In the Know

The Inservice Club for Nursing Assistants

Instructions for the Learner

We hope you enjoy this Inservice, prepared especially for nursing assistants like you. You work very hard, and we appreciate the effort you make to complete these educational materials. It shows your desire to continue learning and growing in your profession.

What will you learn?
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.
- State 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.

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 your 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.

THANK YOU!

In the Know

The Inservice Club for Nursing Assistants

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What is an Advance Directive?

As a health care worker, you've probably heard the term "advance directive". Keep in mind that an advance directive is:

- A general term that describes people's oral and written instructions about their future medical care. A living will is one example of an advance directive.
- Something that all people should consider having. It's not just for people who are sick or old and it's not a sign that people have given up on life.
- A set of instructions to health care professionals about how people want to be treated when they can no longer communicate their wishes. *Advance directives take effect when people can no longer speak for themselves.*

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.

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

Your clients have the right to expect that you will support their advance directives. (It's the law!) But, advance directives are serious business concerning the end of someone's life. For this reason, many people don't like talking about them. 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.

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Special points of interest:

- *See page 5 for information on health care power of attorney.*
- *See page 8 to learn how you can support your clients' advance directives.*
- *See page 9 for information on euthanasia and assisted suicide.*

Legal & Medical Words You Need to Know

Advance Directive: A general term for oral and written instructions about a person's future medical care.

Living Will: A type of advance directive that tells a doctor "how far to go" in keeping a patient alive. It may include refusing medical treatment.

Power of Attorney: A document that designates another person to make decisions for someone who can no longer make his own decisions. This may include decisions about medical care *or* just financial decisions.

Health Care Power of Attorney: A document that allows us to appoint a trusted person to make decisions about our medical care if we aren't able to make the decisions ourselves.

Health Care Proxy: A combination of a Health Care Power of Attorney and a Living Will.

CPR: This stands for cardiopulmonary resuscitation. It's a technique for stimulating a stopped heart.

Do Not Resuscitate Order: An order on a patient's medical chart advising health professionals that extraordinary measures should not be used to attempt to save the person's life.

Euthanasia: Many people refer to this as "pulling the plug". Euthanasia is when medical life-support equipment is disconnected and the patient is allowed to die.

Assisted Suicide: This is when a person commits suicide by 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 and feeding tubes.

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 not stop it.

Persistent Vegetative State: An <u>irreversible</u> 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, feel, communicate or make decisions. But, they may respond to reflexes and seem to "wake up" now and again.

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 medical care for people with terminal illnesses. Hospice care involves treatment for the sick person *and* his/her family, including help from doctors, nurses, nursing assistants, social workers, therapists, and chaplains.

The average cost for a terminal patient to stay in the hospital on life support is well over $1,000.00 per day. In a year, the costs would be <u>at least</u> a half a million dollars!

In the United States, the average cost of living in a nursing home is about $70,000 per year.

The History Behind Advance Directives

- In the old days, most doctors didn't tell patients if they were going to die. Because there weren't many *cures* for terminal illnesses, doctors felt there was no point in telling people that death was near. Physicians believed that patients would give up all hope if they knew they were dying. They wanted to "protect" their patients from the painful truth. Instead, doctors kept quiet and tried to make terminally ill people as comfortable as possible.

- In the 1940's and 50's, medical advancements (including CPR and ventilation machines) changed everything. Instead of *accepting* death, doctors began to fight it. But, many physicians still didn't tell patients about their serious conditions.

- In the 1960's and 70's, there were a number of court cases in which patients sued their doctors for not telling them about their diagnoses and/or available treatments. These court cases became the legal foundation for informed consent.

- In the 1980's, things changed again. Patients started to sue for the right to refuse the treatments recommended by their doctors. Some doctors responded by saying that the patients weren't in their "right minds" when they refused treatment. This led to arguments about when a person is *competent* to make his/her own decisions.

- The courts decided that adults must be proven to be incompetent. 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, competent people may be considered incompetent because of illness or injury. For example, if John is in a terrible car accident and is unable to make health care decisions, John can be proven incompetent in a court.

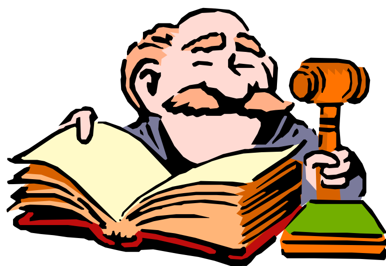
- All of these legal cases helped create the first advance directives. In the 1960's, advance directives consisted of simple letters to family members, friends, physicians or ministers in which people described their wishes for medical end-of-life treatments. These letters became known as "living wills". 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.

- The U. S. Congress passed a law in 1991 that supported the use of advance directives. And, the U. S. Supreme Court recognizes that living wills, powers of attorney and other advance directives should be followed and protected by our Constitution.

THE BOTTOM LINE: 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 a way to say "enough is enough"! This is where advance directives come in. Living wills and health care powers of attorney give people control over what happens to them.

Federal Advance Directive Laws



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 informed of their rights to refuse treatment and to prepare living wills and other 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 care for Medicare and/or Medicaid clients) 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 must be taught about advance directives.

The PDSA law adds more paperwork to the admission process of hospitals, nursing homes, home health agencies and other health care organizations. And, it can be uncomfortable for some health care professionals to discuss death and dying with *every* person they admit.

For example, it can be awkward discussing advance directives with a young man admitted to the hospital to have his appendix out . Some health care workers worry that by talking about the end of his life, the patient might think, "Wait a minute! Am I going to die?" However, it's important to comply with the law—because it supports the rights of every client. And, if a health care organization doesn't follow the rules of the law, they run the risk of losing Medicare and Medicaid payments.

Remember, the purpose of the PDSA law is not so that health care workers can talk people into having an advance directive. The purpose is to educate the public about advance directives and their rights concerning end-of-life medical care.

State Advance Directive Laws

- All 50 states and the District of Columbia have laws recognizing the use of advance directives.
- Every state recognizes living wills and health care proxies as legal documents—but each state has its own idea about which words should be used. Many states have advance directive forms that they like to use—but they are not mandatory.
- Most states will honor an advance directive that was originally written in another state. And many states are starting to use the same language in their advance directives. This will make it easier for the same advance directive to be legal when people move from state to state.
- Most state laws allow a doctor to refuse to honor an advance directive if it goes against his/her beliefs. It's important for people to discuss their advance directives with their doctors so they know that no problem exists.
- State-specific advance directive packages can be downloaded from Choice In Dying (www.choices.org) or they can be ordered by calling 1-800-989-9455. You can also get advance directive forms and more information from:
    - Your local hospital.
    - A local nursing home.
    - Your state or local office on aging.
    - Your state's bar association.
    - Your state's medical association.

Understanding Informed Consent

Remember, for years and years, it was the doctors who knew best. They decided if and when patients needed to know about their own medical condition. "Informed consent" is a fairly new idea that came about when patients began demanding the truth from their doctors.

The idea behind informed consent is that people need to be able to make medical treatment decisions *for themselves*. But, to do so, they must be given enough information to help them make good decisions. Doctors and nurses are responsible for providing this information. For example, let's say that 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 the surgery.
- The procedure for the 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 an 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.

Informed *refusal* is the opposite of informed consent. 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* document to prove that Mr. Jones made an educated decision.

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 DNR order).

Understanding Health Care Power of Attorney

- Generally, a Living Will (see next page) is a set of instructions about end-of-life care. It does not name a particular person to be in charge of future medical decisions. For that, a health care power of attorney (HCPOA) is needed. A HCPOA is a document that gives authority to another person to make decisions about medical treatment. It allows people to turn their decision-making authority over to anyone they choose.
- Often, elderly people choose one of their adult children to be their healthcare power of attorney. Other people choose a close family friend or even a lawyer.
- The idea is that the person named in a HCPOA will make the same decisions that the patient would have if he/she were able.
- Laws regarding HCPOA vary from state to state. It's usually recommended to have *both* a living will and a HCPOA. The living will provides the instructions and the HCPOA designates the person who will carry out those instructions.

Understanding Living Wills

- Living wills are a type of advance directive. They are 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.

- 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
  - Pain medication
  - Surgery
  - Organ transplantation
  - Chemotherapy
  - Antibiotics
  - Dying at home or at the hospital

- 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. These include the Catholic, Church of Christ, Jewish, Presbyterian and Methodist religions.

- 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—<u>even if it goes against the instructions in the patient's living will</u>.

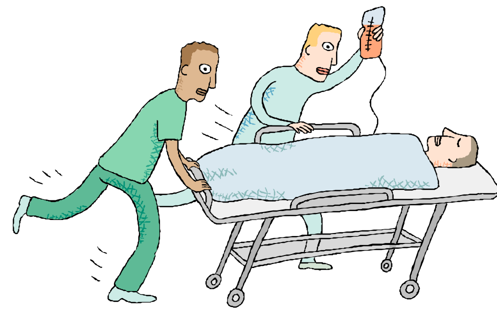
- Living wills must be signed and dated. They must also be signed by two witnesses. <u>Health care workers should never be witnesses to a living will</u>! If a client asks you to be a witness, explain that it's against your workplace policy.

- In most states, 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.

Understanding DNR Orders

- Every year, over two million people die in the United States. Eighty percent of these people die in hospitals, nursing homes and hospices. Nearly 70% of the people who die every year make a decision not to have life-sustaining treatment. One way of making this clear is to have a special physician's order called a DNR order.
- A **D**o **N**ot **R**esuscitate order tells medical professionals not to perform CPR 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 in the final stages of a terminal illness or who suffer from a serious condition that they fear will end their life some day.
- 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 "code" will be called. No one will attempt CPR or use a ventilator to keep him alive.
    - 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, her doctor has signed 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.
- DNR orders must be written and signed by a physician. They may be written for people in hospitals and nursing homes—and, in most states, for people living in their own homes.

- Generally, paramedics working in the community have a duty to provide CPR when needed. It's hard for them to take the time to find out if someone has an advance directive or a DNR order. In many states, a DNR order for people still living at home is called a "Prehospital DNR". This program helps ensure that paramedics will honor a DNR order outside the hospital. Prehospital DNR programs vary from state to state, but most states have:
    - A special form that is posted on a wall in a person's home. Paramedics know to look for this form (and it is often made of a bright colored paper to make it stand out).
    - Special DNR bracelets or necklaces worn by the person with a Prehospital DNR order.
- Remember that no doctor can write a DNR order for a patient without the patient's consent...or the consent of the patient's health care power of attorney or health care proxy.



NOTE: People might include instructions in their advance directives about not wanting CPR or other forms of resuscitation. However, this is *not* the same as a DNR order. Remember:

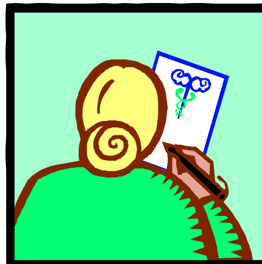
- Advance directives can be useful for anyone—even when their health is excellent. But, the instructions don't take effect until some time in the future.
- A DNR order is written and signed by a doctor only when a person is very ill and death is near. The order takes effect immediately.

Your Role in Advance Directives

- Maintain confidentiality! Keep information about your client's advance directives to yourself. Only coworkers who are working directly with a patient need to know if the patient has a living will or a DNR order.
- If your clients have questions about advance directives, encourage them to talk to their physicians. Also, let your supervisor know.
- If you work in clients' homes, be sure to ask your supervisor if your clients have advance directives and/or DNR orders. Since you may be alone at home with clients, you need to know what their end-of-life wishes are.
- If you have questions about a <u>particular</u> client's advance directive, ask your supervisor. It's important for you to understand your client's wishes.
- 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.

Your Role in Life-Sustaining Therapies

- Pain control is an important part of treatment for the terminally ill. Watch for signs that a dying client may be in pain.
- Provide bedridden clients with as many <u>comfort</u> measures as possible. For example, terminal clients may be unable to move for themselves and may be incontinent. You can help them remain comfortable by keeping them clean and dry and by gently changing their position in bed regularly.
- Range of motion exercises may be ordered for bedridden clients. Ask your supervisor if these exercises are appropriate for your clients.
- Never touch any buttons or dials on a ventilator / respirator machine. But, if the machine sounds different to you or its alarms are beeping, tell your supervisor right away!
- 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.



- For clients who are getting intravenous (IV) therapy, be careful of the tubing as you go about your work. Also, tell your supervisor if you notice:
  - IV fluid leaking around the site of the needle.
  - Blood in the IV tubing.
  - The IV bag getting near empty.
  - The IV machine "beeping".
  - Your client tries to pull the tubing out.
- 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 <u>dry</u> dressing on a feeding tube. Be sure you are comfortable dealing with the dressing and that you use standard precautions.
- If you have clients with feeding tubes, be sure to report any of the following:
  - A full swollen belly
  - Complaints of abdominal cramping
  - Diarrhea, nausea or constipation
  - Rapid changes in weight

Euthanasia

The dictionary says *euthanasia* means:

- An easy and painless death;
- The act of causing death painlessly;
- Ending the suffering of persons dying of incurable, painful diseases.

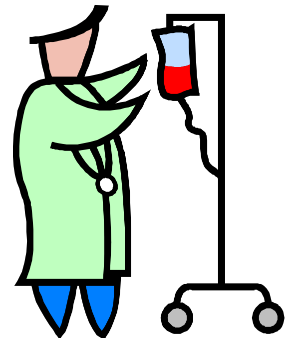
Some people call euthanasia "mercy killing". You've probably seen cases in the news like the husband that was being tried for murder for killing his terminally ill wife. He claimed he couldn't stand to see her suffer anymore and that she wanted her life to end.

When doctors "pull the plug" on life support machines, it is also an act of euthanasia. They know that when they disconnect the machines, the patient will die. But, they also know that the patient has no hope of returning to a healthy life.

There are many different views on euthanasia. Doctors, patients, family members and ministers don't always agree on whether euthanasia should be allowed. If people have their wishes spelled out in a living will or other advance directive, it helps doctors and family members make the "right" decision.

Assisted Suicide

- Have you heard about a man nicknames "Doctor Death"? His name is Jack Kevorkian, and he has helped over 100 people end their lives. Dr. Kevorkian has been arrested several times, and was found guilty of manslaughter for one of the cases of assisted suicide.
- For several years, assisted suicide has been legal in Oregon for people with a terminal illness. In 1998, the Oregon Health Department received reports of 23 cases of assisted suicide. Most were male. All were white. Most of the patients had cancer. 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.



What Do Our Laws Say?

- Suicide is not against the law in any of the United States. However, attempted suicide is considered a crime in some states (though no one has been prosecuted for it for the last thirty years).
- Some lawmakers have had a hard time telling the difference between suicide and refusing treatment.
- Assisted suicide is against the law—except in Oregon. But, 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.

Questions & Answers About Advance Directives

Q: Mr. Smith 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. Smith has an advance directive doesn't mean he has decided to refuse life-saving treatment.

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

A: No. As long 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: People must 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: 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: 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: 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.

Studies have shown that:

- Only 30% of patients discuss life-sustaining treatments with their doctors.
- 50% of people with written advance directives have only <u>one</u> copy of the document—and it is locked away in a safety deposit box at the bank.
- Less than half the people who say they would *not* want CPR used to resuscitate them have that wish written down.