



ADVANCE DIRECTIVES FOR END-OF-LIFE TREATMENT DECISIONS

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The need to determine best care for people dying of old age and illness and for those individuals' loved ones becomes more urgent every day. A large aging population, increases in the incidence of chronic disease, and the reduced availability of paid and unpaid caregivers, among other factors, must soon focus more of our attention on ways to improve the care we offer to individuals nearing the ends of their lives.

Experts and the public generally agree that the best end-of-life care treats the whole person—body, mind, and spirit—an approach called *palliative care*. Palliative care works aggressively to relieve pain and other physical symptoms; it also offers emotional and spiritual support to the patient and family while respecting their culture and traditions. Care for people near the end of life is largely financed and delivered through Medicare and Medicaid, programs that were not designed to provide comprehensive palliative care.

Making end-of-life treatment decisions for patients who are not able to participate in their own care can be difficult. Family members and physicians are often forced to make important treatment decisions without the benefit of knowing what the patient would have chosen. Advance directives (living wills and medical powers of attorney) were created to direct or guide end-of-life treatment decisions for persons who can no longer make decisions for themselves. Although 80% of Americans say that advance directives are important,¹ studies suggest that only 15% to 20% have completed them.² And, few people who complete advance directives actually discuss their treatment wishes with their families or physicians.³

CURRENT REGULATION

Advance directive policies are determined primarily at the state level; however, in 1991 Congress enacted the Patient Self-Determination Act, which requires that all healthcare facilities receiving Medicare or Medicaid reimbursements inform patients of their right to make choices about the treatment they receive and to prepare advance directives.

In addition, all healthcare facilities, including nursing homes and rehabilitation centers, are required to have a Do Not Resuscitate (DNR) order policy in place if they wish to be accredited by the Joint Commission on Accreditation of Healthcare Organizations. For those individuals living at home for whom resuscitation is not appropriate or is unwanted,

many states have authorized “nonhospital” (or out-of-hospital) DNR orders to protect them from resuscitation efforts (which are mandatory if emergency personnel are called). Such orders are signed by a physician and can be presented to emergency medical personnel, allowing them to not begin resuscitation. Currently, 44 states and the District of Columbia have authorized the use of nonhospital DNR orders.

PREPARE FOR THE CONVERSATION

The physician's time with each patient is limited and valuable, and can be taken best advantage of by preparing in advance for a discussion on end-of-life care. Before beginning such a conversation, the physician should be familiar with established advanced directives (make sure to look at those that are approved in the state in which you are practicing), and may complete his or her own advance directive, highlighting some of the questions patients might have.

Having flyers, sample advance directives, and fact sheets on hand for use during the consultation is appropriate. Information and links to other resources are available at www.lastacts.org. Advance directive forms for any state can be downloaded from the Partnership for Caring Web site, at www.partnershipforcaring.org.

INITIATE AND GUIDE THE CONVERSATION

It may seem as though there is never a “good time” to talk about end-of-life decisions and care. In practice, these discussions are often reserved for patients who are near death. However, advance care planning can benefit people much further up the disease continuum—for example, people suffering from chronic illnesses.

Many patients will be uncomfortable discussing the topic—particularly if they are relatively healthy. Some patients, however, will initiate the discussion, ask questions about end-of-life treatments, or send cues that they are ready to discuss end-of-life care. Patients who discuss the death of a friend or relative, wanting to die, or who are asking questions about hospice care may be attempting to open a dialogue about their own end-of-life treatment.

The physician's experience and knowledge of medicine can help guide discussions about end-of-life care and shed light on the reality of some treatment choices—how painful they might be, how long they might last, how often treatment will be needed, or what their chances are of returning to a normal level of functioning. Patients' treatment preferences tend to change based on perceived burden of treatment vs perceived potential gain.⁴

The physician's knowledge of medical language is also

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helpful to patients. Language in advance directives is often too general or vague to provide clear instruction for care.⁵ It should be explained to patients that at some point it might be up to a family member or physician to interpret their directions, therefore they should be as specific and comprehensive as possible.

FOLLOW UP ON THE CONVERSATION

After discussing end-of-life treatment choices with patients, emphasize that this is only the first step of advance care planning, and follow up at their next visit. Patients should be encouraged to complete advance directives, appoint a healthcare agent, and discuss their preferences with family members. Put a copy of the completed document(s) in the patient's chart.

The advance directive should be revisited every 2 years and at critical points in a person's care. Research suggests that patients are more likely to refuse treatments as their hypothetical prognoses worsen.⁶ It is important not only to note changes in treatment preferences, but also to discuss the reasons for the change.

The advance directive should be used to guide end-of-life treatment choices if the patient is no longer able to make treatment decisions. Many patients are able to participate in their care until the end of their lives. While able, any decisions they make should take priority over what is documented in an advance directive.

Family members may hesitate to question medical advice or ask for clarification, and they often feel conflicted about carrying out the end-of-life wishes of their loved ones (even when they are well documented). Encourage family participation by asking if they have unanswered questions or concerns and by connecting them to spiritual and social support.

By remaining a part of their patients' end-of-life decisions, physicians can play a significant role in helping their patients and their patients' families approach these last years comfortably and with dignity.

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