

hospital policy, and review cases if there is a conflict or lack of clarity. Although they will often counsel a patient's family and make a recommendation, the final decision is still up to the patient, the family, and the physician.

WHERE CAN I GET LIVING-WILL AND HEALTH-CARE-POWER-OF-ATTORNEY FORMS?

Choice in Dying,
1035 30th Street, NW,
Washington, DC 20007
(1-800-989-WILL)

Choice in Dying is a national clearinghouse for information on right-to-die issues. It provides legislative testimony, legal and medical seminars, public education and counseling for families. The society will provide copies of living-will forms for each state for a \$5 fee. Information is also available from the American Association of Retired Persons, from your state or local Office on Aging, your local bar association, and many local civic and service organizations.

GLOSSARY

ADVANCE DIRECTIVE A document in which a person either states choices for medical treatment or designates who should make treatment choices if the person should lose decision-making capacity. The term can also include oral statements by the patient.

ARTIFICIAL NUTRITION AND HYDRATION A method of delivering a chemically balanced mix of nutrients and fluids when a patient is unable to eat or drink. The patient may be fed through a tube inserted directly into the stomach, a tube put through the nose and throat into the stomach, or an intravenous tube.

CARDIOPULMONARY RESUSCITATION (CPR) A medical procedure, often involving external chest compression, administration of drugs, and electric shock, used to restore the heartbeat at the time of a cardiac arrest.

DECISION-MAKING CAPACITY The ability to make choices that reflect an understanding and appreciation of the nature and consequences of one's actions.

DECLARATION One type of advance directive, commonly referred to as a living will.

DNR Do Not Resuscitate; a medical order to refrain from cardiopulmonary resuscitation if a patient's heart stops beating.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE (DPOA) An advance directive in which an individual names someone else (the "agent" or "proxy") to make health care decisions in the event the individual becomes unable to make them. The DPOA can also include instructions about specific possible choices to be made.

HOSPICE A program that provides care for the terminally ill in the form of pain relief, counseling, and custodial care, either at home or in a facility.

LEGAL GUARDIAN A person charged (usually by court appointment) with the power and duty of taking care of and managing the property and rights of another person who is considered incapable of administering his or her own affairs.

LIFE-SUSTAINING TREATMENT A medical intervention administered to a patient that prolongs life and delays death.

PALLIATIVE CARE Medical interventions intended to alleviate suffering, discomfort, and dysfunction but not to cure (such as pain medication or treatment of annoying infection).

PERSISTENT VEGETATIVE STATE As defined by the American Academy of Neurology, "a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles but at no time is aware of himself or his environment."

PROXY A person appointed to make decisions for someone else, as in a durable power of attorney for health care (also called a surrogate or agent).

TERMINAL CONDITION In most states, a status that is incurable or irreversible and in which death will occur within a short time. There is no precise, universally accepted definition of "a short time," but in general it is considered to be less than one year.

VENTILATOR A machine that moves air into the lungs for a patient who is unable to breathe naturally.

ADVANCE DIRECTIVES QUESTIONS & ANSWERS

WHAT IF I FILL OUT AN ADVANCE DIRECTIVE IN ONE STATE AND AM HOSPITALIZED IN A DIFFERENT STATE?

The majority of states have reciprocity provisions. Even in those states that do not explicitly address the issue, there is a common law and constitutional right to accept or refuse treatment that may be broader than the rights identified under the state law. Because an advance directive is an expression of your intent regarding your medical care, it will influence that care no matter where you are hospitalized. However, if you spend a great deal of time in more than one state you may wish to consider executing an advance directive in those states.

IF A COMATOSE OR MENTALLY INCOMPETENT PATIENT DOESN'T HAVE A LIVING WILL OR DURABLE POWER OF ATTORNEY, WHO DECIDES WHETHER TO WITHDRAW TREATMENT?

If there is no advance directive by the patient, the decision is left to the patient's family, physician and hospital, and ultimately a judge. Usually the family, physician, and hospital can reach an agreement without resorting to the courts, often with the help of a hospital ethics committee. However, many times the individual who has the authority to make the decision is not the person the patient would have chosen. There also may be more restrictions on a surrogate than an appointed agent.

WHAT WILL THE HOSPITAL DO TO HELP IF I OR MY FAMILY MEMBER SHOULD BE IN THIS SITUATION?

Many hospitals have ethics committees or ethics consultation services, one of whose functions is to help in decision making about the end of life. Physicians, nurses, social workers, lawyers, clergy, patient representatives, and sometimes professional bioethicists discuss issues, advise on

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Many people today are worried about the medical care they would be given if they should become terminally ill and unable to communicate. They don't want to spend months or years dependent on life-support machines, and they don't want to cause unnecessary emotional or financial distress for their loved ones.

That's why a growing number of people are taking an active role in their care before they become seriously ill. They are stating their health care preferences in writing, while they are still healthy and able to make such decisions, through legal documents called advance directives.

Before deciding what choices about your care at the end of life are best, you should talk over the issues involved with your family and your physician. Find out about the laws and forms that apply in your state. Decide whether advance directives are right for you.

This brochure will give some basic facts about advance directives to get you started on this process.

WHAT ARE ADVANCE DIRECTIVES?

Formal advance directives are documents written in advance of serious illness that state your choices for health care, or name someone to make those choices, if you become unable to make decisions. Through advance directives, such as living wills and durable powers of attorney for health care, you can make legally valid decisions about your future medical treatment.

WHY IS THERE SO MUCH INTEREST IN ADVANCE DIRECTIVES NOW?

Questions about medical care at the end of life are of great concern today, partly because of the growing ability of medical technology to prolong life and partly because of highly publicized legal cases involving comatose patients whose families wanted to withdraw treatment. Many people want to avoid extending personal and family suffering by artificial prolongation of life if they are in a vegetative state when there is no hope of recovery.

The best way for you to retain control in such a situation is to record your preferences for medical care in advance and share your decisions with your physician, loved ones and clergyman.

WHAT DOES THE LAW SAY ABOUT THIS ISSUE?

Laws differ somewhat from state to state, but in general a patient's expressed wishes will be honored. No law or court has invalidated the concept of advance directives, and an increasing number of statutes and court decisions support it. In 1990 the U.S. Supreme Court found in the case of Nancy Cruzan that the state of Missouri could require "clear and convincing" evidence of a patient's wishes in order to remove life supports. Formal advance directives can be critical to establishing such clear and convincing evidence of a patient's wishes. The Patient Self-Determination Act of 1990 requires hospitals to inform their patients about advance directives.

WHAT IS A LIVING WILL?

A living will is a document in which you can stipulate the kind of life-prolonging medical care you want if you become terminally ill, permanently unconscious, or in a vegetative state and unable to make your own decisions. Most states have their own living-will forms, each with somewhat different requirements. It is also possible to complete and sign a standard form from a stationery store, draw up your own form, or simply write a statement of your preferences for treatment, as long as you follow the state's witnessing requirements.

A living will should be signed, dated, and witnessed by two people, preferably individuals who know you well but are not related to you and are not your potential heirs or your health care providers. A number of states require a notary or permit a notary in lieu of two witnesses. The living will should be discussed and shared with your physician, family and clergyman, and you should ask your physician to make it a part of your permanent medical record. Verify that the living will is indeed in your medical record, including your hospital chart. Although you

do not need a lawyer to draw up a living will, you may wish to discuss it with a lawyer and leave a copy with the family lawyer.

WHAT IS A DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

A durable power of attorney for health care is another kind of advance directive: a signed, dated, and witnessed document naming another person to make medical decisions for you if you are unable to make them for yourself at any time, not just at the end of life. You can include instructions about any treatment you want or wish to avoid, such as surgery or artificial nutrition and hydration. The majority of states have specific laws allowing a health care power of attorney, and provide suggested forms. You can draw up a durable power of attorney for health care with or without the advice of a lawyer; however most states do not allow the appointed agent to act as a witness.

WHICH IS BETTER - A LIVING WILL OR A DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

Historically, living wills were developed first, and health care powers of attorney were designed later to be more flexible and apply to more situations. Today the distinction between the two types of documents is becoming blurred. It is possible to have both a living will and a durable power of attorney for health care. Some states combine them in a single document that both describes one's treatment preferences in a variety of situations and names a proxy.

HOW CAN I KNOW IN ADVANCE WHICH PROCEDURES I WOULD WANT OR NOT WANT TO PROLONG MY LIFE?

Although it isn't possible to specify every possible procedure under every possible circumstance, it is possible to decide what kind of treatment you would want in most situations. There are certain common conditions (terminal, irreversible brain damage and dementing illnesses) and treatments commonly used in end-of-life situations (CPR,

ventilators, artificial nutrition and hydration, dialysis and antibiotics) that can be discussed in advance.

Preferences can be clarified by thinking about and discussing with your family, friends and others your views about death, being totally dependent on the care of others, the role of family finances, the conditions that would make life intolerable to you, and how artificial life-support would affect the dying process. If you have questions about the kinds of procedures that are often used when illness is severe and recovery unlikely, ask your physician. It is never too early to start this decision-making process, and you should not postpone it until you face serious illness. Patients need to play an active role in determining their own health care decisions.

WHAT IS THE LEGAL STATUS OF ADVANCE DIRECTIVES?

All states legally recognize some form of advance medical directive. Even if a particular instruction in an advance directive might not be enforceable under some circumstances, it is better to express your wishes and intent in some kind of written document than not to express them at all.

WHAT IF I DRAW UP A LIVING WILL OR HEALTH CARE POWER OF ATTORNEY AND THEN CHANGE MY MIND?

You may change or revoke these documents at any time. Any alterations and written revocation should be signed and dated, and copies should be given to your family, physician, and other appropriate people. (For substantial changes, a new living will should be written and witnessed.) Even without an official written change, your orally expressed direction to your physician generally has priority over any statement made in a living will or power of attorney as long as you are able to decide for yourself and can communicate your wishes. If you wish to revoke an advance directive at any time, you should notify your primary physician, family, clergyman, and others who might need to know. If you consulted an attorney in drawing up your document, you should also notify him or her.