

A Patient Rights Module:

UNDERSTANDING AND SUPPORTING **ADVANCE DIRECTIVES**

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Developing Top-Notch CNAs, One Inservice at a Time



A Patient Rights Module:
**UNDERSTANDING &
SUPPORTING ADVANCE
DIRECTIVES**

We hope you enjoy this inservice, prepared by registered nurses especially for nursing assistants like you!

Instructions for the Learner

If you are studying the inservice on your own, please do the following:

- Read through **all** the material. You may find it useful to have a highlighting marker nearby as you read. Highlight any information that is new to you or that you feel is especially important.
- If you have questions about anything you read, please ask _____.
- Take the quiz. Think about each statement and pick the best answer.
- Check with your supervisor for the right answers. You need **8 correct** to pass!
- Print your name, write in the date, and then sign your name.
- Keep the inservice information for yourself and turn in the quiz page to _____ no later than _____. Show your Inservice Club Membership Card to _____ so that it can be initialed.
- Email In the Know at feedback@knowingmore.com with your comments and/or suggestions for improving this inservice.

After finishing this inservice, you will be able to:

Discuss the purpose of an advance directive.



Describe the difference between a living will and a health care power of attorney.



Discuss how federal and state laws support advance directives.



Discuss how a DNR order relates to advance directives.



Demonstrate support of your clients' advance directives during your daily work.

THANK YOU!



Developing Top-Notch CNAs, One Inservice at a Time

Inside This Inservice:

Legal & Medical Terms	2
Advance Directive History	3
Types of Advance Directives	4-5
Informed Consent	6
Legal Issues	7
Terminally Ill Clients	8
Do Not Resuscitate Orders	9
Supporting Your Clients	10-11
Q & A About Advance Directives	12



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A Patient Rights Module: Understanding & Supporting Advance Directives

WHAT IS AN ADVANCE DIRECTIVE?

As a health care worker, you’ve probably heard the term “**advance directive**”. *But, what is an advance directive anyway?* It is a document that outlines people’s preferences for medical care when, in the future, they are unable to communicate their wishes. It is particularly useful when someone is terminally ill, critically ill or has advanced Alzheimer’s disease.



Consider this situation:

Mrs. Brown is 72 years old. Recently, she was hospitalized with pneumonia. During her stay in the hospital, she stopped breathing. She was put on a ventilator to help her breathe and was given antibiotics to fight the pneumonia.

Now, it’s three weeks later. Mrs. Brown has been in the intensive care unit all this time. She has developed bed sores and a bladder infection. She is confused, and keeps trying to pull out her IV and feeding tubes. The nurses have started tying up her hands to keep her from removing the tubes. She still can’t breathe on her own, and the doctors doubt if she ever will.

Unfortunately, Mrs. Brown never spoke to her family about her end-of-life wishes. Her adult children are upset, watching their mother get worse and worse. They worry about her suffering, but don’t know what to do about it.

If Mrs. Brown had an advance directive, her family would know what their mother wanted—and could take comfort in doing the “right thing”. And, Mrs. Brown would still have control over what is happening to her in the hospital.

However, advance directives are not just for people who are sick or old. Advance directives are something that all people should consider having. Keep in mind that having an advance directive is *not* a sign that someone has given up on life since it takes effect *only* when people can no longer communicate their own wishes.

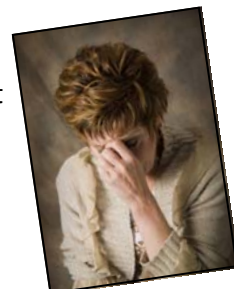
REMEMBER: Advance directives give people a voice in their own medical decisions even after they have lost the ability to speak for themselves.

Keep reading to learn more about the two main types of advance directives and how you can support your clients’ end-of-life decisions.

Legal & Medical Words You Should Know

Your clients have the right to expect that you will support their advance directives. (It's the law!) Many people don't like talking about advance directives because they are concerned with the end of someone's life. If it's hard for you to talk about this subject, remember this: To provide quality care to your clients, it's important that you learn as much as possible about advance directives. *You can start by becoming familiar with the following terms:*

- **Advance Care Planning:** The process of preparing for one's death. This usually involves completion of advance directives and an explanation sheet with *specific* wishes for treatment and comfort care.
- **Advance Directive (or AD for short):** A general term for oral and written instructions about a person's future medical care, primarily used when people are terminally ill and cannot speak for themselves.
- **Power of Attorney:** A document that designates another person to make decisions for someone who can no longer make his own decisions regarding *business or financial* decisions.
- **Health Care Power of Attorney (HCPOA):** A document that allows people to pick someone they trust to make decisions about their medical care if they aren't able to make the decisions themselves.
- **Health Care Proxy or Agent:** Usually the same as a HCPOA. In some states this document is combined with a living will.
- **Living Will:** A type of advance directive that usually tells a doctor not to use "extra-ordinary" means to keep someone alive if he or she is terminally ill.
- **CPR:** This stands for cardiopulmonary resuscitation. It's a technique for stimulating a stopped heart. It is usually unsuccessful, especially in elders or those who have advanced chronic illness.
- **Do Not Resuscitate Order:** An order on a client's medical chart or on a special order form to use at home or in a facility advising health professionals that CPR should not be used to attempt to save the person's life.
- **Assisted Suicide:** This is when a person commits suicide with the help of a doctor or other person.
- **Life-Sustaining Therapy:** Medical treatments that prolong a person's life. They may not *cure* people or bring them back to the way they were, but they keep people alive. Examples of life-sustaining therapies include breathing machines, feeding tubes, and intravenous fluids.
- **Heroic Therapy:** An "old-fashioned" term that means the same thing as life-sustaining therapy.
- **Terminal Illness:** An illness that will lead to death in spite of all medical treatments. Medical care may slow the disease, but will not stop it.
- **Persistent Vegetative State:** An irreversible condition in which a person can't communicate with others but is able to breathe on his/her own. This condition happens when the brain is damaged by a lack of oxygen. People in vegetative states can no longer think, make decisions, or communicate.
- **Brain Death:** This is similar to a vegetative state except that the person needs machines to breathe. Without life-support equipment, the person would die.
- **Hospice:** This is specialized care for people with terminal illnesses. Hospice care involves caring for the sick person and his/her family, including help from doctors, nurses, nursing assistants, social workers, therapists, chaplains, and volunteers.



Studies have shown that:

- Only 30% of American adults discuss life-sustaining treatments with their doctors—and only 20% have some form of advance directive.
- Half of the people who *do* have written advance directives have only one copy of the document—and it is locked away in a safety deposit box at the bank.

The History Behind Advance Directives

- Centuries ago, when people got sick, there were no antibiotics or modern medical treatments. Many people died at an early age, mostly from infections. Ministers and priests worked together to bring comfort and support to dying people and their families. Death was accepted as the natural end of life and people usually died at home surrounded by family members.
- In the 1940's and 50's, medical advancements (including antibiotics, CPR and ventilation machines) changed everything. People started to live longer. Doctors and their patients started *fighting* death instead of accepting it.
- Sometimes, physicians did not always tell patients the truth about their illness. Rather than asking patients what their wishes were, doctors did what they thought was best.
- As the 20th century wore on, people started living even longer and, due to advanced age, developed chronic illnesses, like Alzheimer's and heart disease. Sometimes people's lives were extended through breathing machines even though they were not able to recover or lead normal lives.
- The courts decided that adults must be proven to be incompetent (unable to make their own medical decisions). Just like people are "innocent until proven guilty", people are able to make their own decisions unless it is proven otherwise in a court of law.
- However, people may be considered incapable of making medical decisions because of illness or injury. For example, if John is in a terrible car accident and is unable to make health care decisions, the law allows the family and/or medical professionals to make decisions for him.
- All of these legal cases helped create the first advance directives. In the 1960's, advance directives consisted of simple letters to family members, friends, physicians or ministers in which people described their wishes for medical end-of-life treatments. These letters became known as "living wills". They weren't meant to be legal documents, but to serve as *guidelines* for caregivers. Still, the people who wrote these letters assumed that their wishes would be honored.
- There were problems. The letters weren't very specific. For example, a letter might say that Mr. Jones wants "no extraordinary measures". But, what did this really mean? Family, caregivers and doctors found the letters confusing. As a result, each state began to pass laws about advance medical directives, including the specific language to be used in writing them. The goal was to get rid of the confusion.
- In 1991, the U.S. Congress passed a law that supported the use of advance directives. And, the U.S. Supreme Court recognizes that living wills, health care powers of attorney and other advance directives should be followed and protected by our Constitution.



In 1950, about half of all Americans who died did so at home. Today, partly because of medical advancements, about 85% of Americans die in some type of health care setting: a hospital, a nursing home or a rehabilitation center. At least one of every ten deaths occurs in an intensive care unit.



Living Wills

- There are two main types of advance directives. The first type is a **living will**. This document contains written instructions in which people can describe which life-sustaining treatments they want and which they *don't* want—if a time should come when they are no longer able to make decisions.
- Early living wills were simply letters people wrote listing their wishes. Now, most states have a specific form—or at least specific language—that they like people to use for a living will.
- Keep in mind that living wills deal with *medical* matters as opposed to “regular” wills which concern business and financial issues. All 50 states have some form of living will.
- Generally, a living will expresses someone’s wish not to be kept alive by *artificial* means—such as with a ventilator—if he or she is terminally ill or in a persistent vegetative state.
- However, it is helpful to have *additional* written information attached to the living will that specifies what treatments are desired—and which are not.
- With a living will, a person can communicate his/her wishes for end-of-life care to family members and to doctors. These wishes might include preferences about:
 - CPR
 - Tubes to provide nutrition and/or hydration
 - Kidney dialysis
 - Ventilators
 - Blood transfusions
 - Invasive procedures
 - Pain medication
 - Surgery
 - Organ transplantation
 - Chemotherapy
 - Antibiotics
 - Dying at home or at a medical facility
- All people have their own beliefs about the end of life. Some cultures may not support the idea of a living will. However, leading representatives of many major religions have spoken out in favor of a person’s right to die a natural and dignified death.
- A living will becomes effective when it is determined that a person can no longer make his or her own decisions. As long as the requests in the living will are legal (and don’t go against reasonable medical standards), doctors will usually honor them.
- However, this issue is never completely clear. For example, if a doctor has to choose between a living will that the patient *never* talked to him about and a recent discussion he had with the patient about end-of-life care, he will usually go with the recent discussion—even if it goes against the instructions in the patient’s living will.
- Living wills must be signed and dated. They must also be signed by two witnesses. Health care workers should never be witnesses to a living will! If a client asks you to be a witness, explain that it’s against your workplace policy.
- A person must be at least 18 years old to sign a living will. Children younger than 18 have their medical decisions made by their parents or legal guardians.



NOTE: People can also just *tell* someone about their end-of-life wishes or they can write out their wishes in a personal document. However, this is much less common than using formal “living will” documents.

HCPOA, Health Care Proxy or Health Care Agent

- The second kind of advance directive has a few different names, depending on your state. For example, you may hear it called a **health care power of attorney** or a **health care proxy** or a **health care agent**. (Throughout this inservice, we'll use the name "health care power of attorney—or HCPOA, for short.)
- A HCPOA is a legal document that names a particular person to be in charge of future medical decisions. Many people choose their spouse or an adult child to serve as their health care power of attorney. Other people choose a close family friend or even a lawyer.
- It is against the law for physicians or other health care employees to act as HCPOA for their patients. For example, Mr. Stone lives in a skilled nursing facility. He has a favorite nurse, Marsha, with whom he has discussed his end-of-life wishes. He says he trusts her the most and wants her to be his health care power of attorney. Marsha knows this is against the rules so she asks the social worker to discuss the matter with Mr. Stone. The social worker helps Mr. Stone choose an appropriate person to be his HCPOA.
- The idea is that the person named in a HCPOA will make the *same* decisions that the patient would have made if he or she were able.
- It is very important for people to discuss their end-of-life wishes with whomever they choose as their HCPOA. Good communication helps ensure that those wishes will be honored when the time comes.
- It is wise for people to have *both* a living will and someone appointed as a HCPOA to make decisions. The living will provides general *instructions* and the HCPOA document names the person who will *carry out* those instructions.



- Let's say that Mr. Smith wants to establish a health care power of attorney. *Who should he choose?* It should be someone who:
 - Is trustworthy, knows Mr. Smith well and agrees to represent him.
 - Is willing to have a conversation about what Mr. Smith wants and doesn't want when faced with critical medical decisions.
 - Will stand up for Mr. Smith when doctors may be making strong suggestions that he would not want.
- It is common for people to select an *alternate* person to serve as HCPOA—just in case their "first choice" is not available when decisions need to be made. For example, Mrs. Walters named her daughter as her HCPOA and her son as the alternate HCPOA.



In most states, advance directive documents must be signed and dated in the presence of a notary.



- The simplest way to complete advance directives is to obtain the forms and take them to a bank where a notary is usually available. For people who are in a health care facility, the social worker or chaplain may be able to help complete the appropriate documents.
- Remember that clients who have completed a HCPOA form have not given up the right to make their own medical decisions. A HCPOA takes charge only if and when clients are unable to communicate their own wishes.
- As medical technology has become more advanced over the years, doctors have been able to keep people alive longer and longer. Many people have wanted to say "enough is enough"! This is where advanced directives come in. Living wills and health care powers of attorney give people control over what happens to them.

Informed Consent

- The idea behind informed consent is that people need to be able to make medical treatment decisions *for themselves*. In order for this to happen, they must be given all the necessary information—including the *benefits* and the *risks* of choosing any treatment. If a person is not able to make decisions, their next of kin or HCPOA must be completely informed before making a medical decision.
- Here is an example: Mr. Jones has been admitted to the hospital for hip replacement surgery. Before Mr. Jones signs an informed consent document, the doctor and nurse meet with him to tell him about:
 - His current medical condition.
 - What will happen if he decides not to have surgery.
 - The procedure for hip replacement surgery.
 - All the risks and all the benefits of the recommended surgery.
 - Any alternatives to surgery that Mr. Jones might want to consider.
- To give informed consent, Mr. Jones must:
 - Be given enough information.
 - Understand the information.
 - Be free to say yes or no...without anyone forcing him into a certain decision.
- Along with informed consent, came the right to *refuse* treatment. If a physician wants to use a certain treatment on a patient but the patient is informed and does not agree with the doctor, the patient has the right to say “no”.
- For example, if, after hearing all the information, Mr. Jones decides not to have the hip replacement surgery, he would not sign the informed consent. His doctor may ask him to sign an informed refusal documents to prove that Mr. Jones made an educated decision.
- All these changes in patient rights have come about because people wanted to make their own decisions instead of having physicians in charge.



The rule of **informed consent** is not followed as closely in emergency situations. In an emergency room, for example, doctors can make life or death decisions for patients based on their best medical judgment (unless they know a patient has a **Do Not Resuscitate** order).

What's New With Advance Directives?

- Five Wishes** is a new advance directive that combines wishes about medical treatment with wishes for comfort care. It is accepted as an official AD in 40 states. Check it out at: www.agingwithdignity.org/5wishes.html.
- Medical orders are what makes one's wishes turn into actions. It is possible for people to discuss their wishes with their physicians so they can be written up as “doctor's orders” for the health care staff to follow. Examples include “DNR”, “Do Not Hospitalize” and “No Tube Feeding” orders.
- This type of doctor's order usually happens when a person is critically or terminally ill. If a person cannot ask for these orders, the HCPOA or a family member can. Check it out at <http://www.ohsu.edu/polst/resources/educational-materials.htm>, the Physician Orders for Life-Sustaining Treatment web site. Over one million of these forms are in use.

Some Legal Issues Regarding Advance Directives

- Although most states have both kinds of advance directives (living wills and health care proxies), in some states, the two forms *may* be combined into just one document. You can find your state's advance directive on <http://www.caringinfo.org>.
- It is important to know the requirements for *completion* of the documents. In most states:
 - A person must be 18 years or older.
 - A lawyer is not required, but some states require witnesses and/or notarization.
 - A witness must be a person who is not a relative, not on the health care team, and not someone who will benefit from the person's estate or will.

Remember...a nurse aide *cannot* officially be a witness for the signing of an advance directive. If a client asks you to be a witness, explain that it's against your workplace policy.

- If people travel back and forth, living part of the year in one state and part in another, it is best to have advance directives in *both* states. An advance directive for one state may not be honored anywhere else.
- There are both federal and state laws about advance directives. The federal law, the **Patient Self-Determination Act (PSDA)**, took effect in December of 1991. It requires that patients/clients/residents:
 - Must be asked if they have advance directives on admission to a health care organization.
 - Must be informed of their rights to refuse treatment and to prepare advance directives.
 - Must have documentation of their advance directive status in their charts.
 - Must have their advance directives honored.
- In addition, all health care organizations (that accept Medicare and/or Medicaid funding) must

have a *policy* on advance directives. This policy must be available in writing to all people who are admitted to the facility/agency. And, all staff members must be taught about advance directives.

- The public needs to know that asking about advance directives is a federal requirement. It supports the rights of every client to be involved in decisions regarding their medical care—whether it concerns a simple procedure or the end of life.



- In order for a person to legally complete an advance directive, he or she must have "**decision-making capacity**". In the past, someone with decision-making capacity was said to be "competent", but that term is no longer commonly used when it comes to making medical decisions.

- **Decision-making capacity means that the person:**

- Understands the situation.
- Knows what the options and consequences are.
- Can make a decision with understanding.
- Can communicate his/her decision.

- People with early dementia or Alzheimer's disease may still have decision-making capacity. They may be forgetful, but they continue to know what their values are and what they want to happen to them.

- The process of making medical decisions is often a joint effort between the physician, the patient and the family. By preparing advance directives *ahead* of time, people can guarantee that their ability to make decisions won't be questioned.



Terminally Ill Clients

People who are terminally ill can die several ways:

- When aggressive, life-sustaining treatments fail.** A minority of terminally ill people decide they want “everything” done in order to stay alive as long as possible. They want every treatment, including being put on a ventilator. They want every infection treated with intravenous antibiotics and every serious drop in blood pressure treated with drugs to raise it temporarily. They want CPR attempted if their heart or breathing stops, though in most cases, this proves to be unsuccessful. In the hospital, for every 100 patients who receive a CPR attempt, 15 will survive.
 - In the nursing home, for every 100 patients who receive a CPR attempt, 2-5 will survive.
 - For patients over 90, almost none will survive a CPR attempt.
- Some of these individuals can survive for months, but eventually either their terminal illness, failure of their vital organs or an overwhelming infection will lead to death.
- From a “natural death”.** For most people, when there is no more treatment that will cure them and they have no hope of returning to a healthy life, they want to die comfortably without prolonging the dying stage or being a burden on others. They receive no “extraordinary treatment” such as CPR, ventilators, and, often, no feeding tubes. Instead, they are treated with “comfort measures” to make their death as easy as possible.
- By assisted suicide.** Some people who are approaching the end of life do not want to wait for death to come. They want a physician to prescribe enough medicine to cause their death when they are ready. Oregon is the only state that allows doctors to assist terminally ill persons to commit suicide. In 1998, the Oregon Health Department received reports of 23 cases of assisted suicide.



Most were male and had cancer. All were white. When asked why they were choosing to end their lives, most of the patients talked about being afraid of losing control over their bodily functions—and not about being afraid of severe pain or of costing their families too much money. Some experts in end-of-life care feel that if these people had received adequate comfort care, they would have chosen to die a natural death.

- By mercy killing.** This is when a person actually hastens another’s death by actively *killing* them, whether by administering carbon monoxide from a closed up car or shooting someone. The motivation of people who do this is to end the suffering of someone who has asked for their help to end their lives. “Mercy killing” is not legal in this country. Dr. Jack Kevorkian, nicknamed “Doctor Death”, has helped over 100 people end their lives. Dr. Kevorkian has been arrested several times and was found guilty of manslaughter for one of these cases. He served time in prison.

This inservice focuses on caring for people in the first two categories. When patients have completed advance directives, it helps the health care team and family members carry out their end-of-life instructions.

- What Do Our Laws Say?** Across the United States, suicide is *not* against the law. However, *attempted* suicide is considered a crime in some states (though no one has been prosecuted for it for the last thirty years). Assisted suicide is against the law—except in Oregon. Yet, court cases continue to come before judges in many states. For example, in 1997, the Florida Supreme Court rejected a claim that choosing assisted suicide should be the right of every individual. The Florida judges voted 5 to 1 against the case.



Do Not Resuscitate Orders

- Advance directives give important directions for medical care, but to be *official*, a person's wishes need to be put into medical orders. An important medical order that many people want when they are very old and/or terminally ill is a Do Not Resuscitate order.
- A **Do Not Resuscitate** order tells medical professionals not to take action even if someone's heart and breathing stops. This means that doctors, nurses and emergency medical personnel will *not* use emergency CPR to try to revive someone.
- DNR orders are designed to help people who are in the final stages of a terminal illness, who suffer from a chronic serious condition, or who are old and ready to die.
- Often, the process of establishing a DNR order helps people begin to come to terms with death—whether it is their own or the death of a loved one.
- Consider these examples:
 - Mr. Smith is in the hospital suffering from severe kidney disease. After discussions with his doctor and his family, Mr. Smith has asked his doctor to sign a DNR order. He knows that if his heart and breathing stop, no one will attempt CPR or use a ventilator to keep him alive. In addition, he has asked that he not be put on kidney dialysis. Mr. Smith is ready to die.
 - Mrs. Turner lives in a skilled nursing home. She has severe Alzheimer's disease. Eight years ago, Mrs. Turner created a living will. Her living will states that she does not want CPR performed on her. To honor these wishes, and after speaking with the family, her doctor has written a DNR order. This means that if Mrs. Turner



stops breathing, the staff of the nursing home will not attempt CPR and will not call 911 to transfer Mrs. Turner to a hospital. If Mrs. Turner had not had a living will, her HCPOA or family could have made the decision for her to be a "DNR" because they believe this to be what she wanted.

- Mr. Jones is 90 years old and in fairly good health for his age. He says he has had a good life and if his heart or lungs should stop working, he wants people to wish him well with thankfulness and allow death to come undisturbed.
- DNR orders must be signed and dated by a physician. They may be written for people in hospitals, nursing homes, assisted living facilities—and, in most states, for people living in their own homes.
- Generally, paramedics working in the community have a *duty* to perform CPR when a person's heart or breathing stops. For people still living at home, many states have a special DNR order—called a "Prehospital DNR", an "Out-of-Hospital DNR" or a "Portable DNR". If you are a home health aide, you may see one of these forms. It is usually written on brightly colored paper and should be posted in an obvious place so that the paramedics know not to resuscitate the person.
- Some states have portable DNR bracelets that alert paramedics that a DNR order has been written by the person's physician.
- **NOTE:** A person's advance directive might include instructions about not wanting CPR or other forms of resuscitation. However, to be official, that wish must be written as a physician's *order*. This gives the entire health care team specific instructions which they must follow.



Your Role in End of Life Conversations

- There are times when clients may start talking about dying. It may be when they get very sick suddenly or are gradually, but steadily, declining. It may be when a love one or a friend dies. This is *normal* so don't let it scare you. If a client starts to talk about dying, the most important thing you can do is LISTEN.
- Think of it as an honor that they have chosen you to hear their thoughts and concerns. It is good for them to express their feelings without anyone judging them. Remember you do not have to *fix* anything or tell them not to worry. Just LISTEN, look at them, and nod your head that you hear them.
- If your client seems worried, you may want to say that you notice their feelings by saying, *"You seem worried about this."* Pause and listen.
- Other supportive responses may be:
 - *"I hear you."*
 - *"Tell me more about that."*
 - *"This must be hard for you."*
 - You can ask, *"Where do you find strength in hard times?"*
- Then, support them—whatever they say. They may talk about their faith or relationships. Do not try to influence them with your beliefs. If someone says, *"I would never want to die on machines like my neighbor did,"* you could ask, *"Have you ever talked with your family or doctor about your wishes?"*



You may hear the word **euthanasia** and wonder exactly what it means. Some people think it means *hastening* death while actually the dictionary says *euthanasia* literally means "an easy and painless death." This term means different things to different people, so it's best to avoid it.

Your Role in Advance Directives

- End-of-life conversations sometimes move naturally into conversations about advance directives. If people start expressing their desire for a certain kind of death or not wanting certain treatments, this is an ideal time to say one of the following:
 - *"Do you have a living will or other advance directive?"*
 - *"You can write out your wishes in an advance directive so that they will be followed. Would you like me to help you learn more about this?"*
- If your clients have questions about advance directives, encourage them to talk to their physicians. Also, let your supervisor know about any end-of-life discussion you have with a client.
- Maintain confidentiality! Keep information about your client's advance directives to yourself. Only coworkers who are working *directly* with a client need to know if the client has a living will or a DNR order.
- Be sure to notify your supervisor immediately if clients tell you they have changed their minds about their advance directives. They have the right to cancel or change an advance directive at any time.



Find out from your supervisor *before* you work with a client if he/she has advance directives or a DNR order. Especially if you work in clients' homes, you need to know what their end-of-life wishes are.

Your Role in Comfort Care

- As part of the health care team, it is your responsibility to provide comfort whether your client wants only to be kept comfortable at the end of life or wants to have “everything done” to stay alive.

- Most importantly, your role is to observe your clients and report the things you notice to a nurse or supervisor. Your observations can help your clients get what they need to be more comfortable.



- Pain control is an important part of keeping clients comfortable. Watch for signs that a dying client may be in pain. The first way to know is to ask: “Are you in pain?” or “Are you uncomfortable?” If the answer is “yes”, try to get an idea of how bad the pain is. Ask “Is your pain a great amount? A moderate amount? Or a little amount?” Report the answer to your supervisor.
- Sometimes we ask clients to rate their pain on a scale from 1-5 or 1-10 with the highest number being *excruciating* and the lowest number being *very mild*. Report this promptly. You may be asked to record the client’s response on a pain sheet so the health care team can keep track of the client’s pain.
- Another way to know if your clients are in pain is to notice—and report—their actions:

Does their face look like they are grimacing or frowning? Are they moaning, crying or wincing when moved? Are they lying very still or being very agitated when they are usually the opposite? Are they holding a body part?

- If someone gives your clients pain medicine, watch to see what their response is and report it. They may need more medication.
- If clients can still drink fluids or eat, offer whatever sounds good to them. Check on the consistency that is ordered; liquids may need to be thickened to prevent aspiration. Sit them straight up and offer them small amounts at a time.

- Sometimes clients cannot move by themselves. Helping them turn every two hours and positioning them with pillows is important for their skin—and their comfort. Range of motion exercises may be ordered for bedridden clients. Ask your supervisor if these exercises are appropriate for your client.
- By keeping your clients clean, dry and gently massaged with lotion, if desired, you can bring them great comfort.
- Provide a pleasant environment, surrounding your clients with their favorite flowers, their favorite music or pictures of loved ones.

For patients having life-sustaining care:

- If you are ordered to take vital signs, be sure to report any abnormal signs. If a client stops breathing and/or has no pulse, be sure you know what to do. Does the client have an advance directive or a DNR order? Are you trained in CPR? What is your workplace policy about performing CPR? Be sure you know the answers to these questions before you begin working with a client.
- Never touch any buttons or dials on a ventilator /respiratory machine. But, if the machine sounds different to you or its alarms are beeping, tell your supervisor right away!
- Remember that feeding tubes may go through the nose to the stomach or they may be surgically inserted into the stomach or intestines. Some patients may also be fed through an IV needle. You may be ordered to change or “pad” a dry dressing on a feeding tube. Be sure you are comfortable dealing with the dressing and that you use standard precautions. Always report a wet dressing.



Questions & Answers About Advance Directives

Q: Mr. Marks has an advance directive. Does this mean he wants to be allowed to die?



A: It's true that many people use advance directives so that they *won't* be kept alive when death is near. But, advance directives are also used to spell out all the medical treatments that a person **does** want. Just because Mr. Marks has an advance directive doesn't mean he has decided to refuse life-saving treatment.

Q: Mrs. Brown has made her son her health care power of attorney. Does this mean that she has no right to make any of her own decisions?

A: No. As long as Mrs. Brown is *able* to make her own decisions, she can continue to do so. However, if she becomes too ill to decide for herself, her son will be responsible for making decisions that support her wishes.

Q: Do people have to go to lawyers to make up an advance directive?

A: No, lawyers are not necessary, but they can come in handy since they are familiar with both the federal law and the state laws.

Q: Once a person signs an advance directive, is it permanent?

A: Yes and no. An advance directive is permanent because it stays in effect year after year (though some states recommend that people review and resign their advance directives every few years). However, a person can revoke—or cancel—his/her advance directive at any time. This can be done by crossing out and initialing parts of the document or by completely destroying it. A person can also sign and date a new document to take the place of an older advance directive.

Q: Aren't advance directives just for old people?

A: It's natural to think of death and dying going with old age, but tragedy can happen to anyone. For example, a twenty-five year old could be in a serious car accident and, without an advance directive, might be kept alive on life support. If young people have strong feelings about end-of-life issues, they should consider having an advance directive.

Q: Isn't it better for people to depend on their family members than to worry about creating advance directive documents?

A: Family involvement is very important when medical decisions are being made. However, many people never talk to their loved ones about their end-of-life wishes. For example, it might be a heavy burden to expect Cynthia to tell the doctor to "pull the plug" on her mother unless she knows for sure that's what her mother would want. And, even if Cynthia feels okay with the decision, other family members may not agree. Fights or hard feelings could develop within the family. This just adds to the stress of the situation. It's probably better to spell things out in an advance directive.

Q: What should I do if I'm interested in having an advance directive for myself?



A: You can obtain blank documents for free from www.caringinfo.org. Follow the process your state requires for completion—such as having a witness and/or using a notary. Often, bank personnel can help you complete the forms officially. Be sure to make copies and give one to anyone who would make medical decisions for you.



Q: Where should people keep their completed advance directives?

A: People should keep their advance directives in a readily accessible place where family/friends can find them. They should make sure their family members, physician and lawyer, if they have one, know where the document(s) are located. If they are admitted to a health care facility, they should bring a copy with them.



Developing Top-Notch CNAs, One Inservice at a Time

A Patient Rights Module: Understanding & Supporting Advance Directives

EMPLOYEE NAME
(Please print):

DATE: _____

- ***I understand the information presented in this inservice.***
- ***I have completed this inservice and answered at least eight of the test questions correctly.***

EMPLOYEE SIGNATURE:

SUPERVISOR SIGNATURE:

Inservice Credit:

<input type="checkbox"/> Self Study	1 hour
<input type="checkbox"/> Group Study	1 hour

File completed test in employee's personnel file.

Are you "In the Know" about advance directives? Circle the best choice, or fill in your answer. Then check your answers with your supervisor!

1. TRUE or FALSE

Advance directives help people have control over their health care decisions when they can no longer speak for themselves.

2. The two main types of advance directives are a _____ and a _____.

3. TRUE or FALSE

The Patient Self-Determination Act (PSDA) is a national law that requires that advance directives be discussed with every client who is admitted to your facility/agency.

4. TRUE or FALSE

A person who serves as a Health Care Power of Attorney can make decisions about someone else's finances.

5. TRUE or FALSE

People with Alzheimer's Disease can complete advance directives if they still have the decision-making capacity to express their wishes for end-of-life care.

6. TRUE or FALSE

In addition to a living will, it is helpful to attach another document that explains specific wishes in more detail.

7. TRUE or FALSE

A living will is not legal unless it was written by a lawyer.

8. TRUE or FALSE

People who have advance directives will automatically have a "DNR" order if they enter the hospital.

9. TRUE or FALSE

"Comfort care" is the term for measures that help dying clients be more comfortable and without pain.

10. How can you best help your clients when they talk about end-of-life decisions?

- A. Give advice.
- B. Remind them that they might not live much longer.
- C. Listen.
- D. Tell them about your own advance directive.