Evidence-Based Advance Directives
A STUDY GUIDE FOR NURSES

By Dinah Brothers, RN, JD

As a nurse it's your responsibility to balance the many sensitive issues surrounding end-of-life care. At the same time you must comply with legal and regulatory requirements. Evidence-Based Advance Directives: A Study Guide for Nurses gives you a practical overview of the legal, ethical, and cultural aspects of advance directives to help you provide the best level of care to your patients.

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**Introduction**

A person facing terminal illness has to make intensely personal choices and assessments. As a nurse, you work closely with patients and their families at these difficult times: You are one of the first to know when patients are approaching incapacitation or death, and you are on the frontline for making sure patients receive the care they want.

The advance directive is an increasingly important tool patients can use to stipulate their wishes and control their healthcare, even after they become incapacitated. Thus, nurses must understand advance directives and the legal and regulatory requirements, the ethical and cultural factors, and nurses’ roles in meeting the needs of their patients and being patient advocates.

**Laws mandating advance directives**

Advance directives help patients define their healthcare choices in case they become unable to communicate their wishes at the end of life. State and federal mandates have established them as a legal right for patients making end-of-life decisions.

This legal right stems from the belief that an individual has the right to make his or her own healthcare decisions. In fact, the U.S. Congress has enacted the Patient Self-Determination Act to
safeguard the right of competent adults to make their own healthcare decisions and have those decisions heard through the execution of advance directives.

**The Patient Self-Determination Act**

Under the Patient Self-Determination Act (42 U.S.C. §1395), patients are guaranteed the right to participate in healthcare decisions, including the right to prepare advance directives. The Act, enacted by Congress in 1990, requires hospitals that receive federal funds (such as through Medicare and Medicaid) to provide patients with information concerning their rights, under state law, to

1) participate in and direct healthcare decisions

2) accept or refuse medical treatment

3) initiate advance directives

To meet these mandates, hospitals must, according to the Patient Self-Determination Act,

a) maintain written policies and procedures concerning advance directives

b) provide the adult patient with written information regarding the right to accept or refuse medical or surgical treatment and the right to execute an advance directive

c) document in the patient’s medical record whether the patient has executed an advance directive

d) not condition the provision of care or otherwise discriminate against a patient based on whether that patient has executed an advance directive

e) provide staff and the community with education about advance directives
Advance directives and the law

The Act states that hospitals are required to provide this information to patients at the time that the individual is admitted to the facility as an inpatient. If the patient is medically incapacitated at admission and unable to receive information regarding his or her right to execute an advance directive, the Act permits the hospital to provide advance directive information to the patient’s family or proxy decision-maker.

State laws mandate advance directives

State laws mandate the legal requirements for valid advance directives. These laws may vary regarding what form of advance directives are legally recognized, who may execute an advance directive, the format or written requirements necessary to make an advance directive legal, when or under what conditions the advance directive becomes effective, and the types of medical and surgical treatments to which the advance directive applies. Hospitals must comply with relevant state laws governing advance directives in addition to complying with federal laws. Consult with the legal department at your facility regarding the legal requirements for advance directives in your respective state.

The Advance Directives Improvement and Education Act of 2005

Despite the passage of the Patient Self-Determination Act, only a small portion of the general population has executed an advance directive. It is estimated that advance directive completion rates remain less than 20% for the general public.1

The Advance Directives Improvement and Education Act of 2005 (109 Congress, S. 347) is an effort by Congress to build upon the Patient Self-Determination Act and improve patient access to information about healthcare options and legal rights for end-of-life care. Another objective of the Act is to encourage end-of-life healthcare planning and decision-making to ensure that individuals’ desires regarding end-of-life decisions will still be met if they are medically incapacitated and unable to speak for themselves.

Finally, the Act will engage healthcare providers in disseminating information about advance directives and ensure that patients receive assistance with their preparation. To meet this goal,
Medicare beneficiaries will have access to their primary-care physician for consultations and advice when preparing advance directives. This consultation between the patient and the physician will include

- the importance of preparing advance directives in case an injury or illness causes the individual to be unable to make healthcare decisions
- the situations in which an advance directive is likely to be relied upon
- the reasons for which the development of a comprehensive end-of-life plan is beneficial and the reasons for which such a plan should be updated periodically as the health of the individual changes
- the identification of resources that an individual may use to determine the requirements of the state in which such individual resides so that the treatment wishes of that individual will be carried out if the individual is unable to communicate those wishes, including requirements regarding the designation of a surrogate decision-maker (i.e. healthcare proxy)
- whether the physician is willing to follow the individual’s wishes as expressed in an advance directive

The Act requires these consultations between the patient and the physician to be held annually or immediately following any major change in an individual's health condition that would warrant such a consultation, whichever is most immediate.

The Act also will recognize advance directives as “portable” legal documents that are valid from state to state. Currently, an advance directive executed in one state may not be legal across state lines. Under the Act, however, advance directives legally executed in the originating state must be accepted and honored in the state in which the advance directive is presented unless honoring the document would violate state law. The Act will preempt state law to the extent that state law is inconsistent with the provisions of the Act.
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The Act also will provide funding for a public education campaign to increase awareness of the importance of executing an advance directive and to improve the public’s understanding of various healthcare situations in which advance directives may be beneficial. Studies also will be conducted to determine the effectiveness of advance directives in making patients’ wishes known and honored by healthcare providers.

The language of the Advance Directives Improvement and Education Act of 2005 strongly supports all patients executing advance directives. At press time, the Act has been introduced to the House and Senate.

References

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