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The Health Care Proxy and the Living Will

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out such therapy is perhaps less a sign of their irrationality than a reflection of the failure of orthodox medicine to recognize and respond to their needs and anxieties.

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REFERENCES

1. Woods, NF, Most A, Dery GK. Prevalence of perimenstrual symptoms. *Am J Public Health* 1982; 72:1257-64.
2. Rivera-Tovar AD, Frank E. Late luteal phase dysphoric disorder in young women. *Am J Psychiatry* 1990; 147:1634-6.
3. Reid RL. Premenstrual syndrome. *Curr Probl Obstet Gynecol Fertil* 1985; 8(2):1-57.
4. Trunnell EP, Turner CW, Keyes WR. A comparison of the psychological and hormonal factors in women with and without premenstrual syndrome. *J Abnorm Psychol* 1988; 97:429-36.
5. Schmidt PJ, Nieman LK, Grover GN, Muller KL, Merriam GR, Rubinow DR. Lack of effect of induced menses on symptoms in women with premenstrual syndrome. *N Engl J Med* 1991; 324:1174-9.
6. Freeman EW, Sondheimer S, Weinbaum PJ, Rickels K. Evaluating premenstrual symptoms in medical practice. *Obstet Gynecol* 1985; 65:500-5.
7. DeJong R, Rubinow DR, Roy-Byrne P, Hoban MC, Grover GN, Post RM. Premenstrual mood disorder and psychiatric illness. *Am J Psychiatry* 1985; 142:1359-61.
8. Mortola JF, Gorton L, Yen SS. Depressive episodes in premenstrual syndrome. *Am J Obstet Gynecol* 1989; 161:1682-7.
9. Casson P, Hahn PM, Van Vugt DA, Reid RL. Lasting response to ovariectomy in severe intractable premenstrual syndrome. *Am J Obstet Gynecol* 1990; 162:99-105.
10. Backstrom CT, Boyle H, Baird DT. Persistence of symptoms of premenstrual tension in hysterectomized women. *Br J Obstet Gynaecol* 1981; 88:530-6.

SOUNDING BOARD

THE HEALTH CARE PROXY AND THE LIVING WILL

AMERICAN medicine is awash in forms: insurance forms, disability forms, informed-consent forms, and forms for various examinations, to name just a few. Forms can help make the practice of medicine more efficient, but they can also make it more routinized, impersonal, and bureaucratic. Congress and the President have decreed that beginning December 1, 1991, all hospitals, nursing facilities, hospice programs, and health maintenance organizations that serve Medicare or Medicaid patients must provide all their new adult patients with written information describing the patient's rights under state law to make decisions about medical care, including their right to execute a living will or durable power of attorney.¹ New forms will be routinely added to the practice of medicine. Their purpose is to help implement a right that has been universally recognized: the right to refuse any and all medical interventions, even life-sustaining interventions. The challenge is to use these forms to foster communication between doctor and patient, as well as respect for the patient's autonomy.

HISTORICAL CONTEXT

The term "living will" was coined by Luis Kutner in 1969 to describe a document in which a competent adult sets forth directions regarding medical treat-

ment in the event of his or her future incapacitation.² The document is a will in the sense that it spells out the person's directions. It is "living" because it takes effect before death. Public interest in this document has always been high, and a national organization, Concern for Dying, has devoted most of its resources for the past 20 years to educating the public and professionals about the living will. A sister organization, Society for the Right to Die (which is in the process of merging with Concern for Dying to form the National Council for Death and Dying), simultaneously devoted its primary efforts to encouraging states to pass legislation giving formal legal recognition to the living will.

In 1976 the country's attention focused on the case of Karen Ann Quinlan, a young woman in a persistent vegetative state, and her parents' attempts to have her ventilator removed so she could die a natural death.³ The New Jersey Supreme Court granted the parents' petition and held that an "ethics committee" could grant all parties concerned legal immunity for their actions.³ The court did this because it believed that it was the fear of legal liability that prevented Quinlan's physicians from honoring her parents' request. Her story prompted the enactment of the nation's first living-will statute, California's Natural Death Act, in 1976. The California statute is very narrow. A legally enforceable declaration can be executed only 14 days or more after a person is diagnosed as having a terminal illness, defined as one that will cause the patient's death "imminently," whether or not life-sustaining procedures are continued. Thus, even though this statute was inspired by her story, it would not have helped Quinlan, because she was not terminally ill.

By 1991, more than 40 states had enacted living-will statutes. All these laws provide immunity to physicians and other health care professionals who follow the patient's wishes as expressed in a living will. Virtually all of them also suffer from four major shortcomings, however: they are applicable only to those who are "terminally ill"; they limit the types of treatment that can be refused, usually to "artificial" or "extraordinary" therapies; they make no provision for the person to designate another person to make decisions on his or her behalf or set forth the criteria for such decisions; and there is no penalty if health care providers do not honor these documents.^{4,5}

ADDRESSING THE LIMITATIONS OF THE LIVING WILL

These problems led to calls for second-generation legislation on the living will.⁴ Other shortcomings were also noted. Living wills require a person to predict accurately his or her final illness or injury and what medical interventions might be available to postpone death, and living wills require physicians to make decisions on the basis of their interpretation of a document, rather than a discussion of the treatment options with a person acting on behalf of the patient.

The proposed solution to these problems was not to modify the living will but to replace it with another form, one assigning a durable power of attorney to a designated person (known, in this context, as appointing a health care proxy).^{6,7} The person named in the document (also called the health care proxy) is variously known as the attorney, the agent, the surrogate, or the proxy — four terms that are synonyms in this context.

Every state has a durable-power-of-attorney law that permits persons to designate someone to make decisions for them if they become incapacitated.⁸ Although these statutes were enacted primarily to permit the agent to make financial decisions, no court has ever invalidated a durable power of attorney specifically designed to enable the designated person to make health care decisions. In the recent *Cruzan* case — in which Nancy Cruzan's parents, basing their attempt on their daughter's previous statements, sought to have her tube feeding discontinued after she had been left in a persistent vegetative state by an automobile accident — Justice Sandra Day O'Connor advised citizens to employ this device. In her concurring opinion, O'Connor observed that the decision in *Cruzan* "does not preclude a future determination that the Constitution requires the States to implement the decisions of a duly appointed surrogate."^{9,10} The *Cruzan* case itself, which involved facts essentially identical to those in *Quinlan*, gave impetus to the concept of a health care proxy, just as the *Quinlan* case had previously increased interest in the living will. Physicians are legally and ethically bound to respect the directions of a patient set forth in a living will, but living wills are limited because no one can accurately foretell the future, and interpretation may be difficult.¹¹ Attempts to make the living will less ambiguous by developing comprehensive checklists with alternative scenarios may be too confusing and abstract to be useful to either patients or health care providers, although opinions on this differ.^{12,13}

THE MOVE TO DESIGNATE HEALTH CARE PROXIES

Although new laws are not necessary in any state (because of existing laws regarding the assignment of a durable power of attorney), the current trend in the United States is for states to enact additional proxy laws that specifically deal with health care. Such laws generally specify the information that must be included in the proxy form and the standards on which treatment decisions must be based and grant good-faith immunity for all involved in carrying out the treatment decision. Two of the best-written proxy laws have recently become effective in New York (in January 1991) and Massachusetts (in December 1990).¹⁴ The New York law is based on a recommendation of the New York State Task Force on Life and the Law, and that group's statement of its rationale is still the best introduction to the concept of the health care proxy.¹⁵ The Massachusetts proxy law is largely modeled on the New York law.

The heart of both laws (and all proxy laws) is the

same: to enable a competent adult (the "principal") to choose another person (the "proxy" or "agent") to make treatment decisions for him or her if he or she becomes incompetent to make them. The agent has the same authority to make decisions that the patient would have if he or she were still competent. Instead of having to decipher a document, the physician is able to discuss treatment options with a person who has the legal authority to grant or withhold consent on behalf of the patient. The manner in which the agent must exercise this authority is also crucial. The agent must make decisions that are consistent with the wishes of the patient, if these are known, and otherwise that are consistent with the patient's best interests.

Proxy laws also permit the principal to limit the authority of the agent in the document (for example, by not granting authority to refuse cardiopulmonary resuscitation or tube feeding), but the more limitations the principal puts on the agent, the more the document appointing a health care proxy resembles a living will. In addition, because every limitation is subject to interpretation, the likelihood that a dispute will arise about the meaning of the document is increased. One compromise is to give the agent blanket authority to make decisions and to detail one's values and wishes with as much precision as possible in a private letter to the agent. The agent could use this letter when it was relevant to the actual decision and keep it private when it was not relevant.¹⁶

IMPLEMENTING LAWS REGARDING HEALTH CARE PROXIES

The goal of appointing a proxy is to simplify the process of making decisions and to make it more likely that the patient's wishes will be followed — not to complicate existing problems. If hospitals and hospital lawyers cooperate, this goal will be attained, because the vast majority of physicians will welcome the ability to discuss treatment options with a person chosen by the patient who has the legal authority to give or withhold consent.⁷ Hospitals can help their patients by making a simple proxy form available, by educating their medical, nursing, and social-service staffs about the laws governing health care proxies, and by supporting decisions made by the agents. Hospitals can impede the process of making good decisions, however, if they concentrate on the paperwork rather than on the way in which decisions are made. Some Massachusetts attorneys, for example, have already drafted a 13-page, single-spaced proxy form that is all but unintelligible to nonlawyers. Others have begun to explore and to catalogue all the reasons why physicians and hospitals might want to seek judicial review before honoring the decision of a health care agent. Neither of these strategies is constructive. The use of complex forms and obstructive strategies makes it likely that treatment decisions will actually be made by the hospital's lawyers and the agent's lawyers, not by the agent and the physician. If this happens, the trend to designating a health care agent will be frustratingly counterproductive, since, instead of encour-

aging a focus on the patient and the patient's wishes, where it belongs, the new proxy forms will add another layer of bureaucracy and another outsider to the decision process.

The most useful form for both patients and providers is a simple one-page document that sets forth all necessary information in easily comprehensible language. The one-page form in the Appendix, which is easily understood and meets all the requirements of the new Massachusetts proxy law (as well as those of the New York law) was developed by a broad-based task force made up of representatives of all the major health care organizations in the state, including the Massachusetts Medical Society, the Massachusetts Hospital Association, the Massachusetts Nurses Association, the Massachusetts Federation of Nursing Homes, and the Massachusetts Department of Public Health, as well as the Massachusetts Executive Office of Elder Affairs and the Massachusetts Bar Association. This model form (available in bulk from Massachusetts Health Decisions, 101 Tremont St., No. 600, Boston, MA 02108), which also includes instructions and spaces for the optional signatures of the agent and an alternate (naming an alternate is not required), will be distributed across the state. The degree of cooperation in its development was virtually unprecedented and may provide a model for future efforts.

ADDING TO THE DOCUMENT DESIGNATING A PROXY

Perhaps out of concern for efficiency, some commentators have advocated combining an organ-donor form with the form designating a health care proxy.¹⁰ This is a serious error for at least two reasons. First, much effort has been expended over the past 20 years to separate the issues of organ donation and treatment decisions in the public's mind, since the main reason people do not sign organ-donor cards is that they believe doctors might "do something to me before I'm really dead."¹⁷ Tying organ donation to treatment refusals that might lead to death only heightens this concern and is likely to lead people to use neither form. Second, the proxy form takes effect when the patient becomes incompetent; in contrast, the organ-donor form takes effect only on the patient's death. The health care agent can have nothing to say about organ donation, because the agent can make only treatment decisions, an authority that dies with the patient. Organ donation is laudable, but it is not related to the designation of a health care agent, and the principal should authorize donation on a separate form designed for that purpose. Organ-donor forms may teach another lesson as well. No physician in the United States will honor an organ-donor form over the objections of the patient's family. Similarly, physicians have difficulty honoring a patient's living will over the family's objections. Because it identifies a person with legal authority to talk with the physician, the health care proxy is likely to be a more effective mechanism to implement the patient's wishes.

It should be stressed that forms naming a health care proxy do not substantively change existing law;

they merely make it procedurally easier for a person to designate an agent who is authorized to make whatever health care decisions the person could legally make if competent, and they give health care providers legal immunity for honoring such decisions. The patient can, for example, give the agent the authority to refuse any and all medical care, but the agent has no more legal authority than the principal to insist on assisted suicide or to demand a lethal injection. The naming of an agent also solves the problem of a dispute among family members concerning treatment, since the agent has the legal and ethical right and responsibility to make the decision. When a long-lost relative arrives and demands that "everything be done or I'll sue," the physician can refer that person to the agent, rather than have to try to achieve a consensus.

LIMITS OF THE CONCEPT OF THE HEALTH CARE PROXY

Only competent adults who actually execute a document can name a health care agent. Since fewer than 10 percent of Americans have either living wills or organ-donor cards, few may use this mechanism. It has no application to children, the mentally retarded, or others unable to appreciate the nature and consequences of their decisions. Treatment decisions for these groups will continue to be governed by the vague "best interests" standard, which is the functional equivalent of "reasonable medical care," "appropriate medical care," or "indicated medical care." The document will also be of limited use in the emergency department, although in rare cases the health care agent may arrive with the principal and there may be time for consultation and informed consent before a specific intervention is tried. Nor will the document solve problems of futility. Physicians will retain the right not to offer treatment that is contraindicated, useless, or futile.

THE RESPONSIBILITY OF PHYSICIANS

I have encouraged members of both the Boston Bar Association and the Massachusetts Bar Association to make health care-proxy forms available to the public and their clients free of charge as a public service. Many have agreed. It will also be useful to the public if physicians make such forms available to their patients and encourage them to fill them out. Physicians may also be more comfortable about relying on the decisions of the designated agent if patients are willing to discuss their choice of agent with the physician, although this is not a requirement. Any form that is used must be written in language that both patients and health care providers can easily understand; the form need not be written by a lawyer and should not require a lawyer to interpret.

Like soldiers in past wars, Americans serving in the Persian Gulf wrote their wills. This time, however, many also wrote living wills or executed durable powers of attorney. As one reporter observed, "In the process, the soldiers had to clarify ambiguous personal relationships, chart out their children's lives, and, in

some cases, confront their own mortality for the first time."¹⁸ Designating a health care agent gives us all the opportunity to confront our mortality and to determine who among our friends and relatives we want to make treatment decisions on our behalf when we are unable to make them ourselves. A clear focus on these substantive issues, rather than on forms or formalities, could help patients feel more secure that their wishes regarding medical treatment will be respected and could help health care professionals be more secure that the treatment decisions made for incompetent patients actually reflect the patients' wishes. These are certainly worthy goals.

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APPENDIX: A MODEL HEALTH CARE PROXY FOR USE IN MASSACHUSETTS

I, _____, residing at _____,
(principal — print your name)
(street) (city or town) (state)
appoint as my Health Care Agent _____
(name of person you choose as agent)
of _____,
(street) (city or town) (state) (phone)

Optional: If my agent is unwilling or unable to serve, then I appoint as my alternate _____
(name of person you choose as alternate)
of _____,
(street) (city or town) (state) (phone)

My agent shall have the authority to make all health care decisions for me, subject to any limitations I state below, if I am unable to make decisions myself. My agent'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 agent is then to have the same authority to make health care decisions as I would if I had the capacity to make them, *except* (here list the limitations, *if any*, you wish to place on your agent's authority):

I direct my agent to make decisions on the basis of my agent's assessment of my personal wishes. If my personal wishes are unknown, my agent is to make decisions on the basis of my agent's assessment of my best interests. Photocopies of this Health Care Proxy shall have the same force and effect as the original.

Signed _____

Complete only if principal is physically unable to sign: I have signed the principal's name above at his or her direction in the presence of the principal and two witnesses.

(name)

(street)

(city or town) (state)

Witness Statement

We, the undersigned, each witnessed the signing of this Health Care Proxy by the principal or at the direction of the principal and state that the principal appears to be at least 18 years of age, of sound mind, and under no constraint or undue influence. Neither of us is named as the health care agent or alternate in this document.

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In our presence this _____ day of _____, 199__.

Witness 1 _____ (signature) Witness 2 _____ (signature)

Name (print) _____ Name (print) _____

Address _____ Address _____

REFERENCES

- 42 U.S.C. 1395 cc (a) (1) et. seq. (as amended Nov. 1990).
- Kutner L. Due process of euthanasia: the living will a proposal. *Indiana Law J* 1969; 44:539.
- In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976).
- Legal Advisors Committee, Concern for Dying. The right to refuse treatment: a model act. *Am J Public Health* 1983; 73:918-21.
- Annas GJ. The rights of patients: the basic ACLU guide to patient rights. 2nd ed. Carbondale, Ill.: Southern Illinois University Press, 1989:196-255.
- Veatch RM. Death, dying, and the biological revolution: our last quest for responsibility. New Haven, Conn.: Yale University Press, 1976:184-6.
- Relman AS. Michigan's sensible "living will." *N Engl J Med* 1979; 300:1270-2.
- Sabatino CP. Health care powers of attorney. Chicago: American Bar Association, 1990.
- Cruzan v. Director, Missouri Dept. of Health, 110 S. Ct. 2841 (1990).
- Annas GJ. Nancy Cruzan and the right to die. *N Engl J Med* 1990; 323:670-3.
- Danis M, Southerland LI, Garrett JM, et al. A prospective study of advance directives for life-sustaining care. *N Engl J Med* 1991; 324:882-8.
- Emanuel LL, Emanuel EJ. The medical directive: a new comprehensive advance care document. *JAMA* 1989; 261:3288-93.
- Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care — a case for greater use. *N Engl J Med* 1991; 324:889-95.
- Mass. G.L. c. 201D.
- Life-sustaining treatment: making decisions and appointing a health care agent. New York: New York State Task Force on Life and the Law, 1987.
- Rosenthal E. Filling the gap where a living will won't do. *New York Times*. January 17, 1991:B9.
- Organ transplantation: issues and recommendations: report of the Task Force on Organ Transplantation. Washington, D.C.: Department of Health and Human Services, 1986:38.
- Margolick D. Connecticut army reservists learn to write a will. *New York Times*. February 4, 1991:B1.

CORRESPONDENCE

EVALUATION AND TREATMENT OF SEIZURES

To the Editor: I looked forward to and enjoyed reading the excellent review article by Drs. Scheuer and Pedley (Nov. 22 issue).¹ The authors' reference to the Epilepsy Foundation as an excellent resource is valuable. Unfortunately, the paper also contains unintentionally misleading information that has the potential to stoke the fire of prejudice as well as to promote the belief from the Dark Ages that seizures are a form of mental illness.

The authors state that "psychosocial dysfunction . . . is often long-lasting" and occurs regardless of seizure control, yet give no data to support this. They go on to state that "persons with epilepsy frequently have difficulty in establishing interpersonal relationships, building self-esteem, and obtaining or maintaining employment." In their otherwise well-referenced article, they take these statements for granted. Even if these statements were true, a meaningful approach to the problems should include a further analysis of