

## Wishes in Writing: End-of-Life Decision-making

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Now and again, a story hits the news that regenerates discussions and controversy surrounding end-of-life decision-making. These conversations often leave health care professionals concerned and consumers confused. Written advance care directives are not the answer to all questions. However, they can make a positive difference and enable end-of-life patients to communicate and preserve their wishes for times when they are no longer able to communicate this information.

### **Back to the Beginning: PSDA and Advance Care Directives**

The Patient Self-Determination Act (PSDA), enacted in 1991, federally mandated that people have the right to accept or refuse medical treatment. Toward this end, advance care directives—documents that communicate these preferences and decisions—came into being. With an advance care directive, a person informs family, friends, and health care practitioners about how to care for them when they can no longer speak for themselves. The ability to know and follow plans that reflect a person's values and preferences can comfort family members in the event of serious illness and/or death.

In some states, creating an advance care directive may simply mean having a conversation with one's physician. The specific information from such a discussion, sometimes referred to as an oral advance care directive, should be

placed in the person's medical records.

More often, an advance care directive takes the form of 1 of 2 documents:

- a living will, which enables a person to specify his or her choices for medical care in advance of times when such decisions might have to be made; and
- a durable power of attorney for health care (sometimes referred to as a "proxy"), which appoints another person (referred to as the "health care agent") to make decisions on behalf of the person should he or she become incapacitated.

### **Living Wills and More**

A living will allows people to define what treatment they want to receive in certain situations. They also can indicate any treatment they do not want to receive, such as:

- cardiopulmonary resuscitation (CPR);
- feeding tubes;
- ventilators;
- intravenous lines; and
- antibiotics.

The living will also can define what to do if an accident or serious illness puts an individual in a comatose state, and can spell out what treatments the person wants withheld or stopped if he or she has no hope of recovery.

The durable power of attorney (DPOA) for health care and the health care power of attorney (HCPA) allow people to designate others to make their health care decisions for them if they are incapacitated. They can cover any health care decision, and the person does not need to be dying or unconscious for it to take effect.

The HCPA is a document executed by a competent person to appoint another individual to make health care decisions for him or her if he or she becomes incompetent to make these decisions. It allows the person, whose autonomy is at stake, to decide who will make his or her health care decisions. This, in turn, allows the person to choose the decision-maker most likely to understand and apply his or her values.

A patient's advocate only has the authority to act for that person while he or she is unable to communicate his or her wishes. If the patient gets better, the advocate's authority ends.

## ■ Navigating the Maze of End-of-Life Definitions

Advance care directive, living will, power of attorney. The plethora of legal and medical terms that get thrown out to persons, family members, and others when discussions turn to end-of-life decision-making or advance care planning can be overwhelming. Here are some of the most common terms and their definitions that can be used to help persons, family members, and staff alike understand the issues, make informed choices, and know that they are on the same page when they communicate with each other.

**Advance care directive:** This is a broad term describing both living wills and durable powers of attorney, which enable persons to provide written instructions about future medical care. Advance care directives vary significantly from state to state, but many enable individuals to include instructions for specific situations, such as when they are temporarily unconscious or impaired by Alzheimer's disease. These documents also may include instructions on options for organ or tissue donation.

**Artificial nutrition and hydration:** This encompasses a variety of therapies, the goals of which are to prevent dehydration or malnutrition in patients who cannot swallow. Most common interventions include intravenous therapy, total parenteral nutrition, and tube feeding.

**Assisted suicide:** This term commonly refers to situations in which people with an incurable and ultimately terminal disease or condition ask others (often a physician) to help them end their lives.

**Cardiopulmonary resuscitation (CPR):** This refers to procedures used to revive a person who has stopped breathing or whose heart has stopped beating. It may include mouth-to-mouth breathing, chest compressions, electric shock, and drugs to stimulate the heart.

**Do-Not-Resuscitate (DNR) order:** This is a physician's written order instructing health care providers not to attempt cardiopulmonary resuscitation if a person's heart or lungs stop working. While persons and their family members may request this order, it must be signed by a physician.

**Do-Not-Hospitalize (DNR) order:** This involves written instructions regarding a person's wish not be hospitalized if he or she gets seriously or acutely ill or their existing illness takes a turn for the worse. This often is part of an individual's advance care directive.

**Durable power of attorney:** This is type of advance care directive that provides power of attorney to others in case of an incapacitating medical condition or illness. However, it goes beyond medical care and enables a person to give someone else the legal ability to make bank transactions, sign Social Security checks, apply for disability, or write checks to pay utility and other bills.

**Futile care:** This refers to treatments or therapies that will not cure the person or increase their comfort, but will only prolong their vegetative or dying state.

**Health care proxy:** This is a legal document that enables a person to appoint another person to make health care decisions if he or she is rendered incapable of making his or her preferences or wishes known. The proxy generally has the same legal rights to request or refuse treatment that the person would if he or she could communicate this information.

**Hospice care:** This refers to medical care at the end of a person's life where the focus is on comfort, not cure. Hospice care encompasses palliative care (see definition below) and includes support for family members.

**Living will:** This is a legal document designed to control a person's future health care decisions only when he or she becomes unable to make his or her own decisions and choices. The living will details the person's wishes and preferences about future medical treatment and generally addresses such issues as stopping life-sustaining treatment in the case of a terminal illness or persistent vegetative state.

**Medical power of attorney:** This is a legal document in which a competent adult designates another person to make health care decisions on his or her behalf in cases where the adult is unable to make such decisions.

**Palliative care:** This refers to a comprehensive approach to treating serious or terminal illness that is designed to meet the person's quality of life, comfort, spiritual, and emotional needs. Palliative care involves relief from suffering, pain management, activities and programs to meet the individual's spiritual and emotional needs (such as music or animal-assisted therapy), and includes support for family members.

**Proxy:** This is a person who has been granted the authority to act on behalf of a particular individual.

**Ventilator:** This is a machine that helps a person breathe. It is used temporarily until the person can breathe on his or her own or as a permanent breathing aide (often used in individuals who are in a permanent vegetative state).

## Frequently Asked Questions About the Health Care Power of Attorney

- Is it necessary for a lawyer to write a HCPA?
  - An HCPA sometimes is prepared by a legal professional, but such preparation is not required. However, some states do require that signatures be notarized. The decisions made by the agent may be guided by specific written or spoken instructions from the person. An HCPA may include a living will provision—a description of health care choices—but the living will in such cases serves as guidance for the agent, rather than as a binding directive. To ensure this, the living will should state that in the event of any differences between the living will and the agent, the agent should have final say in the decisions.
- Who decides that a person is incapacitated?
  - A person can specify how they wish to have their incapacity and mental status determined if the need should arise. For example, in an HCPA, a person can name a physician to make this determination, or can stipulate that 2 doctors must agree that the person is incapacitated. Any physician or clinical psychologist who makes evaluations of capacity should have experience in this area. If a person does not provide such instructions, a court ultimately might decide the issue, guided by generally accepted standards used by other courts in making these determinations.
- How are the person's wishes carried out?
  - When a person has an HCPA and becomes incapacitated, the agent discusses treatment alternatives and the outlook for recovery with the health care team. The agent then makes decisions based on current circumstances and on what is known about the person's preferences and values. The agent is also an advocate for the person and can argue for aggressive care or for withholding care as the diagnosis, condition, and outlook change. The agent's flexibility while making decisions makes an HCPA preferable to a living will for many people.

Further, the advocate does not have the authority to end medical treatment if it is likely to cause the person's death unless the person specifically also has given the advocate the authority to make life and death decisions. This

must be spelled out in the person's HCPA.

It is important that people understand the details of, and how to complete, an HCPA properly. Toward that end, here are some tips:

- The person must understand the form he or she is signing.
- The person's signature must be witnessed by at least 2 other adults. Certain people are not allowed to be a witness to an HCPA because of a possible conflict of interest. These include an individual's spouse, child, grandchild, brother, sister, parent, possible heir, person benefiting from the person's will, his or her physician, the person he or she is appointing as their patient advocate in the document, and/or an employee of the person's life or health insurance carrier or of the person's hospital, assisted living facility, or hospice.

In the process of determining whom to designate as their HCPA, persons can ask themselves several questions:

- Who do I want to make decisions about my health care?
- Is quality of life more important than longevity?
- How important is physical and/or mental functioning in decisions to accept, refuse, or limit medical treatment?
- What are my spiritual beliefs, and how do they fit with my choices?
- Is the intake of food and water a basic human right, regardless of delivery (ie, tube, mouth, or vein)?

The person's HCPA should address the answers to these questions.

Persons should give copies of their living will or HCPA to their physicians. A copy of the HCPA also should be given to the person appointed to carry out the wishes, and another placed with important papers. The person's lawyer should hold a copy of all documents, and the person should keep copies at home. **MPM**

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