

# Evidence-Based Advance Directives

A STUDY GUIDE FOR NURSES

Dinah Brothers, RN, JD

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## **ABOUT THE AUTHOR**

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**Dinah Brothers, RN, JD**, is a staff attorney for the Texas State Board of Medical Examiners in Austin. In this position, Brothers litigates cases against physicians for failure to practice medicine within the appropriate standard of care, for sexually inappropriate behavior with patients, and for intemperate drug and alcohol use.

Prior to attending law school, Brothers worked as a nurse for ten years. Her nursing experience includes psychiatric and mental health nursing, nursing management, and nursing education. She was instrumental in opening a new psychiatric facility in west Texas and in securing the hospital's initial accreditation by the Joint Commission on Accreditation of Healthcare Organizations.

## **LEARNING OBJECTIVES**

- Describe hospitals' legal requirements under the Patient Self-Determination Act
- Discuss the Advance Directives Improvement and Education Act of 2005
- Assess nurses' knowledge of advance directives
- Discuss nurses' patient advocacy role regarding advance directives
- Distinguish between the living will and the durable power of attorney for healthcare
- Define the "clear and convincing" language requirement
- Identify when a Do Not Resuscitate order may be medically and ethically appropriate
- Identify when a patient may revoke an advance directive
- Identify special considerations regarding advance directives that must be addressed with some elderly patients
- Verbalize the legal basis upon which advance directives are founded
- Recognize the state's interest in protecting patients
- Enumerate the three-part test of the *Conroy* Court to determine whether life-sustaining treatment may be withheld or withdrawn
- Identify factors that may encourage healthcare providers to deviate from an advance directive when making healthcare decisions for a medically incapacitated patient
- Discuss the nurses' role in ensuring the patient's wishes outlined in an advance directive are respected



## Learning objectives

- Identify sources of conflict concerning end-of-life decisions between the patient's family and the clinician
- Analyze the role of advance directives in reducing healthcare expenditures
- Discuss the European American values regarding healthcare
- Analyze why African Americans may distrust the U.S. health system
- Define the role of Latino families in making healthcare decisions for the medically incapacitated patient
- Identify the elements of a well developed advance directive curriculum
- Identify strategies to include cultural leaders in the promotion of nurses' cultural competency regarding end-of-life decisions
- Discuss the standards of the Joint Commission on Accreditation of Healthcare Organizations regarding advance directives
- Identify the necessary contents of hospital policies and procedures to meet legal mandates and accreditation standards for advance directives

**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

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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.<sup>1</sup>

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,

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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.

## **Advance directives and the law**

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**

1. David Goldblatt, "A Messy Necessary End: Healthcare Proxies Need Our Support," *Neurology* 56 (2001): 148–152.

**Introduction**

The Patient Self-Determination Act mandates that information about advance directives be presented to adult patients admitted to federally funded facilities. Thus, every nurse, at some point, will face questions and concerns from patients and their families regarding advance directives. In addition, nurses have been shown to play a key role in whether patients draw up advance directives, so ensure that you are educated and informed about advance directives and that you are prepared to communicate correctly when questioned by patients and their families about important end-of-life decisions.

**Nurses' knowledge of advance directives**

The recent study by Lipson et al.<sup>1</sup> determined that nurses' knowledge about, attitudes toward, and confidence in discussing advance directives with patients related directly to their exposure to information about advance directives. Specifically, Lipson found those nurses who had been educated and were knowledgeable about advance directives were more likely to discuss them with patients.

Another significant finding was that, surprisingly, those nurses with more years of nursing experience and higher levels of education were actually less likely to engage patients in discussions regarding advance directives. Despite their advanced education, they had not learned how to broach this subject.

## Chapter 2

Thus, the study identified that all nurses, even those with advanced degrees, needed additional education about advance directives. Lipson's study also determined that nurses' confidence in discussing advance directives was a "significant predictor of actual advance directive discussions."<sup>2</sup>

Although nurses who are knowledgeable about advance directives are more likely to broach the subject with patients, research has indicated that most nurses have a limited knowledge of advance directives and are not confident in their ability to assist patients. In a recent study by Mary Ann Jezewski et al.,<sup>3</sup> the nurses surveyed had general knowledge about advance directives but knew less about the Patient Self-Determination Act and the relevant laws in their state.

The nurses also expressed a lack of confidence in helping patients complete advance directives. They specifically identified that they were not confident in their ability to discuss advance direc-

### Nursing implications

The educational implications identified in Lipson's and Jezewski's studies are significant: Because nurses' level of knowledge was found to correlate positively with advance directive discussions, we must create educational methods of disseminating information about advance directives to nurses. Although nursing educational programs discuss them briefly, Lipson's study determined that such education is limited. For nurses who reported learning about advance directives during their formal education at all, this education was often limited to a single lecture.

Lipson theorized that nursing schools lack advance directive curricula because advance directive content is scarce in nursing textbooks.

Based on Lipson's findings that nurses with more years of experience are less likely to discuss advance directives, and based on the finding that nursing education programs provide only cursory education regarding advance directives, nurses at all levels need basic education regarding advance directives. This need is also supported by Jezewski's findings that nurses have only general knowledge of advance directives.



## Nurses' role in promoting advance directives

tives with patients and families, to answer questions regarding advance directives, to advocate for patients, to implement institutional policies and procedures, to speak to the laws governing advance directives, and to mediate disagreements between patients and families regarding end-of-life decisions.

### Nurses' role in discussing advance directives

In its position statement entitled “Nursing and the Patient Self-Determination Acts,” the American Nurses Association emphasized that nurses “play a primary role in implementation of the Patient Self-Determination Act.”<sup>4</sup> It also states that nurses must facilitate “informed decision making”<sup>5</sup> regarding advance directives through patient education and advocacy.

To help nurses fulfill this patient educational and advocacy role, Briggs and Colvin call for a “revised commitment from nurses to adequately prepare patients and families to fully participate in their healthcare decision making.”<sup>6</sup> They describe discussions of end-of-life decisions with patients as a dynamic process that changes as the patient’s health status changes, and they identify the following steps in discussing future medical conditions with patients:

1. **Exploring and understanding:** The patient should be educated about his or her medical condition and the treatment choices that may be available if the patient is unable to participate in his or her own treatment decisions.
2. **Reflecting on possible decisions:** The patient examines his or her personal values and how those values translate into individual healthcare goals.
3. **Decision-making:** The patient plans his or her end-of-life choices and makes decisions that are consistent with the individual’s medical condition and values. The patient also discusses these choices with family members and healthcare providers.
4. **Documenting the choices:** The patient reduces his or her decisions and choices concerning end-of-life care to writing an advance directive.

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This progressive approach acknowledges that patients cannot complete an advance directive in one sitting, nor should they be asked to do so. Advance directives require extensive thought and reflection on the part of the patient and family, and the nurses' advocacy role extends beyond questioning patients regarding whether they have completed an advance directive.

Ideally, advance directives would be completed by all patients—with input from significant others—prior to the patient's hospital admission and prior to the occurrence of a serious medical condition. A study by Mortimer D. Gross, however, found that few people actually complete advance directives.<sup>7</sup> Since the enactment of the Patient Self-Determination Act, hospitals have given patients information about advance directives, but research has indicated that simply providing information and questioning patients to ascertain whether they have completed advance directives does not increase the completion rate.<sup>8</sup>

One proven way to influence the completion rate positively is to use patient advocacy and education, as well as holding direct discussions about advance directives between patients and healthcare providers.<sup>9</sup>

### **Patients' lack of knowledge about end-of-life options**

Nurses also must be educated about advance directives because patients often misunderstand their options for end-of-life care. Maria J. Silveira found that although most patients knew that they could refuse life support, many patients did not understand that, once initiated, this life support could be withdrawn.<sup>10</sup> Patients also did not understand their options for aggressive pain management. These findings indicate that nurses must take a proactive role in educating patients about end-of-life options and alleviating patient fears.

### Nursing implications

As the primary providers of patient care, nurses invariably will be questioned about advance directives. Therefore, be ready to discuss these documents and be mindful of the legal, ethical, and cultural implications they have. Becoming educated about advance directives, preparing to answer patient questions, and advocating for patients during difficult situations will elevate nursing practice to a higher level of professionalism.

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**Advance directive documents**

Although advance directives are often oversimplified and misunderstood, these documents include much more than the single decision to terminate a patient's life-support. Under the broad heading of advance directives fall legal documents that provide written instructions regarding a patient's final (or in some cases interim) wishes concerning healthcare when that patient is personally unable to express his or her desires due to medical incapacitation or lack of decision-making capability.

Advance directives include

1. the living will
2. durable power of attorney for healthcare

If a person wants to create an advance directive, he or she must be considered competent at the time the document is created. New York state law defines this competency as the "capacity to make healthcare decisions,"<sup>1</sup> which means he or she must have the ability to understand and appreciate the nature and consequences of healthcare decisions—including the benefits and risks of any proposed treatment or care, as well as any alternatives—and the ability to reach an informed decision.

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### ***The living will***

The living will is a written legal document through which an individual specifies his or her instructions regarding personal healthcare issues. The objective of the living will is to establish an individual's wishes concerning pain relief, mechanical means of prolonging life, nutrition and hydration, and organ donation, as well as burial instructions. Terminology varies between states and, in some states, the living will may be known as a healthcare directive or healthcare declaration.

### ***Durable power of attorney for healthcare***

The durable power of attorney for healthcare allows a competent adult to name a person to make healthcare decisions in the event that the adult patient is unable to make his or her own decisions due to a medical condition. It only becomes effective when the patient becomes incapacitated and is not able to make his or her own decisions. Once again, terminology may vary. In some states, the durable power of attorney for healthcare may be known as a medical power of attorney or a healthcare proxy.

### ***Choosing a healthcare proxy***

The designated decision-maker named in the durable power of attorney for healthcare is known as the healthcare proxy and substitutes his or her judgment for the judgment of the patient. The healthcare proxy, as the decision-maker for the patient's healthcare, must be able to put himself or herself in the patient's shoes and apply the patient's values and ethics when evaluating decisions for the patient. For this reason, patients should choose a healthcare proxy carefully. The healthcare proxy must be someone the patient trusts and who can proceed methodically through the difficult decision-making process, who understands that his or her decisions may not be accepted by all family members, and who accepts that his or her decisions may hasten the death of the patient.

The healthcare proxy may be required to make difficult decisions, and the emotional toll may be great; therefore, naming a close relative, such as a spouse or a child, as the healthcare proxy may not always be wise. Some family members are simply unwilling or incapable of undertaking such a daunting responsibility. Also note that naming more than one healthcare proxy is unwise: Healthcare providers will experience difficulty providing patient care when two named healthcare proxies disagree on the level of care to be provided the patient.

## What is an advance directive?

State law also may restrict who can be named as a healthcare proxy. For example, under New York state law, an administrator or employee of a hospital may not be appointed as a healthcare proxy by a person who, at the time of the appointment, is a patient or resident of the hospital or who has applied for admission to the hospital.<sup>2</sup> Such mandates are designed to protect patients' interests and to guarantee that a conflict of interest does not arise when the healthcare proxy makes decisions for the patient.

### Communicating with the healthcare proxy

When the patient becomes incapacitated and the named healthcare proxy assumes the role of decision-maker for the patient, the nurses' communication responsibility shifts from the patient to the proxy decision-maker. The healthcare proxy must be given all the information necessary to make an informed choice for the patient. Under New York state law, for example, the healthcare proxy must receive medical information and the medical and clinical records necessary to make informed decisions about the patient's healthcare.<sup>3</sup>

### Decisions of the healthcare proxy

The decisions of the healthcare proxy must reflect the patient's best interests, and state laws restrict the proxy's decisions to protect the patient's interests. For example, in Illinois, a proxy decision-maker cannot tell the healthcare professional to withdraw or withhold life support measures unless the patient has a "qualifying condition"—that is, a terminal condition, vegetative state, or incurable or irreversible condition. Two physicians then must certify that the patient cannot make decisions and that the patient has a "qualifying condition" in order to withdraw or withhold life-sustaining treatment.<sup>4</sup>

### ***The living will v. the durable power of attorney for healthcare***

The living will and the durable power of attorney for healthcare are two separate legal documents. The most important difference between them is that the latter allows a named agent to make all healthcare decisions for the patient under certain circumstances and the former does not. Because it is impossible to conceive of all healthcare situations or medical conditions that may need to be addressed by a living will, the durable power of attorney can complete the picture based on the guidelines patients establish in their living wills. So if patients create a living will, they should also decide on a durable power of attorney for healthcare.

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### ***The ‘clear and convincing’ language requirement***

Because the living will and the durable power of attorney for healthcare only become effective when patients are no longer competent to communicate their own desires, the written instructions contained in these documents must establish clearly the patient’s wishes. Courts want evidence that a patient communicated his or her healthcare wishes in a manner that can reasonably be understood and interpreted, so courts generally conclude that a patient’s wishes must be demonstrated by “clear and convincing” language.

For example, patients often indicate in their living wills that they do not want any “heroic measures” or “extraordinary means” to prolong life, but there are many different interpretations of these terms. Therefore, rather than using such ambiguous language, living wills should address specific interventions—such as nutrition and hydration or mechanical means of prolonging life—that the patient desires to be administered or withheld.

Patients must also use “clear and convincing” language when outlining a proxy’s authority in the durable power of attorney for healthcare. The patient should grant the proxy a broad range of authority, not just the authority to make end-of-life decisions. For example, additional authority could be granted to the proxy to make decisions concerning consent for specific medical treatments, procedures, or tests; convalescent or hospice care; and funeral arrangements.

### **What should patients address in their advance directives?**

Numerous treatment and healthcare decisions must be made when a patient becomes medically incapacitated. Although it is difficult to anticipate every issue, the patient’s living will should address the patient’s preferences for specific treatment options, and the healthcare proxy needs to be aware of these preferences.

Thorough advance directives should address the following issues:

1. Pain relief through medication

## What is an advance directive?

2. Mechanical means and extreme measures to prolong patient life
3. Nutrition and hydration
4. Organ donation
5. Burial instructions and religious concerns

### **1. Pain relief through medication**

Consider a patient's personal and ethical beliefs when addressing the issue of pain relief medications. Such medications may hasten the death of the patient, and this potential outcome must be weighed in the context of the patient's personal beliefs.

Some patients will prefer maximum pain relief, even if the medication may hasten death, and others will desire maximum pain relief but do not want it to intentionally hasten death. The living will must clearly state and address these wishes.

The adequacy of pain relief also needs to be addressed in advance directives. Some patients near the end of life may not be able to communicate whether pain is being adequately managed. Therefore, the living will should address the level of pain medication patients desire.

Administration of pain medication also raises religious issues. Patients with specific religious faiths may want to be lucid at or near the end of life for final religious functions. Pain relief medication may dull the senses and make the patient unable to participate in important final rituals. Thus, the living will should address the patient's preferences regarding lucidity for participation in these rituals.

### **2. Mechanical means and extreme measures to prolong patient life**

Technological advances in the medical field occur quickly, and treatments that were considered experimental when a patient executed an advance directive may be accepted practice when the



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patient's advance directive becomes effective. The patient must consider this fact when stipulating what kind of mechanical measures he or she would want used to prolong his or her life.

Ethical issues are an important part of this discussion and enter into the patient's consideration. The treatment team, the patient, or the patient's healthcare proxy must determine whether mechanical means should be used to prolong a patient's life if the patient will be in a persistent vegetative state or is in one already. Patients must weigh the benefits and burdens of mechanical means of prolonging life against their own personal beliefs. They must consider what determines quality of life for them and what they consider to be an extreme measure to prolong their life.

Patients must be specific in their advance directives concerning what mechanical means and extreme measures they desire. If a patient desires that every mechanical means and life-saving procedure available be performed—such as cardiac resuscitation, ventilator respiration, nutrition, and hydration—then the patient's advance directives should clearly indicate such instructions.

Patients must be well informed concerning the treatments and equipment available to them in the healthcare arena before they make specific statements concerning mechanical means and extreme measures. For example, a patient may state in a living will that “no ventilator support [should] be initiated,” but this blanket statement may not be appropriate for each healthcare scenario the patient may encounter. If a patient becomes incapacitated and could receive temporary ventilator support that would allow him or her to return to normal health functioning, then not initiating a ventilator would arguably be inappropriate. To avoid such dilemmas, educate patients about their options. Their living will must specifically identify what they consider to be mechanical means. They must be very clear about when they want to use those options—and when they choose to refuse them.

### **3. Artificial nutrition and hydration**

Whether nutrition and hydration constitutes medical care or simply palliative care is hotly debated. In Texas, the legal definition of “artificial nutrition and hydration” is “the provision of nutrients or fluids by a tube inserted in a vein, under the skin in the subcutaneous tissues, or in the stomach

## What is an advance directive?

(gastrointestinal tract).”<sup>5</sup> According to this legal definition, treatment as basic as intravenous fluid replacement constitutes artificial nutrition and hydration.

In addition to defining artificial nutrition and hydration, state laws may dictate when and how nutrition and hydration may be withdrawn. In such cases, nurses and other healthcare practitioners must ensure that they follow these legal mandates. For example, healthcare proxies in New York are strictly regulated when making decisions for patients concerning nutrition and hydration. New York law allows healthcare proxies to make decisions for the patient after consultation with the healthcare team and in accordance with the patient’s wishes, or if the patient’s wishes are not known and cannot be ascertained, in accordance with the patient’s best interests. However, if the patient’s wishes are not known or cannot be ascertained regarding the patient’s desires for nutrition and hydration, the healthcare proxy does not have the authority to make decisions regarding this matter.<sup>6</sup>

State laws may alleviate some of the legal questions surrounding the issue of artificial nutrition and hydration, but moral and ethical discussions often provide the most controversy, as in the Terri Schiavo case. In that case, one of the contentious issues debated by both the courts and the wider general public was whether the nutrition and hydration she received constituted medical care. For those patients who deem artificial nutrition and hydration to be palliative care, nutrition and hydration should not be discontinued under any circumstances, even when the patient is in a persistent vegetative state. For this reason, patients executing advance directives must determine when they desire artificial nutrition and hydration, as well as whether and when they wish to discontinue this supportive measure.

### Careful definitions help avoid controversy

Patients should consider the following options when defining desires for artificial nutrition and hydration in advance directives:

1. **Nutrition and hydration under all circumstances:** If the patient wishes to receive nutrition and hydration regardless of medical condition, he or she should address it specifically in the living will.

## Chapter 3

2. **Withholding nutrition and hydration under the written direction of a physician:** The patient may stipulate in the living will to discontinue artificial nutrition and hydration when the patient's attending physician states in writing that, to a reasonable degree of medical certainty, the patient is in a terminal condition or a permanently vegetative state, and that the provision of nutrition and hydration will not prolong the life or provide comfort to the patient.
3. **Identifying artificial nutrition and hydration as medical care:** For the patient who defines artificial nutrition and hydration as medical care, the patient may stipulate that artificial nutrition and hydration are to be withheld or withdrawn according to the patient's directives of withholding or withdrawing other life-sustaining treatments or medical care.

### **4. Organ donation**

Patients who wish to be organ donors should outline in detail their specific desires in the advance directive. A statement such as "I wish to donate my organs" is open to interpretation and could include donating to medical schools or research institutions, which some patients may find objectionable. If patients want to donate organs for life-saving transplants only, they must specify this stipulation in their advance directive.

Patients also should discuss this issue with family members. Organ donation must occur quickly after death, so the family should have advance notice that this is what the patient wants.

### **5. Burial instructions and religious concerns**

In the living will, the patient may address funeral arrangements, religious preferences, and burial instructions. Regardless of patients' religious beliefs, they should not assume their families are familiar with their wishes concerning a final ceremony. Even those who do not consider themselves religious and do not desire a religious service should make this desire known within the living will. Family members or others may have religious beliefs that conflict with those of the patient and may make burial decisions that conflict with the patient's wishes unless they are specified within the living will.

Burial instructions also may be communicated in a letter of last instructions. If the patient chooses this route, the living will should include, at the very minimum, a statement that the

## What is an advance directive?

patient's detailed burial instructions may be found in the letter of last instruction and the location of that document.

### The 'Do Not Resuscitate' order

The Do Not Resuscitate (DNR) order is a narrowly-defined directive to healthcare professionals that cardiopulmonary resuscitation (CPR) not be initiated after a patient suffers a cardiac or respiratory arrest. The DNR order concerns decisions about CPR and does not relate to any other therapeutic measures or medical treatments a patient may desire or decline.

DNR orders are considered medically and ethically appropriate under certain circumstances. According to the American Medical Association, DNR orders should be considered when resuscitative efforts cannot be expected to restore cardiac or respiratory function to the patient.<sup>7</sup> Although factors such as age influence the outcome of CPR, the patient's medical condition is highly predictive of the success of CPR. CPR has consistently failed to result in a desirable outcome for patients with medical conditions such as septic shock, acute stroke, metastatic cancer, and severe pneumonia.<sup>8</sup> Therefore, CPR may be futile for patients with these diagnoses, which means that the patient's illness is beyond the means of medical treatment.

Depending upon state law, DNR orders also may be written for hospitalized patients or persons at home. DNR orders for hospitalized patients tell hospital staff not to revive the patient if he or she experiences cardiac or respiratory arrest. For persons at home, DNR orders tell emergency medical personnel not to initiate emergency resuscitation efforts and not to transfer the patient to the hospital for resuscitation. For these homebound persons, states have identified certain tools, such as identification bracelets, to notify emergency personnel that the person does not desire CPR.<sup>9</sup>

For hospitalized patients, facilities must take care to identify at every stage of the hospital stay those with DNR instructions. For example, nurses on a unit may know that a patient has a DNR order, but if the patient is sent to another unit or department for tests, staff at that location may be unaware of the DNR order and perform CPR against the patient's wishes. Therefore, hospitals must

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develop some means of identifying these patients throughout the facility and to all personnel. One way to do this is to have DNR patients wear an identification band of a particular color and to educate all staff as to what that band means.

### **Customizable examples of advance directives**

Advance directives are legal documents and must meet certain legal requirements. However, it is imperative that these documents are kept simple and easy to understand. To meet this objective, advance directives should be written with minimal legal jargon and should outline the patient's options clearly.

The following examples of the living will and the durable power of attorney for healthcare provide examples of advance directives that are reader-friendly. Remember to be aware of the patient's reading and comprehension level because additional changes may need to be made to these documents to allow patients with lower reading levels to participate in their healthcare decisions.

As always, these documents must be executed in accordance with your state law and need to be approved through the proper channels of your hospital. Modify the documents as needed.

## What is an advance directive?

### Living will

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I, \_\_\_\_\_ (insert name), being a competent adult capable of making decisions about my own medical care, make this directive to be followed if I become incapacitated or incompetent and unable to participate in decisions regarding my own medical care.

#### **Mechanical means and extreme measures to prolong life**

If, in the judgment of my physician, I have an incurable or irreversible medical condition or am in a persistent vegetative state and I am not expected to reasonably recover, even with available life-sustaining treatment provided in accordance with prevailing standards of medical care,

\_\_\_ I request that all medical treatments other than those needed to keep me comfortable be discontinued or withheld and that my physician allow me to die

\_\_\_ I request that all available life-sustaining treatments be administered to me

#### **Pain relief through medication**

Even if medical treatments are to be withheld or withdrawn, I wish that pain relief measures be continued in the following manner:

\_\_\_ I request maximum pain relief through medications, even though such measures may hasten my death.

\_\_\_ I request pain relief through medications. However, pain medications should not be used to the extent that they affirmatively hasten my death.

\_\_\_ I request pain relief. However, I wish to remain lucid at or near the end of life to participate in final religious functions.

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### Nutrition and hydration

If my attending physician certifies that I have an incurable or irreversible medical condition or am in a persistent vegetative state and I am not expected to reasonably recover, I wish artificial nutrition and hydration to be continued in the following manner:

\_\_\_ Artificial nutrition and hydration may not be withheld or withdrawn, and I request that artificial nutrition and hydration be continued regardless of my medical condition.

\_\_\_ Artificial nutrition and hydration may be withheld or withdrawn if my attending physician certifies in writing that my medical condition is terminal or that I am in a persistent vegetative state and that the provision of artificial nutrition and hydration will not prolong my life or provide me comfort.

\_\_\_ Artificial nutrition and hydration are to be withheld or withdrawn when other life-sustaining treatments are withheld or withdrawn in accordance with the standards set forth above.

### Organ donation

My organs are to be donated only in the following manner:

\_\_\_ I do not want to donate my organs or tissues in any manner

\_\_\_ I wish to donate my organs or tissues as a transplant to save another person's life

\_\_\_ I wish to donate my organs or tissues for medical research or education

\_\_\_ I wish to donate my organs or tissues in any needed legitimate capacity

\_\_\_ I wish to donate only the following organs and tissues:

\_\_\_\_\_ (list specific organs and tissue to be donated)

## What is an advance directive?

### Burial instructions and religious concerns

My burial instructions and religious concerns are as follows:

\_\_\_ I request that my funeral services and burial follow \_\_\_\_\_ [insert name of religion]  
religious customs

\_\_\_ I request that no religious principles apply to my funeral services and burial

\_\_\_ My burial instructions have been detailed in a “letter of last instructions,” which is located at  
\_\_\_\_\_ [location]

I have executed this document on \_\_\_\_/\_\_\_\_/\_\_\_\_ [month, date, year].

Signature \_\_\_\_\_

Witness \_\_\_\_\_



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### Durable power of attorney for healthcare

I, \_\_\_\_\_ [insert name], being a competent adult capable of making decisions about my own medical care, appoint:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

as my healthcare proxy to make any and all healthcare decisions for me, except to the extent that I limit that authority in this document. This durable power of attorney for healthcare takes effect if I become unable to make my own healthcare decisions as a result of becoming medically incapacitated.

#### **Limitations on the decision-making authority of my agent**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I have executed this document on \_\_\_\_/\_\_\_\_/\_\_\_\_ (month, date, year).

Signature \_\_\_\_\_

Witness \_\_\_\_\_

### References

1. Health Care Agents and Proxies, New York Public Health Law, Chapter 45 (McKinney's Ann.).
2. Ibid.
3. Ibid.
4. Illinois Department of Public Health, "Statement of Illinois Law on Advance Directives and DNR Orders," [www.idph.state.il.us/public/books/advdir4.htm](http://www.idph.state.il.us/public/books/advdir4.htm) (accessed July 3, 2005).
5. Texas Advance Directives Act, Texas Health & Safety Code Ann., Chapter 166 (Vernon Supp. 2004).
6. Health Care Agents and Proxies, New York Public Health Law, Chapter 45 (McKinney's Ann.).
7. American Medical Association, "E-2.22 Do-Not-Resuscitate Orders," [www.ama-assn.org/ama/pub/category/8461.html](http://www.ama-assn.org/ama/pub/category/8461.html) (issued March 1992). Based on the report "Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders," adopted December 1990 (*The Journal of the American Medical Association* 265, (1991): 1868-1871, updated June 1994).
8. Clarence H. Barddock III, "Do Not Resuscitate Orders," University of Washington School of Medicine 1998, <http://depts.washington.edu/bioethx/topics/dnr.html> (accessed June 18, 2005).
9. Texas Department of State Health Services, "Out-of-Hospital Do-Not-Resuscitate Program," EMS Trauma System, [www.tdh.state.tx.us/hcqs/ems/dnrhome.htm](http://www.tdh.state.tx.us/hcqs/ems/dnrhome.htm) (accessed June 18, 2005).

**Can I change my mind?**

One concern that prevents some patients from making advance directives is that they are frightened of being locked into decisions regarding their care and fear they will change their mind at a later date. Therefore, nurses should reassure patients that the law allows a competent adult to revoke the living will or the durable power of attorney for healthcare at any time. Informed decisions made by competent patients always trump advance directives.

***Revoking advance directives***

State laws describe the legal way in which a patient may revoke written advance directives. For example, patients in Texas may revoke advance directives by oral or written notification or by any other act evidencing a specific intent to revoke.<sup>1</sup> Nurses should note the laws and requirements for their particular state.

Certain legal conditions may automatically revoke advance directives as well. For example, if the patient's spouse is the healthcare proxy, divorce of the patient and the spouse will revoke the spouse's authority to make decisions for the patient unless the advance directive provides otherwise.

**Limitations on liability**

Healthcare professionals may fear legal action will be taken against them if they follow a patient's advance directive and withdraw certain life-support measures, especially if the family wants the

## Chapter 4

measures continued or if some segments of society consider withdrawal of a measure to be undesirable or controversial. This is one reason healthcare providers have given for not following a patient's stated wishes in his or her advance directive.

State laws have addressed this issue and absolved healthcare professionals from legal liability for withholding or withdrawing life-support measures when the professional exercises reasonable care in applying the patient's advance directive. The standard of reasonable care is most often understood to be exercising the degree of care that a healthcare professional of ordinary prudence and skill would exercise under the same or similar circumstances.<sup>2</sup> Nurses should know their state's specific law concerning limitations on liability for following an advance directive.

### **Special considerations**

Advance directives for certain patients require the nurse to be aware of additional care needs and different information requirements.

#### ***Special considerations for the elderly***

For the elderly patient, specific health concerns deserve special consideration when discussing advance directives. For persons with Alzheimer's disease or dementia, for example, nurses must address unique issues. Some particular disease characteristics identified in "End-of-Life Care for Patients with Advanced Dementia"<sup>3</sup> include the unpredictable progression of the disease, which causes cognitive and functional impairments that predispose patients to behavioral difficulties. Because Alzheimer's disease and dementia destroy the patient's intellectual capacity and ability to communicate individual wishes and desires, advance planning for end-of-life care must begin when the patient is diagnosed with Alzheimer's disease or dementia.

But this advance planning may be in direct conflict with the patient's new diagnosis. When patients are diagnosed with a terminal illness, they generally have to progress to a period of acceptance or, at the very least, understanding of the disease. As previously discussed, patients also need time to consider, discuss, and execute advance directives. Patients with Alzheimer's disease or dementia, however, must begin executing advance directives quickly due to the unpredictable pro-

## **Special considerations for patients and healthcare providers**

gression of the disease. In such cases, the healthcare professional must be especially sensitive to the newly diagnosed patient while discussing advance directives.

### ***Special considerations for the pregnant patient***

Patients who are pregnant, who may be pregnant, or who are anticipating pregnancy should address this issue in their advance directive. Numerous ethical and legal issues could be debated, but one primary issue to consider is what to do when a choice has to be made between the patient and the fetus, and what medical treatments should be administered. The patient must assess this issue carefully and specifically identify her desires through her advance directive.

The following options are available:

1. **Preference to the patient.** The advance directive identifies that preference is given to the life of the patient over the life of the fetus in any medical or treatment decisions that must be made. In this decision, the patient receives primary consideration over the fetus.
2. **Preference to the fetus.** The advance directive identifies that all life-sustaining treatment be continued during the pregnancy if it is medically reasonable that the fetus could be delivered as a viable and healthy infant. In this decision, the fetus receives primary consideration over the patient in any medical or treatment decisions.
3. **No action taken.** The advance directive identifies that no action be taken in favor of the patient's life or the life of the fetus.

Ultimately, state law may determine whether a pregnant patient can refuse life-sustaining treatments. For example, under Texas law, life-sustaining treatments may not be withheld from a person known by the healthcare professional to be pregnant.<sup>4</sup>

### ***Special considerations for minor or pediatric patients***

State law defines who is under the age of legal majority or not a legal adult. For these pediatric patients, parents or legal guardians most often make the medical decisions. Special considerations influence the execution of advance directives in such cases.

## Chapter 4

For parents, grief issues and the unthinkable anticipation of losing a child may impede discussion of end-of-life care. A study by Joanne Wolfe, et al.,<sup>5</sup> found that the majority of parents who lost a child to cancer believed that a cure was likely at the time that the child was diagnosed.

Consequently, as the child's cancer advanced and there was no realistic chance for the child's survival, these parents experienced difficulty recognizing that their child's death was imminent.

Although the parents recalled discussions with healthcare providers about their child's prognosis, only 49% of those parents reached an understanding that their child was terminally ill. For those parents who did obtain an earlier understanding regarding the terminal condition of their child, palliative care—such as hospice and comfort measures—was more likely to be integrated into the child's care plan.

In “Pediatrics and the Patient Self-Determination Act,”<sup>6</sup> Sahler advocates for the execution of advance directives for older pediatric patients prior to the patient's loss of capacity. In certain situations, caregivers may elicit the input of the minor about his or her care or even allow the minor to make decisions about his or her care because the caregiver has determined that the minor holds the level of maturity necessary to do so. In such situations, Sahler feels that the execution of an advance directive for a minor would allow the minor's opinions regarding their care to be respected. In this situation, the advance directive will be legally executed by the patient's parent or guardian; however, the patient will exercise some control over the decision-making process.

The pediatric nurse must be especially cognizant of the difficulty parents will have accepting their child's impending death. Such insight will require the nurse to engage in frequent communication with the parents to help them reach a greater understanding of the patient's projected health outcome.

### ***Special considerations concerning patients' ability to read and understand***

Patients must be able to read and understand the content of advance directives if they are to make informed decisions and execute advance directives that reflect their wishes. Research has shown that advance directives are difficult documents for patients to read and that there can be a wide discrepancy between the readability of these documents and the reading levels of patients.<sup>7</sup> This discrepancy ultimately can prevent patients from understanding the choices available to them.

## Special considerations for patients and healthcare providers

Findings from this study indicate that appropriate documents and materials about advance directives must be designed for patients with limited reading abilities. Nurses must be aware of patients' reading limits and intervene when patients are unable to understand the legal document in front of them.

### Financial matters

Although preparing financial matters is a significant part of end-of-life planning, advance directives are not intended to address this issue. Financial matters should be addressed in a separate document that focuses on them; it never should be part of the living will or the durable power of attorney for healthcare. Patients may execute a durable power of attorney with financial powers to secure their estate planning, and there are alternative methods, such as a living trust, that can be established to meet the patient's estate planning needs.

### Time to consider important decisions

The decisions that must be made regarding end-of-life care are extensive and require patients and their families to confront difficult topics. Therefore, patients will need time to consider these important decisions and weigh their options.

Patients must consider these decisions while they are competent to do so—they should not wait for a medical emergency or tragic accident to force the decision-making process. Advance directive discussions must be part of an ongoing process through which patients and their families can come to terms with the medical situation and increase their comfort in making end-of-life decisions.

### Nursing implications

To increase the patient's comfort in making end-of-life decisions, involve the right persons in discussions about them. Depending upon the individual patient, these persons may include family members or significant others, religious advisors, financial advisors, and members of the healthcare team. Be aware of all these issues and be prepared to call on the appropriate people to assist patients and their families with making these difficult decisions.

## Chapter 4

### References

1. Texas Advance Directives Act, Texas Health and Safety Code Ann., Chapter 166 (Vernon Supp., 2004).
2. Ibid.
3. Ann Hurley, et al., “End-of-Life Care for Patients with Advanced Dementia,” *The Journal of the American Medical Association* 284, no. 19 (2000): 2449–2450.
4. Texas Advance Directives Act, Texas Health and Safety Code Ann., Chapter 166 (Vernon Supp., 2004).
5. Joanne Wolfe, et al., “Understanding of Prognosis Among Parents of Children Who Died of Cancer: Impact on Treatment Goals and Integration of Palliative Care,” *The Journal of the American Medical Association* 284, no. 19 (2000): 2469–2475.
6. Olle Jane Z. Sahler, “Pediatrics and the Patient Self-Determination Act,” *Pediatrics* 90, no. 6 (1992): 999–1001.
7. Barbara B. Ott and Thomas L. Hardie, “Readability of Advance Directive Documents,” *Image: The Journal of Nursing Scholarship* 29, no. 1 (1997): 53–57.



**Introduction**

Regardless of the healthcare professional's personal opinions about what healthcare treatments or options a patient should receive, it has long been enshrined in law that patients have the right to make their own choices about their health and may choose which courses of medical treatment to accept or reject. In addition to understanding your patients' rights in these matters, healthcare providers sometimes will face cases in which patients are unable to make those decisions, so it is important that you understand situations in which life-sustaining treatment can be withdrawn.

***Informed consent***

The legal foundation for a patient being able to establish an advance directive is based on the doctrine of informed consent. As early as 1891, the United States Supreme Court recognized that "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."<sup>1</sup> The landmark decision *Schloendorff v. Society of New York Hospitals* affirmed a patient's right to approve his or her own medical treatment.<sup>2</sup> In this decision, Justice Cardozo wrote, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." The Supreme Court has solidly recognized that a competent person has a "liberty interest" in refusing unwanted medical treatment.<sup>3</sup>

## Chapter 5

Although numerous legal challenges have been mounted concerning a patient's right to refuse life-sustaining treatments, courts have consistently affirmed a competent person's right to make this decision. A brief review of landmark cases, often referred to as "right-to-die" decisions, illustrates how the United States legal system has dealt with difficult life and death decisions. Note, however, that legislation has been proposed in nearly every state since the death of Terri Schiavo that may influence or change this legal landscape.

One of the seminal cases regarding a patient's right to refuse medical treatment is the case of Karen Quinlan.<sup>4</sup>

### CASE STUDY

#### The case of Karen Quinlan

Karen Quinlan suffered severe brain damage and entered a persistent vegetative state. Her parents wanted to withdraw medical intervention and allow their daughter to die. The legal issue concerned whether the parents of a person in a persistent vegetative state could decide on the person's behalf to withdraw respirator support.

The New Jersey Supreme Court granted the parent's request, holding that Ms. Quinlan had a privacy right grounded in the Constitution to terminate treatment.<sup>5</sup> The Court recognized that although the state had an interest in preserving Ms. Quinlan's life, the state's interest gave way in this case because it "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."<sup>6</sup> The Court concluded the "only practical way" to prevent Ms. Quinlan's loss of privacy right was to allow her family to decide whether she would refuse medical treatment under the circumstances.

### The state's interest in protecting patients

As seen in the Karen Quinlan case, one key restriction on a patient's right to direct his or her medical care is the state's interest in protecting persons of that state. States have legal responsibilities to protect those who cannot protect themselves. A 1977 case involving the discontinuation of painful chemotherapy from a mentally incompetent man, *Superintendent of Belchertown State School v. Saikewicz*,<sup>7</sup> determined that states' interests include the

1. preservation of life
2. protection of the interests of innocent third parties
3. prevention of suicide
4. maintenance of the ethical integrity of the medical profession<sup>8</sup>

### The preservation of life

Although the *Saikewicz* Court recognized that a state's most significant interest is the preservation of human life, the Court also recognized that the state interest of prolonging life must be reconciled with the interest of the terminally ill individual to refuse treatment.<sup>9</sup> That is, although it has been legally enshrined that states must work to preserve a person's life, they must not do so at the cost of the person's own free will. The Court drew a distinction between the state's interest in preserving human life when the patient's illness is curable and the state's interest in prolonging the life of a terminally ill person. The *Saikewicz* Court stated the following:

*"The constitutional right of privacy . . . is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice."*<sup>10</sup>

### CASE STUDY

### Cruzan v. Missouri Department of Health

As the result of injuries sustained in an automobile accident, Nancy Cruzan was rendered incompetent. After it became apparent Ms. Cruzan would not recover from her injuries and would remain in a persistent vegetative state, Ms. Cruzan's parents sought a court order to withdraw artificial nutrition and hydration. The Supreme Court of Missouri held that Ms. Cruzan's parents lacked authority to make such a request because there was no clear evidence of Ms. Cruzan's desires to have life-sustaining treatment withdrawn under such circumstances. The United States Supreme Court affirmed the holdings of the Supreme Court of Missouri.<sup>11</sup>

In this case, the issue was whether there was “clear and convincing” evidence from Nancy Cruzan's past statements, made when competent, concerning her desire for medical treatment if she were to become incompetent to carry out those wishes. The evidence offered to the court was a conversation Cruzan had with a housemate at age twenty-five. During this conversation, Cruzan had stated that if she became sick or injured, she would not want to continue her life unless she could live normally. The Supreme Court of Missouri found that Cruzan's statements to her housemate were “unreliable for the purpose of determining her intent.”<sup>12</sup> Thus, the statements did not provide “clear and convincing” evidence regarding Ms. Cruzan's desires and did not provide sufficient information for Ms. Cruzan's parents to substitute judgment on her behalf.

Missouri recognized that, under certain circumstances, a proxy decision-maker may act for the patient and authorize the withdrawal of nutrition and hydration. However, the state established a procedural safeguard—the “clear and convincing” evidence standard—to ensure that the proxy conforms his or her decisions to the wishes that the patient expressed while competent.<sup>13</sup>

Evident from the Court's opinion was the position that an advance directive would have easily alleviated any question regarding Nancy Cruzan's medical treatment preferences and satisfied the “clear and convincing” standard imposed by the state of Missouri.<sup>14</sup>

### **Artificial nutrition and hydration**

Another element of the Cruzan case that has also been the subject of recent legal battles was the provision of nutrition and hydration. Although some argue that nutrition and hydration constitute palliative care, not medical care, courts have held that patients have the right to refuse nutrition and hydration as a medical intervention. In *Cruzan*, Justice O'Connor wrote that "artificial feeding cannot readily be distinguished from other forms of medical treatment."<sup>15</sup>

### **CASE STUDY**

### **Terminating nutrition and hydration**

Mac has been in a persistent vegetative state for six weeks, and his family has decided to discontinue all medical care. All family members agree with this decision except for Mac's youngest son, Seth. Seth does not view artificial nutrition and hydration as medical care and considers it palliative care. You are part of the treatment team that begins to withdraw Mac's feeding tube. Seth becomes very angry and threatens legal action against the treatment team if the feeding tube is discontinued. May the treatment team legally proceed with withdrawing the feeding tube?

**Issue:** The treatment team can proceed without fear of legal action because it is settled in law that artificial nutrition and hydration are medical care. As Justice Sandra Day O'Connor wrote in the Cruzan case, "artificial feeding cannot readily be distinguished from other forms of medical treatment." With the legal issue settled, the treatment team must be respectful of the feelings and emotions of all family members.

### **Making the decisions to withhold or withdraw treatment**

There is much debate over whether withdrawing treatment is ethically and morally sound because doing so requires an affirmative act that may be a causative factor in the death of a patient. Families, nurses caring for patients, and other healthcare providers will, understandably, agonize over the difficult decisions.

## Chapter 5

An additional concern is the legal reaction such decisions may engender. However, courts have made no legal distinction between withholding and withdrawing life support. As was determined by the Conroy case in 1985, “whether necessary treatment is withheld at the outset or withdrawn later on, the consequence—the patient’s death—is the same.”<sup>16</sup>

### CASE STUDY

#### The case of Claire Conroy

The case of Claire Conroy concerned an elderly patient who was unable to make healthcare decisions for herself due to physical and mental impairments. Ms. Conroy’s health continued to deteriorate, and a nasogastric tube ultimately was inserted to allow artificial nutrition and hydration to be administered.<sup>17</sup> In addition to suffering from numerous physical ailments, Ms. Conroy was severely demented, unable to respond to verbal stimuli, and had no functioning consciousness. Although she was not brain dead, comatose, or in a chronic vegetative state, experts testified that her intellectual capacity was very limited and that her mental condition would not improve.<sup>18</sup>

#### ***Three-part Conroy Court test to determine whether life-sustaining treatment may be withdrawn or withheld***

The decisions of the *Conroy* Court provided a three-part test that may be used to determine whether life-sustaining treatment may be withdrawn or withheld from an incompetent patient:

- **The subjective test:** If there is clear and convincing evidence of the patient’s subjective intent, that intent should be honored. This subjective intent is not what a reasonable or average person would have chosen under the circumstances but, rather, what the particular patient would choose if able to do so.
- **The limited objective test:** Medical treatments may be withheld or withdrawn from the patient if there is some “trustworthy” evidence that the patient would have refused the treatment involved and if the decision-maker is satisfied that it is clear that the burdens of

## Legal foundation for end-of-life decisions

the patient's continued life with the treatment outweigh the benefits of that life. Here, the limited objective test would permit the termination of treatment for a patient who had not unequivocally expressed his or her desires before becoming incompetent, when it is clear that the treatment in question prolongs the patient's suffering.

- **The pure objective test:** If there is no evidence at all as to the patient's wishes, life-sustaining treatment may be withheld only if the pain to the patient is so severe that prolonging the patient's life would be considered inhumane. Here the Court noted that even in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who previously had expressed a wish to be kept alive in spite of any pain he or she might experience.

The decision to withhold or withdraw life-sustaining treatment must be made only after an element of the three-part test has been satisfied. The *Conroy* Court cautioned that "when evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life."<sup>19</sup>

### Nursing implications

The cases discussed here provide a cursory overview of the legal battles that have been waged regarding a patient's right to refuse life-sustaining treatment. As is evident from these decisions, the issue requires much ethical and legal consideration and should not be taken lightly. Be aware of the issues, and be prepared to call on your hospital's ethics team and legal department for help and advice.

## Chapter 5

### References

1. *Union Pacific Railroad Company v. Botsford*, 141 U.S. 250, 251 (1891).
2. *Schloendorff v. Society of New York Hospitals*, 105 N.E. 92, 93 (N.Y. 1914).
3. *Washington v. Harper*, 494 US 210, 221-22 (1990).
4. *In re Quinlan*, 355 A.2d 647, (1976).
5. Ibid.
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8. Ibid.
9. Ibid.
10. Ibid.
11. *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 265 (1990).
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## *The ethical and moral implications of end-of-life decisions*

### **Introduction**

Strong ethical and moral beliefs surround end-of-life decisions, as evident from the media attention paid to the death of Terri Schiavo. Advance directives may mitigate some of these strong reactions because, by allowing patients to clearly communicate their wishes regarding end-of-life decisions, they remove some of the uncertainty that can lead to discord. Nevertheless, these situations can become highly volatile.

Ethical and moral dilemmas can never be avoided completely. As the nurse confronting these dilemmas, you may be required to make difficult decisions and take a strong patient advocacy role to ensure that the patient's desires are respected.

### **Will advance directives be honored?**

#### ***Why healthcare providers deviate from a patient's stated wishes***

Research has discovered that physicians do not always follow patients' treatment preferences as defined in advance directives. Hardin and Yusufaly found a variety of other factors influenced physicians' treatment decisions for medically incapacitated patients.

The study presented physicians with hypothetical situations in which the patient's advance directive preferences directly conflicted with the clinical scenario. Physicians then were asked to make

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treatment decisions for the patient. Despite the existence of a hypothetical advance directive, physicians frequently chose treatment decisions that differed from those preferences stated by the patient. Factors in the physicians' rationale for deviating from the written advance directive included the patient's quality of life, treatment outcomes, and family preferences. Thus advance directives are only one aspect of the decision-making process.<sup>1</sup>

Concerns regarding how well physicians know and follow patient's treatment preferences were also identified in "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments" (SUPPORT). In the study, findings revealed communication shortcomings between patients and physicians about the existence of advance directives: For example, only 47% of physicians participating in the study knew when their patients preferred to avoid CPR. Even after the study added a phase aimed to improve communication between patients and physicians, physicians' communication behaviors regarding end-of-life decisions remained unchanged, which indicates that enhancing opportunities for communication about end-of-life decisions may not adequately change physicians' established patterns of care.<sup>2</sup>

When asked why their facilities did not follow advance directives, Weiler et al. wrote that nurses identified various issues that took precedence over advance directives. These factors included family opposition to the terms of the living will, a physician's unwillingness to follow the living will, healthcare providers not knowing the patient had executed a living will, healthcare providers' fear of litigation, nurses' lack of knowledge regarding the law, no written physician orders, the patient's revocation of the document, and the patient's lack of understanding about the document.<sup>3</sup>

### ***Nurse as patient advocate***

Numerous nursing implications arise from the finding that, despite the execution of an advance directive, patients' wishes may not be followed. The nurse must acknowledge that his or her allegiance is first with the patient. Nurses have long been recognized as strong patient advocates, and they have a responsibility to ensure that patients' end-of-life wishes are respected.

## The ethical and moral implications of end-of-life decisions

To meet this goal, nurses must be knowledgeable of the patient's end-of-life wishes by reading and understanding the patient's advance directive. Nurses then must know how to interpret the document and how relevant state law will apply. When a nurse experiences difficulty interpreting an advance directive or questions a provision of the document, the nurse should consult the hospital's risk manager or legal department.

As identified in Weiler's study, advance directives were not followed in some instances because healthcare providers did not know that the patient had executed a living will or because the nurses lacked knowledge regarding the law. But nurses have a professional obligation to know when an advance directive exists. Institutional policies and procedures must define where the advance directive will be placed in the patient's chart and how the existence of this document will be communicated between professional staff members. Nurses likewise have a professional obligation to know the laws of their state that govern advance directives.

### Nursing implications

When you become aware of patient care that is not in accordance with the patient's advance directive, you must take proactive steps through the proper organizational channels. First, point out to the appropriate party, whether a clinician or a family member, that the patient has an advance directive that identifies that the patient does or does not wish to receive a specific medical treatment or procedure. It may be necessary for the healthcare treatment team to meet with the patient's family to review the terms of the advance directive and to discuss treatment goals in relation to those terms.

Finally, you may need to appeal to the hospital ethics committee and verbalize your concerns about why the patient's treatment is not being provided in accordance with the advance directive. When such an appeal is required, you must be able to give objective statements that specifically illustrate deviations from the advance directive and avoid generalizations like, "This is not how Mr. Smith wanted to live." In each step of this process, involve the nursing management team to ensure that proper procedure is followed and that actions taken are within the boundaries of the institution and state law.

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These patient advocacy actions will not be easy and may put the nurse in conflict with other clinicians or the patient's family. Weiler has acknowledged this obstacle and opines that nurses may be reluctant or refuse to challenge the assertions of the patient's family members or physicians who believe that they, and not the patient, know what is the best medical approach. But the nurse is the primary patient advocate and must take the necessary steps to ensure that the patient's wishes are respected.

### **Conflict in the care of the terminally ill patient**

Studies show that conflict in the care of terminally ill patients is common.<sup>4</sup> Conflict is defined as “a dispute, disagreement, or difference of opinion related to the management of a patient involving more than one individual and requiring some decision or action.”<sup>5</sup>

#### ***Family-clinician conflict***

Family opposition is one of the primary reasons healthcare providers deviate from patients' advance directives and, according to Hardin and Yusufaly, physicians often defer to the family rather than honoring the patient's wishes. Research has shown that the primary issue of conflict between the family and clinicians is the decision to withdraw or withhold life-sustaining treatments.<sup>6</sup> Sometimes family members want to continue aggressive patient care, and sometimes clinicians prefer a more aggressive treatment approach. In the latter situations, the family considers additional treatment futile but the physician wants to continue aggressive care. Other sources of conflict between family and clinicians are adequate pain control, communication issues, and the decision-making process.

Conflict in the pediatric population also has been studied, and communication breakdown between the family and the clinician is a key factor resulting in conflict. Studdert identifies the various risk factors for family-clinician conflict, including increased conflict among Medicaid-insured patients. The study opined that increased conflict in this population may be due to lower levels of education, parental unavailability due to the difficulties poorer families have in visiting the hospital regularly, and a lower level of trust in providers and satisfaction with medical care among persons of lower socioeconomic status.<sup>7</sup>

# The ethical and moral implications of end-of-life decisions

## Nursing implications

The nursing implications regarding clinician-patient conflict require you to remain a calm and stable force during the patient's hospitalization. Families of a loved one facing death may not confront stressful situations calmly or rationally. Therefore, understand that when a family member is angry or aggressive toward healthcare professionals, the behavior is more likely anger at the situation than anger at the nursing staff. When necessary, you must advocate for involvement of additional support persons, such as clergy, to help the family find peace with the patient's impending death. If you find you are becoming angry with the patient or the family, temporarily remove yourself from the situation so that calmer heads may prevail.

## Advance directives are not cost-saving methods

Although healthcare costs are often considered when determining treatment goals, encouraging patients to complete advance directives as part of a cost-saving measure is a highly questionable ethical practice. Loewy states that “too many healthcare systems these days have jumped on the bandwagon of having patients execute advance directives to save costs.”<sup>8</sup>

In theory, executing an advance directive should reduce healthcare expenditures because patients often choose to limit life-sustaining medical care, which means that expensive technology may not be used to prolong a patient's life. However, studies have found that advance directives do not result in financial savings at the end of life.

In “The Economics of Dying: The Illusion of Cost Savings at the End-of-Life,” the difficulty of reducing healthcare expenditures in end-of-life care is addressed. Even for those patients who choose to forego technologically advanced life-saving interventions, expensive care at the end-of-life is still needed. Patients accessing palliative care—such as pain medications and assistance with activities of daily living—continue to require the costly assistance of skilled personnel.<sup>9</sup>

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To combat the use of advance directives as a cost-saving device, Loewy argues that patients must fully understand all the terms and ramifications of the advance directives they create, so that they can give meaningful consent. Furthermore, patients should not be coerced to sign documents when they are admitted to the hospital or are under the stress of a pending medical procedure.<sup>10</sup>

### Preventing patient manipulation

#### CASE STUDY

#### Motivated by money?

Chad is a 43-year-old mentally disabled male who is admitted to the hospital with terminal cancer. Chad is currently being maintained by a ventilator, and it has been estimated that he has approximately six weeks to live. Chad is not competent to make decisions for himself or to understand his medical condition based upon his mental capacity. His guardian and healthcare proxy is Sally, his 53-year-old aunt. His parents are both deceased, and he has a substantial trust fund. Sally is very eager to discontinue Chad's ventilator and says, "Let the boy die." As the nurse taking care of Chad one evening, you learn that Sally is the sole beneficiary to Chad's money. What should you do?

# The ethical and moral implications of end-of-life decisions

## Nursing implications

In these situations, your advocacy role is to be attentive to those instances where a patient may be encouraged by either family members or clinicians to execute an advance directive against his or her wishes. Be especially diligent with patients who are more vulnerable, such as the elderly. Sometimes these patients may be viewed as a financial or emotional burden upon society and may be encouraged to execute an advance directive for inappropriate reasons.

Another vulnerable population is the mentally disabled. Because they are not competent to execute an advance directive, mentally disabled patients will often have a healthcare proxy making decisions for them. Be diligent in monitoring the healthcare proxy's decision-making for the patient to ensure that the decisions being made are in the patient's best interests and are not made for financial reasons.

If nurses observe a patient being encouraged to execute an advance directive even though the patient has verbalized that he or she does not desire to do so, the nurse must intervene through the appropriate organizational channels. First, notify nursing management that the patient may be under unwarranted influence to execute an advance directive. Nursing management must determine the appropriate steps to take, which may include involving the hospital's legal department to protect the best interests of the patient.

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## ***Ethnic and cultural beliefs that influence advance directives***

### **Introduction**

When a patient executes an advance directive, that patient asserts independence and exercises autonomy over healthcare decisions. The dominant belief in the United States is that individuals want this independence and autonomy when making decisions about terminal illness, death, and dying.<sup>1</sup> However, many ethnic and cultural groups in the United States do not place the same value on individual decision-making and instead hold a higher regard for interpersonal, family, and social responsibilities.<sup>2</sup>

Among healthcare professionals, nurses have been leaders in recognizing that cultural factors influence healthcare practices and disease processes. You must be aware of the beliefs and understandings of various populations when discussing advance directives and recognize that end-of-life decisions are made within the cultural context.

### ***Cultural background***

Culture has been defined as “the values, beliefs, norms, and practices of a particular group that are learned and shared and that guide thinking, decisions, and actions in a patterned way.”<sup>3</sup> As with other healthcare decisions, ethnic and cultural groups vary regarding their beliefs and opinions around end-of-life decisions. These beliefs may affect the appropriateness of talking about or planning for death, the appropriateness of telling a person they have a terminal disease and are

## Chapter 7

dying, and the roles of the individual, family members, and the healthcare profession regarding end-of-life decisions.

Research has examined the different cultural beliefs regarding this subject. Note, however, that individual differences within the same ethnic or cultural groups can be extensive. As individuals, we are all exposed to many (sometimes contradictory) ideas, values, and beliefs.<sup>4</sup> With this in mind, nurses must refrain from generalizing certain beliefs regarding end-of-life decisions to specific ethnic or cultural groups.

### European American values

Patient autonomy and independence are strongly rooted European American or Caucasian values, which include that patients should

1. make informed decisions about their healthcare needs
2. know the truth about their disease process and expected outcomes
3. have control over the dying process<sup>5</sup>

Under these values, patients who are to make informed decisions regarding healthcare must be given all the information relevant to a particular decision, such as a diagnosis, prognosis, and treatment options. The patient must be told the benefits and burdens of treatment and the full range of treatment side effects in order to make an informed decision over their healthcare. Likewise, patients must be told the truth regarding the expected outcomes of their disease process, regardless of whether this information provokes anxiety. In the general European American view, withholding this information is to deny the individual patient his or her autonomy and independence.<sup>6</sup> So strong is this belief in informed decision-making that virtually all procedures within the healthcare community are completed only after the patient has been educated about the procedure and has given written informed consent to undergo that procedure.

## **Ethnic and cultural beliefs that influence advance directives**

European American values tend to hold that individuals can and should control their life and death. This value is so strong that written laws, such as the Patient Self-Determination Act and state laws, have been enacted to allow patients to exercise control over their own lives, with the use of advance directives, even when patients are no longer able to communicate their individual desires.

### **Other cultures' values regarding death**

#### ***Autonomy v. family***

The significance of autonomy, informed decisions, and control over the dying process are understood differently by different ethnic or cultural groups in America. Autonomy, to the level often expected by European Americans, is not accepted in many cultures that have a long tradition of family-centered healthcare decisions. For example, Latinos and Korean Americans may tolerate less individual autonomy than that permitted in families of European descent and may place more value on the family, rather than on the individual alone. Another example can be found in many Asian cultures, where an individual's boundaries include the family as the decision-making unit and healthcare decisions are guided by the family. An individual's illness is considered a family event, and the family plans, manages, and participates in all aspects of an individual's end-of-life care because the terminally ill family member is not assessed outside the family unit.

In cultures where the familial unit is the decision-making unit, recognize that some family members have additional responsibilities to the patient. For example, Korean American children are expected to preserve the lives of their parents at all costs. A child's directive to discontinue life support, even if it is the parent's wish, may be considered dishonorable by other relatives or by the community.<sup>7</sup>

In Latino communities, the mother is typically seen as the heart of the family and the father as the disciplinarian. In these communities, sharing and kinship are valued, and the mother and grandmother may maintain major responsibilities for family and healthcare.<sup>8</sup>

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### ***Access to information***

Not all cultures value informed decision-making in healthcare. Certain cultures place a greater value on protecting the dying person from negative information. Serious medical diagnoses are often concealed from patients by using communication strategies that minimize direct disclosure, including the use of terminology that obscures the seriousness of a condition or communicating diagnostic and treatment information only with the patient's family members.<sup>9</sup> For example, in Japan and some African countries, cancer is discussed as a “growth” or a “mass” rather than as a terminal condition. Likewise, in Latino, Chinese, and Pakistani communities, family members often actively protect terminally ill patients from knowledge of their condition.<sup>10</sup> For descendants of cultures who hold this belief, family members may deliberately withhold information and not discuss the impending death with the dying person.

### ***Patient control over death***

Ethnic and cultural beliefs regarding a patient's control over death and dying are also diverse. Both African Americans and Latinos often believe that longevity—regardless of the patient's health status—is an intrinsic good. These ethnic and cultural groups are more likely than European Americans to express a preference for life-sustaining treatments, regardless of the severity of the disease process.<sup>11</sup>

African Americans are also less likely than European Americans to desire assisted deaths. A study concluded that African Americans are more likely to request life-sustaining treatments, such as CPR, artificial nutrition and hydration, ventilator support, and ICU monitoring, than are European Americans.<sup>12</sup> It also found that European Americans are most likely to accept narcotic analgesics even if their life is unintentionally shortened by them.

### ***Empowerment***

In making end-of-life decisions, European Americans' choices often are influenced by their sense of empowerment and control.<sup>13</sup> Other ethnic and cultural groups, however, may not have this sense of empowerment toward healthcare.

### ***Tuskegee syphilis study denied treatment to African American population***

For example, when reviewing the history of African Americans' experiences in healthcare, one

## **Ethnic and cultural beliefs that influence advance directives**

gains a greater understanding of cultural health preferences and the solid basis for distrust of the healthcare community.

Indeed, the Tuskegee syphilis study highlights a case of deception of African Americans by the healthcare community. From 1932 to 1972, in Macon County, AL, almost 400 black sharecroppers with syphilis were denied treatment and deceived by healthcare providers of the U.S. Public Health Service when they were told they were receiving treatment for syphilis. This charade was carried out so healthcare officials could document the natural progression of syphilis in an untreated population. As a result of this collective history, African Americans often place a greater emphasis on security, survival, and community and devalue personal autonomy.<sup>14</sup>

### **Treatment preferences and advance directives**

As one would expect, cultural experiences influence patients' attitudes regarding treatment preferences and advance directives. European Americans are more likely to execute advance directives than are African Americans, Latinos, or Asian Americans.<sup>15</sup>

Executing an advance directive generally means discussing death to some degree, but for some cultures, the mere discussion of death is considered a bad omen. In many Asian cultures, especially Chinese populations, speaking about death is seen as bringing about negative consequences, and such conversations are avoided.<sup>16</sup> Likewise, Native Americans often avoid discussions regarding advance health planning, as well as negative thoughts about illness, because these conversations conflict with many Native American philosophies of goodness, harmony, positive attitude, and universal beauty. Some Native Americans believe that discussing negative information, such as death, is harmful and that such discussions may be self-fulfilling—that is, may bring about the feared negative outcome.<sup>17</sup>

There is another cultural component that may influence Native Americans' decisions to execute advance directives: According to one study, Navaho Indians are often present-oriented. Therefore, healthcare professionals who attempt to plan for future healthcare needs with them may experience difficulties because advance planning may be culturally irrelevant.

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### ***Family decision-making often most important for Latino patients***

Latinos are another group that sees a low incidence of advance directives. One suggested reason is that they may be reluctant to formally appoint a specific family member to be in charge of a patient's healthcare decisions due to concerns about isolating this person or offending other relatives. Instead, a consensually oriented decision-making approach appears to be more acceptable among this population. Formalizing this decision-making process with a written advance directive is viewed as unnecessary and potentially harmful because it may lead to increased family conflict.

Creating a legal advance directive requires an individual to reduce his or her desires to a written format. For some cultures, this requirement may prevent people from initiating advance directives. For example, in many cultures a verbal agreement is binding and preferable to a written contract. In some cultures, such as Arab populations, the requirement of a written document may signify mistrust of a person's promise and be considered dishonorable.<sup>18</sup>

### **CASE STUDY**

### **Culture really matters**

Nurse Jones knows that Sally Lopez, a Latino female, has a terminal diagnosis of cancer and does not have long to live. Nurse Jones approaches Sally several times to discuss the execution of an advance directive. Each time, Sally is very non-committal and states, "I just don't want to hurt anyone." Nurse Jones interprets Sally's comments to mean that Sally doesn't want to hurt anyone when she dies. Nurse Jones continues to approach Sally about executing an advance directive. Has Nurse Jones communicated appropriately with regard to Sally's cultural influences?

**Issue:** The issue here is whether Nurse Jones has correctly interpreted Sally's cultural cues regarding her reluctance to execute an advance directive. As discussed earlier, Latinos may be reluctant to formally appoint a specific family member to be in charge of the patient's healthcare decisions due to concerns about isolating that person or offending other relatives. Nurse Jones has potentially misunderstood Sally's comments.

## Ethnic and cultural beliefs that influence advance directives

### Culturally competent care

The practice implications for nurses promoting culturally sensitive advance directives are significant. As already mentioned, care must be taken not to generalize these ethnic or cultural beliefs to each member of a specific group. A patient's background and experiences should provide the starting point from which to verify and validate individual values. Knowledge and understanding of a person's ethnicity and culture should serve as a guideline only; stereotyping a person should be strictly avoided because individuals or family members of an ethnic or cultural group may not subscribe to specific cultural norms.

### Nursing implications

Work to develop a rapport with ethnically and culturally diverse patients. When introducing advance directives, question the patient to gain more information regarding the role that ethnic or cultural identity plays in end-of-life decisions. For example, ask patients if they want to know everything about their medical care and condition or if they prefer that this information be relayed to a family member. Ask the patient and the family if there is anything about the family, its community, or its cultural practices that is important to consider when discussing a serious illness or the patient's treatment.

Remember that the culturally competent nurse will ask about the patient's preferences. In the article "Cultural Diversity at the End-of-life: Issues and Guidelines for Family Physicians," Drs. Searight and Gafford list *Cross-Cultural Questions Regarding Serious Illness and End-of-Life Care*. This set of questions, which focuses on the patient's preference, can be adapted easily for your interaction with the patient.

Take care to also examine your own cultural beliefs regarding death and dying. Failing to understand our own biases and fears will make it difficult to approach patients regarding advance directives.

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## **Ethnic and cultural beliefs that influence advance directives**

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**Introduction**

As this book has identified, approaching patients about advance directives is a multifaceted undertaking that requires you to discuss difficult moral, ethical, and cultural issues surrounding end-of-life decisions. As Lipson's and Jezewski's studies show, educational programs that improve nurses' knowledge of advance directives and their comfort in discussing them are important. Educating patients and their families about advance directives takes the collective efforts of the staff development department, the legal/ethics department, and nursing management.

**Advance directives curriculum**

A well-developed advance directives curriculum should provide didactic instruction, role-play opportunities, and communication demonstrations through which nurses can prepare for situations that may arise when discussing end-of-life issues with patients. The content of this book provides a strong outline for didactic instruction regarding advance directives. In addition to this content, pursue education regarding the policies and procedures of your specific institution, and be sure to incorporate relevant state law.

Your hospital's legal/ethics department is a valuable resource for help and information regarding patient's advance directives and other end-of-life issues. You should make an appointment to talk

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with the legal/ethics department and expand your knowledge about advance directives. Refer to Figure 8.1 on page 68 for a list of suggested questions you can use or adapt or suit your needs.

### **Cultural competency and advance directives**

To ensure cultural competency in discussing advance directives, nurses must become familiar with the cultural practices prevalent in their communities. For example, have representatives from various cultural populations speak to the nursing staff about existing cultural beliefs and end-of-life decisions. Because they work closely with families who have experienced the death of loved ones, experts in this area will often be religious leaders in the community. Ask these leaders to address the following questions when providing cultural education regarding end-of-life care:

1. What should nurses know about this culture concerning end-of-life decisions?
2. Are there any gestures or questions a nurse might ask concerning end-of-life decisions that might offend someone from this culture?
3. Who is the traditional decision-maker regarding healthcare within this culture?
4. What are the cultural barriers, if any, to having a patient complete an advance directive?
5. How much information about the patient's diagnosis is generally expected within this culture?
6. Does this culture place any restrictions on the nurse when discussing death and dying?

Modify these questions to meet the needs of your community and your hospital. All nurses should remember, however, that the primary source of information and understanding about a patient's cultural and ethnic preferences is the patient.

### **Role-play to promote comfort in discussing end-of-life decisions**

The first difficult discussion a nurse has regarding end-of-life decisions should not occur under stress when a terminally ill patient is pressing the nurse for assistance. Therefore, as part of the edu-

cational process, nurses should role-play various case scenarios with one another regarding how to address end-of-life issues and discussions appropriately. The intent of this role-play activity is to increase nurses' comfort levels in discussing advance directives.

The following case scenarios can guide this role-play activity. Additionally, ask nursing staff to share actual experiences they have encountered when discussing advance directives with patients, and role-play how these situations were handled or could have been handled differently.

**Note:** Modify the following case studies according to your state's advance directives law and your hospital's policies and procedures. The role-play will allow you to identify the relevant issues and let you experience how you would react to each scenario. Before the activity, share these cases scenarios with your hospital's legal department to determine how your state law and hospital policies and procedures would be applied.

### CASE STUDY

#### Should the advance directive be followed?

Sally Jones, a 63-year-old woman who suffers from chronic obstructive pulmonary disease (COPD), is admitted to the emergency room in respiratory distress. Two years ago, Sally executed an advance directive stating that she did not want mechanical ventilator support. A copy of this advance directive is available in the emergency room (ER). Sally is in respiratory distress that becomes progressively worse while she is in the ER. Sally tells the ER staff she wants everything done to save her life, and then she codes. What is the responsibility of the ER staff? Should the advance directive be followed? Should mechanical ventilation be initiated?

**Issue:** The issue here is whether Sally revoked her advance directive prior to coding when she instructed the ER staff that she wanted everything done to save her life. To analyze this issue, consult your state law regarding revocation of an advance directive. But remember, informed decisions made by competent adults always trump advance directives.

**CASE  
STUDY**

**Is the living will legitimate?**

Mr. Todd, a 66-year-old man, is admitted to intensive care following a boating accident. Mr. Todd is unconscious at admission and remains so. You are the nurse assigned to Mr. Todd. Although you don't know him, you know his reputation in your community as a very prominent and wealthy business man who has endured much family discord related to fighting over his money. Mr. Todd's second wife, Virginia, presents you with a living will that states that Mr. Todd does not want any life-saving measures taken on his behalf. Virginia has been married to Mr. Todd for six months. Mr. Todd's adult son, Charles, overhears the conversation and becomes very angry. Charles states that Mr. Todd did not have a living will and that Virginia is trying to pull "a fast one to get all the money." What should the nurse do?

**Issue:** The issue here is whether the living will presented by Virginia Todd is valid. First, notify nursing management that there may be a validity concern with Mr. Todd's living will. The hospital legal department also should be involved. The legitimacy of the living will then should be evaluated within the mandates of state law. The living will should not be implemented until its validity is established.

**CASE  
STUDY****Who makes the decisions?**

Mary Clark, a 43-year-old female, was diagnosed with multiple sclerosis several years ago. At diagnosis, she executed a healthcare proxy and named Joe Miller, her life-long trusted friend, as healthcare proxy in the event that she became unable to make healthcare decisions for herself.

Mary is admitted to the hospital and is unable to communicate her healthcare decisions due to her medical condition. Joe Miller is contacted and rushes to the hospital immediately. Mary's elderly parents are also at Mary's bedside. When the healthcare team begins to discuss important decisions with Joe Miller, Mary's parents become very angry and state that "Mr. Miller does not have the authority to make these kinds of decisions. We are Mary's parents, and that is our job." As the nurse taking care of Mary, what should you do?

**Issue:** As the legally appointed healthcare proxy, Joe Miller has the authority to make healthcare decisions for Mary Clark. As the nurse, your patient advocacy role is to communicate with Mary's parents to help them understand that Mary's wishes were that Joe Miller make her healthcare decisions. Achieving this goal may be difficult, and it may be necessary for the healthcare treatment team to meet with Mary's parents. This situation is difficult for the nurse and will require extensive communication.

### CASE STUDY

#### 'Tell me about this advance directive thing'

You are the nurse who has been assigned to care for Patti, a 53-year-old female, who has recently been diagnosed with cancer. You enter Patti's room for initial rounds, and Patti says: "Hey, tell me about this advance directive thing." How do you respond? Patti then asks: "If I sign one, can I change my mind at a later date?"

**Issue:** The issue is whether Patti will be able to revoke an advance directive once she has executed it properly. The nurse should educate Patti about advance directives and reassure her that she may revoke the advance directive any time she wishes, as long as she is competent to do so. Also communicate to Patti that the advance directive will only become effective if Patti becomes medically incapacitated, as defined by state law, and unable to make healthcare decisions for herself. Remember, the competent patient always trumps the advance directive.

### Respect and support nurses' individual beliefs concerning end-of-life decisions

Because death is so personal, nurses will have strong individual beliefs concerning end-of-life decisions. Hospital management must respect that some nurses may have difficulty discussing end-of-life decisions with patients. This difficulty may be especially apparent if the values and beliefs regarding end-of-life decisions differ between the patient and the nurse. Therefore, nursing staff should be encouraged to keep discussions regarding advance directives within the nurses' and patients' comfort zone. If a topic arises such as an ethical concern or a religious issue, the nurse should tell the patient that the subject may be more appropriately addressed by the hospital's chaplain or another appropriate party.

### Nursing implications

Respect and support the individual beliefs of all patients regarding end-of-life decisions. A nurse interacting with patients who are making end-of-life decisions is there in a supportive role and as an educational resource. You and your facility should not place undue pressure on patients to execute advance directives or encourage patients to refrain from doing so. When a patient has been educated about advance directives and then makes an informed decision not to execute one, respect the patient's desires.



FIGURE 8.1

### Questions to ask the legal/ethics department

After you review your state's law governing advance directives and your hospital's policies and procedures, make an appointment with the legal/ethics department for an information-gathering interview. Use the following questions, modified to meet your state's law, as a guide for the interview.

#### Advance directives and state law: Information-gathering interview

1. Under state law, only a competent adult can execute an advance directive. It is my understanding of the law that "a competent adult" means a person over the age of 18 or an emancipated minor. Is this understanding of the law correct? Are there other exceptions?
2. Under state law, a competent adult can name a healthcare proxy. Is the decision-making authority of the healthcare proxy unlimited, or does state law limit the authority of the healthcare proxy in any way?
3. Are there situations that may arise in which an advance directive would not be honored by this facility?
4. What is my role as the nurse manager if a physician refuses to honor a patient's end-of-life wishes?
5. What is my role as the nurse manager when family members disagree with the patient's wishes as outlined in an advance directive?
6. Under state law, an ethics committee is charged with making decisions for the patient when the patient does not have an advance directive. What does the ethics committee consider in reaching its decision concerning patient treatment? Would it be possible for me to attend a meeting of the ethics committee to gain a better understanding of this process?
7. What types of ethical issues have arisen in our hospital concerning advance directives?

# *Hospital compliance with advance directive mandates and standards*

## **Introduction**

Having nurses who are well-educated and comfortable with discussing advance directives is only part of the implementation of advance directives in hospitals. According to the Patient Self-Determination Act, the hospital must take specific actions to ensure that patients' legal rights to make decisions about their healthcare are protected. In addition, although they are not legal requirements, the standards of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) regarding advance directives are also highly influential for accredited hospitals. Hospitals must implement policies and procedures that specifically identify how the organization will meet the mandates of the Patient Self-Determination Act and the standards of the JCAHO.

Hospital policies and procedures must be consistent with state and federal law. Under the Patient Self-Determination Act, hospitals must

1. maintain written policies and procedures concerning advance directives
2. provide the patient with written information regarding the right to accept or refuse medical or surgical treatment and the right to execute an advance directive
3. document in the patient's medical record whether the patient has executed an advance directive

## Chapter 9

To ensure that each of these steps is completed, policies and procedures must provide detailed instructions for healthcare professionals and establish who is responsible for each step of the process to ensure that the policy is followed appropriately.

### JCAHO regulations

The JCAHO has established the following standards concerning patients' rights and advance directives:

1. **Standard RI.2.20—Patients receive information about their rights:** The hospital gives the patient information at admission concerning the extent to which the hospital is able, unable, or unwilling to honor the terms of the patient's advance directive.
2. **Standard RI.2.80—End-of-life issues:** The hospital has organization-wide policies that clearly explain the process for ascertaining the presence of advance directives, the follow-up process for obtaining copies for the patient's record, and the means for educating staff about the existence of a patient's advance directive. The policies should explain when patients are to be given information about their right to refuse treatment, and detail the mechanism for providing patients with assistance in formulating their advance directives. The policies should stipulate that the existence of an advance directive does not determine an individual's access to care or treatment, as well as discuss the process for invoking the patient's directive.

The JCAHO has additional standards that directly influence a patient's end-of-life decisions, although these do not specifically mention advance directives. These standards include the following:

1. **Standard RI.2.40—Informed consent is obtained:** This standard requires hospitals to gather information concerning the patient's informed consent for a surrogate decision-maker and document when a surrogate decision-maker can give informed consent for the patient.
2. **Standard RI.2.70—Patients have the right to refuse care, treatment, and services in accordance with law and regulation:** Although this standard does not directly mention advance directives, it acknowledges the patient's right to refuse medical treatment.

## **Hospital compliance with advance directive mandates and standards**

The JCAHO standards for advance directives closely parallel the Patient Self-Determination Act. As in federal law, the JCAHO standards require the hospital to honor the wishes of each individual patient concerning end-of-life decisions.

### **Written policies and procedures**

Hospital policies and procedures should identify when patients will be given written information concerning their right to execute an advance directive. According to the Patient Self-Determination Act, it should occur when the patient is admitted to the hospital. The hospital policies and procedures should identify who—whether the admitting clerk or the nurse—is responsible for distributing advance directives information to patients. Patients also should be asked to acknowledge—and hospital policies and procedures should address acknowledgment of—receipt of the advance directive information on the admission registration form via the patient’s signature.

If it is determined that a patient has an existing advance directive and the patient has brought the document to the hospital, then the policies and procedures must identify where the advance directive will be maintained in the patient’s record and how that advance directive will be made known to healthcare professionals. A copy must be maintained in the medical record as verification that the patient has indeed executed one. If there is a question concerning the validity of the advance directive, then the hospital’s legal department must be contacted immediately.

### ***Follow up on existing advance directives***

If a patient arrives at the hospital saying that he or she has an advance directive but failed to bring a copy, the policies and procedures must address how the hospital will obtain copies of it. The person gathering this information must elicit the name of a specific person who knows where the patient’s advance directive is maintained and who can bring the legal document to the hospital. This person may be a family member or a legal representative. The policies and procedures should identify specific hospital personnel who will contact the patient’s representative to initiate this process.

## Chapter 9

Timing is extremely important in these cases, and every effort should be made to have a valid copy of the patient's advance directive on the hospital chart within 24 hours of the patient's admission or before any major medical or surgical procedure is scheduled. An alternative course of action is to offer the patient the option of completing a new advance directive while at the hospital. Once a valid advance directive is on record, staff must follow the hospital's policies and procedures concerning the living will or the durable power of attorney for healthcare.

### ***Tracking advance directives***

To help track the advance directive, the hospital may wish to employ an "Advance Directives Tracking Form" (Figure 9.1 on page 73). When using such a tracking device, staff should be educated regarding its implementation and where in the patient's chart it will be maintained.

### ***Staff's role***

The hospital's policies and procedures also must address the staff's role in knowing that the patient has an advance directive. Upon assuming care of the patient, the nurse must check the patient's medical record to determine whether an advance directive exists and the terms of the document.

The hospital's policies and procedures also must address how staff should respond to patients' questions regarding advance directives and staff's role in helping patients prepare an advance directive. Many hospital's policies indicate that staff members shall provide "general information" to patients regarding advance directives but nurses need to know what that means.

That is, hospitals must educate staff members about what the facility considers to be "general information." For some facilities, it may include only basic written information about advance directives. For other facilities, it may be a more detailed and candid discussion of the ethical, moral, and cultural issues surrounding advance directives. Hospital management must determine these communication boundaries and ensure that policies and procedures detail communication expectations.

### ***Definitions***

The policies and procedures should identify who can legally execute an advance directive and define what is meant by the term "incompetent." Here, the policies and procedures should track with state law.

## Hospital compliance with advance directive mandates and standards

FIGURE 9.1

### Bright Valley Hospital advance directives tracking form

At Bright Valley Hospital, your right to make decisions concerning your healthcare is very important to us. Please complete the following questions. This form will become part of your medical record. We are required to obtain this information under federal law.

Have you completed any of the following advance directives? Check all that apply:

- Living will  
 Durable power of attorney for healthcare

If you have completed any of these documents and do not have a copy with you, where is a copy located? \_\_\_\_\_

Can a friend or family member bring a copy of the advance directive to the hospital?

- Yes     No

If you have an advance directive but a copy is not available at this time, what does your advance directive say about your treatment wishes if you should become terminally or irreversibly ill?

\_\_\_\_\_

If we are unable to communicate with you as a result of your illness, to whom should we speak on your behalf, what is their relationship to you, and what is their telephone number?

\_\_\_\_\_

If you do not have an advance directive or you wish to complete a new one, we will provide you with the proper forms and other information necessary to complete an advance directive.

I do not wish to complete an advance directive at this time. **I am aware that if I become unable to make decisions for myself and I have not completed an advance directive, state law will require that my physicians turn to the following persons, in the order listed, for medical decision-making: my spouse, my reasonably available adult children, my parents, or my nearest living relative. If none of those persons are available or willing to act on my behalf, I am aware that state law allows my doctors to turn to the hospital's medical ethics committee or to a court of law for medical decision-making.**

Patient's signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Chapter 9

### ***Calling for help***

The policies also should address how difficult or unresolved treatment decisions will be made. It is best to make such decisions through an “ethics committee” that can meet to review difficult cases and provide directional advice concerning treatment decisions.

Hospital management may wish to establish an “advance directives education team” consisting of nurses and other healthcare professionals who are well versed in advance directives. This team could provide assistance when a patient is preparing an advance directive and could support nurses when difficult legal, ethical, or cultural issues arise concerning advance directives.

Following is an example of policy and procedure for advance directives in a hospital setting. Remember to modify the policy and procedure to meet the mandates of your state’s law. Format the policy in accordance with your hospital’s requirements and have the policy accepted through the proper channels.

FIGURE 9.2

### Bright Valley Hospital policy and procedure

#### Subject/Title: Advance directives

##### **Objective**

- To define Bright Valley Hospital's policies and procedures for informing patients about their right to accept or refuse medical treatment.
- To promote Bright Valley Hospital's compliance with state and federal laws governing advance directives, including but not limited to the Patient Self-Determination Act and [insert state name] law.
- To ensure that patients who wish to complete advance directives have the opportunity and means to do so.
- To respect the known wishes of patients who have become incapable of making their own healthcare decisions.

##### **Policy**

The wishes of an adult patient, who is competent to make his or her own healthcare decisions and who has done so through the execution of an advance directive, shall be followed in accordance with federal and state law and hospital policy.

##### **Definitions**

**Advance directive:** Any written document representing the healthcare wishes of a competent adult—either while a patient or prior to becoming one—that does one of the following:

- a) Designates another person to make healthcare decisions for the patient if the patient becomes unable to make healthcare decisions for himself or herself
- b) Gives written instructions to healthcare professionals concerning the patient's desires for medical treatment should the patient become incapacitated

**Competent person:** A person who is at least 18 years of age and who has the ability to understand and appreciate the nature and consequences of healthcare decisions and medical treatment.



**Policy guidelines*****Admission to the hospital***

At admission to Bright Valley Hospital, adult patients shall be provided with information concerning their rights to accept or refuse medical treatment and their right to execute an advance directive. This information shall be given to the patient by the admitting clerk that processes the patient's admission to the hospital. Patients shall be asked to certify receipt of this information by signing the admission registration form under the heading "received advance directive information."

Bright Valley Hospital shall not condition the provision of patient care, or otherwise discriminate against a patient, based on whether the patient has executed an advance directive.

***Advance directives availability***

If a patient has a copy of his or her advance directive at the time of admission to the hospital, the admitting clerk shall place a photocopy of the advance directive in the patient's medical record at the front of the patient's chart. The original advance directive shall be returned to the patient.

If a patient states that he or she has executed an advance directive but has failed to bring it to the hospital, the admitting clerk shall question the patient to determine whether there is a person who can bring a copy of the advance directive to the hospital. The admitting clerk shall record the name of that person on the "Advance Directives Tracking Form." The admitting clerk shall encourage the patient to have the named person bring a copy of the advance directive to the hospital. In the alternative, the admitting clerk shall offer the patient the option of completing another advance directive.

FIGURE 9.2

### Bright Valley Hospital policy and procedure (cont.)

#### ***Validity of advance directives***

In all cases, an advance directive is considered valid unless it can be established by persuasive and credible evidence that

- the patient was not competent at the time the advance directive was executed
- the advance directive is a forgery
- the advance directive has subsequently been revoked by the patient

In the event that a member of the Bright Valley Hospital healthcare staff questions the validity of an advance directive, the nursing management and the legal department should be notified immediately.

#### **Maintenance of the advance directive on a patient's chart**

A written advance directive shall be kept in the front of the patient's active medical chart in a plastic folder.

#### ***Effect of a valid advance directive***

An advance directive should be followed to the extent that it does not require a healthcare professional to perform any act that violates the professional's ethical responsibilities or does not violate accepted standards of professional practice. If a healthcare professional is unwilling to honor a patient's advance directive because it violates the healthcare professional's personal ethical beliefs, then the healthcare professional's immediate supervisor must be notified and care of the patient must be transferred to another equally qualified professional.

#### ***Ethics committee***

When unresolved issues regarding an advance directive arise or when there is conflict between the patient's written wishes and the family's desires, consult the Hospital Ethics Committee.

# ***Nursing education instructional guide***

## ***Target audience***

Nurse Managers

VPs of Nursing

Chief Nursing Officers

Directors of Nursing

Nursing Home Administrators

Directors of Training

Staff Educators

## ***Statement of need***

This book provides an educational study guide for nurses to give them a practical overview of the legal, ethical, and cultural aspects of advance directives. It provides the nurse with basic information and discusses the cultural elements that influence advance directives. It offers case-studies and role-play activities for the nurse to become more comfortable discussing advance directives with patients.

It will help fulfill the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) requirements that policies regarding advance directives are in place and that staff are aware of the policies and procedures. This book will prepare nurses for when an end-of-life situation involving advance directives comes up.

# Nursing education instructional guide

## ***Educational objectives***

Upon completion of this activity, participants should be able to

- describe the hospitals' legal requirements under the Patient Self-Determination Act
- discuss the Advance Directives Improvement and Education Act of 2005
- assess nurses' knowledge of advance directives
- discuss nurses' patient advocacy role regarding advance directives
- distinguish between the living will and the durable power of attorney for healthcare
- define the "clear and convincing" language requirement
- identify when a 'Do Not Resuscitate' order may be medically and ethically appropriate
- identify when a patient may revoke an advance directive
- identify special considerations regarding advance directives that must be addressed with some elderly patients
- verbalize the legal basis upon which advance directives are founded
- recognize the state's interest in protecting patients
- enumerate the three-part test of the *Conroy* Court to determine whether life-sustaining treatment may be withheld or withdrawn
- identify factors that may encourage healthcare providers to deviate from an advance directive when making healthcare decisions for a medically incapacitated patient
- discuss the nurses' role in ensuring the patient's wishes outlined in an advance directive are respected
- identify sources of conflict concerning end-of-life decisions between the patient's family and the clinician
- analyze the role of advance directives in reducing healthcare expenditures
- discuss the European American values regarding healthcare
- analyze why African Americans may distrust the U.S. health system
- define the role of Latino families in making healthcare decisions for the medically incapacitated patient
- identify the elements of a well developed advance directive curriculum
- identify strategies to include cultural leaders in the promotion of nurses' cultural competency regarding end-of-life decisions
- discuss the standards of the JCAHO regarding advance directives
- identify the necessary contents of hospital policies and procedures to meet legal mandates and accreditation standards for advance directives

### **Author**

Dinah Brothers, RN, JD

### **Accreditation/designation statement**

This educational activity for three contact hours is provided by HCPro, Inc. HCPro is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

### **Disclosure statements**

Dinah Brothers has declared that she has no commercial/financial vested interest in this activity.

### **Instructions**

In order to be eligible to receive your nursing contact hour(s) for this activity, you are required to do the following:

1. Read the book
2. Complete the exam
3. Complete the evaluation
4. Provide your contact information in the space provided on the exam and evaluation
5. Submit the exam and evaluation to HCPro, Inc.

Please provide all of the information requested above and mail or fax your completed exam, program evaluation, and contact information to

Robin L. Flynn  
Manager, Continuing Education  
HCPro, Inc.  
200 Hoods Lane  
P.O. Box 1168  
Marblehead, MA 01945  
Fax: 781/639-0179

If you have any questions, please contact Robin Flynn at 781/639-1872 or [rflynn@hcpro.com](mailto:rflynn@hcpro.com).

# Nursing education instructional guide

## Nursing education exam

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Facility name: \_\_\_\_\_

Address: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_

Phone number: \_\_\_\_\_ Fax number: \_\_\_\_\_

E-mail: \_\_\_\_\_

Nursing license number: \_\_\_\_\_

(ANCC requires a unique identifier for each learner)

### 1. The Patient Self-Determination Act mandates that healthcare facilities

- a. require patients to complete advance directives
- b. gain consent from a patient's family prior to treating the patient
- c. provide patients with information concerning their rights to initiate advance directives
- d. assess a patient's medical condition prior to the patient completing an advance directive

### 2. Under the Advance Directives Improvement and Education Act of 2005,

- a. treatment options for a patient with a terminal illness will be confined to the written contents of the patient's advance directives
- b. hospitals will limit a patient's information about healthcare options and legal rights for end-of-life care to what the patient's primary care physician deems necessary
- c. the physician will inform the patient about whether he or she is willing to follow the individual's wishes as expressed in the advance directive
- d. amendments to an already written advance directive will only be permitted in very limited circumstances

**3. According to the research findings of Lipson et al., nurses become more confident in discussing advance directives with patients when nurses**

- a. execute their own advance directives
- b. are exposed to information about advance directives through nursing school or formal education
- c. discuss advance directives with physicians
- d. have experience dealing with death and end-of-life decisions on a personal level

**4. According to the American Nurses Association, nurses**

- a. should not be involved in the discussions of advance directives because they work too closely with patients and these discussions could interfere with patient care
- b. play a primary role in the implementation of the Patient Self-Determination Act
- c. are not the preferred healthcare providers to initiate discussions regarding advance directives; rather, this discussion should be left to the patient's physician
- d. are too emotional to discuss advance directives with patients

**5. The primary difference between the living will and the durable power of attorney for healthcare is that**

- a. the patient must be competent when the living will becomes effective
- b. the durable power of attorney allows the patient to name an agent to make all the healthcare decisions for the patient
- c. the living will considers the patient's best interest, whereas the durable power of attorney for healthcare considers the healthcare proxy's best interests
- d. there is no primary difference, and the patient needs to execute either the living will or the healthcare proxy but does not need both legal documents

**6. "Clear and convincing" language includes wording such as**

- a. "heroic measures"
- b. the specific wishes of a patient concerning mechanical ventilation
- c. "extraordinary means"
- d. "whatever it takes"

## **Nursing education instructional guide**

- 7. A Do Not Resuscitate (DNR) order may be medically and ethically appropriate when**
  - a. resuscitative efforts cannot be expected to restore cardiac or respiratory function to the patient
  - b. the patient is temporarily maintained on a ventilator
  - c. the patient's illness can reasonably be expected to respond to aggressive medical treatment
  - d. the patient is initially diagnosed with cancer
  
- 8. When is it possible for a patient to revoke his or her advance directive?**
  - a. A patient may verbally revoke the advance directive once the physician has made a determination and issues a certification that the patient is competent to make the decision to revoke.
  - b. A patient may revoke an advance directive at any time, and state laws address the legal ways in which a patient may revoke written advance directives.
  - c. A patient may only revoke an advance directive through a written document that expresses the patient's clear intent to revoke the advance directive.
  - d. A patient may revoke an advance directive in accordance with the Patient Self-Determination Act, which addresses the legal ways in which a patient may revoke a written advance directive.
  
- 9. For elderly persons who are recently diagnosed with dementia or Alzheimer's disease,**
  - a. discussions regarding advance directives should be avoided until a later date because these discussions can upset the patient
  - b. discussions regarding advance directives should occur only after the patient has reached an understanding of his or her diagnosis and prognosis
  - c. discussions regarding advance directives should not be addressed until the patient begins to experience behavioral difficulties
  - d. discussions regarding advance directives should be initiated immediately with the patient because of the unpredictability of the progression of the disease
  
- 10. The legal basis upon which advance directives are founded is**
  - a. the doctrine of informed consent
  - b. the paternalistic belief that healthcare providers know what is best for the patient
  - c. the charitable hospital doctrine
  - d. the belief that patients should not be given all the information about their diagnosis because it may destroy their hope for a recovery



**11. The state's interest in protecting patients**

- a. includes the preservation of life
- b. leaves the protection of innocent third parties up to the parent or guardian of that party
- c. always includes prolonging the life of terminally ill patients
- d. does not concern itself with the integrity of the medical profession

**12. The decisions of the *Conroy* Court established a test that may be used to determine whether life-sustaining treatment may be withdrawn or withheld from an incompetent patient. One of the criteria is the subjective test, which provides for treatment to be withdrawn or withheld**

- a. if the physician decides it is in the best interest of the patient
- b. if the patient's family does not wish to continue treatment
- c. if there is clear and convincing evidence of the patient's subjective intent and it is clear what the patient would choose if able to do so
- d. if a certain length of time has passed and the patient's condition has not improved

**13. Factors that may encourage healthcare providers to deviate from an advance directive when making healthcare decisions for a medically incapacitated patient include**

- a. the patient's quality of life, treatment outcomes, and family preferences
- b. family preferences only, because if the family so desires, they can change the terms of the patient's advance directive
- c. extraordinary circumstances only, because physicians don't generally deviate from the patient's advance directives
- d. the financial element of providing care to the patient

**14. When the nurse determines that the patient's advance directive is not being followed, he or she should**

- a. do nothing—the physician knows what is best for the patient
- b. refuse to follow the physician's orders that are not in compliance with the patient's advance directive
- c. tell the family that they are being disrespectful to the patient and that they should follow the wishes of the patient
- d. consult with nursing management, the hospital risk manager, or the legal department

## **Nursing education instructional guide**

### **15. Sources of conflict that occur between the clinician and the family**

- a. are rare because the clinician and family generally agree on treatment for the patient
- b. only occur with pediatric patients because the family has greater difficulty understanding the death of a child
- c. are not that common among Medicaid-insured patients
- d. often include the decision to withdraw or withhold life-sustaining treatments and communication breakdown

### **16. Research has shown that, when it comes to reducing healthcare expenditures,**

- a. advance directives help lower the cost of hospital stays, and patients should be strongly encouraged to execute advance directives as cost-saving measures
- b. elderly patients should be encouraged to execute advance directives because medical care for elderly patients is very expensive
- c. advance directives do not lower the cost of healthcare expenditures because expensive end-of-life care is still needed even when patients don't undergo advanced life-saving treatments
- d. the financial element has not been a factor in encouraging patients to execute advance directives

### **17. European American values regarding healthcare may include**

- a. the patient's right to make informed decisions about his or her healthcare
- b. that patients be protected from the true nature of the disease process
- c. that patients leave the dying process to nature and not exercise any control over it
- d. that the patient defer decision-making to the physician

### **18. The Tuskegee syphilis study, in which U.S. healthcare providers documented the natural progression of syphilis by fraudulently treating infected persons, has greatly influenced which ethnic group's distrust of the U.S. health system?**

- a. Korean Americans
- b. Latinos
- c. African Americans
- d. Native Americans

**19. In Latino families, healthcare decisions for the medically incapacitated patient are**

- a. always made by the patriarchal member of the family
- b. generally defined within advance directives, and families do not have much input regarding the care of the patient
- c. made by one member of the family who makes all the decisions about the patient's healthcare without consulting other members of the family
- d. often made through a consensually oriented decision-making approach that is more acceptable to the Latino culture

**20. The elements of a well-developed advance directive curriculum include**

- a. didactic instruction, role-play opportunities, and communication demonstrations through which the nurse can prepare for situations that may arise when discussing end-of-life issues with patients
- b. providing the nurse with a written manual to read and implement in clinical practice
- c. nursing school education and a brief overview during hospital orientation
- d. learning about advance directives while on the job

**21. When questioning cultural leaders regarding end-of-life decisions, nursing management and staff development should ask them**

- a. about any gestures or questions nurses might ask concerning end-of-life decisions that might offend someone from a specific culture
- b. to give hard and fast rules about the culture that the nurse can apply when discussing advance directives
- c. what techniques the nurses should employ to get the members of that culture to execute an advance directive
- d. how the nurse can change the cultural views of a specific group so the cultural group will be more accepting of advance directives

## **Nursing education instructional guide**

**22. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) promotes advance directives through**

- a. specific accreditation standards that establish how a hospital can demonstrate compliance
- b. standards that address informed consent; however, advance directives are implied within the informed consent standard
- c. a 'Do Not Resuscitate' standard only
- d. deference to the Patient Self-Determination Act

**23. Hospital policies and procedures concerning advance directives should**

- a. parallel state law and the Patient Self-Determination Act
- b. provide a cursory overview of the hospital's actions
- c. address advance directives only for patients who are undergoing major surgical procedures
- d. not identify a specific time at which patients will be given information about advance directives because that should be decided on a case-by-case basis, depending upon the patient's situation

### Nursing education evaluation

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Facility name: \_\_\_\_\_

Address: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP: \_\_\_\_\_

Phone number: \_\_\_\_\_ Fax number: \_\_\_\_\_

E-mail: \_\_\_\_\_

Nursing license number: \_\_\_\_\_

(ANCC requires a unique identifier for each learner)

#### 1. This activity met the following learning objectives:

a.) *Described the hospitals' legal requirements under the Patient Self-Determination Act*  
 Strongly disagree    1       2       3       4       5       Strongly agree

b.) *Discussed the Advance Directives Improvement and Education Act of 2005*  
 Strongly disagree    1       2       3       4       5       Strongly agree

c.) *Assessed nurses' knowledge of advance directives*  
 Strongly disagree    1       2       3       4       5       Strongly agree

d.) *Discussed nurses' patient advocacy role regarding advance directives*  
 Strongly disagree    1       2       3       4       5       Strongly agree

e.) *Distinguished between the living will and the durable power of attorney for healthcare*  
 Strongly disagree    1       2       3       4       5       Strongly agree

f.) *Defined the "clear and convincing" language requirement*  
 Strongly disagree    1       2       3       4       5       Strongly agree

g.) *Identified when a 'Do Not Resuscitate' order may be medically and ethically appropriate*  
 Strongly disagree    1       2       3       4       5       Strongly agree

h.) *Identified when a patient may revoke an advance directive*  
 Strongly disagree    1       2       3       4       5       Strongly agree

## Nursing education instructional guide

i.) *Identified special considerations regarding advance directives that must be addressed with some elderly patients*

Strongly disagree    1       2       3       4       5       Strongly agree

j.) *Verbalized the legal basis upon which advance directives are founded*

Strongly disagree    1       2       3       4       5       Strongly agree

k.) *Recognized the state's interest in protecting patients*

Strongly disagree    1       2       3       4       5       Strongly agree

l.) *Enumerated the three-part test of the Conroy Court to determine whether life-sustaining treatment may be withheld or withdrawn*

Strongly disagree    1       2       3       4       5       Strongly agree

m.) *Identified factors that may encourage healthcare providers to deviate from an advance directive when making healthcare decisions for a medically incapacitated patient*

Strongly disagree    1       2       3       4       5       Strongly agree

n.) *Discussed the nurses' role in ensuring the patient's wishes outlined in an advance directive are respected*

Strongly disagree    1       2       3       4       5       Strongly agree

o.) *Identified sources of conflict concerning end-of-life decisions between the patient's family and the clinician*

Strongly disagree    1       2       3       4       5       Strongly agree

p.) *Analyzed the role of advance directives in reducing healthcare expenditures*

Strongly disagree    1       2       3       4       5       Strongly agree

q.) *Discussed the European American values regarding healthcare*

Strongly disagree    1       2       3       4       5       Strongly agree

r.) *Analyzed why African Americans may distrust the U.S. health system*

Strongly disagree    1       2       3       4       5       Strongly agree

s.) *Defined the role of Latino families in making healthcare decisions for the medically incapacitated patient*

Strongly disagree    1       2       3       4       5       Strongly agree

t.) *Identified the elements of a well developed advance directive curriculum*

Strongly disagree    1       2       3       4       5       Strongly agree

u.) *Identified strategies to include cultural leaders in the promotion of nurses' cultural competency regarding end-of-life decisions*

Strongly disagree    1       2       3       4       5       Strongly agree

## Nursing education instructional guide

v.) *Discussed the standards of the JCAHO regarding advance directives*

Strongly disagree    1    2    3    4    5    Strongly agree

w.) *Identified the necessary contents of hospital policies and procedures to meet legal mandates and accreditation standards for advance directives*

Strongly disagree    1    2    3    4    5    Strongly agree

2. Objectives were related to the overall purpose/goal of the activity.

Strongly disagree    1    2    3    4    5    Strongly agree

3. This activity was related to my nursing activity needs.

Strongly disagree    1    2    3    4    5    Strongly agree

4. The exam for the activity was an accurate test of the knowledge gained.

Strongly disagree    1    2    3    4    5    Strongly agree

5. The activity avoided commercial bias or influence.

Strongly disagree    1    2    3    4    5    Strongly agree

6. This activity met my expectations.

Strongly disagree    1    2    3    4    5    Strongly agree

7. Will this learning activity enhance your professional nursing practice?

Yes

No

8. This educational method was an appropriate delivery tool for the nursing/clinical audience.

Strongly disagree    1    2    3    4    5    Strongly agree

9. How committed are you to making the behavioral changes suggested in this activity?

a) Very committed

b) Somewhat committed

c) Not committed

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10. Please provide us with your degree.

- a) ADN
- b) BSN
- c) MSN
- d) Other, please state

11. Please provide us with your credentials.

- a) LVN
- b) LPN
- c) RN
- d) NP
- e) Other, please state

12. The fact that this product provides nursing contact hours influenced my decision to buy it.

Strongly disagree    1    2    3    4    5    Strongly agree

13. I found the process of obtaining my continuing education credits for this activity easy to complete.

Strongly disagree    1    2    3    4    5    Strongly agree

14. If you did not find the process easy to complete, which of the following areas did you find the most difficult?

- a) Understanding the content of the activity
- b) Understanding the instructions
- c) Completing the exam
- d) Completing the evaluation
- e) Other, please state:

15. How much time did it take for you to complete this activity (including reading the book and completing the exam and the evaluation)? \_\_\_\_\_



## Nursing education instructional guide

16. If you have any comments on this activity, process, or selection of topics for nursing continuing education, please note them below.

17. Would you be interested in participating as a pilot tester for the development of future HCPro nursing education activities?

Yes

No

Thank you for completing this evaluation of our nursing continuing education activity.