

Advance Directives

The ethical basis for preparing an advance directive regarding health care is the moral and legal right of every adult to accept or refuse recommended medical treatments. Each individual can decide what medical care to accept and what to reject. Physicians, hospitals, and nursing homes must respect the wishes of competent adults, even if they disagree with certain decisions. Some people may decide that they do not want to accept a medical treatment or be on a type of life support system if they have a terminal or progressive illness and functional or cognitive disabilities, while others in similar situations may want to make sure that such treatments are continued.

If an injury or illness prevents a person from making decisions or communicating wishes, however, the situation may become far more complicated. Often the hardest decisions about life-sustaining or invasive treatments must be made by others, usually family members, who may not know whether their loved one would or would not want treatment. Therefore, it is advisable

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A living will is a document that allows you to specify which treatments you would or would not want if you become incapacitated (i.e., unable to speak for yourself). The authority of a living will is limited: in most states, living wills apply only to people who have a terminal illness. In some other states, a persistent vegetative state (a neurologic diagnosis when an individual can breathe independently and appears to have sleep-wake cycles but has no evidence of consciousness) is also a "qualifying condition."

Because it is difficult to anticipate all the medical conditions you might encounter or all the treatments that might be available, and because living wills are so limited, it is important for you to designate a person to make decisions on your behalf if you cannot speak for yourself. Depending on the individual state law or regulation, such a tool is called a durable power of attorney for health care, a health care agent, or any of several other names. This document does not require that you be terminally ill or in a persistent vegetative state for the named individual to make medical decisions for you, only that you be incapacitated and unable to make or communicate your own decisions. Therefore, it is more broadly applicable than a living will.

Designating a substitute decision maker has an additional benefit. If the substitute agrees to act on your behalf, she or he must try to determine what *you* would have chosen if you could have foreseen your current situation. So the doctor would not say to her or him, "Do you think we should stop treatment for your

loved one?" Instead, the doctor should say, "What do you think your loved one would tell us to do if she could be fully here with us for just a moment?" This is comforting to many family members, especially adult children, who do not want to feel somehow responsible for a parent's death. Further, designation of an agent does not require patients to imagine some number of awful things that could happen to them, as completing a living will does.

Federal regulations require hospitals and nursing homes to provide patients with information about advance directives and to give them an opportunity to complete these documents, often upon admission. However, attempting to fill out an advance directive during a hospital or nursing home admission is challenging, given the stressful nature of that moment. It is not the best time to consider such significant health matters carefully and make important decisions. It is difficult for patients to gather all the information about the various medical circumstances they may encounter, carefully weigh their options, and then communicate their wishes and desires to their family and physician at the time of admission. Ideally, these matters should be investigated and the documents completed at a time when a person is not so ill as to require admission to a hospital or nursing home. Also, these documents can be revised later as needed.

"Do not resuscitate" orders can also be a part of advance medical planning. These orders, placed in a hospital or nursing home chart, inform the staff that the patient does not wish to undergo attempted cardiopulmonary resuscitation (also known as CPR) if he or she experiences cardiac arrest. In some jurisdictions, individuals keep "do not resuscitate" directives in their homes so that those responding to a 911 call for emergency care

do not initiate unwanted interventions. Patients' health care providers may provide them with additional information and advice about this subject.

The Risk of Failing to Use Advance Directives

People who fail to use advance directives run the risk of receiving treatment or medical care that they would not have wanted and perhaps of being kept alive under conditions they would not find acceptable. Further, major decisions about their medical care could be made by individuals who have different values and expectations.

The absence of advance planning can also result in painful and destructive conflicts among family members. One member of the family may feel strongly that the patient would not want to be kept on life support systems, whereas another family member may feel equally strongly that it would be wrong to withdraw support. When there is a conflict and the patient has not completed a living will or designated a substitute decision maker, the health care facility and doctor may need to choose a decision maker from a predetermined list of relatives. Legal involvement becomes more likely, and the decision that is ultimately made may not reflect the patient's wishes.

What Can Be Done to Prevent Loss of Control Over Medical Decisions?

Most people are aware of advance directives—at least living wills—and say they are in favor of using them. However, surveys show that few adults have formally expressed their wishes and completed appropriate forms. One reason that people fail to complete these forms is that both health care providers and patients are reluctant to broach the subject. Therefore,

it is important to encourage people to discuss this matter with their health care providers and not to wait for their providers to take the initiative.

One misconception people often have is that they must have an attorney prepare a living will or a durable power of attorney for health care (health care agent) and thus are reluctant to incur the costs associated with hiring legal counsel. Fortunately, establishing advance directives does not require the services of an attorney. Forms can be obtained from hospitals, home health agencies, and several other national organizations. Further, the forms obtained from these organizations can be modified to suit each person's wishes. Another option is for people to write their own advance directives. These are legal and acceptable directives as long as they are properly witnessed by two adults, only one of whom may be a member of the immediate family and neither of whom may be designated as the surrogate (substitute) decision maker. They are, however, subject to the same restrictions as the more formal documents.

Another misconception held by some people is that they will permanently lose control of decisions about their medical care once a living will or durable power of attorney for health care has been prepared and signed. They think they are signing a document that is irrevocable. However, these documents are used only when patients are unable to communicate their wishes. People can change or revoke an advance directive at any time, including naming another individual to be the health care agent.

People need to be encouraged to discuss their wishes and feelings about end-of-life matters with family members or other designated decision makers. These individu-

als need to know that the documents exist and that they were executed after careful consideration of the medical circumstances and options. A statement or declaration of personal values completed by the patient can be helpful to family members who need to understand the patient's wishes and decisions. Additionally, a statement of values can serve as a useful guide for a person who has the durable power of attorney for health care.

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