals the right to direct their own medical care.³ Over time, the right to die concept came to be seen as part of a patient's right to self-determination, including a recognition that some patients prefer that all possible treatments and procedures be used to treat them.

³In re Quinlan, 355 A.2d 647, (N.J.), cert. denied, 429 U.S. 922 (1976).

PSDA, which became effective in December 1991, applies to most institutional providers and prepaid plans that participate in Medicare or Medicaid. These include hospitals, nursing homes, home health care providers, hospices, and health maintenance organizations, but not providers of outpatient services or emergency medical teams.⁴ Specifically, the provider or organization is required to

- provide to all adult patients, residents, and enrollees written information on their rights under state law to make decisions concerning medical care, including the right to execute an advance directive, as well as maintain the policies of the provider regarding implementation of advance directives;
- document in the medical record whether the individual has an advance directive;
- educate the staff and the community about advance directives;
- not condition the provision of care, or otherwise discriminate, on the basis of whether a patient has an advance directive; and
- ensure compliance with state law respecting advance directives.

In addition, PSDA requires that HHS conduct a public education campaign about advance directives and oversee provider compliance.

An advance directive sets out an individual's preferences about treatment should the person become incompetent or unable to communicate these preferences to medical personnel.⁵ In addition to directing physicians to withdraw or withhold life-sustaining procedures, advance directives may be used to record a patient's wish to receive all available medical treatment. (See app. I for examples of advance directive forms.) There are essentially two types of advance directives: living wills and health care powers of attorney.

A living will is a document that informs health care providers of the kind of medical care the individual wants provided or withheld. Living wills can be nonspecific statements, scenario- and treatment-specific statements, or include value profiles. Under state laws, a living will typically takes effect when the patient (1) is diagnosed as close to death from a terminal illness

⁴Ambulance staff may not honor a living will because to do so they generally need a physician's certification that the patient is dying.

⁵Situations involving people who are incompetent and receiving life-sustaining treatment are not rare. For example, one study of intensive care units (ICU) found that although life-sustaining care was withheld or withdrawn relatively infrequently, about half of all deaths in the ICU were precipitated by decisions to do so. Virtually all of the patients for whom support was withheld or withdrawn were incompetent at the time. See N.G. Smedira, B.H. Evans, L.S. Grais, and others, "Withholding and Withdrawal of Life Support from the Critically Ill," *The New England Journal of Medicine*, Vol. 322 (1990), pp. 309-15.

or is permanently comatose and (2) cannot communicate his or her wishes for medical care. In general, once a physician receives a living will, he or she either must honor its instructions or transfer the patient to another physician who will honor them. State laws on living wills typically exempt physicians from liability for complying with advance directives and prescribe minimal penalties for physicians who refuse to follow them. As discussed in appendix II, states have imposed requirements on what medical conditions can make a living will operative.

A health care power of attorney is a document that identifies a health care agent as decisionmaker for the patient. The health care agent has decision-making authority when the individual is terminally ill or permanently comatose. In addition, the agent may be given the authority to make any other kind of health care decisions regardless of the condition of the patient, thereby giving the agent broader decision-making authority than typically specified in a living will.⁶ Under state law, a health care power of attorney typically becomes operative when a physician decides the patient is unable to make a decision.⁷

Advance directives are not universally supported. A number of groups have expressed concerns about the ethics of patient self-determination laws and the laws' potential effects. They are concerned that a lower standard of care for all patients, active euthanasia, or discrimination against people with disabilities could result. Some physicians also have raised concerns about advance directives. Some believe that such documents will reduce their authority over treatment decisions and could produce an adversarial physician-patient relationship. More generally, physicians may oppose any extension of legal regulation into medical practice.

Institutional Providers and HHS Appear to Comply With Most PSDA Requirements

Institutional providers and HHS generally appear to be complying with most of the act's requirements. Limited data indicate that most providers offer information to patients about executing an advance directive, but problems may occur in documenting whether a patient actually has one. HHS, through the Health Care Financing Administration (HCFA), has

⁶While a patient may appoint a representative in his or her living will, that representative may be able to make decisions for the patient only about life-support treatments and only if the patient is in one of the medical conditions specified in the state law.

⁷Before a health care agent can make life-support decisions, many states require that a second physician confirm that the patient is unable to make treatment decisions.

complied with most PSDA provisions. However, it has not conducted a required mailing to Social Security beneficiaries about advance directives.

Limited Information Suggests That Institutions Comply With Most Requirements

Under PSDA, Medicare and Medicaid hospitals, nursing facilities, and other providers must inform patients of their decision-making rights, distribute state-specific information about advance directives, and inquire and document whether a patient has an advance directive. Information on the degree to which providers fulfill these requirements is limited. Few surveys have looked specifically at compliance with advance directive requirements. These sources indicate that most health care institutions comply with the requirement to develop and distribute information on advance directives. However, it also appears that fewer facilities meet the requirements that the existence of an advance directive be documented in an individual's medical record and that an organization provide for community education on advance directives.

In early 1992, the HHS Office of the Inspector General (OIG) conducted a survey of the institutional implementation of PSDA.⁸ OIG concluded that most of the facilities sampled were complying with the administrative requirements of the act. All, or almost all, facilities had (1) developed written policies and procedures about advance directives; (2) developed written materials on advance directives and provided them to each adult patient on admission or when commencing services; (3) provided materials to patients, including an explanation of state law; and (4) educated staff about advance directives. At about three-quarters of the facilities, the materials provided to the patient clearly state that a patient does not have to have an advance directive to receive treatment. Approximately two-thirds of the facilities had planned or provided community education on advance directives.

However, the report also concluded that "performance in clearly and consistently documenting the existence of an advance directive in the chart needed improvement." At 15 percent of the facilities, more than half of the charts had missing or incomplete documentation on whether a

⁸Department of Health and Human Services, Office of Inspector General, *Patient Advance Directives: Early Implementation Experience*, OEI 06-91-01130 (Aug. 1993), pp. 6-7. The inspection included 24 hospitals, 24 nursing facilities, and 24 home health agencies; 1,553 charts were reviewed. The information from charts was projected to all Medicaid- and Medicare-participating organizations. The report states that "while some of the projections have poor precision due to the limited number of facilities and the four stage sampling technique, it is still felt that they represent a reasonable estimate of initial implementation efforts."

patient had an advance directive.⁹ The report noted that personnel in many sampled facilities attributed chart documentation problems to confused or disoriented patients, emergency room admissions, or pregnant patients not qualified to implement an advance directive under state law.

Additional information on compliance is available from accreditation surveys performed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).¹⁰ While JCAHO's standards pertaining to advance directives are somewhat different than the PSDA requirements, they overlap on most of the requirements.¹¹ Results from 514 hospitals surveyed from January through May 1994 showed that almost all hospitals were complying with the standards common to PSDA and JCAHO. According to a JCAHO official, these results are similar to those for the 1992 and 1993 surveys.

Furthermore, HCFA officials we spoke with believe that, based mainly on self-reported information, nearly all Medicare and Medicaid facilities are complying with PSDA's administrative and documentation provisions. Similarly, officials in HCFA's Office of Managed Care noted that, to their knowledge, almost no health plans have been found noncompliant with PSDA requirements. Compliance is determined through providers' written assurances to state survey agencies or routine on-site validation surveys.

HHS Complied With Most PSDA Provisions

PSDA requires HHS to take several actions to ensure provider compliance and to educate the general public. HCFA incorporated PSDA requirements into Medicare contracts and survey protocols for prepaid plans, home health agencies, nursing homes, and skilled nursing facilities. HCFA also released state Medicaid manual instructions containing guidelines for implementing PSDA provisions.

⁹In agency comments on the OIG report, the HCFA Administrator noted, "We believe it is contradictory to assert that most facilities are complying with the legislative requirements, but at the same time find that only 26 percent of facilities clearly and consistently document whether the patient has an advance directive. Significantly, this report measured initial implementation efforts only 1 month after the regulation was in place."

¹⁰JCAHO provides "deemed" certification for roughly 85 percent of participating hospitals. That is, HCFA "deems" hospitals that meet JCAHO accreditation standards to be certified to participate in Medicare.

¹¹For example, JCAHO did not have a standard requiring community education as required by PSDA. Conversely, until the 1995 surveys, JCAHO standards included a provision that a copy of the patient's advance directive be kept in the medical record and reviewed periodically with the patient or health care agent.

In addition, PSDA requires HHS to provide technical assistance to the states and to conduct a public education campaign on advance directives. As shown in table 1, HHS has fulfilled some but not all of these responsibilities. HCFA prepared and distributed a brochure and videos to provider organizations and groups that work with Medicare beneficiaries and also placed brochures in information displays at targeted locations. However, HHS did not mail information about advance directives to all Social Security beneficiaries as mandated. A HCFA representative we spoke with explained that HHS had not been appropriated the funds needed to comply with this provision. He estimated that such a mailing would cost HHS several million dollars.

HCFA also did not fully assist states in developing documents describing state-specific laws or help states ensure that providers receive documents that are to be distributed. According to a HCFA official, there was no need to duplicate efforts of private organizations that had developed summaries of state laws regarding advance directives and made them available to providers and state agencies. In fact, we found that the American Bar Association and Choice In Dying (a national, not-for-profit advocacy group concerned with the rights and needs of the dying, their families, caregivers, and health care providers) prepared state-specific information on advance directives that would meet this need.¹²

¹²See, for example, American Bar Association, Commission on Legal Problems of the Elderly, Patient Self-Determination Act State Law Guide (Washington, D.C.), a comprehensive guide to assist states and other groups in implementing the PSDA mandate to develop written descriptions of state laws. It explains PSDA, outlines the basic principles and a process for developing written descriptions, provides background on patients' rights, and includes a model statement.

Table 1: HHS/HCFA Compliance With PSDA's Public Education Provisions

Requirement	Implementation activities
Develop or approve nationwide informational materials to be distributed by providers	In September 1991, HCFA released a technical assistance information package. It included a sample public information document about advance directives for use by national news media, consumer publications, and state agencies on aging. Also, HCFA issued a press package that included a list of organizations and publications that have information on the issue.
Assist state agencies, associations, or other private entities in developing state-specific documents to be distributed by providers	HHS required each state, acting through a state agency, association, or other private nonprofit entity, to develop a written description of the state law (statutory or judge-made) concerning advance directives.
Assist state agencies, associations, or other private entities in ensuring that providers receive copies of the documents	HCFA sent a letter to each state Medicaid director, along with a sample public information document suggestive of the written information to be disseminated by providers.
Mail information to Social Security recipients	HHS has not conducted a mailing to Social Security recipients.
Add a page on advance directives to the Medicare handbook	HCFA inserted a section on advance directives in the Medicare handbook.

Few Individuals Complete Advance Directives

The underlying assumption of PSDA is that individuals will prepare advance directives if given sufficient information. Despite improved public awareness of patient self-determination issues, however, the number of individuals completing formal advance directives has been estimated at between 10 and 25 percent (with some estimates as low as 5 percent) of the adult population.

Discomfort with the subject of death and dying is not typically the reason people fail to complete advance directives. Rather, a number of social factors, particularly poor communication among individuals, physicians, and family members, present barriers to developing the required documents. Noting that only 50 percent of the population completes an estate will, a leading researcher we spoke with predicted that the proportion completing an advance directive will likely never be any greater than that.

**More People Express
Interest in Advance
Directives Than Actually
Complete One**

There are no recent nationally representative studies on how many Americans have completed advance directives. However, researchers have conducted many small studies on discrete populations, such as nursing home residents or hospital patients. These studies are consistent in their finding that completion rates are one-third to one-half awareness rates.

These proportions vary depending on the sex, age, and health of the population surveyed. A representative of Choice In Dying told us that most people who complete advance directives are white, middle- to upper-class, educated, older females. A 1993 study by the HHS OIG found that only 18 percent of hospital patients had advance directives, compared with almost 50 percent of patients in a nursing facility.¹³ The OIG study also reported that only 9 percent of patients under 30 had a directive, while 35 percent of patients over 75 had one. Table 2 shows the results of several studies that measured the public's familiarity with and completion of advance directives.

¹³Patient Advance Directives: Early Implementation Experience.

Table 2: Selected Surveys of Advance Directive Awareness and Completion Rates

Study author and date	Population surveyed	Awareness rate	Completion rate
Teno and others (1994)	Over 3,000 severely ill patients	Living will-62% HCPA-42%	Advance directive-20%
HHS/OIG (1993)	1,500 patient charts at hospitals, nursing facilities, home health agencies	Advance directive-67%	Advance directive-21%
Janofsky and Rovner (1993)	191 nursing home residents	Living will- 87% HCPA-82%	Living will-18% HCPA-48%
Elpern and others (1993)	46 inpatients; 50 outpatients	Heard of living will or HCPA-77%	Advance directive-29%
Daly and Sobal (1992)	116 home care patients and caregivers	Living will-33% HCPA-60%	Living will-5% HCPA-50%
Emanuel and others (1991)	405 outpatients and 102 general public	Advance directive-90%	Advance directive-15 to 18%
Cohen-Mansfield and others (1991)	97 elderly inpatients	HCPA-62%	HCPA-16%

Legend

HCPA = Health Care Power of Attorney

Sources:

J.M. Teno, J. Lynn, R.S. Phillips, and others, "Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients," The Journal of Clinical Ethics, Vol. 5, No. 1 (Spring 1994), pp. 23-30.

Department of Health and Human Services, Office of Inspector General, Patient Advance Directives: Facility and Patient Responses, OEI 06-91-01131 (Aug. 1993).

J.S. Janofsky and B.W. Rovner, "Prevalence of Advance Directives and Guardianship in Nursing Home Patients," Journal of Geriatric Psychiatry and Neurology, Vol. 6 (Oct.-Dec. 1993), pp. 214-16.

E.H. Elpern, S.B. Yellen, and L.A. Burton, "A Preliminary Investigation of Opinions and Behaviors Regarding Advance Directives for Medical Care," American Journal of Critical Care, Vol. 2, No. 2 (Mar. 1993), pp. 161-67.

M.P. Daly and J. Sobal, "Advance Directives Among Patients in a House Call Program," Journal of the American Board of Family Practice, Vol. 5, No. 1 (Jan.-Feb. 1992), pp. 11-15.

L.L. Emanuel, M.J. Barry, J.D. Stoeckle, and others, "Advance Directives for Medical Care—A Case for Greater Use," The New England Journal of Medicine, Vol. 324 (1991), pp. 889-95.

J. Cohen-Mansfield, J.A. Droge, and N. Billig, "The Utilization of the Durable Power of Attorney for Health Care Among Hospitalized Elderly Patients," Journal of the American Geriatrics Society, Vol. 39, No. 12 (Dec. 1991), pp. 1174-78.

Barriers to Developing Advance Directives Remain

Individuals may not complete advance directives for a number of reasons. How a patient learns of advance directives may be an important factor. Many experts with whom we spoke believe that to improve completion rates, patients must discuss advance directives with their physicians or health care agents.¹⁴ This communication would ideally occur before a patient reached a state that made the necessity of end-of-life planning imminent to allow adequate time for thoughtful and in-depth discussions.

Although the importance of communication is understood, the frequency of discussions between patients and physicians on advance directives has not significantly increased. According to a 1991 Harvard study, one of the most frequently cited barriers to completing an advance directive was the patient's expectation that the physician would take the initiative.¹⁵ Other studies have shown that some patients may not want to initiate such discussions because they have not established a personal relationship with the physician or they feel that such a discussion may present the physician with a conflict of interest.¹⁶ However, many health care providers assume patients will bring up the issue.

Physicians are often reluctant to discuss end-of-life care because they (1) lack the knowledge or the training on how to formulate advance directives;¹⁷ (2) believe directives are unnecessary for young, healthy patients;¹⁸ (3) are not compensated for the time it takes to carefully discuss the topic;¹⁹ or (4) feel death is not an appropriate outcome of care. As one study noted, "The notion of shared medical decision making is a

¹⁴A study of physician-initiated discussions of advance directives found that a high proportion of patients at a nursing home and in home care completed advance directives after they were approached by a physician. L.J. Markson, J. Fanale, K. Steel, and others, "Implementing Advance Directives in the Primary Care Setting," *Archives of Internal Medicine*, Vol. 154 (1994), pp. 2321-27.

¹⁵L.L. Emanuel, M.J. Barry, J.D. Stoeckle, and others, "Advance Directives for Medical Care—A Case for Greater Use," *The New England Journal of Medicine*, Vol. 324 (1991), pp. 889-95.

¹⁶S. Evans and P. Clarke, "Rethinking How We Communicate About Advance Directives: Hidden Errors in Our Assumptions About Planning for Care," presented at the Annenberg Washington Program and the American Association of Critical Care Nurses (Nov. 9-10, 1992).

¹⁷The American Medical Association has developed two companion booklets on advance directives. The version for physicians explains PSDA, discusses the role of the physician, and gives specific suggestions for working with patients. The patient brochure includes commonly raised questions and suggestions for discussing treatment options. According to an association spokesman, there has been little demand for these materials.

¹⁸R.S. Morrison, E.W. Morrison, and D.F. Glickman, "Physician Reluctance to Discuss Advance Directives," *Archives of Internal Medicine*, Vol. 154 (1994), pp. 2311-18.

¹⁹The American Medical Association and others believe that financial incentives would encourage discussion of advance directives. They would like insurance companies to reimburse physicians for time spent counseling patients about advance directives.

relatively recent phenomenon, and physicians traditionally have placed greater value on protecting patient welfare than respecting patient rights.”²⁰

Another possible barrier is that PSDA requires providers and organizations to discuss advance directives at the time a patient is admitted to a medical facility or comes under the care of a home health agency or hospice. Providers, researchers, and interest groups agree that admission is not a particularly good time for people to first think about their end-of-life treatment preferences, although it may be an appropriate time to reconsider them. Hospitals and nursing homes, in particular, find that such timing could be problematic, since newly admitted patients are often ill, traumatized, or simply overwhelmed.²¹ Furthermore, hospitals generally use nurses, social workers, patient representatives, and clergy to distribute a limited amount of information on advance directives such as forms and brochures.²² One medical ethicist we spoke with suggested that this could pose a problem if medical questions or issues arise that the people providing the information cannot respond to appropriately.

A number of other issues may also present barriers to developing advance directives. Some individuals misunderstand advance directives, believing that they are only relevant for older people or those in poor health. For others, social impediments may interfere. For example, individuals may not have family members or friends who can serve as surrogate decisionmakers or may fear that family members would be upset by the discussion or the document. In addition, individuals who have difficulty gaining access to the health care system may be suspicious of advance directives, fearing that if they express a preference to terminate care under certain conditions, it will be used to limit other or all types of care.

Advance Directives May Have Limited Effectiveness

The provider groups we spoke with generally supported advance directives. Yet, advance directives may not always be implemented as patients intend. Although providers generally are legally required to implement a patient’s advance directive, it is not clear that they always do

²⁰Markson, Fanale, Steel, and others, p. 2324.

²¹If a patient is incapacitated at the time of admission and is unable to receive information, the facility should give advance directive information to the patient’s family or surrogate.

²²A hospital official noted that the shortening of hospital stays limits the hospital’s ability to make further information available.

so. In one study, for example, patient care as expressed in living wills was provided 75 percent of the time.²³

A variety of factors affects whether an advance directive actually controls end-of-life care decisions, including the availability or specificity of a living will, family wishes, physicians' attitudes, and legal issues. Although advance directives may be effective in designating proxy decisionmakers, there is evidence that health care agents may not accurately express the patients' wishes. Furthermore, some patients may want their physicians or agents to override their advance directives in some cases or at least interpret them with broad discretion.

Experts agree that the effectiveness of an advance directive is contingent upon the patient's discussions of end-of-life treatment preferences with those who may need to make such medical decisions, be they providers or health care agents. Better communication with patients may help physicians in interpreting living wills and improve the accuracy of proxy assessment of patient treatment wishes.

Directives Are Often Unavailable

The patient's advance directive may not be followed simply because it is not available when needed. PSDA does not require that the provider keep a copy of the patient's directive with the patient's chart. In fact, the 1992 OIG survey of facilities found that only 60 percent of patients with advance directives had copies with their medical charts.²⁴ Similarly, in its 1994 hospital survey, JCAHO found that only 79 percent of hospitals fully met its standard that "any advance directive(s) is in the patient's medical record and is reviewed periodically with the patient or surrogate decision maker." It is not unusual for a patient to keep the only copy in a safe deposit box.²⁵

In addition, the directive may not accompany a patient who is transferred from one institution to another. In one study, an advance directive was with the nursing home chart for 74 percent of the patients transferred to a hospital, but the document was successfully delivered to the hospital and incorporated into the hospital record for only about one-third of the cases. (Staff at the nursing home suggested staff turnover as a cause.)

²³M. Danis, L.I. Southerland, J.M. Garrett, and others, "A Prospective Study of Advance Directives for Life-Sustaining Care," *The New England Journal of Medicine*, Vol. 324 (1991), pp. 882-88.

²⁴Patient Advance Directives: Early Implementation Experience.

²⁵In a self-administered questionnaire distributed to 200 outpatients, 50 percent of those who had completed an advance directive kept the only copy of the document(s) in a safe deposit box. See A.W. Broadwell, E.V. Boisaubin, J.K. Dunn, and others, "Advance Directives on Hospital Admission: A Survey of Patient Attitudes," *Southern Medical Journal*, Vol. 86, No. 2 (1993), pp. 165-68.

Simply having advance directives available is not necessarily enough to make these documents effective. One study indicated that physicians are often not aware of patients' advance directives. Only one-third of the physicians providing care to terminally ill patients with advance directives knew that the directives were in the patients' charts on day 10 of their hospital stays. Some physicians do not treat the documents as important.²⁶

Directives Often Lack Clarity

Some advance directives may not be followed because how they should be interpreted is unclear. Living wills may specify conditions that cannot easily be translated into medical terms. For example, "heroic measures" may or may not include cardiopulmonary resuscitation, and "no hope of recovery" may actually mean "very remote chance" since absolute certainty is impossible. Similarly, the definition of "terminal" can be subject to interpretation or the care being given may be said to be only palliative. Such linguistic or medical vagueness commonly found in predrafted forms may cause physicians to disregard the document.

Another problem is that an individual with an advance directive may not have previously discussed specific treatment preferences with a designated health care agent. A study of discharged hospital patients found that although 73 percent had general discussions with their agents, only 33 percent had discussions about specific end-of-life interventions, such as mechanical ventilation.²⁷ Some studies have shown that proxy assessments, and even physician predictions, of patient preferences vary, but are sometimes no better than chance. One study found "the only predictor of accurate surrogate decision making was specific discussion between patient and surrogate about life support."²⁸

In addition, many people are not clear in their own minds what they would want. Medical decisions can be particularly complicated. Anticipating all the possible facts and variables is a daunting, if not impossible, task. That is why some ethicists focus on the importance of discussing values rather than specific instructions.²⁹

²⁶Personal communication with Dr. J.M. Teno.

²⁷E.J. Emanuel, D.S. Weinberg, R.G. Gonin, and others, "How Well Is the Patient Self-Determination Act Working?: An Early Assessment," *The American Journal of Medicine*, Vol. 95 (1993), pp. 619-28.

²⁸J. Suhl, P. Simons, T. Reedy, and others, "Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable," *Archives of Internal Medicine*, Vol. 154 (1994), pp. 90-96.

²⁹For an example of this type of form, see appendix I.

Conflict With Family Wishes

Even if a patient has an advance directive, physicians still consult the family. Although it is contrary to law, physicians sometimes do not implement an advance directive if it conflicts with the family's wishes. This is most likely to occur if the treatment is somewhat controversial, such as the withdrawal of artificial nutrition and hydration. For example, a study of tube feeding found that family opinion was the most influential factor affecting the physician's recommendation and that most physicians said they would follow family preferences even when contrary to the living will.³⁰ Similarly, a physician may try to influence the family or other health care agent's decision.³¹ Family members may not be assertive enough about their rights to continually question and assert themselves with the physician.

Physician Autonomy

Physicians' traditional pattern of practicing independently may also affect the implementation of directives. According to ethicists and provider representatives with whom we spoke, physicians typically handle end-of-life decisions appropriately. However, they noted that some physicians may be substituting their own values in not implementing directives as written. A review of recent trends in health care decision-making laws stated that

"The evidence suggests that physicians generally still consider it their responsibility to make treatment decisions that they believe are in the patient's best interest and that patient preferences should be ignored if they are inconsistent with the physician's view of the patient's best interests. In other words, it appears that end-of-life decisions are frequently driven by the physician's values rather than the patient's values."³²

Examples of this predominance of physicians' values are becoming more evident. A recent study at the University of Pennsylvania Medical Center found that 39 percent of ICU doctors surveyed had ended life-sustaining treatment on the basis of medical futility³³ without the consent—or sometimes the knowledge—of the patient or family. In addition, 3 percent

³⁰J.W. Ely, P.G. Peters, S. Zweig, and others, "The Physician's Decision to Use Tube Feedings: The Role of the Family, the Living Will, and the Cruzan Decision," *Journal of the American Geriatric Society*, Vol. 40 (1992), pp. 471-75.

³¹Contrary to public opinion, physicians may actually be more willing than family members to withhold or withdraw life-sustaining treatment. There is some evidence that physicians and nurses are more troubled about the provision of overly burdensome treatment than about undertreatment. See M.Z. Solomon, L. O'Donnell, B. Jennings, and others, "Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments," *American Journal of Public Health*, Vol. 83, No. 1 (1993), pp. 14-23.

³²D. Orentlicher, "The Limits of Legislation," *Maryland Law Review*, Vol. 53, No. 4 (1994), pp. 1281.

³³In general, medical futility refers to treatments that will not positively affect the patient.

said they had made similar decisions over the objection of a patient's family, and 34 percent "declined to withdraw" life support despite a family's wishes.³⁴

Ethical and Legal Issues

Physicians' ethical views may also influence implementation of advance directives.³⁵ Although some experts hold that there is little or no legal or ethical distinction between withholding and withdrawing treatment, be it "ordinary" or "extraordinary" care, a significant proportion of providers do see a distinction. Similarly, some state statutes allow the termination of artificial nutrition and hydration only when explicit statements are present in the directive. However, many providers believe that such care should always be continued, even if other life supports, such as ventilation and dialysis, are stopped.³⁶

Concern over litigation may be an issue for both the facility and the direct provider. For example, nursing homes and home care agencies, which are closely regulated, are especially concerned about litigation. Physicians may be apprehensive about being sued by a family member who wants a different level of care provided than specified in the patient's directive. While this concern is largely unfounded, deviating from the directive leaves a physician susceptible to being sued by other family members, insurers, or other patient advocates.

Conclusions and Recommendation

With the exception of the mailing to Social Security recipients, HHS and most institutional providers appear to be complying with PSDA's provisions. Although they have not done as much as many legal and health care experts feel they should have to educate the public about advance directives, there is some question about the effectiveness of such activities. First, few people have chosen to exercise this form of self-determination in spite of public and private efforts to encourage its use. Second, even in cases of completed advance directives, the lack of

³⁴D.A. Asch, J. Hansen-Flaschen, and P.N. Lanken, "Decisions to Limit or Continue Life-Sustaining Treatment by Critical Care Physicians in the United States: Conflicts Between Physicians' Practices and Patients' Wishes," *American Journal of Respiratory and Critical Care Medicine*, Vol. 151 (1995), pp. 288-92.

³⁵Even philosophies of medical treatment can influence implementation of advance directives. The Hippocratic tradition was one of the first to question ethical limits of medicine and consider when and when not to intervene—emphasizing a balance of nature and man. In contrast, Baconian science was intended to conquer nature. Thus Hippocratic medicine would be more amenable to withholding or withdrawing care, while Baconian would not. See N.S. Jecker, "Knowing When to Stop: The Limits of Medicine," *Hastings Center Report* (May-June 1991), pp. 5-8.

³⁶M.Z. Solomon, L. O'Donnell, B. Jennings, and others.

appropriate discussions with physicians and health care agents about specific preferences may diminish the documents' effectiveness. As a result, some experts in the field are rethinking how best to ensure that patients' wishes for end-of-life care are known and acted on.

Although PSDA does not impose a deadline for compliance, HHS, because of the related costs, has not mailed information about advance directives to Social Security recipients as required under the law. For that reason, we recommend that the Secretary of Health and Human Services analyze whether such a mailing would be a cost-effective way of further meeting the needs addressed by the Congress in PSDA and, if not, seek a legislative amendment repealing the requirement.

Agency Comments

The Secretary of Health and Human Services acknowledged that not every Social Security recipient was sent a mailing on advance directives, noting that such a mailing could cost \$4 million to \$6 million. She believes, however, that "a substantive number of activities have been undertaken to provide such information." For example, HCFA plans to distribute the 1996 Medicare handbook containing specific information about PSDA and advance directives to approximately 40 million beneficiaries. While we recognize that HHS has taken an alternative approach to providing information to recipients, these activities are not consistent with the legislative mandate. If HHS believes that its public education campaign activities fully satisfy the needs addressed by the Congress in PSDA, the Secretary should specifically seek legislative relief from the requirement to conduct a mass mailing to Social Security beneficiaries, as we recommend.

We are sending copies of this report to the Secretary of Health and Human Services, interested congressional committees, and others. Copies will also be made available to others on request. If you or your staff have any questions about this report, please call me at (202) 512-7119. Major contributors are listed in appendix III.

Sincerely yours,



Mark V. Nadel
Associate Director,
Health Financing and Public Health Issues

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Abbreviations

CPR	cardiopulmonary resuscitation
HCFA	Health Care Financing Administration
HCPA	health care power of attorney
HHS	Department of Health and Human Services
ICU	intensive care unit
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
OIG	Office of the Inspector General, HHS
PSDA	Patient Self-Determination Act
UHCDA	Uniform Health-Care Decisions Act

Sample Advance Directive Forms

Some experts and interest groups believe that a good advance directive combines medical care instructions and a designation of a health care agent who can “resolve apparent uncertainties.” Three samples of advance directives are shown in this appendix. All three have sections for assigning a health care power of attorney and personal preferences for medical treatment, and two have a section on patient wishes about organ donation. The instructions accompanying two of these forms state that any or all of the sections may be completed.

Figure I.1 is the form included in the Uniform Health-Care Decisions Act of 1993. (For further discussion of the act, see app. II.) This form does not refer to specific treatments except for artificial nutrition and hydration and relief from pain. It does, however, provide room to list additional preferences.

Figure I.2 is the medical directive form developed by Linda L. Emanuel and Ezekiel J. Emanuel. The medical directive portion includes various scenarios and treatment options; individuals indicate whether they want specific treatments and under what conditions. The patient may also check off a general statement for each scenario without specifying treatments.

Figure I.3 is a values history form from the University of New Mexico. The stated intent of the form is to assist people in thinking and writing about what is important about their health. The first section provides an opportunity to discuss values, wishes, and preferences about issues such as personal relationships, overall attitude toward life, and thoughts about illness. The second portion of the form includes sections to identify which written legal documents have been completed and where they are located, and to express wishes concerning specific medical procedures. The packet also includes a copy of a New Mexico living will and a form to assign power of attorney.

Figure I.1: Excerpt From the 1993
Uniform Health-Care Decisions Act

4. Optional Form.

The following form may, but need not, be used to create an advance health-care directive. The other sections of this [Act] govern the effect of this or any other writing used to create an advance health-care directive. An individual may complete or modify all or any part of the following form:

ADVANCE HEALTH-CARE DIRECTIVE

Explanation

You have the right to give instructions about your own health care. You also have the right to name someone else to make health-care decisions for you. This form lets you do either or both of these things. It also lets you express your wishes regarding donation of organs and the designation of your primary physician. If you use this form, you may complete or modify all or any part of it. You are free to use a different form.

Part 1 of this form is a power of attorney for health care. Part 1 lets you name another individual as agent to make health-care decisions for you if you become incapable of making your own decisions or if you want someone else to make those decisions for you now even though you are still capable. You may also name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to make decisions for you. Unless related to you, your agent may not be an owner, operator, or employee of [a residential long-term health-care institution] at which you are receiving care.

Unless the form you sign limits the authority of your agent, your agent may make all health-care decisions for you. This form has a place for you to limit the authority of your agent. You need not limit the authority of your agent if you wish to rely on your agent for all health-care decisions that may have to be made. If you choose not to limit the authority of your agent, your agent will have the right to:

- a) consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition;
- b) select or discharge health-care providers and institution;
- c) approve or disapprove diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate; and
- d) direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care.

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Part 2 of this form lets you give specific instructions about any aspect of your health care. Choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, including the provision of artificial nutrition and hydration, as well as the provision of pain relief. Space is also provided for you to add to the choices you have made or for you to write out any additional wishes.

Part 3 of this form lets you express an intention to donate your bodily organs and tissues following your death.

Part 4 of this form lets you designate a physician to have primary responsibility for your health care.

After completing this form, sign and date the form at the end. It is recommended but not required that you request two other individuals to sign as witnesses. Give a copy of the signed and completed form to your physician, to any other health-care providers you may have, to any health-care institution at which you are receiving care, and to any health-care agents you have named. You should talk to the person you have named as agent to make sure that he or she understands your wishes and is willing to take the responsibility.

You have the right to revoke this advance health-care directive or replace this form at any time.

* * * * *

PART 1
POWER OF ATTORNEY FOR HEALTH CARE

1) DESIGNATION OF AGENT: I designate the following individual as my agent to make health-care decisions for me:

(name of individual you choose as agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

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OPTIONAL: If I revoke my agent's authority or if my agent is not willing, able, or reasonably available to make a health-care decision for me, I designate as my first alternate agent:

(name of individual you choose as first alternate agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

OPTIONAL: If I revoke the authority of my agent and first alternate agent or if neither is willing, able, or reasonably available to make a health-care decision for me, I designate as my second alternate agent:

(name of individual you choose as second alternate agent)

(address) (city) (state) (zip code)

(home phone) (work phone)

2) AGENT'S AUTHORITY: My agent is authorized to make all health-care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and other forms of health care to keep me alive, except as I state here:

(Add additional sheets if needed.)

3) WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE: My agent's authority becomes effective when my primary physician determines that I am unable to make my own health-care decisions unless I mark the following box. If I mark this box , my agent's authority to make health-care decisions for me takes effect immediately.

4) AGENT'S OBLIGATION: My agent shall make health-care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part 2 of this form, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, my agent shall make health-care decisions for me in accordance with what my agent determines to be in my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

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5) NOMINATION OF GUARDIAN: If a guardian of my person needs to be appointed for me by a court, I nominate the agent designated in this form. If that agent is not willing, able, or reasonably available to act as guardian, I nominate the alternate agents whom I have named, in the order designated.

PART 2
INSTRUCTIONS FOR HEALTH CARE

If you are satisfied to allow your agent to determine what is best for you in making end-of-life decisions, you need not fill out this part of the form. If you do fill out this part of the form, you may strike any wording you do not want.

6) END-OF-LIFE DECISIONS: I direct that my health-care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

a) Choice Not To Prolong Life

I do not want my life to be prolonged if (i) I have an incurable and irreversible condition that will result in my death within a relatively short time, (ii) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (iii) the likely risks and burdens of treatment would outweigh the expected benefits, OR

b) Choice To Prolong Life

I want my life to be prolonged as long as possible within the limits of generally accepted health-care standards.

7) ARTIFICIAL NUTRITION AND HYDRATION: Artificial nutrition and hydration must be provided, withheld, or withdrawn in accordance with the choice I have made in paragraph (6) unless I mark the following box. If I mark this box , artificial nutrition and hydration must be provided regardless of my condition and regardless of the choice I have made in paragraph (6).

8) RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

9) OTHER WISHES: (If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

(Add additional sheets if needed.)

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PART 3
DONATION OF ORGANS AT DEATH
(OPTIONAL)

- 10) Upon my death (mark applicable box)
 a) I give any needed organs, tissues, or parts, OR
 b) I give the following organs, tissues, or parts only

- c) My gift is for the following purposes (strike any of the following you do not want)
(i) Transplant
(ii) Therapy
(iii) Research
(iv) Education

PART 4
PRIMARY PHYSICIAN
(OPTIONAL)

- 11) I designate the following physician as my primary physician:

(name of physician)

(address) (city) (state) (zip code)

(phone)

OPTIONAL: If the physician I have designated above is not willing, able, or reasonably available to act as my primary physician, I designate the following physician as my primary physician:

(name of physician)

(address) (city) (state) (zip code)

(phone)

* * * * *

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12) EFFECT OF COPY: A copy of this form has the same effect as the original.

13) SIGNATURES: Sign and date the form here:

(date) (sign your name)

(address) (print your name)

(city) (state)

Optional SIGNATURES OF WITNESSES:

First witness

Second Witness

(print name)

(print name)

(address)

(address)

(city) (state)

(city) (state)

(signature of witness)

(signature of witness)

(date)

(date)

Figure I.2: Medical Directive Form
Developed by L.I. Emanuel and E.J.
Emanuel

The Medical Directive

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

The Medical Directive allows you to record your wishes regarding various types of medical treatments in several representative situations so that your desires can be respected. It also lets you appoint a proxy, someone to make medical decisions for you if you should become unable to make them on your own.

The Medical Directive comes into effect only if you become incompetent (unable to make decisions and too sick to have wishes). You can change it at any time until then. As long as you are competent, you should discuss your care directly with your physician.

Completing the form. You should, if possible, complete the form in the context of a discussion with your physician. Ideally, this should occur in the presence of your proxy. This lets your physician and your proxy know how you think about these decisions, and it provides you and your physician with the opportunity to give or clarify relevant personal or medical information. You may also wish to discuss the issues with your family, friends, or religious mentor.

The Medical Directive contains six illness situations that include incompetence. For each one, you consider possible interventions and goals of medical care. Situations A and B involve coma; C and D, dementia; E, a situation you describe; and F, temporary inability to make decisions.

For each scenario you identify your general goals for care and specific intervention choices. The interventions are divided into six groups: 1) cardiopulmonary resuscitation or major surgery; 2) mechanical breathing or dialysis; 3) blood transfusions or blood products; 4) artificial nutrition and hydration; 5) simple diagnostic tests or antibiotics; and 6) pain medications, even if they dull consciousness and indirectly shorten life. Most of these treatments are described briefly. If you have further questions, consult your physician.

Your wishes for treatment options (I want this treatment; I want this treatment tried, but stopped if there is no clear improvement; I am undecided; I do not want this treatment) should be indicated. If you choose a trial of treatment, you should understand that this indicates you want the treatment *withdrawn*

if your physician and proxy believe that it has become futile.

The Personal Statement section allows you to mention anything that you consider important to tell those who may make decisions for you concerning the limits of your life and the goals of intervention. For example, in situation B, if you wish to define "uncertain chance" with numerical probability, you may do so here.

Next you may express your preferences concerning organ donation. Do you wish to donate your body or some or all of your organs after your death? If so, for what purpose(s) and to which physician or institution? If not, this should also be indicated in the appropriate box.

In the final section you may designate one or more proxies, who would be asked to make choices under circumstances in which your wishes are unclear. You can indicate whether or not the decisions of the proxy should override your wishes if there are differences. And, should you name more than one proxy, you can state who is to have the final say if there is disagreement. Your proxy must understand that this role usually involves making judgments that you would have made for yourself, had you been able — and making them by the criteria you have outlined. Proxy decisions should ideally be made in discussion with your family, friends, and physician.

What to do with the form. Once you have completed the form, you and two adult witnesses (other than your proxy) who have no interest in your estate need to sign and date it.

Many states have legislation covering documents of this sort. To determine the laws in your state, you should call the state attorney general's office or consult a lawyer. If your state has a statutory document, you may wish to use the Medical Directive and append it to this form.

You should give a copy of the completed document to your physician. His or her signature is desirable but not mandatory. The Directive should be placed in your medical records and flagged so that anyone who might be involved in your care can be aware of its presence. Your proxy, a family member, and/or a friend should also have a copy. In addition, you may want to carry a wallet card noting that you have such a document and where it can be found.

Copyright 1995 by Linda L. Emanuel and Ezekiel J. Emanuel.

An earlier version of this form was originally published as part of an article by Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261:3288-3293, June 9, 1989. It does not reflect the official policy of the American Medical Association.

MY MEDICAL DIRECTIVE

This Medical Directive shall stand as a guide to my wishes regarding medical treatments in the event that illness should make me unable to communicate them directly. I make this Directive, being 18 years or more of age, of sound mind, and appreciating the consequences of my decisions.

Please check appropriate boxes:

- 1. Cardiopulmonary resuscitation** (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying).
- 2. Major surgery** (for example, removing the gallbladder or part of the colon).
- 3. Mechanical breathing** (respiration by machine, through a tube in the throat).
- 4. Dialysis** (cleaning the blood by machine or by fluid passed through the belly).
- 5. Blood transfusions or blood products.**
- 6. Artificial nutrition and hydration** (given through a tube in a vein or in the stomach).
- 7. Simple diagnostic tests** (for example, blood tests or x-rays).
- 8. Antibiotics** (drugs to fight infection).
- 9. Pain medications, even if they dull consciousness and indirectly shorten my life.**

SITUATION A

If I am in a coma or a persistent vegetative state and, in the opinion of my physician and two consultants, have no known hope of regaining awareness and higher mental functions no matter what is done, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

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SITUATION B

If I am near death and in a coma and, in the opinion of my physician and two consultants, have a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent mental and physical disability, and a much greater chance of not recovering at all, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (*please specify*): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
		Not applicable	
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION C

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to recognize people, to speak meaningfully to them, or to live independently, *and I also have a terminal illness*, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (*please specify*): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
		Not applicable	
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

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SITUATION D

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to recognize people, to speak meaningfully to them, or to live independently, *but I have no terminal illness*, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (*please specify*): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION E

If I... (describe situation that is important to you and/or your doctor believes you should consider in view of your current medical situation):

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (*please specify*): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION F

If I am in my current state of health (describe briefly): _____

and then have an illness that, in the opinion of my physician and two consultants, is life threatening but reversible, and I am temporarily unable to make decisions, then my goals and specific wishes — if medically reasonable — would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	<i>Not applicable</i>		
	<i>Not applicable</i>		
	<i>Not applicable</i>		
	<i>Not applicable</i>		
	<i>Not applicable</i>		
	<i>Not applicable</i>		

MY PERSONAL STATEMENT

(use back page if necessary)

Please mention anything that would be important for your physician and your proxy to know. In particular, try to answer the following questions: 1) What medical conditions, if any, would make living so unpleasant that you would want life-sustaining treatment *withheld*? (Intractable pain? Irreversible mental damage? Inability to share love? Dependence on others? Another condition you would regard as intolerable?) 2) Under what medical circumstances would you want to *stop* interventions that might already have been started?

If there is any difference between my preferences detailed in the illness situations and those understood from my goals or from my personal statement, I wish my treatment selections / my goals / my personal statement (please delete as appropriate) to be given greater weight.

When I am dying, I would like — if my proxy and my health-care team think it is reasonable — to be cared for:

- at home or in a hospice
- in a nursing home
- in a hospital
- other (please specify): _____

ORGAN DONATION

(please check boxes and fill in blanks where appropriate)

__ I hereby make this anatomical gift, to take effect after my death:

- I give my body
 any needed organs or parts
 the following parts: _____
- to the following person or institution: _____
 the physician in attendance at my death
 the hospital in which I die
 the following physician, hospital storage bank, or other medical institution:

- for any purpose authorized by law
 therapy of another person
 medical education
 transplantation
 research

__ I do not wish to make any anatomical gift from my body.

HEALTH CARE PROXY

I appoint as my proxy decision-maker(s):

Name and Address

and (optional)

Name and Address

I direct my proxy to make health-care decisions based on his/her assessment of my personal wishes. If my personal desires are unknown, my proxy is to make health-care decisions based on his/her best guess as to my wishes. My proxy shall have the authority to make all health-care decisions for me, including decisions about life-sustaining treatment, if I am unable to make them myself. My proxy's authority becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health-care decisions. My proxy is then to have the same authority to make health-care decisions as I would if I had the capacity to make them, EXCEPT (*list the limitations, if any, you wish to place on your proxy's authority*):

I wish my written preference to be applied as exactly as possible / with flexibility according to my proxy's judgment. (*Delete as appropriate*)

Should there be any disagreement between the wishes I have indicated in this document and the decisions favored by my above-named proxy, I wish my proxy to have authority over my written statements / I wish my written statements to bind my proxy. (*Delete as appropriate*)

If I have appointed more than one proxy and there is disagreement between their wishes, _____ shall have final authority.

Signed:

Signature

Printed Name

Address

Date

Witness:

Signature

Printed Name

Address

Date

Witness:

Signature

Printed Name

Address

Date

Physician (optional):

I am _____'s physician. I have seen this advance care document and have had an opportunity to discuss his/her preferences regarding medical interventions at the end of life. If _____ becomes incompetent, I understand that it is my duty to interpret and implement the preferences contained in this document in order to fulfill his/her wishes.

Signature

Printed Name

Address

Date

Figure I.3: Values History Form
Developed at the University of New
Mexico



The University of New Mexico

Center for Health Law and Ethics
Institute of Public Law
School of Law
1117 Stanford NE
Albuquerque, NM 87131-1446
Telephone (505) 277-5006
FAX (505) 277-7064

VALUES HISTORY FORM

NAME: _____

DATE: _____

If someone assisted you in completing this form, please fill in his or her name, address, and relationship to you.

Name: _____

Address: _____

Relationship: _____

It is important that your medical treatment be **your choice**.

The purpose of this form is to assist you in thinking about and writing down what is important to you about your health. If you should at some time become unable to make health care decisions, this form may help others make a decision for you in accordance with your values.

The first section of this form provides an opportunity for you to discuss your values, wishes, and preferences in a number of different areas such as your personal relationships, your overall attitude toward life, and your thoughts about illness.

The second section of this form provides a space for indicating whether you have completed an Advance Directive, e.g., a Living Will, Durable Power of Attorney for Health Care Decisions or Health Care Proxy, and where such documents may be found.

This form is not copyrighted; you may make as many copies as you wish.

OVERALL ATTITUDE TOWARD LIFE AND HEALTH

What would you like to say to someone reading this document about your overall attitude toward life?

What goals do you have for the future?

How satisfied are you with what you have achieved in your life?

What, for you, makes life worth living?

What do you fear most? What frightens or upsets you?

What activities do you enjoy (e.g., hobbies, watching TV, etc.?)

How would you describe your current state of health?

If you currently have any health problems or disabilities, how do they affect: You? Your family? Your work? Your ability to function?

If you have health problems or disabilities, how do you feel about them? What would you like others (family, friends, doctors) to know about this?

Do you have difficulties in getting through the day with activities such as: eating? preparing food? sleeping? dressing and bathing? etc.

What would you like to say to someone reading this document about your general health?

PERSONAL RELATIONSHIPS

What role do family and friends play in your life?

How do you expect friends, family and others to support your decisions regarding medical treatment you may need now or in the future?

Have you made any arrangements for family or friends to make medical treatment decisions on your behalf? If so, who has agreed to make decisions for you and in what circumstances?

What general comments would you like to make about the personal relationships in your life?

THOUGHTS ABOUT INDEPENDENCE AND SELF-SUFFICIENCY

How does independence or dependence affect your life?

If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency?

If your current physical or mental health gets worse, how would you feel?

LIVING ENVIRONMENT

Have you lived alone or with others over the last 10 years?

How comfortable have you been in your surroundings? How might illness, disability or age affect this?

What general comments would you like to make about your surroundings.

RELIGIOUS BACKGROUND AND BELIEFS

What is your spiritual/religious background?

How do your beliefs affect your feelings toward serious, chronic or terminal illness?

How does your faith community, church or synagogue support you?

What general comments would you like to make about your beliefs?

RELATIONSHIPS WITH DOCTORS AND OTHER HEALTH CAREGIVERS

How do you relate to your doctors? Please comment on: trust; decision making; time for satisfactory communication; respectful treatment.

How do you feel about other caregivers, including nurses, therapists, chaplains, social workers, etc.?

What else would you like to say about doctors and other caregivers?

THOUGHTS ABOUT ILLNESS, DYING AND DEATH

What general comments would you like to make about illness, dying and death?

What will be important to you when you are dying (e.g., physical comfort, no pain, family members present, etc.)?

Where would you prefer to die?

How do you feel about the use of life-sustaining measures if you were: suffering from an irreversible chronic illness (e.g., Alzheimer's disease)? terminally ill? in a permanent coma?

What general comments would you like to make about medical treatment?

FINANCES

What general comments would you like to make about your finances and the cost of health care?

What are your feelings about having enough money to provide for your care?

FUNERAL PLANS

What general comments would you like to make about your funeral and burial or cremation.

Have you made your funeral arrangements? If so, with whom?

OPTIONAL QUESTIONS

How would you like your obituary (announcement of your death) to read?

Write yourself a brief eulogy (a statement about yourself to be read at your funeral).

What would you like to say to someone reading this Values History Form?

LEGAL DOCUMENTS

What legal documents about health care decisions have you signed?

Living Will? Yes ___ No ___
Where can it be found? Name, Address and Phone Number.

Durable Power of Attorney for Health Care Decisions?
Yes ___ No ___
Where can it be found? Name, Address and Phone Number.

Health Care Proxy? Yes ___ No ___
Where can it be found? Name, Address and Phone Number.

Developments in State Law Regarding Advance Directives

Although the Patient Self-Determination Act (PSDA) and the U.S. Supreme Court's landmark right-to-die decision, Cruzan v. Director, Missouri Dept. of Health,³⁷ were significant developments at the federal level, they came well after states had begun to grapple with the legal issues related to end-of-life decisions. State law, in fact, is generally considered the most reliable source of guidance on advance directives. As a result, medical personnel and others may reasonably assume that an advance directive may only be used if a state statute permits. However, several legal experts with whom we spoke suggested that many statutory limitations on the scope of advance directives may be unconstitutional.

Advance Directive Laws Are Widespread and Varied

When PSDA was passed in November 1990, 46 states³⁸ had laws providing a statutory basis for some type of advance directive.³⁹ Between 1990 and 1995, 45 states amended or enacted laws dealing with advance directives. As of March 1995, 46 states had laws providing for both living wills and appointments of health care agents. Of the remaining five states, two have laws providing only for living wills and three only for appointments of health care agents.

The requirements and application of state living will and health care agent statutes vary significantly. Although health care agent statutes in 49 states permit an agent to make decisions when a patient is permanently unconscious, living will statutes in only 38 states include permanent unconsciousness as a qualifying condition.⁴⁰ (Nancy Cruzan, whose care was at issue in the Cruzan case, was characterized not as terminally ill but

³⁷497 U.S. 261 (1990). The Supreme Court held that individuals have a right to refuse life-sustaining treatment, a right that may, in some circumstances, be exercised for them by another. The Court went on to conclude, however, that states may impose procedural safeguards to ensure that another's exercise of that right conforms to the individual's true wishes. For example, as was the case in Cruzan, a state may require clear and convincing evidence before permitting the withdrawal of life-sustaining treatment. The most reliable evidence of an individual's wishes is a written document directly expressing such wishes.

³⁸In this appendix, "states" refers to the 50 states plus the District of Columbia.

³⁹Information regarding the number of states with each type of law was provided by Choice In Dying, which tracks and distributes information about state and federal legislation dealing with end-of-life decisions and has been instrumental in the development of such legislation.

⁴⁰Many of the medical and legal experts with whom we spoke identified medical conditions other than terminal illness, such as locked-in state and severe Alzheimer's disease, in addition to permanent unconsciousness, as conditions for which individuals frequently indicate they do not want life-sustaining treatment. Locked-in state refers to a condition in which a patient may be fully aware of his or her condition and surroundings but unable to move or respond in any way, except possibly by coded eye movements. Because such patients presumably experience pain and can comprehend the suffering their condition is causing others, some consider this condition more horrific than permanent unconsciousness.

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as permanently unconscious.) Similarly, only about two-thirds of the states have statutory language permitting living wills or health care agents to withhold or withdraw artificial nutrition and hydration.⁴¹ Also, 34 states have living will statutes that explicitly forbid the withholding or withdrawal of life support from pregnant patients, and 14 states forbid health care agents from making such a decision.⁴² Table II.1 shows the variation among state living will and health care agent statutes.

⁴¹In *Cruzan*, the Supreme Court assumed that a competent person would have the right to refuse life-saving hydration and nutrition. Yet, difficulties have been reported in connection with requests to withhold or withdraw artificial nutrition and hydration. The consensus among experts with whom we spoke was that when an individual's wishes are clear, such difficulties typically arise from confusion about the legal implications and not an actual legal impediment.

⁴²Most legal experts with whom we spoke indicated that statutes restricting the application of advance directives with respect to pregnant women may, depending on their specific provisions, be vulnerable to legal challenge. For a discussion of this issue, which concludes that the Supreme Court would be unlikely to find such restrictions unconstitutional, see Molly C. Dyke, "A Matter of Life and Death: Pregnancy Clauses in Living Will Statutes," *Boston University Law Review*, Vol. 70 (1990), p. 867.

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Table II.1: Variation in Qualifying Conditions Among State Statutes, 1995

Qualifying conditions	Number of states ^a	
	Living will statutes ^b	Health care agent statutes ^c
Permanent unconsciousness		
Explicitly include/permit	30	22
Implicitly include/permit	8	27
Implicitly exclude	6	•
Explicitly exclude	1	•
Applicability unclear	3	•
Refusal of artificial nutrition and hydration		
Explicitly permit	35	33
Forbid except in limited circumstances	1	•
Not addressed in statute	12	16
Withholding/withdrawing life support from pregnant patients		
Explicitly forbid	34 ^d	14 ^e
Explicitly permit	3	4
Not addressed in statute	11	31

^a“States” refers to the 50 states plus the District of Columbia.

^bThree states (Massachusetts, Michigan, and New York) do not have living will statutes.

^cTwo states (Alabama and Alaska) do not have statutes authorizing the appointment of health care agents.

^dIn 14 of these states, life support cannot be withdrawn or withheld if the fetus is viable or can develop to the point of live birth with continued life support.

^eIn five of these states, life support must be continued unless it is unlikely that the fetus will develop to the point of live birth.

Source: Choice In Dying, March 1995.

**Some Legal Issues
Remain Unsettled**

Although state legislation related to end-of-life decisions is widespread, there are legal issues that, at least in many states, remain largely unsettled: Are advance directives written in one state valid in another? Must an advance directive be in writing? Does a living will apply to emergency medical services? Who makes decisions if a patient has not designated a health care agent? Are advance directives binding on all physicians and institutions? What about “futile” treatment or assisted suicide?

Reciprocity of Advance Directives

Some individuals are concerned that an advance directive that complies with the requirements of one state may not be honored in another state.

Although we could not document such a problem, evidence suggests that an advance directive should be honored in any state, regardless of where it was originally executed. The statutes of 29 states explicitly recognize the validity of living wills that are in accord with either laws of their own state or another state. Similarly, 29 state statutes recognize the powers of health care agents appointed by documents executed in other states.

Even beyond state statutes, a living will should be valid in any state because *Cruzan* and a long tradition of state courts have found that the constitutional right to refuse medical treatment is not lost upon incapacity. Just as a competent person has the right to refuse unwanted medical treatment in any state, an incompetent person's previously articulated wish should also be honored in any state. On the other hand, we are unaware of any court that has held there is a constitutional right to appoint a health care agent although, in her concurrence in *Cruzan*, Justice O'Connor speculated that there may be such a right. Thus, an agent who attempts to exercise authority in one of the 22 states without a reciprocity provision in its health care agent statute is more apt to encounter some justifiable resistance.

**Validity of Oral
Instructions or
Nonconforming Advance
Directives**

Courts have consistently held that a clearly and convincingly expressed oral statement of an individual's treatment wishes should be honored. However, in part because PSDA defines "advance directive" to include only written instructions, medical personnel may erroneously assume that an incompetent individual's previously expressed wishes must be in writing to have legal effect.

Some states include a detailed form in their statute for use in drafting an advance directive, which may reinforce the belief that only written instructions are valid. However, if a patient's clearly expressed treatment wishes generally must be followed even if they are not in writing, it should not matter whether written instructions follow the detailed form included in a state law. The PSDA definition of advance directives states that the form directives take may be specified by state statute or precedents set in court decisions. Legal experts we consulted said that clearly expressed treatment wishes should be honored whether or not they are in writing or follow a statutorily prescribed format; but until clarified in statute, confusion about the validity of oral instructions or what constitutes a valid advance directive is apt to continue.

Conflict With Emergency
Medical Service
Requirements

Another issue is the potential conflict between advance directive statutes and laws involving the provision of emergency medical services. In an emergency, it may not be clear that an individual has an advance directive. Even when emergency medical technicians are presented with a valid advance directive, they are frequently unwilling to comply unless they have authorization specifically applicable to them because they are generally required to administer life-saving procedures. This has resulted in seriously ill patients being resuscitated against their stated wishes and over the objections of their families.

To address this issue, 25 states authorize nonhospital do-not-resuscitate orders. (Such orders, however, cover a narrower spectrum of treatments than typical living wills.) In Virginia, for example, certain individuals may complete a form ordering emergency medical technicians not to revive them. In Oregon, individuals who are terminally ill or permanently unconscious, and only those individuals, can wear bracelets saying “no CPR” (cardiopulmonary resuscitation).

Uncertainties About
Surrogate Decision-Making

Most people believe that in the absence of a written advance directive, their family or partner will decide their final care. As of March 1995, 25 states have statutes providing for surrogate decision-making in the absence of an advance directive. These laws typically establish a hierarchy of related persons (similar to the order of inheritance) who, if the patient has not designated an individual to act as his or her health care agent, may make health care decisions for the incompetent patient. In states with surrogate decision-making laws, families are expected to make decisions consistent with the patients' wishes.

In some states, however, families have no legal right to make end-of-life decisions unless patients have explicitly given them that right. In Cruzan, the Court rejected the argument that the Constitution compels the state to accept the substituted judgment of close family members and to permit them to make medical decisions for an incompetent patient. This gives rise to concern that in states without surrogate laws, there may be a reluctance to rely on the guidance of family members when making end-of-life decisions about a patient.

Concerns Related to
Conscience Exceptions

In legal terms, any provision of unwanted medical care is generally considered to be an assault on the patient. Yet, if a physician morally objects to the withholding or withdrawal of life-sustaining treatment from

a particular patient, he or she cannot be compelled to be involved in that patient's care. (Such a physician cannot abandon a patient until a new physician agrees to take over the patient's care.) Similarly, a health care institution may refuse to honor a living will or the decision of a health care agent if it has established policies based on religious beliefs or moral convictions. PSDA requires both individual providers and health care institutions to inform patients upon admission if they cannot implement an advance directive as a matter of conscience.

Although patients may be able to choose another physician who will honor their advance directive, they may have little meaningful choice about what organization will provide their medical care, especially in the event of an emergency. Legal experts we consulted suggested that provider organizations should be required to arrange an appropriate transfer when they are unwilling, as a matter of conscience, to implement an individual's advance directive. Even so, transfers may not always be practical. Other provider organizations may be reluctant to admit an individual for the sole purpose of withholding life-sustaining treatment, and some communities may have only one hospital or nursing home. At least one court has held that when a transfer is not possible, the provider must comply with a patient's clearly stated wishes regarding treatment.⁴³

Limited Conditions for Application of Advance Directives

Although advance directives are frequently thought of as instruments only for facilitating the refusal of treatment, they can also be used to ensure that individuals receive all possible treatment. Yet, a conflict may arise when medical treatment requested in a living will or by a health care agent is considered futile (unnecessary or of no benefit) by the provider. Medical professionals may also disagree about when a medical treatment is truly futile. Some states have begun to address this issue through case law or statute. For example, Maryland's 1993 advance directives law states that physicians do not have to provide treatment that is "medically ineffective or ethically inappropriate."⁴⁴

Another issue centers on states' limiting the use of advance directives to only incapacitated individuals who are terminally ill or in a permanent vegetative state. Since a competent person always has the right to refuse

⁴³Elbaum v. Grace Plaza of Great Neck, Inc., 544 N.Y.S.2d 840 (1989).

⁴⁴Virginia's statute dealing with advance directives also states that a physician need not provide medical treatment the physician considers medically or ethically inappropriate. However, in 1994, a federal court held that the Emergency Medical Treatment and Active Labor Act preempts the Virginia law, and required a hospital to continue life-sustaining treatment for an anencephalic infant. In the Matter of Baby K, 16 F.3d 590 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994).

treatment, some legal experts have suggested that an incompetent individual in any medical condition should be free to refuse treatment through living wills or health care agents.

At some point, however, the line blurs between the right to refuse treatment and suicide, raising the issue of assisted suicide. Thirty-two states have laws that explicitly criminalize assisted suicide and 11 criminalize assisted suicide through the common law, while in 7 states the law concerning assisted suicide is unclear. Although a few states have considered allowing assisted suicide, there is no clear consensus on the issue. In 1994, Oregon became the first state to have an assisted suicide statute that specifically allows terminally ill patients to obtain lethal prescriptions. But this law, the result of a ballot initiative, has been blocked until a court can rule on its constitutionality. In 1995, a federal appeals court upheld as constitutional the state of Washington's prohibition on physician-assisted suicide, overturning a lower court ruling.

Uniform Health-Care Decisions Act Could Ease Concerns

Recognizing the benefits of more uniformity among state advance directive laws, the National Conference of Commissioners on Uniform State Laws⁴⁵ approved the model Uniform Health-Care Decisions Act⁴⁶ (UHCDA) in 1993. Although UHCDA has been adopted in only one state, New Mexico, many states have enacted laws containing substantially similar provisions. (According to one legal expert we spoke with, by the time UHCDA was passed, most states already had advance directive laws that incorporate many UHCDA provisions.) Widespread adoption of UHCDA would not only lessen state variations discussed earlier, but could clarify a number of unsettled legal issues, including the following:

- An advance directive that complies with UHCDA would be valid regardless of where executed or communicated, which would ease concerns about portability.
- The appointment of a health care agent would have to be in writing, but an individual instruction, authorized in lieu of a living will, could be oral or written.

⁴⁵Established in 1892, the Conference has a dual identity as an organization closely affiliated with the American Bar Association, representing the legal profession, and the original state government association, predating the National Governors Association. The purpose of the Conference is to provide uniform model laws for the states to enact; each state is represented by an average of six commissioners, typically appointed by the governor.

⁴⁶UHCDA supersedes earlier, less comprehensive model acts related to advance directives. A state that has passed one of these predecessor or other laws related to advance directives would be expected to repeal that law if enacting UHCDA.

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- Uncertainties about surrogate decision-making would be lessened by establishing a hierarchy for identifying an appropriate surrogate, including selection of a nonfamily member if no family member is available.
- Health care providers could decline to comply with a living will or other health care decision for reasons of conscience. Organizational providers could decline to comply only if the decision were contrary to a policy expressly based on reasons of conscience and the policy had been communicated in a timely fashion to the patient or person authorized to make health care decisions for the patient.
- An individual would not have to be terminally ill or in a permanent vegetative state for an advance directive to take effect. The authority of a health care agent would be effective whenever an individual lacks capacity unless otherwise specified in the instrument appointing the agent.
- Providers would not have to provide medically ineffective health care or care contrary to generally accepted medical standards.

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