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John J. Lynch & Sue Shevlin Edwards

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# Advance Directives

by John J. Lynch, M.D., F.A.C.P., and Sue Shevlin Edwards, Ph.D.

*Cancer care providers have an obligation to participate in advance care planning and advance directives.*

# W

e all will die. Death itself is not an option. Yet, however

certain death may be, we cannot always predict when we will die, from what cause, or what our own individual end-of-life course will be. We do know that, more than ever, advances in medicine and technology are changing the way we look at death and dying.

Increasingly Americans are turning away from what they view as highly technological medical interventions, such as invasive procedures for feeding and hydration and the use of ventilators, that may prolong life in a manner inconsistent with their own personal values. A 1997 focus group study conducted by American Health Decisions/ Robert Wood Johnson Foundation found that Americans of all ages and ethnic and religious backgrounds fear dying in hospitals while connected to impersonal machines.<sup>1</sup> Similarly, a 1996 Gallup/National Hospice Organization poll had found that the vast majority of Americans would prefer to die at home in the company of loved ones.<sup>2</sup>

Americans have a constitutional-

*John J. Lynch, M.D., F.A.C.P., is associate medical director of the Washington Cancer Institute at the Washington Hospital Center in Washington, D.C., and a member of the Bioethics Committee for Washington Hospital Center, the National Rehabilitation Hospital, and the Visiting Nurses Association. Sue Shevlin Edwards, Ph.D., is a bioethicist within the Department of Bioethics at the Washington Hospital Center.*

ly protected right (grounded in the right to privacy) that permits them to decline medical and/or surgical procedures and opt for comfort measures only. This right is present whether a person has the capacity to make decisions or not. When an individual has lost the capacity to make decisions, the only way he or she has any control over the level and extent of any future medical intervention is through an "advance directive"—that is, a statement in which an individual has previously specified, while still able to communicate, his or her wishes regarding medical interventions should a time ever come when the individual is no longer able to speak for him- or herself.

The advance directive has a number of bioethical implications. By following a competent person's wishes, physicians and other care givers show respect for that person's autonomy (self-determination). The advance directive also recognizes a long-held legal principle that individuals are the ones who should determine what can and cannot be done to their persons/bodies (informed consent).

The recognition that comatose patients have the same rights as patients who are able to make decisions goes back to 1976 with the case of Karen Quinlan in which the New Jersey State Supreme Court permitted Quinlan, a comatose patient, to be removed from a ventilator.<sup>3</sup> Death was expected; however, once removed from the ventilator, Ms. Quinlan lived another ten years due to excellent nursing care, artificial feeding, hydration, and appropriate antibiotics as needed.

During that same time, California passed the Natural Death Act, which permits individuals to specify in writing their intentions regarding end-of-life care. By 1983

the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research reported that "an advance directive is a statement by a competent person indicating his [or her] wishes in the event of future incompetence."<sup>4</sup>

In 1990 the U.S. Supreme Court ruled in *Cruzan v. Director, Missouri Department of Health* that an incompetent patient has the right to have his or her wishes carried out as they relate to withdrawal of treatment. The court also declared that the state has a right to "clear and convincing evidence" that the patient has indicated such action.<sup>5</sup>

In an effort to protect patients' rights regarding end-of-life care, Congress passed the Patient Self-Determination Act in December 1990. Speaking before the Senate, legislative sponsor Senator John Danforth (R-Mo.-ret.) argued, "The traditional right to accept or reject medical or surgical treatment should be available to an adult while competent, so that in the event that such adult becomes unconscious or otherwise incompetent to make decisions, such adult would more easily continue to control decisions affecting their health care."<sup>6</sup>

The legislation, which was implemented in December 1991, requires all hospitals, nursing homes, home health agencies, hospice programs, and HMOs receiving federal Medicare/Medicaid to create formal procedures that provide written information at admission to patients about decision making and treatment refusal rights in their health care. The law also states that patients' advance directives will be respected and that non-compliance could result in the loss of Medicare and Medicaid funds.

Nevertheless, most patients (and, for that matter, most care

givers) do not make advance directives and may never have discussed these issues with their families or physicians. As care givers, we then assume that patients want "everything done" ... whatever that means.

### **CARRYING OUT THE ADVANCE DIRECTIVE**

The barriers to executing an advance directive are many, but the most common reasons are procrastination, apathy, general discomfort with the topic, the feeling that the family will (and should) decide or would be upset by the process of planning for and making end-of-life decisions, and failure of the treating physician to raise the issue.

The advantages of advance directives are that end-of-life care will be tailored to the patient's wishes and values system. Care givers can better attend to a patient's needs when that patient's intentions regarding end-of-life care are clearly indicated. The burden for decision making by adult children or other family members will be significantly reduced or even removed when they know what the patient wants.

Advance directives can be carried out by four different methods:

**Oral instructions.** Prior to the 1970s, oral instructions from a patient to his or her physician or family were the only option available for determining how far treatment would be carried out at the end of life. These instructions frequently involved conversations with the physician about the likely course of events leading up to death and any options the patient might have.

**Living will.** This form of advance directive was first legalized in the early 1970s in California as the Natural Death Act. This legislation was the first instrument that generally informed the public of a right to state in writing their intentions regarding their care at the end of life, even if they are unable to participate in discussions at the time treatment is being rendered. Over time, however, certain limitations associated with living wills have surfaced. For example, living wills can only be activated when the individual is deemed terminally ill, which can be a relatively ambiguous term in some patient cases. More importantly, the living will is an inflexible document that does not allow for interpretation when

## **Talking About Advance Directives**

by Karen Orloff Kaplan, Sc.D.

**T**wo significant problems remain to be conquered in this end-of-life business.

The first of these problems involves a truly disastrous lack of communication among patients, families, and care givers, who are not talking early enough, frequently enough, and thoroughly enough about end-of-life issues.

Advance directives, living wills, and medical powers of attorney are useful tools to facilitate that talking. Without the talking, these documents may well not work. Unless the talking takes place, the disagreements between patients and care givers will continue. Important wishes will be disregarded, and the last weeks or days of life are apt to become a battleground.

Choice in Dying receives several thousand calls each month requesting the most basic kind of information about end of life. Many people call about advance directives but are very confused about how to use them. An amazing number of people don't know what home care or hospice is. They don't know that pain control is possible. They don't know that they can choose to die

at home. They don't know about Do-Not-Resuscitate (DNR) orders. All this information should be provided by care givers at the bedside *before* a crisis—not for the first time at the bedside during a crisis, and certainly not in court, an all too-frequent outcome of this lack of communication.

The second problem is the failure of health care consumers and care givers to jointly put their weight behind improving care at the end of life. There has not been a real partnership between health care consumers and care givers to give policy makers, legislators, and the health care system a momentous message. The message is that everyone deserves compassionate, high-quality care at the end of his or her life, care that respects an individual's needs and values, care that offers opportunities to complete last business in a reasonably comfortable and caring setting.

*Karen Orloff Kaplan, Sc.D., is executive director of Choice in Dying in Washington, D.C.*

unforeseen treatment options arise.

**Durable power of attorney for health care decisions.** With this method, the individual appoints a "proxy" or agent who will speak for the patient when the patient is no longer able to speak for him- or herself. This method improves upon the living will by having someone entrusted with making decisions when further questions about treatment arise that were not anticipated by the individual executing the living will. The major focus of discussion then centers on the proxy determining what may or may not be acceptable to the patient. The durable power of attorney can come into effect anytime the patient does not have the capacity for decision making.

**Combination of a living will and a durable power of attorney.** In our opinion, perhaps the most ideal sit-

uation is to have a combination of a living will and a durable power of attorney. In this instance a surrogate decision maker is appointed by the person executing the document. Additionally, an individual has stated in writing some of the acceptable or unacceptable medical interventions.

It is vital that the person wishing to put together a durable power of attorney for health care decisions, in combination with a living will, have extensive conversations with the designated proxy or surrogate decision maker. No one could ever anticipate all the possibilities that might occur during an individual's end-of-life course. Thus, it is particularly beneficial to be able to appoint someone who can then interpret the patient's feelings to the care givers at such time the

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advance directive is brought into play. Because this proxy is responsible for speaking for the person executing the document and not for him- or herself, he or she must fully understand the values, wishes, and concerns of the individual in question and be willing and able to carry them out.

Once the advance directive has been completed, it is very important that the individual discuss its contents with family, physicians, friends, and clergy, and ensure that copies of it are appropriately distributed. Each time one enters the health care system—whether a hospital, nursing home, or hospice—a copy of this document should be attached to the patient's chart. Patients should discuss the contents of the advance directive in detail with the physician who will be directing their care and ascertain whether or not that physician will be able to comply with those wishes.

Before initiating the durable power of attorney, two physicians, one of whom should be the patient's regular physician, must document that the patient no longer has the capacity to make decisions for him- or herself. The state laws governing living wills and durable powers of attorney vary from state to state, so individuals should review the applications in their particular state. Choice in Dying, a national organization that serves to foster communication about complex end-of-life decisions, provides such information. (See *Talking About Advance Directives*, page 32.)

#### **WASHINGTON HOSPITAL CENTER POLICY**

At the Washington Hospital Center (WHC), we provide patients with instruction and information relative to the Patient Self-Determination Act of 1990. As part of the admitting process, a representative of the admitting department provides each adult patient with written information regarding the patient's right to make decisions concerning health care, including the right to accept or refuse medical or surgical treatment, even if that treatment is life-sustaining, and the right to execute advance directives as determined by Washington, D.C., law. Patients are also provided a written statement of WHC's policy on implementing the patient's rights to make decisions about health care.

If the patient (or his or her surrogate) states that an advance directive has been completed, the patient or surrogate is asked to furnish a copy to WHC for placement in the patient's medical record. If no advance directive is immediately available, the patient or surrogate is instructed to provide a copy to WHC as soon as possible. Patients requesting further information on advance directives are referred to the Bioethics, Pastoral, or Social Service departments.

Occasionally we encounter a situation in which the question of withdrawing or withholding treatment involves a patient without an advance directive and with no surrogate to speak for the patient. In such an instance, the patient's care giver may request a consult with WHC's Bioethics Consultation Subcommittee, a multidisciplinary team of consultants from the hospital's Ethics Committee, that offers ethically justifiable options for the resolution of difficult cases. Members of the subcommittee may confer with the patient's attending physician to determine an acceptable course of action. If appropriate, WHC's Legal Affairs Department is consulted to ensure that the patient's rights are respected. Requests for bioethics consultation may be made at any time by physicians, other health care providers, patients and family members, or others who are directly participating in the care of a specific patient for assistance with ethical issues.

#### **WHAT YOU CAN DO**

Despite the great intentions of the Patient Self-Determination Act, only 15 to 20 percent of Americans have actually executed an advance directive. Many believe that the setting—admission to the health care system—is not the appropriate place to raise the issue. Most believe that advance directive discussions should take place within a more appropriate context such as continuing care or following hospitalization for a serious illness.

There are a number of ways care givers can increase the execution of advance directives and advance care planning. Perhaps one of the most important is the direct discussion between the physician and the patient about the realities relative to prognosis. This type of outpatient

intervention can markedly increase the execution of a large number of advance directives by the frail and the elderly who are often relieved to have the issues raised. Community-based education with follow-up is another effective means. Those seeking legal counsel relative to estate planning should also expect to raise the issue of advance directives with their attorneys. Face-to-face education provided by physicians and legal counsel is certainly one of the primary ways to increase execution of these documents.

People have the right to expect physicians to respect their wishes and values. When no longer able to speak for themselves, they should be able to have a surrogate or durable power of attorney to speak for them. We as health care providers have an obligation to participate in advance care planning and advance directives. We must explain the potential benefits and burdens of the treatment candidly and in a compassionate and caring manner.

Physicians and other care givers can practice good end-of-life care by thinking of death as a personal family event, not the last trial of medical treatment. We need more human conversation, refocusing our thinking so that death is not viewed as a failure of our treatments. Advance directives and advance care planning are ways to accomplish better end-of-life care. ■

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- <sup>5</sup>*Cruzan v. Director, Missouri Dept. of Health*, 497, U.S. 261 (1990).
- <sup>6</sup>As quoted in *Practicing the PSDA*. Special Supplement, *Hastings Center Report* 21(5):S1, 1991.