

Advance Care Planning: What You Need to Know

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Basics of informed consent

Advance care planning and advance directives are rooted in the principle of individual autonomy, the right to exercise self-determination. Legally, full autonomy is granted only to adults with the mental capacity to make decisions; these individuals have the right to accept or refuse medical treatment through a process of informed consent. In emergency situations, consent is presumed. In all other situations, a patient must provide informed consent prior to receiving medical care. The process of providing consent can be very formal, involving signatures on many pages filled with legal language. Or it can be as simple as the doctor explaining the procedure and its risks and the patient answering, “OK, let’s do that.” Either way, consent is necessary.

Autonomous adults in the United States have the right to refuse any treatment, at any time, and for any reason, even if the likely outcome is death. Providing treatment against the will of the patient is considered battery and is cause for criminal prosecution.

What is advance care planning?

Advance care planning involves considering possible major medical treatments in advance of a health crisis and making choices about which are acceptable and which are not. Typically, although not exclusively, the treatments considered are “life-sustaining” treatments, such as artificial respiration (breathing machine), artificial nutrition and hydration (tube feeding), and cardiopulmonary resuscitation (CPR). Advance care planning is a process that should be revisited as life events,

personal circumstances, and health conditions change. Ideally it involves conversations among the person doing the planning, her close family members, personal and professional advisors, and medical caregivers.

What is an advance directive?

Advance directives are forms used to clarify the treatment choices a person wants to consent to—or not. Completion of these forms is the result of the conversations that make up the planning process. The forms are written records of decisions and instructions, formally executed in ways that carry legal, moral, and medical weight. Each state has its own laws governing advance directives and medical decision-making authority. Sample forms for any state can be downloaded from the [Caring Connections](http://www.caringinfo.org) website (www.caringinfo.org).

The three most common types of advance directives are:

- Living will
- Medical power of attorney
- CPR directive, also known as out-of-hospital Do Not Resuscitate order (DNR)

Some states offer an “omnibus advance directive,” which incorporates the features of all three directives into a single document. The omnibus advance directive is available in New Hampshire, New Jersey, Ohio, Oregon, Tennessee, Vermont, and other states. Most states accept the Five Wishes® document, described below, as a legal replacement for living will and medical power-of-attorney forms.

In addition, 12 states offer a standardized form called the Physician Orders for Life-

Sustaining Treatment (POLST) or one of its variants. These forms list treatment decisions in areas such as CPR, general scope of treatment, antibiotics, and artificial nutrition and hydration. The POLST does not replace a patient's advance directives, but provides details about the patient's preferences for a number of specific treatment options, ranging from "Yes/full treatment" to "No/comfort measures only." After being signed by a physician or other health-care provider, the POLST is honored in any health-care setting as medical orders.

What is a living will?

A living will is typically used to refuse life-sustaining treatment in the context of terminal illness or irreversible unconsciousness. Living wills vary from state to state, but in general, by signing a living will, a person (the "declarant") instructs health-care providers to withhold or withdraw all life-sustaining treatment if he is terminally ill and cannot make or express his own decisions, and/or if he is permanently unconscious (due to irreversible coma or "persistent vegetative state"). Physician certification of the terminal illness/unconsciousness is required, and there may be a waiting period during which family members must be notified of the impending withdrawal of treatment.

Other living wills are more free-form, allowing medical instructions of all kinds and even statements of values, fears, goals, and beliefs (such as in Minnesota and North Dakota). Most living wills provide separate options to indicate continuation or discontinuation of artificial nutrition and hydration. Only Massachusetts and Michigan do not offer some kind of living will. In these states, instructions may be included in the medical power-of-attorney document.

What is a medical power of attorney?

A medical power of attorney is a document used by a person (the "principal") to officially



appoint a substitute decision-maker (called a health-care "agent," "surrogate," "proxy," or "patient advocate," depending on the state) for situations in which the principal cannot speak for herself. The health-care agent is typically granted all the powers that the principal might have to review or obtain copies of medical records, to consult with health-care providers, to determine the place of care (such as hospital, nursing facility, or hospice), and to make all necessary decisions related to medical care.

The intention behind a medical power of attorney is for the health-care agent to act and decide *as the principal would*, based on the agent's knowledge of the principal's wishes. The document can also include either specific instructions or general guidance. If there are no instructions, and the agent is not certain what the principal would want, he must act according to the best interests of the principal. All 50 states and the District of Columbia offer some form of medical power of attorney. Medical powers of attorney should be kept separate from financial or general powers of attorney. It is generally recommended that different people hold the different powers, if possible, to avoid any potential conflicts of interest.

In addition to a medical power-of-attorney document, almost all states offer a default process for determining a substitute medical decision-maker. Often, the first choice is the patient's spouse, if she has one; then her

parents; then adult children; then siblings; and so on. States' priority lists differ somewhat, and some include physicians as last-resort decision-makers. Only one state, Colorado, does not have a default process, instead requiring a group of "interested persons" (typically family members and close friends) to reach consensus among themselves about who will serve as the decision-maker. A medical decision-maker selected through this process is called a proxy-by-statute.

What is a CPR directive?

When a patient is in the care of a doctor in a health-care facility, and the doctor believes that CPR would not be successful or would cause significant harm, the doctor may enter a "DNR" or "Do-Not-Resuscitate" order in the patient's chart. A CPR directive, or "out-of-hospital DNR," allows an individual to refuse CPR if her heart or lungs malfunction or stop when she is not in a health-care facility.

CPR directives are intended for people who have an advanced or terminal illness, or are elderly, and would likely not survive a resuscitation attempt. Only about 17 percent of all adults receiving CPR survive to hospital discharge. Among the elderly, this rate drops below 4 percent, and most of those who do survive experience trauma such as broken ribs, collapsed lungs, or brain damage. CPR directives typically must be signed by both the individual and his physician, indicating that there is a medical reason for the refusal of CPR and that the person understands that if CPR is refused, the likely outcome is death.

What is the Five Wishes®?

A popular document that is not state-specific is the Five Wishes® developed by [Aging with Dignity](http://www.agingwithdignity.org) (www.agingwithdignity.org). The Five Wishes document combines guidance for the advance care planning process and documentation of choices ranging from a health-care agent, to personal care preferences,

to specific conditions under which the patient doesn't want to be kept alive. The wishes it refers to are:

- The person whom I want to make care decisions for me when I can't.
- The kind of medical treatment I want or don't want.
- How comfortable I want to be.
- How I want people to treat me.
- What I want my loved ones to know.

Five Wishes meets the legal requirements for an advance directive in [42 states](#). In the other eight states, a Five Wishes form can be attached to the state's required advance directive form.

Each section of the Five Wishes presents statements addressing medical issues (for example, "I do not want life-sustaining treatment. If it has been started, I want it stopped.") and personal matters ("I want my family and friends to know that I love them"). The person completing the form is instructed to strike out any statements with which she disagrees, and space is provided for additional instructions to be added. In the 42 states in which Five Wishes is a legal advance directive, signing a Five Wishes document automatically revokes any previously completed advance directives.

Five Wishes has a devoted following, and it does a good job of laying out the sorts of issues that advance care planning should encompass. However, it has some drawbacks. By striking out statements in the medical power-of-attorney section, a person may unwittingly constrain the authority of her health-care agent. In addition, emergency medical personnel do not have time to read through an eight-page booklet to uncover instructions about whether to start CPR.

That said, the Five Wishes document can be a helpful guide for the advance care planning process. Now is a good time to speak with your family members, your medical professionals, and your qualified professional

advisors about your five wishes, especially your choice of health-care agent and your preferences for life-sustaining treatment.



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Sources:

ABA Commission on Law and Aging. 2008. "[Default Surrogate Consent Statutes as of November 2008.](#)"

Adams, D.H., & D.P. Snedden. 2006. "How Misconceptions Among Elderly Patients Regarding

Survival Outcomes of Inpatient Cardiopulmonary Resuscitation Affect Do-Not-Resuscitate Orders." *Journal of the American Osteopathic Association*, 106:402-404.

Cantor, N.L. 1987. *Legal Frontiers of Death and Dying*. Bloomington: Indiana University Press.

Murphy, D.J., A.M. Murray, B.E. Robinson, & E.W. Campion. 1989. "Outcomes of Cardiopulmonary Resuscitation in the Elderly." *Annals of Internal Medicine*, 111(3):199-205.

Peberdy, M.A., W. Kaye, & J.P. Ornato, et al. 2003. "Cardiopulmonary Resuscitation of Adults in the Hospital: A Report of 14,720 Cardiac Arrests from the National Registry of Cardiopulmonary Resuscitation." *Resuscitation*, 58:297-308.

Ulrich, Lawrence P. 1999. *The Patient Self-Determination Act: Meeting the Challenges in Patient Care*. Washington, DC: Georgetown University Press.

Zucker, M.B. 1999. *The Right to Die Debate: A Documentary History*. Westport, CT: Greenwood Press.