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INCREASING THE AWARENESS OF ADVANCE DIRECTIVES IN MARYLAND

Maria Ellena Carey*

A mentally competent person has the right to make his own medical decisions. Unfortunately, accident or illness can impair the ability to make these decisions. An advance directive enables a person to set forth certain health care decisions, such as whether to withhold or withdraw life-sustaining treatment and who should make these health care decisions if he is rendered incapable of doing so. Without an advance directive, someone unaware of the person’s health care preferences may be given the power to make the medical decisions for him.

Medical and technological advancements have made it possible to extend a person’s life longer than ever before. As a result, a person may face a multitude of medical decisions never before considered. Despite the compelling reasons for advance directives, little is known about their actual use.

Although physicians seem to favor advance directives for medical care, they are reluctant to initiate discussion about them. In fact, physicians are often unaware of whether patients have directives. Recent studies reveal that while an overwhelming majority of individuals want to participate in their health care decisions, very few people actually discuss such issues with their doctors, family, or friends. In 1987, only nine percent of Americans had written advance directives for medical care.

Recent studies have identified several barriers to executing directives. The most common is the lack of physician initiative in discussing the issue. Another is the patient’s difficulty in completing an advance directive due to lack of reading comprehension. Other impediments include procrastination, the belief that advance planning is relevant only to the sick and elderly, and the belief that someone else will take care of these decisions. One of the least frequently cited barriers is the disturbing nature of the topic.

Three events have increased the awareness of advance directives in Maryland. First, the United States Supreme Court decision in Cruzan v. Director, Missouri Department of Health addressed constitutional issues in the termination of life support. Second, the Patient Self-Determination Act was passed, requiring Medicare-certified health care facilities to educate their patients, their staff, and the community about the rights of a patient to make his own health care decisions. Third, the Maryland Health Care Decision Act expanded state law as to advance directives and extended the requirements of the Patient Self-Determination Act to all health care facilities.

CRUZAN V. DIRECTOR, MISSOURI DEPARTMENT OF HEALTH

In 1990, the United States Supreme Court considered the case of Nancy Beth Cruzan, a young woman left in a persistent vegetative state as a result of an automobile accident. After the accident, doctors implanted a gastrostomy feeding tube. Years later, Cruzan’s parents sought to have the feeding tube removed. The trial court approved the request of Cruzan’s parents, basing its decision on a conversation between Cruzan and a friend. According to her friend, Cruzan stated that if she were sick or injured she would not want to continue her life unless she could live somewhat normally.

The trial court approved the request of Cruzan’s parents, basing its decision on a conversation between Cruzan and a friend. According to her friend, Cruzan stated that if she were sick or injured she would not want to continue her life unless she could live somewhat normally. The United States Supreme Court reversed the trial court’s decision, holding that the state’s interest in maintaining Cruzan’s life outweighed Cruzan’s right to refuse treatment.

The Missouri Supreme Court reversed the trial court’s decision, holding that the state’s interest in maintaining Cruzan’s life outweighed Cruzan’s right to refuse treatment. The court stated that clear and convincing evidence of the patient’s desire to forego life-sustaining treatment is needed before such treatment can be withheld, and, in this case, the evidence offered was not sufficient.

The United States Supreme Court, by a five-to-four...
vote, affirmed the decision of the Missouri Supreme Court. The Court held that a state may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state. The Court invoked the same balancing test, weighing a competent person’s constitutionally protected liberty interest in refusing unwanted medical treatment against a state’s interest in the preservation of human life. Because the choice between life and death is a deeply personal decision, a state may seek to safeguard the personal element of the decision through the imposition of a heightened evidentiary requirement.

The dissents vigorously argued that the right to be free from unwanted treatment cannot be outweighed by any interest of the state and that the clear and convincing standard was too stringent.

The Court implied that the right to refuse medical treatment generally encompasses the right to refuse artificially administered food and water. It appears that at least five justices, but as many as eight, accepted the proposition that a competent person has a constitutional right to withhold or withdraw the medical intervention necessary to supply food and water. The Supreme Court, however, has never ruled on this issue.

In an opinion written shortly after the Cruzan decision, the Maryland Office of the Attorney General stated that Cruzan reaffirmed the following conclusions discussed in an opinion written two years earlier: (1) that a competent person has a right to decide whether to accept life-sustaining treatment, including artificially administered sustenance; (2) that a competent person can use an advance directive to plan for decisionmaking even if the person later becomes disabled; and (3) that a disabled person who has not prepared an advance directive nonetheless has a right to have a surrogate (e.g., a family member or a guardian) make the decision on the person’s behalf.

The Attorney General’s opinion implies that Maryland also uses a balancing of interests test. The relevant state interests to be considered are “the preservation of life; the prevention of suicide; the protection of the interests of innocent third parties; and the maintenance of the ethical integrity of the medical profession.”

The Court of Appeals of Maryland addressed life-sustaining treatment issues in Mack v. Mack, which was in accord with the opinion of the Attorney General.

**THE PATIENT SELF-DETERMINATION ACT**

In October 1989, while the Cruzan case was pending before the Supreme Court, the Patient Self-Determination Act (the “PSDA”) was introduced. The PSDA applies to all Medicare-certified facilities, requiring them to provide for the dissemination of information regarding advance directives to the public. Signed into law on November 5, 1990, the PSDA became effective on December 1, 1991.

Cruzan and the statistics regarding advance directives were the driving forces behind the enactment of the PSDA. In 1939, only thirty-seven percent of the population died in institutions; in 1990, it was estimated that eighty percent of the population died in institutions. Approximately eighty percent of the deaths in institutions involve a decision regarding whether to apply, withhold, or withdraw a medical procedure.

By the time the PSDA was introduced, most states had provisions for living wills and/or durable powers of attorney for health care. Most people, however, did not know anything about the laws or the availability of the documents, including physicians. In a survey in Colorado, it was found that seventy-four percent of physicians had no knowledge about the living will law of that state. In a similar survey in Arkansas, only thirty-eight percent of doctors reported being familiar with the state advance directive laws. While ninety-five percent of the people in the country had indicated that they would like to make an advance directive for the future of their health care, only nine percent had actually...
done so.\textsuperscript{40} In addition, only four percent of the hospitals in the country asked patients upon admission whether they had an advance directive.\textsuperscript{41}

Requirements of health care providers. The PSDA requires hospitals, skilled care facilities, home health agencies, hospice programs, and health maintenance organizations that participate in the Medicare program to maintain written policies and procedures guaranteeing that every adult receiving medical care be given written information concerning a patient's right to be involved in his own health care decisions.\textsuperscript{42} Specifically, the provider or organization must provide written information describing the individual's right to make his own decisions under state law, including the right to accept or reject treatment and the right to execute an advance directive as well as information describing the written policies of the provider or organization regarding the implementation of those rights.\textsuperscript{43}

The written information must be provided by hospitals at the time of admission as an inpatient, by skilled nursing facilities at the time of admission as a resident, by home health agencies before the individual comes under the care of the agency, by hospice programs at the time of the initial receipt of hospice care, and by health maintenance organizations at the time of enrollment.\textsuperscript{44} If a patient is incapacitated at the time that he is to receive the information, the patient's family or surrogate must be given the information. Once the patient is no longer incapacitated, however, the facility is obligated to provide the information to the patient.\textsuperscript{45} Although the PSDA applies only to Medicare-certified facilities, the information must be given to all patients, not just Medicare patients.

In addition to distributing written information, the provider or organization must document each patient's medical record as to whether the patient has executed an advance directive.\textsuperscript{46} Furthermore, the PSDA explicitly states that a provider may not condition the provision of care or otherwise discriminate against an individual based on whether he has executed an advance directive.\textsuperscript{47}

Health care providers are also required to provide or participate in the education of their staff and the community on issues concerning advance directives.\textsuperscript{48} To fulfill its community education obligation, a provider or organization may incorporate information in its existing publications or it may simply distribute to the public the same pamphlet which it distributes to its inpatients.\textsuperscript{49} All that is required is that “[t]he educational materials . . . inform the public of their rights under state law to make decisions concerning the receipt of medical care by or through the provider or organization; the right to formulate advance directives; and the provider or organization’s implementation policies concerning advance directives.”\textsuperscript{50}

Requirements of the states. Each state is required to develop and maintain a written description of the state's law concerning advance directives.\textsuperscript{51} The description may be written by a state agency, association, or other private nonprofit entity, and is to be made available to health care providers or organizations for distribution to the public.\textsuperscript{52}

Requirements of the Secretary of Health and Human Services. In accordance with the PSDA, the Secretary of Health and Human Services is required to develop and implement a national campaign to inform the public of the option to execute advance directives and the right to participate in and direct health care decisions.\textsuperscript{53} The Secretary is also responsible for developing or approving nationwide informational materials to be distributed by providers to inform the public and the medical and legal professions of a person's rights concerning medical care decisions. These materials must address the right to accept or refuse medical or surgical treatment and the existence of advance directives.\textsuperscript{54} Finally, the Secretary is required to work with the states in preparing material describing applicable state law,\textsuperscript{55} to mail information to Social Security recipients, and to add a description of the new law to the Medicare handbook.\textsuperscript{56}

Effect of the PSDA. Information provided at a
national conference on the PSDA in January 1993 revealed that both the number of people completing advance directives and the public's knowledge about advance directives increased after the PSDA was passed. After the PSDA went into effect, the percentage of patients who had completed an advance directive, either in the form of a living will or a power of attorney for health care, increased approximately 2.5 percent. While this increase is marginal, the proportion of patients with increased knowledge regarding advance directives increased approximately 10 percent. Although public awareness may have increased slightly, more needs to be done to increase the awareness and encourage the execution of advance directives.

THE MARYLAND HEALTH CARE DECISION ACT

Enacted almost two years after the implementation of the PSDA, the Maryland Health Care Decision Act (the "HCDA") is a comprehensive reform of the law in Maryland regarding health care decisionmaking. The first of the four parts of the HCDA increases the number of available methods by which an individual may make decisions about future medical contingencies and confirms an individual's right to designate a health care agent. The HCDA provides that a competent person may make an advance directive by one or more of three methods: (1) a written directive authorizing the provision, withholding, or withdrawal of health care; (2) a written directive appointing an agent to make health care decisions according to the advance directive, the known wishes of the declarant, or, if the declarant's wishes are not known, the best interest of the declarant; and (3) an oral directive authorizing the provision, withholding, or withdrawal of health care or appointing an agent to make health care decisions.

The HCDA contains two suggested health care decisionmaking forms. The first (Form I) is a living will, which under prior Maryland law applied only if the person was terminally ill. The HCDA allows a person to direct that life-sustaining procedures be withheld or withdrawn not only if the person is in a terminal condition but also if he is in a persistent vegetative state. A terminal condition is defined as "an incurable condition ... which ... makes death imminent." A persistent vegetative state is "a condition ... in which a patient has suffered a loss of consciousness ... and from which ... it can be determined ... that there can be no recovery.

The second form (Form II) has two parts. Part A allows a person to appoint a health care agent who is given the authority to make health care decisions, obtain and consent to the disclosure of medical information, employ and discharge health care providers, authorize admission to or discharge from health care facilities, and consent to the provision, withholding, or withdrawal of health care, including life-sustaining procedures. The document also allows the person to limit the authority of the agent and to specify when the directive becomes effective, either when two physicians certify that he is incapable of making his own decisions or when the document is signed. The agent is instructed to make decisions based on the declarant's wishes or, if his wishes are unknown or unclear, based on what is in the declarant's best interest.

Part B of Form II is similar to Form I in that it is a living will directing the refusal of life-sustaining treatment when a person is in a terminal condition or a persistent vegetative state. This form, however, also allows a person to direct the provision, withholding, or withdrawal of life-sustaining treatment if he is in an end-stage condition. An end-stage condition is "an advanced, progressive, irreversible condition ... that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency ... and ... for which ... treatment of the irreversible condition would be medically ineffective." Both suggested advance directive forms permit a person to state that he be given all available medical treatment in accordance with accepted health care standards. These forms also allow for modifications in decisions concerning life-sustaining procedures if the person is pregnant.

The second part of the HCDA authorizes surrogate decisionmaking on behalf of incapacitated patients who did not designate a health care agent, subject to certain standards and limitations. In order of priority, a surrogate may be:

1. a guardian for the patient, if one has been appointed;
2. the patient's spouse;
3. an adult child of the patient;
4. a parent of the patient;
5. an adult brother or sister of the patient; or
6. a friend or other relative of the patient who presents an affidavit to the attending physician stating that the surrogate is a relative or close friend of the
patient and stating the facts and circumstances demonstrating that the person has maintained regular contact with the patient sufficient to be familiar with the patient’s activities, health, and personal beliefs.77

If a surrogate knows enough to judge what the person would decide if he were able, the surrogate should be able to make that decision. This form of decisionmaking is called “substituted judgment.”78 If the surrogate does not know what the person would choose if he were able, the surrogate must base a decision on the objective costs and benefits of treatment to determine what is in the person’s best interest.79 The “substituted judgment” standard is preferred because the surrogate is carrying out the decisions the patient would have chosen.80

Under the HCDA, any dispute among surrogates with equal decisionmaking priority shall be referred to the institution’s patient care advisory committee. The health care provider may either act in accordance with the committee’s recommendation or transfer the patient to another health care provider.81


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ENCOURAGING ADVANCE DECISION-MAKING

The Cruzan case, the PSDA, and the HCDA have made the public aware of its rights to participate in and control future health care decisions. The three events have had several positive effects.

The PSDA encourages patient, staff, and community education. In addition, the HCDA extends the requirements of the PSDA to all health care facilities, not just those that are Medicare-certified.82 A person’s knowledge about his rights enables him to get past some of the barriers which kept him from executing an advance directive.83

Each of these three events recognizes advance directives as the best method of ensuring that personal health care decisions will be followed.84 In addition, the advance directive provides the necessary evidence of the patient’s preferences.

Even if a person does not execute an advance directive, he may be stimulated to discuss health care preferences with family members, friends, and health care providers. The surrogate must rely on his knowledge about the patient and his discussions with the patient so that, in the absence of an advance directive, his wishes may be followed. This, however, is not a reliable method of providing for health care preferences. The state may limit the authority of the surrogate, and the surrogate may not actually know the patient’s desires.

Although public awareness of advance directives and their import has increased, there are still several problems left unresolved.

Only minimum communication is required by the PSDA. A provider or organization is only required to give written information. The materials do not ensure knowledge and understanding of the subject matter. As mentioned earlier, reading comprehension of the patient may present an obstacle. Furthermore, the abundance of paperwork may inhibit examination.

There is no requirement that the patient be given the opportunity to execute an advance directive. In fact, no one is required to discuss the information with a patient.

Only inpatients are targeted by the PSDA. Routine medical services, such as physicals and outpatient visits, are not covered by the PSDA.

The PSDA, while focusing on informing the public, only requires that information be provided upon admission as an inpatient. The need for an advance directive may arise before admission. By the time of admission, the patient is often unable to execute an advance directive or communicate his wishes due to incapacity or incompetency.

The PSDA requires that a patient’s medical record indicate if he has an advance directive but does not require the provider or organization to obtain a copy of the advance directive. The directive is essentially worthless if the provider or organization does not know the content of the directive.

The PSDA requires education, but it provides no funding for the education. A provider or organization is left to balance the obligation to inform the public with the burden of funding the education. The competing interests are likely to result in a minimum of education.

Additional factors that must be considered are the reliability and effectiveness of advance directives. Problems surrounding advance directives include the possibility that a person completing an advance directive may not understand it, he may change his mind regarding the health care decisions made, or he may not anticipate conditions that might arise later. Further, he may appoint a surrogate who is unknown to the health care provider, someone with whom the provider is uncomfortable, or someone unaware of his health care preferences.
CONCLUSION

Although the effect of the HCDA on public awareness of advanced directives in Maryland is relatively unknown, the 1993 conference regarding the effect of the PSDA demonstrates that there is room for improvement. More people must be encouraged to execute advance directives. Following are some suggestions:

1. Health care providers should do more to provide information to patients than disseminate it through brochures. The admission process when a person initially obtains the information should only be the beginning. Employees and staff should be ready at all times to answer questions regarding health care decisions. In addition, forms should be made available so that patients are given the opportunity to execute advance directives if they wish. Social workers should be available to initiate discussions and respond to questions. Furthermore, the health care provider should do everything possible to obtain a copy of an advance directive if a patient has executed one.

2. Health care providers must provide education for their employees and staff. Virtually everyone in an institution who has patient contact should be prepared to respond to requests for information about advance directives. They should be provided with education regarding both the law and institutional policies. In-service training should provide information about advance directives and strengthen communication skills so that employees and staff may respond with sensitivity and compassion to patients and families in emotional distress. Publications and newsletters may assist in informing the employees and staff. Ethics committees and social service workers would be ideal groups to disseminate information.

3. Health care providers must also provide community education. They should distribute literature and sample forms through their institutions as well as churches, service clubs, seniors organizations, legal offices, physicians’ offices, and libraries. They should also establish speaker bureaus, in which trained volunteers speak to various organizations. Educational programs and informational sessions, with representatives from the institution, physicians, and attorneys, should also be provided.

4. Physicians should assume part of the responsibility for encouraging advance directives. As mentioned earlier, an overwhelming majority of patients would like to discuss their health care preferences with their physicians, but few actually do. Even if the discussions do not lead to written advance directives, a legally effective oral directive may result.

5. The legal profession should also encourage advance directives. Approximately seventy-four percent of Americans have wills, but only nine percent have advance directives. Attorneys are afforded an ideal opportunity to discuss advance directives when discussing estate planning.

6. The Secretary of Health and Human Services should provide funding for studies on advance directives. If the barriers to execution of advance directives are precisely defined, the medical profession, the legal profession, and health care policymakers will be in a better position to develop measures to respond to the problem.

7. The media should also take part in a nationwide campaign to encourage advance directives. Many vehicles should be used, including editorials, newspaper features, public service announcements, and radio and television talk shows.

Advance directives protect a patient’s right to make his own health care decisions before he loses his decisionmaking capacity. They ensure that a patient’s wishes regarding life-sustaining treatment or a surrogate decisionmaker are honored even when the patient is no longer able to articulate preferences. Furthermore, advance directives minimize legal risk and reduce the chances of conflicts within the setting of the health care provider.

ENDNOTES


2 Emanuel, supra note 1, at 889.

4Emanuel, supra note 1, at 889.

5Steven R. Steiber, Right to Die: Public Balks at Deciding for Others, 61 Hosp. 72, 72 (Mar. 5, 1987).

6See Emanuel, supra note 1, at 891. See also Stelter, supra note 3, at 957.


9See Emanuel, supra note 1, at 891-92. See also Paul Cotton, Talk to People About Dying - They Can Handle It, Say Geriatricians and Patients, 269 JAMA 321, 321 (Jan. 20, 1993).


13497 U.S. at 265-67.

14See 760 S.W.2d 408, 433 (Mo. 1988) (trial court judgment reprinted in dissenting opinion).

15760 S.W.2d 408, 424 (Mo. 1988).

16Id. at 425.

17Id. at 426.


19Id. at 269-85.

20Id. at 278-80.

21See id. at 301-57.


23Id.


27See id. at 10-11.


29329 Md. 188, 618 A.2d 744 (1993).


33Fred H. Cate, Implementing the Patient Self-Determination Act, 6 Med. Staff Couns. 9, 10 (1992).


36Levin, supra note 35.


38Danforth, supra note 37.

39Levin, supra note 35.

40Danforth, supra note 37.

41Id.


50 Id.
52 Id.
57 The Patient Self-Determination Act’s First Year, supra note 57.
63 See Md. Code Ann., Health-Gen. §§ 5-602(a) and (c) (1990).
64 See Md. Code Ann., Health-Gen. § 5-603 Form I (Supp. 1993). In addition, the Maryland Office of the Attorney General has construed the living will law to allow a person to explicitly state in his living will his decision whether to continue, withhold, or withdraw the artificial administration of food and water. 73 Op. Att’y Gen. at 182; 75 Op. Att’y Gen. No. 44, at 12. The opinion also stated that, if a person modified the language of a living will to include conditions other than terminal illnesses, the changes may be probative though they will not be self-executing as a living will otherwise is. 75 Op. Att’y Gen. No. 44, at 12-13.
67 Md. Code Ann., Health-Gen. § 5-603 Form II (Supp. 1993). This is referred to as a durable power of attorney or a health care power of attorney.
68 Id.
69 Id.
70 Id.
71 Id.
72 See id.
77 Md. Code Ann., Health-Gen. §§ 5-605(a)(2) and (3) (Supp. 1993).
79 Id. See also Md. Code Ann., Health-Gen. § 5-605(c) (Supp. 1993). Although the HCDA does not explicitly state that a surrogate may authorize the withholding or withdrawal of life-sustaining treatment, such is implied. See Md. Code Ann., Health-Gen. §§ 5-605(b)(2), (c), and (d) (Supp. 1993).
80 Id.
83 See notes 6-9 and accompanying text.
84 In the months following the Cruzan holding, the Concern for Dying/Society for the Right to Die (now known as Choice in Dying, Inc.) received more than 100,000 requests a month for living will forms. Terese Hudson, Hospitals Work to Provide Advance Directives Information, 65 Hosp. 26, 26 (Feb. 5, 1991).
85 Emanuel, supra note 1, at 891.
86 See supra notes 5 and 40.
87 A newspaper article in the Baltimore Sun near the beginning of October 1993 spurred awareness, resulting in approximately 5,000 weekly requests for sample forms from the Maryland Office of the Attorney General. Telephone interview with Jack Schwartz, Chief Counsel, Opinions and Advice section of the Maryland Office of the Attorney General (Nov. 24, 1993).


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