

Advance Directives: Patient Self-Determination

NYSNA Continuing Education

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How to Take This Course

Please take a look at the steps below; these will help you to progress through the course material, complete the course examination and receive your certificate of completion.

1. REVIEW THE OBJECTIVES

The objectives provide an overview of the entire course and identify what information will be focused on. Objectives are stated in terms of what you, the learner, will know or be able to do upon successful completion of the course. They let you know what you should expect to learn by taking a particular course and can help focus your study.

2. STUDY EACH SECTION IN ORDER

Keep your learning "programmed" by reviewing the materials in order. This will help you understand the sections that follow.

3. COMPLETE THE COURSE EXAM

After studying the course, click on the "Course Exam" option located on the course navigation toolbar. Answer each question by clicking on the button corresponding to the correct answer. All questions must be answered before the test can be graded; there is only one correct answer per question. You may refer back to the course material by minimizing the course exam window.

4. GRADE THE TEST

Next, click on "Submit Test." You will know immediately whether you passed or failed. If you do not successfully complete the exam on the first attempt, you may take the exam again. If you do not pass the exam on your second attempt, you will need to purchase the course again.

5. FILL OUT THE EVALUATION FORM

Upon passing the course exam you will be prompted to complete a course evaluation. You will have access to the certificate of completion **after you complete the evaluation**. At this point, you should print the certificate and keep it for your records.

Course Introduction

During basic nursing education, few nurses have classes or clinical experience in caring for the dying patient and her or his family. Yet, hardly a week goes by where you don't deal with issues related to death and dying at some level. Most nurses learned these skills from other nurses and from clinical experience itself. Nurses have said that they feel powerless to help people whom are at the end of their life.

This course provides information about issues related to healthcare advance directives including legal and ethical issues.

Course Objectives

At the completion of this learning activity the learner will be able to:

- Define advance directives.
- Discuss the purpose of an advance directive.
- Discuss considerations prior to developing an advance directive.
- State the impact of the Patient Self-Determination Act of 1991 on healthcare.
- Discuss ethical questions relative to patient self-determination.
- Identify resources for the development of advance directives.

About the Author

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Definitions

1. **Advance Directive:** instructions given by a patient while they still have decisional capacity concerning medical treatment they would or would not want. Formal advance directives typically consist of either a living will or a written healthcare proxy.
2. **Living Will:** most common form of advance directive, specifies what the patient would want under certain conditions.
3. **Durable Power of Attorney for Healthcare (AKA Health Care Proxy):** a legal document that an individual signs, while competent, to designate who will make their healthcare decisions if they become incompetent (e.g. comatose, confused).
4. **Patient Self-Determination Act of 1990:** mandates that all hospitals, nursing facilities, home healthcare agencies, hospices, and HMO's receiving federal reimbursement under Medicare and Medicaid provide adult clients with information on living wills and other forms of advance directives, and to:
 1. Provide written information to patients upon admission about their legal rights to make decisions affecting their medical care;
 2. Maintain written policies and procedures with regard to advance directives and provide written information to patients about such policies;
 3. Document in the individual's record the existence, or non-existence, of a completed advance directive;
 4. Ensure compliance with state law regarding advance directives, and
 5. Educate the staff and community on issues surrounding advance directives.
5. **Euthanasia:** To bring about the death of a terminally ill and/or suffering person (from the Greek, *eu*: easy, *thanos*: death) A distinction can be made between "active" euthanasia, which is acting to ensure death, and "passive" euthanasia which is the failure to intervene to prevent death.
6. **Assisted Suicide:** Providing a person the means to end their own life.
7. **Double Effect:** Outcome when the intended consequence of alleviating pain results in the unintended consequence of hastening death.

Historical Events That Impacted Legislation

There have been a number of landmark cases that have greatly impacted on current legislation.

In 1975, Karen Ann Quinlan ingested alcohol and tranquilizers. She was brought to the hospital in a coma. The diagnosis was brain damage with persistent vegetative state (PVS); she was on a ventilator and had feeding tubes. The family requested that she be removed from the ventilator. The hospital refused to do so.

The family went to court, arguing that her death was God's will and that Karen would not want to live this way. The lower court decision was not supportive of the family's petition to remove her from the ventilator. Karen's father took the case to the New Jersey Supreme Court. That court made her father her guardian. The case was argued from the view of the individual's right to privacy and the burden of life support.

Karen Ann Quinlan was taken off of life support at the request of her family; she lived for an additional 10 years and eventually died of pneumonia. She remained on feeding tubes and IV fluids during those years.

This case brought to light the issues of ordinary vs. extraordinary care, where food and fluids were considered to be ordinary care and the ventilator was considered extraordinary care.

In 1983 Nancy Cruzan, age 25, had a car accident and never regained consciousness. She was diagnosed as having Persistent Vegetative State (PVS) and was on a feeding tube. The family wanted the feeding tube removed, allowing Nancy to die. The Missouri Rehabilitation Center refused; the family went to court.

The lower court ruled in the family's favor and said the feeding tube could be removed. The Missouri Rehabilitation Center still refused to follow the order and took the case to the State Supreme Court. The ruling of the lower court was overturned by the State Supreme Court on the basis of the state's greater duty to preserve life, which outweighed any right that the parents might have to make decisions for their daughter.

This case went to the US Supreme Court in 1989 and became the first right-to-die case. The US Supreme Court upheld the State Supreme Court, stating that not even the family should make choices for an incompetent patient in the absence of "clear and convincing evidence" of the patient's wishes.

This call for a "clear and convincing evidence standard" resulted in most states passing legislation regarding some form of a "living will".

Between 1976 and 1990, due to the influential cases of Quinlan and Cruzan courts reached consensus related to matters of end-of-life. The courts and bioethicists have confirmed a person's right to refuse life-sustaining treatment and determined that this right remains intact even when the person is unable to speak for oneself. With all this consensus in the Spring of 2005, Theresa (Terri) Marie Schiavo became the focus of publicity as her story became the most litigated medical case in history (Gostin, 2005).

Timeline of Events of the Schiavo Case

1990-2000

- 1990-Schiavo suffers cardiac arrest leading to brain damage, subsequently, percutaneous endoscopic gastrostomy (PEG) tube inserted.
- 1993-County Circuit Court appoints Michael Schiavo as her guardian. Terri's parents the Schindlers do not object to this decision.
- 1994-Schindlers seek removal of Michael as guardian and court dismisses the suit. A court appoints the first guardian to represent Terri's wishes and interest. The guardian finds that Michael is acting appropriately and attentively.
- 1998-Michael files a petition to have Terri's PEG tube removed. The Schindlers oppose. A second guardian is appointed who reports that Terri is in a PVS and that Michael may be influenced by potential inheritance.
- 2000-County Circuit Court rules that Terri would have chosen to have the PEG removed. An order to remove is granted.

2001-2005

- 2001-Florida Second District Court of Appeal upholds the 2000 ruling. The Florida Supreme Court declines to review the Second District Court decision. The U.S. Supreme Court refuses to review the case. PEG tube is removed by court order. Schindlers file a motion stating that Michael perjured himself. The County Circuit Court orders reinsertion of the PEG tube. The PEG tube is reinserted. On remand the County Circuit Court again rules the PEG tube can be removed. At the end of 2001 the Florida Second District Court rules that 5 physicians should examine Terri.
- 2002-County Circuit Court rules the PEG tube should be removed.
- 2003- Florida Second District Court of Appeal affirms the County ruling. Florida Supreme court declines review of the decision and Schindlers file a federal lawsuit challenging removal of the PEG tube. Governor Jeb Bush files a brief to the federal district court in support of the Schindlers. Federal District Court rules that the Governor lacks jurisdiction to hear federal cases. The PEG tube is removed by court order. The Florida legislature enacts "Terri's Law," which would allow a Governor to issue "one-time stay in certain cases." Thus, the Governor issues an executive order to have the PEG tube reinserted. The PEG tube is reinserted by court order. The third guardian is appointed, a physician, who concludes that Terri is in PVS with no chance of improving.
- 2004-Florida Supreme Court declares "Terri's Law" unconstitutional. Governor Bush seeks review by the U.S. Supreme Court.
- 2005-The U.S. Supreme Court refuses to grant this review. Next, the US House of Representatives Committee issues 5 subpoenas commanding: Michael and Schiavo to appear and bring "hydration and nutrition equipment" in working order and demanding that physicians and hospice personnel to do the same. The PEG is removed for the third time by court order. President Bush signs a bill which would grant federal courts the ability to review the case. The Schindlers seek assistance from the federal court for reinsertion of the PEG tube. The federal court denies this motion. The US Court of Appeals for the 11th Circuit upholds the federal court ruling and the US Supreme Court refused to hear the case. The US Court of Appeals denies a motion for a rehearing.

Terri Schiavo dies at 9:05AM on March 31, 2005. Her body is sent for an autopsy (Gostin, 2005).

Understanding Advance Directives

An **advance directive** (AAFP, 2000) tells the healthcare provider what kind of care is desired in the event that one is unable to make medical decisions. The law now says that at the time of admission to the hospital, the hospital staff must tell each patient about advance directives. Advance directives can take many forms. Laws about advance directives vary from state to state. Each person should be aware of the guidelines of the state laws, in the state of legal residence, regarding the scope and technical requirements that apply to advance directives. A good advance directive describes the kind of treatment one would want to receive for different levels of illness. For example, the directives would describe what kind of care one would want if one experiences a critical illness, a terminal illness or permanent unconsciousness. Advance directives usually inform the doctor that certain kinds of treatment are unwanted if the above conditions are experienced. However, the advance directive can also indicate which treatments are wanted by the individual, no matter how severe the condition.

The limitations to advance directives are that new technologies may emerge after the document is written that might not have anticipated at the time they were developed. The interests of the patient may change from the time the directive was written. People may not want their Advance Directive to be strictly followed. Also, some people may generate an Advance Directive and never talk about it with their family members or physicians.

Living wills (AAFP, 2000) are one type of advance directive. They only come into effect in the case of terminal illness. Being terminally ill generally means that one has less than six months to live. In a living will, one can describe the kind of treatment that is desired in particular situations. A living will doesn't allow for the selection of a proxy, that is, someone to make decisions for you. Despite endorsement by physicians and medical ethicists, living wills have created many problems. Only about 9% of the population has made living wills; people fear that rejecting life support, if they have a terminal illness, means rejecting all care.

A **durable power of attorney** (DPA) (AAFP, 2000) for healthcare is like a living will, but it becomes active any time you are unconscious or unable to make medical decisions. In a DPA, a family member or friend is identified who will be the medical decision-maker if one becomes unconscious or is unable to make medical decisions. A DPA is generally more useful than a living will. This is because of the possibility that a medical situation may arise that was not included in the living will, so no guidance about one's wishes can be followed. For example, many people discuss their preferences in the presence of a terminal condition. But when the prognosis is not terminal, but serious, and antibiotics, for example, are required (and not addressed in the living will) the DPA can make a decision in alignment with how the patient would have decided if she or he were able to do so.

If one does not have a trusted person to make these decisions, the DPA may not be the right choice. This document invokes the "best interests" standard. The best interests standard directs the proxy to choose the intervention that will best promote and protect the patient's interests. There may be problems with this system if the patient has not told their DPA what their wishes are if they are unable to advocate for themselves. The proxy decision-maker may also incorporate his or her own beliefs or misinterpret or ignore the wishes of the patient. The DPA may also have trouble discerning the best interests of the patient if there are financial or emotional conflicts.

According to Grady (2005), fewer than 30% of Americans have an advance directive. Due to the publicity of the Schiavo case, agencies offering assistance with living wills and DPA documents had unprecedented inquiry numbers. After the dust has settled from the Schiavo case even with the increase in knowledge, less than 40% of Americans hold an advance directive (Roman and Metules, 2005).

Common Questions About Advance Directives

Why is An Advance Directive Useful?

Unlike most Living Wills, a Healthcare Advance Directive is not limited to cases of terminal illness. If one cannot make or communicate decisions because of a temporary or permanent illness or injury, a Healthcare Advance Directive helps one keep control over healthcare decisions that one believes are important. In a Healthcare Advance Directive, wishes can be stated about any aspect of healthcare, including decisions about life-sustaining treatment, and a person can be identified who can make and communicate these decisions.

Appointing an agent is particularly important. At the time a decision needs to be made, the agent can participate in discussions and can weigh the pros and cons of treatment decisions based on the patient's wishes. The agent can make decisions whenever the patient is unable to decide for him or herself, even if the decision-making ability is only temporarily affected.

Unless the patient formally appoints someone to make decisions, many healthcare providers and institutions will make critical decisions that might not be based on the patient's wishes. In some situations, a court may have to appoint a guardian unless there is an advance directive.

An advance directive also can relieve family stress. By expressing wishes in advance, the patient helps family or friends who might otherwise struggle to decide on their own what the patient would want done.

Are Healthcare Advance Directives Legally Valid in Every State?

Yes, every state and the District of Columbia have laws that permit individuals to sign documents stating their wishes about healthcare decisions when they cannot speak for themselves. The specifics of these laws vary, but the basic principle of listening to the patient's wishes is the same from state to state. The law gives great weight to any form of written directive. If the courts become involved, they usually try to follow the patient's stated values and preferences, especially if they are in written form. A Healthcare Advance Directive may be the most convincing evidence one can create.

What Does A Healthcare Advance Directive Say?

There are two parts to the Healthcare Advance Directive.

The most important part of the advance directive is the appointment of someone, the agent, to make healthcare decisions in the event that one cannot decide for oneself. How much or how little authority the agent can have, can be identified. Alternate agents can also be named. This can be helpful if the primary agent cannot act for the patient. Specific persons, who the patient does not want to make decisions for her or him, can also be identified.

If one cannot identify a trusted individual to serve as the agent, then no agent should be named. In such a case, the second part of the Advance Directive will be relied upon to inform others of the patient's wishes.

In the second part of the Advance Directive specific instructions regarding healthcare treatment are identified. A statement can also be made about organ donation. The instructions in the second part provide evidence of the patient's wishes that the agent, or any healthcare providers, should follow.

One can complete either or both parts of the Healthcare Advance Directive.

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How Is a Healthcare Advance Directive Made?

The process for creating a Healthcare Advance Directive depends on the state of legal residence. Most states have laws that provide special forms and signing procedures.

Most states also have special witnessing requirements and restrictions on who can be appointed as the agent (such as prohibiting a healthcare provider from being your agent). Follow these rules carefully.

Typically, states require two witnesses. Some require or permit a notarized signature. Some have special witnessing requirements if the patient lives in a nursing home or similar facility. Even where witnesses are not required, consider using them anyway to reinforce the deliberate nature of the act and to increase the likelihood those care providers in other states will accept the document.

See the "Resource" section at the end of this course for state-specific downloadable advance directive forms and state specific advance directive information.

If I Change My Mind, Can I Cancel Or Change A Healthcare Advance Directive?

Yes, a Healthcare Advance Directive can be cancelled or changed by telling the agent or healthcare provider in writing of any new decisions. Destroying all copies of the old one and creating a new one is the best way. Make sure a copy of the new Healthcare Advance Directive is provided to your physician or other healthcare provider and to anyone else who received the old one.

What Needs to be Considered Before Making A Healthcare Advance Directive?

There are at least four important questions to ask:

First - What Are The Goals for Medical Treatment?

The Healthcare Advance Directive may determine what happens to the patient over a period of disability or at the very final stage of life. Others can be helped to respect the patient's wishes, if the steps are taken, prior to when they are needed, in order to make treatment preferences clear.

While it is impossible to anticipate all the different medical decisions that may come up, one can make one's preferences clear by stating one's goals for medical treatment. What does the patient want treatment to accomplish? Is it enough that treatment could prolong life, whatever the quality of life? Or, if life-sustaining treatment could not restore consciousness or one's ability to communicate with family members or friends, would it be preferable that treatment be stopped?

In formulating goals of treatment, it is often helpful to consider one's wishes about different end-of-life treatments and then asking oneself " why do I feel that way?". If one would not want to be kept alive by a ventilator, what is it about being on a ventilator that is troubling? Is it the loss of mobility, the lack of independence, or some other factor? Would it matter if the ventilator were needed only temporarily, say for only a few days rather than many months? The answers to these kinds of questions will reflect important values that one holds and will help shape the goals of treatment.

Another way to become clear about goals of treatment is to create a "Values History." In doing a Values History, one should examine one's values and attitudes, discuss them with loved ones or advisors and write down responses to questions such as:

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- How do I feel about my current health?
- How important is independence and self-sufficiency in my life?
- How do I imagine handling illness, disability, dying, and death?
- How might my personal relationships affect medical decision-making, especially near the end of life?
- What role should doctors and other health professionals play in such decisions?
- What kind of living environment is important to me if I become seriously ill or disabled?
- How much of the cost to my family is a part of the decision-making process?
- What role do religious beliefs play in decisions about healthcare?
- What are my thoughts about life in general in its final stages: my hopes and fears, enjoyments and sorrows?

Once the goals of treatment have been stated, family and physicians can make medical decisions for the patient on the basis of the patient's goals. If treatment would help achieve one of the goals, the treatment may be provided. If treatment would not help achieve one of the goals, the treatment may not be provided.

Second - Who Should Be The Agent? Choosing one's agent is the most important part of this process. The agent will have great power over the patient's health and personal care if the patient cannot make her or his own decisions. Normally no one oversees or monitors the agent's decisions.

Choose one person to serve as the agent to avoid disagreements. If two or more agents are appointed to serve together and they disagree, healthcare providers will have no clear direction. If possible, appoint at least one alternate agent in case the primary agent is not available.

Speak to the person (and alternate agents) you wish to appoint beforehand to explain your desires. Confirm his or her willingness to act for you and their understanding of your wishes. Also be aware that some states will not let certain persons (such as your doctor) act as your agent. If you can think of no one you trust to carry out this responsibility, then do not name an agent. Make sure, however, that you provide instructions that will guide your doctor or a court-appointed decision-maker.

When choosing an agent, consider the agent's potential abilities to understand and communicate with medical providers, the often complex elements that may surround your situation. An agent who is concerned and committed but who may not be comfortable "speaking up" in controversial situations may not be able to represent your wishes fully. Negotiating healthcare decisions for another person requires time, effort and a basic understanding of healthcare.

Third - How Specific Should I Be?

A Healthcare Advance Directive does not have to give directions or guidelines for the agent. However, if specific wishes or preferences exist, it is important to spell them out in the document itself. Also discuss them with the agent and healthcare providers. These discussions will help ensure that the patient's wishes, values and preferences will be respected. Make sure to include consideration of artificial feeding (nutrition and hydration), since people sometimes have very different views on this topic.

At the same time, be aware that all possible bases cannot be covered. It is impossible to predict all the circumstances that may arise. Simple statements like "I never want to be placed on a ventilator" may not reflect the patient's true wishes. Ventilator assistance may be needed only temporarily and then normal activities could be resumed. Would your decision about ventilator use change if you knew it would be time-limited?

No matter how much direction is provided in the document, the agent will still need considerable discretion and flexibility. Write instructions carefully so they do not restrict the authority of the agent in ways the patient did not intend.

Fourth - How Can I Make Sure that Healthcare Providers Will Follow My Advance Directive?

Regardless of the laws about advance directives in the state of residence, some healthcare providers or hospitals may have personal views or values that do not agree with the patient's stated desires. As a result, they may not want to follow the patient's Healthcare Advance Directive.

Most state laws give healthcare providers the right to refuse to honor an advance directive on conscience grounds. However, they generally must help the patient find a healthcare provider or hospital that will honor the directive. The best way to avoid this problem is for the patient to talk to her or his healthcare provider ahead of time. Make sure they understand the document and the patient's wishes, and they have no objections. If there are objections, work them out, or change providers.

Once a Healthcare Advance Directive has been signed by the patient, be sure that a copy is given to the healthcare provider, to the agent, close relatives, and anyone else that may be involved in the patient's care.

What Happens If I Do Not Have an Advance Directive?

If one does not have an advance directive and one cannot make healthcare decisions, some state laws give decision-making power to default decision-makers or "surrogates." These surrogates, who are usually family members in order of kinship, can make some or all healthcare decisions. Some states authorize a "close friend" to make decisions, but usually only when family members are unavailable.

Even without such statutes, most healthcare providers and health facilities routinely consult family, as long as there are close family members available and there is no disagreement. However, problems can arise because family members may not know what the patient would want in a given situation. They also may disagree about the best course of action. Disagreement can easily undermine family consent. A hospital physician or specialist who does not know the patient well may become the decision-maker, or a court proceeding may be necessary to resolve a disagreement.

In these situations, decisions about healthcare may not reflect the patient's wishes or may be made by persons the patient would not choose. Family members and persons close to the patient may go through needless agony in making life and death decisions without the patient's guidance. It is far better to make one's wishes known and appoint an agent ahead of time through a Healthcare Advance Directive.

Who Can Help Me Create A Healthcare Advance Directive?

A lawyer is not needed in order to make a Healthcare Advance Directive. However, a lawyer can be helpful if the family situation is uncertain or complex, or if problems are expected to arise. Start by talking to someone who knows the patient well and can help to state the patient's values and wishes considering the particular family and medical history.

The patient's healthcare provider is an important participant in creating the Healthcare Advance Directive. Discuss the kinds of medical problems that might be faced, based on current health and family history. One's healthcare provider can assist in helping one understand the treatment

choices that the agent may face. Share ideas for instructions with the doctor to make sure medical care providers can understand them.

Multiple other resources exist to assist in the creation of a healthcare advance directive. See the “Resource” section at the end of this course for additional information, including downloadable forms and information that is specific to each state.

Patient Self-Determination and Decision Making

In 1991 The American Nurses Association (ANA) issued the following position statement.

Nursing and the Patient Self-Determination Act

Summary: The ANA believes that nurses should play a primary role in implementation of the Patient Self-Determination Act, passed as part of the Omnibus Budget Reconciliation Act of 1990. It is the responsibility of nurses to facilitate informed decision-making for patients making choices about end-of-life care. The nurse's role in education, research, patient care and advocacy is critical to implementation of the Patient Self-Determination Act within all healthcare settings.

The Patient Self-Determination Act, passed as part of the Omnibus Budget Reconciliation Act of 1990, becomes effective December 1, 1991. The federal law applies to all healthcare institutions receiving Medicaid funds and requires that all individuals receiving medical care must be given written information about their rights under state law to make decisions about medical care, including the right to accept or refuse medical or surgical treatment. Individuals must also be given information about their rights to formulate advance directives such as living wills and durable powers of attorney for healthcare. Patients must be made aware of their rights to make decisions about these issues upon admission (in the case of hospitals or skilled nursing facilities), enrollment (in the case of health maintenance organizations), on first receipt of care (in the case of hospices) or before the patient comes under an agency's care (in the case of home health personal care agencies).

ANA supports the patient's right to self-determination and believes that nurses will and must play a primary role in implementation of the law. Ideally, the patient should make a decision about advance directives with the family and the primary provider prior to admission. The formation of advance directives is an important decision and will inevitably involve nurses who are the most omnipresent professionals in healthcare facilities. It is imperative that the decision making that will fall to patients and their families as they make choices about end of life care are facilitated by nurses.

Each nurse should know the laws of the state in which she/he is practicing pertaining to advance directives, and should be familiar with the strengths and limitations of the various forms of advance directives.

The nurse is one of several healthcare professionals who has a responsibility for ensuring that the advance care directives initiated by the patient are current and reflective of the patient's choices. Facilitating self-determination of patients with respect to end of life decisions is a process that includes evaluating changes in the patient's perspective and health state. The nurse has a responsibility to facilitate informed decision making, including but not limited to advance directives.

ANA recommends that these questions about advance directives be part of the nursing admission assessment: Do you have basic information about advance care directives including living wills and durable power of attorney? Do you wish to initiate an advance care directive? If you have already prepared an advance care directive, can you provide it now? Have you discussed your end of life choices with your family and/or designated surrogate and healthcare team worker?

The role of the nurse is critical in implementation of the Patient Self-Determination Act and includes public education, research, patient care, advocacy, and education of the profession and in-service education of other healthcare providers.

Advance Directives: Patient Self-Determination

Advance medical directives are of two types: treatment directives, often referred to as "living wills," and appointment directives, often referred to as "power of attorney" or "health proxies".

A Living Will - states what medical treatment you choose to omit or refuse in the event that you are unable to make those decisions yourself and are terminally ill.

A Durable Power of Attorney for Healthcare - appoints a proxy - usually a relative or trusted friend - to make medical decisions on your behalf if you can no longer decide for yourself. It has broader applications than a living will and can apply to any illness or injury that could leave you incapacitated.

An advance directive does not need to be written, reviewed, and signed by an attorney. It must be witnessed by two people (in many states witnesses may not be your heirs, relatives or physicians). An advance directive applies only if you are unable to make your own decisions because you are incapacitated or if, in the opinion of two physicians, you are otherwise unable to make decisions for yourself. It can be changed or canceled at any time.

An advance directive is intended to help others make decision for you. It may be as simple or as complex as you feel necessary. For example, a simple statement indicating that in the case of an incurable illness or catastrophic injury you do not wish to be kept alive by artificial means such as CPR, artificial respiration or tube-feeding is an advance directive. A copy of the advance directive should be given to your family, physician and anyone you designate as a proxy. In addition, you should bring a copy of it with you if you are admitted to a hospital or nursing home.

The Patient Self-Determination Act (PSDA), effective December 1, 1991, does not require patients to have or fill out an advance directive. It does require hospitals and other healthcare organizations to tell patients what they have the right to do in accordance with existing state law. PSDA is not applicable in federal facilities such as Veterans Administration Hospitals that do not receive Medicare or Medicaid funds.

Beyond Advance Directives

Beyond Advance Directives – Ethics and CPR for Terminally Ill Patient

Discussion:

Some identifiable groups of patients are highly unlikely to survive a resuscitation attempt. Such groups include unmonitored patients with multi-system organ failure, a description that includes terminally ill patients with cancer on an oncology unit, at home or in a hospice. Should these patients who will most likely not survive resuscitation be offered the option to be resuscitated? Should they rather be designated as Do Not Resuscitate (DNR) without their knowledge or consent? Is informed consent required for withholding treatment? Do patients have a right to request futile treatment? Does a patient need to be informed that a futile treatment (such as CPR) is being withheld? Are nurses and physicians obligated to provide futile treatment at a patient's request?

Dilemma:

The patient's right to choose and refuse medical treatment conflicts with the professional's obligation not to offer or perform futile therapy (autonomy versus integrity of health professions). The patient's right to choose conflicts with the professional's judgment about what is best for the patient (autonomy versus beneficence).

Arguments for designating terminally ill patients as DNR without their consent:

There is consensus that physicians are not required to offer or perform futile therapy. An offer of futile therapy makes it appear to the patient that the futile therapy is a viable option. It is considered a misuse of resources to provide therapy that will not benefit the patient. The patient's autonomy should not override professional judgment about which therapies are scientifically proven to be appropriate or not appropriate for the patient. Patients do not have the right to choose any treatment; they have the right to choose among viable treatments. Dying patients expect DNR status along with a non-aggressive, comfort-oriented treatment.

Implications of choosing this position:

Resources will be saved. Patients will not be given therapies that have been shown to be useless. Information about the patient's DNR status may be withheld from patients. Nurses may feel obligated to lie to patients and families about the patient's DNR status if the patient or family is not aware of the DNR order. Patients or families or both may become angry if they discover that the patient has been designated DNR without their knowledge or consent. Some patients may be designated DNR who would survive a resuscitation attempt. An overly broad definition of futile treatment may lead to the withholding of treatment from patients because of a subjective opinion that the patient's quality of life (rather than scientific evaluation of probable success of treatment) is not sufficient to justify benefit of the treatment.

Arguments that patients should NOT be designated DNR without their knowledge or consent:

Scientific studies that describe the futility of CPR for terminally ill patients track the patients' survival to discharge, not their survival of the resuscitation. This indicates that CPR is not always futile for terminally ill patients. The definition of "terminally ill" is not precise enough to justify a policy of withholding resuscitation from patients. Patients' request for CPR should be honored because their goals for treatment (for example, to live a few days longer to see family member

arriving from out of town) are more important than professional obligations not to provide treatment that is highly unlikely to be effective. After many years of publicity in lay press about DNR orders, patients expect to discuss DNR status with physicians before a DNR status is assigned. Professionals should not have to conceal the DNR status from the patient and family. All treatment options should be presented to the patient along with realistic data on chances for success and expected outcome.

Implications of choosing this position:

No patient would be designated DNR without the consent of the patient or family. Some patients would undergo futile procedures at their own request. The public may come to expect that they can demand any treatment, which could become problematic if a demand arises for scarce resources. Some nurses and doctors may be angry at being forced to provide treatment such as CPR. Some patients would remain in full resuscitation status despite the improbability of their surviving CPR. The staff might feel coerced to offer all futile therapies which patients might interpret as viable therapies.

Potential compromise:

Designate patients as DNR when strong scientific studies show that CPR would be futile for those patients' conditions, but discuss the DNR order and the reasons for it with those patients.

Implications of choosing this position:

Patients may still be designated DNR in cases where CPR may not be futile, but problems with communication between professionals and patients would be overcome. Patients may be angry at their DNR status, but they would be given the option of finding another physician to care for them that would keep them in a full resuscitation status.

Guidelines

Guidelines for the nurse caring for a patient whose status has been designated as DNR without the patient's knowledge:

1. Review the chart to verify the patient's diagnosis, course of treatment, current status, care plan and goals of treatment. Look for documentation of the patient's views of treatment. Are there any advance directives (Living Will, Durable Medical Power of Attorney) that indicate the patient's support of a DNR order?
2. Discuss the DNR order with the physician and discuss the physician's rationale for the order. Encourage the physician to discuss the DNR order with the patient.
3. If the patient does not know his DNR status and asks the nurse for information about his resuscitation status, the nurse should explore with the patient what the physician has told him and gently explore the patient's feelings about his disease and his views on death and dying. Encourage the patient to talk to the physician about the resuscitation status. Be honest with the patient. Document the conversation in the patient's chart. Obtain psychiatric nurse, chaplain or social worker consultation for the patient as appropriate.
4. If the physician refuses to discuss the DNR order with the patient: inform the physician of the patient's requests for information about his resuscitation status; show the physician documentation of the patient's requests for information about resuscitation status; inform the physician that you will be informing your supervisor about this issue; inform the physician that you will give the patient the information he is requesting if the patient asks you specifically; refuse to lie to the patient; explain to the physician how lack of communication between the physician and the patient places nurses in difficult positions.

When a patient, their family, friends or healthcare providers are faced with a dilemma regarding difficult decisions the use of a facility's ethics committee can be beneficial. Ethics committees help to resolve dilemmas and frequently assist those involved to come to consensus and find peace (Gostin, 2005).

Conclusion

How can you as a nurse impact end of life care? One important contribution that you can make is through public education. Talking with your patients about end of life care can help them to make more thoughtful decisions. It often helps to describe the effects of life prolonging treatment on their body and just what occurs during CPR. Discuss thoughts about the goals of a medical cure and what their views are regarding quality versus quantity of life. Help them to think about what their goals and values are regarding end of life care. Be sure that copies of advance directives are in their charts and transferred with the patient.

This module has given you the opportunity to understand the historical and ethical underpinnings of the patient self-determination act and the resulting development of advance directives. When working with patients we need to remember that as long as they are alert enough to verbalize what their wishes are regarding medical or nursing interventions that these wishes must be honored. Patients need to know that by signing an advance directive they are taking the step to ensure that their wishes are followed. Too often, though, these documents are signed, durable power of attorney are named, and the patient has never communicated their wishes to their proxy. The resulting situations can be frustrating for all involved.

Advance directives are not just for the terminally ill or for older adults. We never know what life has in store for us and documents like advance directives can help our significant others make the decisions that we would want made regarding our care.

Resources

Legal Counsel for the Elderly (LCE) American Association of Retired Persons (AARP)

P.O. Box 96474
Washington, DC 20090-6474
202/ 434-2277
<http://www.aarp.org/>

AARP, which supports individual autonomy in healthcare decision-making, is conducting community education workshops on medical decision-making and advance directives around the country. These workshops, led by trained volunteers, provide basic information about advance directives and state-specific forms. In addition, workshop participants can return to a later session for assistance in completing their documents. For information about these workshops, call your AARP regional office or AARP at 1-800-424-3410.

Choice in Dying

200 Varick Street
New York, NY 10014
212-366-5540

This national organization provides state-specific advance directive forms and instructions, as well as a number of booklets about healthcare powers of attorney and living wills.

The Medical Directive, by Linda L. Emanuel, M.D. and Ezekiel J. Emanuel, M.D. This directive form has been revised to include six illness situations. For each illness, you indicate whether you would want particular interventions and your goals for medical care. For single copy requests, write to:

32 Fruit Street
Boston, MA 02114

Values History Form, by Joan Gibson. This form provides a framework for thinking about medical decision-making issues, and can be used to help communicate your general goals for medical care and your underlying values in medical decisions. For single copy requests, write to:

Joan Gibson, Director
University of New Mexico
Health Sciences Ethics Program
Nursing/Pharmacy Building, Room 368
Albuquerque, NM 87131

Aging with Dignity “Five Wishes”

My wish For:
The person I want to make care decisions for me when I can't
The kind of medical treatment I want or don't want
How comfortable I want to be
How I want people to treat me
What I want my loved ones to know

Aging with Dignity
P.O. Box 1661

Tallahassee, Florida 32302-1661
www.agingwithdignity.org

American Bar Association
1800 M ST., NE, South Lobby
Washington, DC 20036

Alzheimer's Association
70 East Lake St., Suite 600
Chicago, IL 60601
1-800-621-0379

Association for Death Education & Counseling
638 Prospect Ave.
Hartford, CT 06105
203-232-4825

Children of Aging Parents
2761 Trenton Rd.
Levittown, PA 19056
215-945-6900

Internet Links

State-specific downloadable advance directive forms and state-specific information regarding advance directives can be obtained at www.partnershipforcaring.org

Web site for healthcare providers, good descriptions and case studies.
<http://depts.washington.edu/bioethx/>

A nurse and a doctor from Dartmouth Medical School's Center discuss goals of decision making and patient participation in care planning in an article for Evaluative Clinical Sciences.
[\[http://oncolink.upenn.edu/psychosocial/qol/qol_3.html\]](http://oncolink.upenn.edu/psychosocial/qol/qol_3.html)

Last Acts is a campaign to improve end-of-life care by a coalition of professional and consumer organizations. Palliative care, focused on managing pain and making life better for individuals and families facing death, is the focus. This site is for professionals and volunteers working to improve care of the dying. Last Acts can be accessed at www.lastacts.org.

Growth House's mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Growth House can be accessed at www.growthhouse.org.

Information and advice regarding the law in your state may be obtained from the following:

- State Department of Health
- State Office on Aging
- State or Regional Hospital Association
- State Bar Association
- University Centers on Aging

You also can obtain state forms and literature from:

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- Your local hospital
- Your local nursing home
- Your state or local office on aging
- Your state's bar association
- Your state's hospital association
- Your state's medical association

References

- American Nurses Association. (1991). *Position statement: Nursing and the Patient Self-Determination Act*. Washington, DC: Author.
- Commission on Legal Problems of the Elderly, American Bar Association. (2002). *Healthcare decision-making legislation*. Retrieved August 9, 2006, from <http://www.abanet.org/aging/update.html>.
- Council on Ethical and Judicial Affairs, American Medical Association. (1991). Guidelines for the appropriate use of do-not-resuscitate orders. *Journal of the American Medical Association*, 265(14), 1868-1875.
- Cruzan vs. Director, Missouri Department of Health, (497 U.S. 261; 110 S.Ct. 2841, 1990).
- Emanuel, L.L., Barry, M.J., Stoeckle, J.D., Ettelson, L.M., & Emanuel, E.J. (1991). ADs for medical care: A case for greater use. *The New England Journal of Medicine*, 324(13), 889-895.
- Emanuel, L.L., & Emanuel, E.J. (1989). The medical directive: A new comprehensive advance care document. *Journal of the American Medical Association*, 261(22), 3288-3293.
- Gostin, L.O. (2005). Ethics, the Constitution, and the dying process. The case of Theresa Marie Schiavo. *Journal of the American Medical Association*, 293(19), 2403-2407.
- Grady, D. (2005, March 29). The best way to keep control: Leave instructions. *The New York Times*, p. A5.
- Greve P. (1995). Has the PSDA made a difference? *RN*, 57(2), 59.
- Kellermann, A. (1993). Predicting the outcome of unsuccessful prehospital advanced cardiac life support. *Journal of the American Medical Association*, 270(12), 1433-1436.
- Lewin, T. (1996, June 2). Ignoring 'Right to Die' directives, medical community is being sued. *The New York Times*, p. A1.
- Miles, S.H., Koeppe, R., & Weber, E.P. (1996). Advance end-of-life treatment planning: A research review. *Archives of Internal Medicine*, 156, 162-168.
- Murphy, D.J. (1988). Do-not-resuscitate orders: Time for reappraisal in long-term care institution. *Journal of the American Medical Association*, 260(14), 2998-3101.
- Murphy, D.J. (1989). Outcomes of cardiopulmonary resuscitation in the elderly. *Annals of Internal Medicine*, 111(3), 199-205.
- Omnibus Reconciliation Act (OBRA) Patient Self-Determination Act (PSDA). PL 101508, Sect. 4206, 4751. 1990 November 5.
- Pelligrino, E.D. (1995). Toward a virtue-based normative ethics for the health professionals. *Kennedy Institute of Ethics Journal*, 5(3), 253-277.
- President's Commission for the Study of Ethical Problems in Medicine Biomedical & Behavior Research. (1983). *Deciding to forego life-sustaining treatment*. Washington, DC: Government Printing Office.

Roman, L.M. & Metules, T.J. (2005). What we can learn from the Schiavo Case. *RN*, 68 (8): 53-57.

Taffet, G.E. (1998). In-hospital cardiopulmonary resuscitation. *Journal of the American Medical Association*, 260(14), 2069-2072.

Tomlinson, T. & Brody, H. (1998). Ethics and communication in do-not-resuscitate orders. *New England Journal of Medicine*, 318(1), 43-46.

Wolfe, S. (1998). When is it time to die? *RN*, 60(11), 51.

Youngner, S. (1988). Who defines futility? *Journal of the American Medical Association*, 260(14), 2094-2095.

Advance Directives: Patient Self-Determination

Course Exam

***NOTE:** After studying the downloaded course and completing the exam, you need to enter your exam answers **ONLINE**; answers cannot be answered and graded on this downloadable version of the course. To enter your answers return to NYSNA's Web site, www.nysna.org and click on the Online Continuing Education icon. Next, login using your username and password, follow the prompts from your account to access the course material and proceed to the course exam.

1. An advance directive is all of the following EXCEPT:
 - A. An instruction given by a person while they still have decisional capacity concerning medical treatment they would or would not want.
 - B. Typically consists of either a living will or a written healthcare proxy.
 - C. Always written by the primary healthcare provider.
 - D. Legally required to be discussed with patients at the time of hospital admission.

2. The purpose of an advance directive is all of the following EXCEPT:
 - A. Communicate and control healthcare decisions when the person is unable to because of temporary or permanent illness or injury.
 - B. Appoint an agent to represent you in treatment decisions when you cannot decide for yourself.
 - C. Relieve family/friends/healthcare providers of the burden of struggling to decide what you would want done.
 - D. To provide monetary benefit to your heirs.

3. Prior to making an advance direction, the individual should determine their goals for medical treatment.
 - A. True.
 - B. False.

4. Prior to making an advance directive, the individual should discuss their healthcare wishes with the person of their choice and confirm that person's willingness to act for you.
 - A. True.
 - B. False.

5. Prior to making an advance directive, it is **not** helpful to determine the specifics of treatments you do or do not want.
 - A. True.
 - B. False.

6. Once you have completed your advance directive, it is important to provide copies to your healthcare provider, your agent, close relatives and friends who may be involved in your care.
 - A. True.
 - B. False.

7. The Patient Self-Determination Act of 1990 specifies that adult patients receive written information on advance directives at the time of admission to hospitals, nursing facilities, home healthcare agencies, hospices and HMOs receiving federal reimbursement.
- A. True.
 - B. False.
8. The American Nurses Association's Position Statement : Nursing and the Patient Self-Determination Act recommends:
- A. That each nurse know the laws of the state in which she/he is practicing pertaining to advance directives.
 - B. That nursing's role in the implementation of this act includes: public education, research, patient care, advocacy, education of the profession and other healthcare providers.
 - C. That questions about advance directives be part of the nursing admission assessment.
 - D. All of the above.
9. The Patient Self-Determination Act of 1990 requires that patients have an advance directive prior to admission to a Veterans Administration Hospital that does not receive medicare reimbursement.
- A. True.
 - B. False.
10. Patients' only resource for the development of advance directives is through legal channels such as the American Bar Association.
- A. True.
 - B. False.