

Hospice Aide
On-the-Go™ In-service



The Patient's
Right to Choose

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According to the *Conditions of Participation*, a patient deciding to enter a hospice program must be informed of his or her rights, both verbally and in writing. The hospice provider must protect and promote these rights for all patients. As members of the hospice staff, hospice aides play an important role in protecting and promoting these rights for their patients.

Patient rights are so important that Medicare's *Conditions of Participation* for hospices have specific rules related to this topic. The Medicare *Conditions of Participation* are federal statutes that all Medicare-certified hospice agencies must follow. All patients in a Medicare-certified hospice have the same rights, even patients who are paying privately or are covered by insurance other than Medicare. There are also other federal and state laws concerning patient rights, and hospice provider staff members must follow all of them.

THE RIGHT TO CHOOSE

According to the *Conditions of Participation*, one of the most important rights hospice patients have is a right to choose. Because some hospice patients are not able to make choices for themselves, state and federal laws exist to protect them. These laws provide incapacitated patients with a patient representative who will make decisions for them. According to Medicare, this representative is a person who, under state law, can authorize or terminate medical care on behalf of a patient who is mentally or physically incapacitated. This representative may also elect or revoke the election of hospice care. The representative is the patient's surrogate, a person who tries to make the decisions the patient would make if he or she were able.

In some cases, a patient who could make decisions is not interested in doing so and asks someone else to do it on his or her behalf. In other cases, a patient may not be able to make decisions because he or she has lost decision-making ability or is incapacitated.

Key Terms

Conditions of Participation

Federal statutes that all Medicare-certified hospice agencies must follow

Elect

To choose

Grievances

Complaints

Incapacitated

Incapable or unable

Medicare Part A

Hospital insurance

Representative

One appointed to act in place of another

Reprisal

Retaliation or payback

Revoke

To cancel

Basic Patient Rights

Basic patient rights are:

- To receive verbal and written information about available services and treatment
- To receive information about the hospice's policies and procedures
- To have property treated with respect
- To be able to voice grievances (complain) without fear of reprisal (punishment)
- To receive effective pain management and symptom control
- To have a confidential clinical record
- To be free from mistreatment and neglect
- To have a legal representative appointed to make decisions, if necessary
- To make choices about important care decisions, if able



It's important that the hospice aide knows who is making the decisions—the patient or the patient's representative. The legal representative can be a family member or friend, or someone else such as an attorney. Even when a representative makes choices on behalf of the patient, the patient continues to be involved in the decision-making process as much as possible.

Choices in hospice care

These are some of the areas where patients have the right to choose:

- **THE MEDICARE HOSPICE BENEFIT.** When a person is referred to a hospice, the hospice is required to explain what hospice care is about. This includes financial information, as well as information about the scope of services. Patients who are entitled to Medicare Part A can choose to have Medicare pay for hospice care through the Medicare hospice benefit. The patient must meet certain requirements to be eligible for hospice care coverage through Medicare. Each hospice provider must establish a process for working with patients who are considering hospice care. A hospice aide is not involved in explaining hospice care to a person who is considering hospice. However, an aide's friends and family and others in the community may have questions about hospice. Being able to answer those questions correctly is important.
- **CHOOSE AN ATTENDING PHYSICIAN.** As part of the admission process, patients will be asked to choose an attending physician. According to Medicare, the attending physician will have the most significant role in determining and delivering the patient's medical care. Patients may choose a personal physician, a hospice physician, or nurse practitioner to play this role. Patients may change their selection at any time. The hospice aide must be aware of the patient's choice. If questions arise, the aide will generally communicate with the hospice RN.
- **CHOOSE SPECIFIC CARE, TREATMENT, AND SERVICES AS PART OF A HOSPICE PLAN OF CARE.** The hospice plan of care is unique to each patient. It reflects input from the patient and the patient's family regarding goals, treatment, and services options. It's important that the hospice aide know about this plan of care.
- **PARTICIPATE IN PLANNING THE CARE THEY RECEIVE.** Hospice patients may participate in planning the care they receive. They should be encouraged to participate as much as they are able and willing in planning the daily care routine.

Medicare eligibility requirements

- The patient must be eligible for Medicare Part A (hospital insurance).
- The patient must be terminally ill, according to an attending physician and the hospice physician.
- The patient must have six months or less to live, assuming the illness runs its normal course.
- The patient wants to receive services under the Medicare hospice benefit for treatment of the terminal illness.
- The patient signs an election statement, choosing the hospice benefit instead of traditional Medicare.

Aides play an important role by respecting and protecting patients' rights to participate in their care. The hospice aide should carefully review with the patient each day's assigned care duties. The aide should ask



how the patient would like the personal care tasks to be done and follow the patient's preferences as much as possible. If the patient requests a task not on the assignment sheet, the aide should contact the hospice RN or appropriate hospice staff to see whether it is permissible. The aide should explain to the patient what he or she can do to help with the tasks. It is best to allow patients to do as much as possible for themselves, even when it takes longer than doing everything for the patient.

If the patient's caregivers wish to assist with care, the aide should let them help as much as the patient will allow. Hospice aides frequently act as role models to others in how to offer choices to the patient. Hospice aides must be aware that offering choices requires communication skills, and they should provide options in a non-judgmental manner.

- **REFUSE CARE OR TREATMENT.** A hospice patient can refuse part or all of the care assigned, for any reason or for no particular reason. For example, a patient may refuse a scheduled bath because unexpected visitors arrived. Another patient may refuse a shower because it has become too difficult.



When a situation like this happens, the hospice aide must document what aspects of care the patient refused and then contact the hospice RN, according to the hospice's communication plan. The aide's documentation should record the time of contact, the person with whom the aide spoke, and instructions for dealing with the refusal. Patients have the right to refuse any care, and aides must not force the care.

Hospice patients may also refuse social worker attention, spiritual counseling, and volunteer efforts. An aide who observes these refusals should communicate them to the RN. It's important to be sure that patients are fully informed about the services being refused.

- **RELOCATE TO A DIFFERENT HOSPICE PROGRAM.** A hospice patient may decide to change hospice providers for any reason. For example, a patient may prefer to be in a hospice in a city closer to children or other family, who could visit more often during the final days. This choice can be made only once during an election period.

The hospice aide may be the first person to learn of the patient's wish to change to a different hospice. Coordinating a transfer from one hospice to another is generally the responsibility of the hospice RN, with other members of the team assisting. When a patient wishes to change hospice providers, the hospice aide should contact the hospice RN and communicate this information.

- **CHOOSE TO STOP RECEIVING HOSPICE CARE.** Hospice patients may choose to stop receiving hospice care at any time and for any reason. When a patient revokes the Medicare hospice benefit, he or she returns to standard Medicare coverage. A patient who qualifies may return to hospice care at any time and may once again elect the Medicare hospice benefit.



The hospice must develop a procedure for managing a patient's choice to stop receiving hospice care. Sometimes a hospice aide may receive questions about stopping hospice care from a patient, a patient's representative, or a family member. Every aide should know that hospice care is based on patient choice, and that patients may choose to end care at any time. The aide should communicate to the hospice RN about the patient's wish to be discharged. The RN or social worker will manage this process.

- **VOICE GRIEVANCES (COMPLAIN) ABOUT POOR TREATMENT OR LACK OF RESPECT FROM STAFF WITHOUT FEAR OF DISCRIMINATION OR REPRISAL.** The patient has a right to complain, and no one at the agency should discriminate against the patient for making a complaint. The hospice must investigate complaints made by a patient or family and must document the complaint, as well as how it was resolved. If the violation is verified by an official agency, the hospice must take corrective action. It must also report violations to the state survey and certification board within five days.

How the Aide Can Help

- Allow the patient to speak freely and listen to what he or she has to say.
- Explain that you will let your supervisor know about the concerns.
- Report any concerns or complaints the patient expresses. Follow your agency's policy for documenting this report. It is very important for the agency to investigate any patient complaints expressed to you or another staff member.
- Continue to provide the same high-quality care after a patient has complained.

KEY POINTS TO REMEMBER

1. Hospice aides, along with all of the hospice staff and volunteers, have a duty to protect the patient's rights, especially those related to choice.
2. It is important that the aide knows who—the patient or patient's representative—is making choices about care the aide provides to the patient.
3. Aides must allow the patient to participate as much as possible in care planning and delivery, based on the hospice aide's assignment.
4. When the patient or patient's representative informs an aide about choices being made that are beyond the scope of a hospice aide's role, it is the aide's responsibility to communicate this important information to the hospice RN, according to the hospice program's communication plan.

CMS Expectations

A hospice must maintain a quality assessment and performance improvement (QA/PI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.



OUTCOMES AND THE HOSPICE HEALTH AIDE

The care provided by the hospice aide improves outcomes for the terminally ill patient. Hospice outcomes focus on the relief of pain and other symptoms and on the patient's right to choose and participate in care delivery whenever possible. By providing care and relief of symptoms, the hospice aide provides physical comfort to the patient. An aide who is aware of patient rights can alert the RN, a social worker, or another member of the team about issues that arise. This also contributes to the patient's ability to die with dignity.





CASE STUDY

Omer, a 67-year-old gentleman, who lives in his own home with his wife Mary, was admitted to your hospice program last week. His terminal illness is prostate cancer, and you are at his home for his first hospice aide visit. Your assignment sheet indicates that he is making his own decisions, that he is having bone pain that requires pre-medicating with morphine prior to his care (which you are to remind him to do), and that you are to do a partial bath and assist him in getting ready for bed.

When you arrive, you introduce yourself to Omer and Mary. Omer says he is tired and isn't sure he wants to have a bath tonight because it hurts when people touch him. You know the RN has reviewed pain management with them, including the idea of pre-medicating before his bath. You talk over his request, and suggest that he take some of his morphine in preparation for his bath. His wife assists him in doing that. You ask for a brief tour of where he spends his time. Mary takes you on a tour of their bedroom, the bathroom, and the kitchen, and then shows you where to put the dirty laundry. After the tour, you offer to get Omer's bath ready.

During his bath, Omer says, "Now that I've signed up for hospice, I guess I'm stuck. I'll never be able to get out, even if they discover the cure for my cancer." You explain to him that he can always choose to stop hospice care, for any reason and at any time. He wonders, "Can I ever come back in if it doesn't work?" You explain that there are no strings attached. As long as he qualifies for hospice care, he can start up again if he chooses.

You mention the printed material they received from the hospice. Mary and Omer agree that they should look at the literature again and pay attention to the details. You reassure them that it is good to ask questions. Then you tell them that if they have any questions you can't answer, you will ask one of the hospice team members to call them for a discussion.

After finishing your aide assignment, you say good-bye to Mary and Omer. Although he is a bit tired, he smiles and says, "So, I'm still the boss, right?" You reassure him that he is, at least when it comes to his hospice care.

You complete your documentation. Using the hospice communication plan, you notify the RN about Omer's concerns related to his right to choose.

THINK ABOUT IT

1. How do you react when someone tells you that you must do something, and have no choice?
2. How does your hospice want you to communicate concerns related to a patient's choice?
3. How would you find out who is authorized to make decisions, the patient or the patient's representative?
4. The hospice patient makes choices as a part of the care you provide to him or her as a hospice aide. How do you know where the boundaries are for choices the patient can make as part of your assignment?

