

Hospice Aide On-the-Go™ In-service



Advance Directives

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Since the 1950s, modern medicine has developed technology to keep people alive, even in the face of life-threatening trauma or terminal illness. This technology includes cardiopulmonary resuscitation (CPR), artificial hydration, respirators, and feeding tubes. Many people are certain that they would not want heroic measures (aggressive medical intervention) taken to keep them alive. They worry about being able to make important decisions about their health when they are very old or very sick. They want to make those decisions while they are well and able to think clearly.

People who are unable to speak for themselves are said to be incapacitated. A person who is comatose, near death, or severely ill and unable to make his or her wishes known may be considered incapacitated.

One solution to this problem is called an advance directive. It simply means to “give directions in advance.” An advance directive is a statement that tells a person’s physicians, family, and other caregivers what kind of treatment that patient would want if he or she were not able to speak.

Advance directives are legal in every state in one form or another. Advance directives can be oral statements made to the family and physician, but they should be more than just casual conversation. Although an advance directive need not be in writing, a written document is stronger evidence of a person’s wishes.

BACKGROUND

In the United States, we believe that an individual has the right to make his or her own healthcare decisions. In 1991, the U.S. Congress established the Patient Self-Determination Act (PSDA) to protect this right. The Act also sets standards Medicare and Medicaid providers must follow regarding a patient’s right to self-determination.

The PSDA requires that information about advance directives be presented to adult patients admitted to hospices and other agencies that receive funding from the federal government. Special Medicare *Conditions of Participation* for hospices relate to patients’ rights. These *Conditions* specify that a hospice must inform patients, verbally and in writing, about hospice policies on advance directives.

Generally, any adult aged 18 years or older is able to create, change, and revoke a living will or an advance directive, as long as the

Key Terms

Advance directive

A way to give instructions in advance about the types of care wanted at the end of life

Competent

Having the ability to complete a function. A mentally competent person is able to make decisions using information.

CPR

Cardiopulmonary resuscitation; restores the heartbeat

DNR

Do not resuscitate; do not perform CPR if a person’s heart stops beating

DPAHC

A durable power of attorney for health care; a legal document that names someone else to make healthcare decisions for a person who is unable to make them

Heroic measures

Aggressive medical intervention

Palliative care

Medical care that relieves pain and increases comfort, but does not cure

Proxy

A person who is approved to act in place of another person

Revoke

To cancel

Ventilator

A machine that moves air into the lungs for a patient who is unable to breathe naturally



person has decision-making ability. These documents should not be created, changed, or revoked by the patient's physician, family member, proxy, representative named in a power of attorney for health care, or anyone else.

The states have different legal requirements for valid advance directives. These laws vary regarding:

- What form of advance directives are legally recognized
- Who may establish an advance directive
- The format or written requirements necessary to make an advance directive legal
- When or under what conditions the advance directive becomes effective
- The types of medical and surgical treatments to which the advance directive applies

TYPES OF ADVANCE DIRECTIVE

There are two types of advance directive: a living will and a durable power of attorney.

The living will allows people to participate in future medical care, even when they are unable to speak for themselves. In a living will, patients specify the kinds of treatment they are willing to accept. Some may be willing to accept artificial hydration and tube feeding, but refuse "machinery" (respirators and ventilators). Others accept pain medication, but refuse artificial nutrition and hydration. The living will protects the patient's rights and removes the burden of making decisions from a person's family.

Issues to be addressed in a living will include:

- Artificial hydration
- Tube feeding
- Respirators and ventilators
- Dialysis machines
- DNR (do not resuscitate) orders
- Cardiopulmonary resuscitation (CPR)
- End-of-life treatments such as pain medications
- Palliative (comfort) care
- Organ donation
- Funeral and burial instructions

The other type of advance directive is called a durable power of attorney for health care (DPAHC). This is a legal document that names a proxy. A proxy is a person who is allowed to speak or act for another person. As designated by a DPAHC, a proxy makes important end-of-life medical decisions for someone who is not able to make them. Generally, a husband or wife speaks for an incapacitated spouse. If the person is unmarried, state law names



someone to fill that role, generally a family member. People in nontraditional relationships or those without close family may prefer to choose the person who will act as their proxy. They can do this by means of a DPAHC.

Because the proxy is often a close friend, relative, or spouse, emotions may affect the person's judgment and influence decisions. To carry out someone's advance directives, the proxy must know the other person's wishes and views about end-of-life care.

Conscience objections

The most important thing about an advance directive is that the person discusses it and shares his or her wishes in advance with a physician, family, clergy, and healthcare providers. It's important that the care team know how to reach the proxy or representative. It's also important to have a copy of the living will in the plan of care and readily accessible wherever the patient lives. This removes the chance that someone with conscience objections can interfere with the patient's wishes. For example, a patient may prefer that no life support or other extraordinary measures be taken, but a family member may have religious convictions that say extraordinary measures must be taken. Aides who work in hospice should discuss their beliefs with the RN or another member of the interdisciplinary team if they feel they may have personal conscience objections to a patient's wishes regarding end-of-life care.

A healthcare proxy or representative may be called upon to make difficult decisions. Sometimes these decisions are not accepted by the patient's family members. Sometimes the healthcare proxy is seen as speeding up the death of the patient.

It's a good idea for the patient and the patient's representative to have ongoing conversations to keep the advance directives up to date. A person may change a living will at any time for any reason. It may be necessary to select a new healthcare proxy if the first proxy is no longer willing or able to serve in this role.

Some states have specific requirements about who can be a proxy. Some states allow for a back-up proxy in case the original one is unable or unwilling to serve in this position. Because making decisions about someone else's health can be emotionally difficult, many people think it's not a good idea to name a close relative, such as a spouse or a child. Some family members are simply unwilling or unable to take on this responsibility.

End-of-life issues can be complicated, and decisions must be made. Having an advance directive can be helpful to caregivers and family members. It's beneficial to know what the hospice patient's desires were when he or she had the ability to choose. Having an identified healthcare proxy named in a DPAHC makes it clear who will make decisions, which often decreases stress at a difficult time.

Advance directives in hospice care

By law, education about advance directives must begin at the start of hospice care. Patients may accept and refuse treatment and may create advance directives to be included in the plan of care. Advance directives state the patient's rights and wishes regarding end-of-life care. A hospice must provide information about its policies related to advance directives. A hospice may also provide education to the community and to staff about advance directives.



Advance directives are used in hospice care to guide discussions between patient and family about the patient's wishes regarding future care while the patient still has decision-making ability. Assistance in establishing an advance directive or updating it may be part of hospice care. These discussions often include the patient, patient's representative, caregivers, and family members. Many people are not comfortable talking about end-of-life issues. When the hospice supplies written information about these issues, it may help people begin to talk about them.

When the hospice patient no longer has decision-making ability, the hospice will follow the patient's advance directives. Physicians and psychologists determine when a patient is unable to function and make decisions. The determination may be time limited, such as a period of time after surgery. The determination may be reversed if the patient regains decision-making capacity.

Medicare requires hospices to publish clear policies about a patient's rights related to advance directives.

DNR and palliative care

If a patient, through an advance directive, has decided against heroic measures to prolong his or her life, that patient may create a DNR (do not resuscitate) order. If the patient stops breathing, emergency responders will not be called to perform CPR. A hospice cannot force a patient to sign a DNR order, but many patients do sign one because hospices promote simple palliative care, not life-saving measures. For example, hospice staff are not employed to perform CPR. Their mission is to provide comfort care and relieve pain, not to prolong life. In some hospices, the family must make the phone call if they want to summon emergency care. If the family asks the hospice aide to call emergency services, the aide should refer them to the hospice RN. This can be controversial for some staff. The hospice may encourage a patient or the patient's representative to file a DNR order to make the patient's wishes clear to everyone.

Remember that a patient who does not want heroic measures or aggressive treatment will still receive comfort care and interventions that reduce pain.

Information about advance directives

Medicare rules and state laws provide general information and patient-specific information about advance directives. In addition, each hospice must educate aides and other staff about its policies and procedures.

The patient-specific information includes:

- The existence of an advance directive
- The hospice's system for including advance directives in the patient's medical record
- The hospice's policy on providing copies of the advance directive to a healthcare facility, if necessary



THE HOSPICE AIDE'S ROLE

Your role as a hospice aide includes working closely with patients, caregivers, and family members as part of the interdisciplinary team. Decision-making happens in hospice care on an ongoing basis, sometimes very quickly. As a hospice aide, it's important for you to follow these guidelines:

- Know your hospice's policies related to advance directives.
- If patients, caregivers, or family members have questions or concerns about advance directives, refer them to the hospice RN or other team members.
- If a patient wishes to change or revoke an advance directive, contact the hospice RN.
- Review your values and beliefs to determine whether you have any conscience objections related to a patient's advance directives. If you do, discuss your concerns with your supervisor.
- If you have concerns about your patient's decision-making ability, inform the hospice RN.
- If your patient does not have decision-making ability, know how to reach the patient's representative or healthcare proxy. If decisions must be made as part of your hospice aide assignment, follow the directives of the patient's representative.
- Know whether your patient has a living will and what your patient's wishes are for end-of-life care.
- In case of emergency, know where to find a copy of the living will.

Caretakers and aides must be aware of patient's wishes

Patients have the right to refuse care, either at the moment or by means of an advance directive. In an emergency, the patient's family, caretaker, or even a stranger who doesn't know the patient's wishes could call for an emergency response team. When that happens, the emergency responders must provide CPR and other care, unless they are immediately shown clear evidence of the patient's advance directive.

The best way for a patient to prevent unwanted care is to keep a copy of this information handy. Patients may wear a Medic Alert bracelet or neck medallion engraved with DNR requirements. Even patients who reside in a skilled nursing facility or other hospice setting are encouraged to wear the Medic Alert bracelet. Some states require a special DNR bracelet.

Sometimes an aide may be caught in a situation in which the patient's wishes cannot be immediately verified. When this happens, the aide should follow agency policy and arrange to transport the patient to the hospital, where another member of the interdisciplinary team will locate and authenticate the patient's advance directive.





CASE STUDY

Ralph, age 67, was admitted to a hospice program yesterday. His terminal illness, colon cancer, is quickly progressing, and he and his wife Barb are still dealing with the news. The nurse told you that Ralph was making decisions very slowly. There was some confusion related to Ralph's advance directive. The couple thought he had one, but were not sure where to find a copy of it. They were hopeful that their son Tom might have a copy.

Ralph, who lives at home, has agreed to aide assistance. The assignment includes helping him with his shower, shaving, and getting dressed. When you arrive at the home, Tom greets you at the door. He tells you he is his dad's healthcare proxy and says, "I have the papers to prove it."

You remind Barb and Tom that the social worker is coming in the afternoon, and that he will discuss Ralph's advance directive with all of them. You also tell Tom that the social worker will ask for a copy for the hospice files. Tom tells you he does not have a copy, but that he will make a copy before the social worker visits. You thank Tom for taking the time to do that, and explain that your hospice will also gladly make a copy if that is more convenient. Tom says, "No, I'll do it. I don't want to lose this paper. Dad was very clear with me what his wishes were, and I agreed to be here when he needed me."

Barb says Ralph is awake and that he is looking forward to help with his shower. You find Ralph resting in bed. He is able to answer your questions about his care preferences very clearly. You assist with his shower, shaving, and dressing as assigned. At one point he says to you, "I thought Tom would be able to stay cool and follow my wishes when the time came. Now I'm not so sure. And my wife doesn't want the responsibility. She agrees with my wishes, but just doesn't think she can make the calls I want. It really worries me that I'll get stuck in a hospital on tubes. I don't want that."

You listen carefully to his concerns. Then you say, "You sound worried. I know our hospice social worker is visiting you this afternoon. I'll let him know that you have concerns before he gets here." Ralph looks relieved and says, "Maybe he can go over this with me and Tom. I'd like Barb here, too. Can you pass that along?" You promise to do that.

After finishing your assignment, you remind the family that the social worker will be coming in the afternoon. Ralph speaks up. "We are all going to discuss my wishes. Do you have the papers, Tom?" "Got them right here, Dad. Let's not worry about that right now." Barb says, "It will be good to review them; it seems so long ago that we talked this all over." She sounds very sad, and Tom reaches over and gives her hand a squeeze. "Don't you worry, Mom. I'll make sure Dad's wishes are followed."

After you leave the home, you contact the hospice RN, using your hospice's communication plan. The RN asks that you page Bill, the social worker, and tell him about your visit. You do that and finish your documentation.

THINK ABOUT IT

1. What would you have done if Ralph had been confused when you went in to start your assignment?
2. What information should you communicate to the hospice RN and the social worker?
3. How does your hospice communicate to you who the patient's representative is?
4. How does your hospice communicate the patient's status related to a durable power of attorney for health care?

