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ELDER CARE

A Resource for Interprofessional Providers

Advance Directives

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Understanding, respecting, and honoring a patient's wishes for the kind of care they wish to receive at the end of life is a basic tenet of palliative care and is essential to improving the care of dying patients. Advance directives are legal documents designed to provide guidance to a patient's family, friends, designated decision makers, and clinicians about the patient's wishes for the care they want to receive if they become seriously ill or face a diagnosis with a terminal prognosis, and are unable to speak for themselves.

Most people don't like to think about their own death, nor that of their loved ones, and so believe that they will deal with this issue if they become seriously ill. However, the sad reality is that following the receipt of bad news such as a terminal diagnosis, there is often chaos and confusion in a person's life, and decisions may then be made out of fear or panic. Completing an initial advance directive in reaction to a sudden illness or crisis is therefore not ideal, as the decisions may end up being different than decisions they might have made if they had time to think about and consider the issues involved. Thus, completing an advance directive in reaction to a sudden illness or crisis is not ideal.

What Are Advance Directives?

Many documents and forms are considered part of advance directives. One of the key documents is the medical power of attorney for health care, which designates a health care proxy or surrogate decision maker who is an individual selected by the patient to speak on their behalf in the event they are unable to communicate. Another widely used document is a living will, which specifies a patient's choice to refuse or agree to treatment in a variety of clinical circumstances.

In some states there are also physician orders for life sustaining treatments (POLST). POLST are actual physician's orders, signed by a physician and the patient, which specify the care a patient is to receive. Emergency personnel are able to follow its directives in the community, which is not true of living wills. However, research has

shown that the POLST form is often filled out by other healthcare professionals such as social workers, followed by the physician signing the form without actually having had a discussion with the patient or the patient's family.

Nonetheless use of POLSTs has been shown to decrease the number of hospital admissions of terminally ill patients and they have been identified by several professional organizations as a preferred advance planning document. They are most widely used by patients in nursing homes who are very near the end of life. Note that POLSTs are not currently recognized in a number of US states (Alabama, Arizona, Arkansas, Florida, Michigan, Nebraska, New Jersey, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Texas, Virginia).

Advance directives also include patient instructions about organ/body donation and funeral arrangements.

Medico-Legal Considerations

Advance care directives have medical and legal implications, so it is important that patients understand what they are signing. Unfortunately, that is not always the case. Many legal documents may be involved, and many of the documents are written above 12th-grade level, making them difficult for most adults to understand, especially those with limited English proficiency. Advance directive discussion should always be in a patient's preferred language.

There are also state-by-state variations in the language used in advance care documents and in the rights and responsibilities of surrogate decision makers. If a patient did not specifically designate a surrogate, states vary in whether or not same-sex partners or domestic partners can serve as surrogates (about 40 states do not permit this).

The requirement by some states for the document to be witnessed (most states require 2 witnesses) makes it difficult for patients who are homeless, institutionalized, or estranged from family members to complete the documents. West Virginia and North Carolina require not only 2 witnesses but also notarization of the document.

TIPS ABOUT DISCUSSING ADVANCE DIRECTIVES WITH PATIENTS

- Discussions about end of life care and advance directives should occur before, not during, a time of crisis.
- If there is disagreement between clinicians, surrogate decision makers, and advance directive documents about what should be done in a patient's care, consider obtaining an ethics consult.
- It is important to know and consider a patient's ethnic and cultural background when communicating about advance care planning.
- Consider using the Five Wishes approach to address patient's values in making end of life decisions.

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Nearly all states allow physicians and hospitals to follow advance directives from another state, providing that the wishes are in alignment with that of the hosting state.

Clinicians are sometimes reluctant to follow advance directives that forego treatment. It is important to note that laws protect clinicians against malpractice or other legal actions when they follow properly prepared advance directives.

Ethical Considerations

Sometimes there is uncertainty about what should be done in a patient's care. For example, there may be discordance between the wishes of the patient as stated in a living will and a surrogate decision maker's decision. The recommended approach in such situations is to seek legal advice or consult an ethics committee.

Four issues are usually considered in resolving such uncertainties. One is whether the treatment being considered has benefits that outweigh its risks. Another is whether other family members or friends can corroborate the recommendations of the surrogate decision maker and reflect what the patient would have wanted. A third is to consider whether the patient misunderstood the purpose of the advance directives. For example, were they completed during a workup for suspected cancer but the patient never considered that they might be used in the setting of some other medical condition that might have different outcomes? And finally, some medical power of attorney documents are written to specifically state that a designated surrogate decision maker can override stipulations in other advance directive documents. However, except for unusual circumstances, the patient's stated wishes should be followed.

Special Considerations

Clinicians should know common misconceptions about advance care documents. For example, many people think a living will is nothing more than a document which states that they should not be kept on life support if they are

unconscious. They don't realize that it can specify a number of options applicable in different circumstances. Advance directive documents should be reviewed annually and with major health changes. It is important that clinicians discuss the various advance directive options with patients to be sure they understand them. Medicare now provides reimbursement for time spent in such discussions and provides specific billing codes for doing so (99497 for initial discussions and 99498 for additional 30-minute time blocks).

Clinicians should be aware of cultural differences in the use and understanding of advance directives. For example, more whites than African Americans and Hispanics have advance directives. The reasons for this are varied and include lack of awareness and knowledge about advance directives, as well as lack of trust and concern that if patients sign advance directives, they will not receive care.

There are also ethnic or racial groups in which discussing death is considered taboo and discussions about advance directives may seem inappropriate. In other cultures or religions there may be a tenet that hope and miracles are options to be relied on, rather than planning for death.

In addition, in some cultures important medical decisions are made by families or by community groups, and the western culture's sense of autonomy is not appropriate. This situation is not addressed by advance care documents in the U.S., which allow only for designation of a single decision maker and not a family. It is thus important that a designated decision maker understand the family's and community's beliefs and cultural practices.

In all of the above situations, it is essential to understand a patient's values and wishes and not push for completion of standard forms. An alternative is the "Five Wishes" approach developed by the non-profit organization, Aging with Dignity. Five Wishes currently meets legal requirements in more than 40 states. Still another approach, though less widely used, is the Stanford Letters Project, in which patients write letters to their clinicians explaining their priorities.

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