

Family Caregiver's Guide to Hospice and Palliative Care



Even though you have been through transitions before, this one may be harder.

If you have been a family caregiver for a while, you probably have been through a lot of transitions. Maybe your family member was in and out of the hospital several times. Perhaps he or she spent a few weeks in a rehabilitation unit or received home care services. Or perhaps he or she is now a resident in a long-term care facility. In each of these transitions, you had to meet new health care professionals, learn more about your family member's health, and adjust to new caregiving tasks and routines.

Now you are coming to a new transition. Maybe your family member's health is getting worse. Perhaps the treatments intended to prolong his or her life are not working or causing a lot of pain and suffering. You may have a lot of questions and concerns about what to do. You may also be dealing with many feelings as your family member faces a serious and life-threatening illness, or is dying.

When you are thinking about whether your family member's current care is appropriate for his or her condition, here are some questions to ask:

- ▶ What is the prognosis – the expected course – of my family member's illness?
- ▶ What are the goals for care? For instance, is the goal to cure the disease or to provide comfort and improve the quality of my family member's life?

This guide is written as a way to help you through this transition. The first section explains palliative (PAL-ee-a-tive) care. The second section answers questions about hospice care.



Hospice is not the same as palliative care. Hospice is a special kind of palliative care used for patients who are either not being helped by active treatment or for whom the burden of their treatment outweighs any benefits. Medicare has special coverage for hospice care, which is only for patients who are expected to live for 6 months or less. Patients in hospice must stop all treatments meant to cure their illness.

Palliative Care

Palliative care can make a big difference in your family member's treatment and quality of life when he or she has cancer, heart disease, respiratory disease, kidney failure, or other serious illness.

Palliative care is a special form of medical care that helps patients feel relief from the pain, symptoms, and emotional distress caused by a serious illness or its treatment. This is much more than just "comfort care." The goal of palliative care is to improve how a patient functions each day as well as improve his or her quality of life throughout the course of a serious illness. Palliative care can be used along with treatments meant to cure.

A team provides palliative care. Team members often include specially trained doctors, nurses, and social workers along with pharmacists, nutritionists, chaplains, and other medical professionals. Palliative team members also include the patient and his or her family caregivers. The palliative care team works closely with family caregivers, your family member's regular doctors, and others involved in the patient's care. This offers an extra level of support.

Palliative care can be useful at any time during a person's illness. It is better to begin palliative care sooner, rather than later, but it is never too late. It may involve a few consultations, or ongoing care. While most palliative care services are given in hospitals, it sometimes is offered in outpatient clinics, home care, and long-term care facilities. Talk with your family member's doctor if you think palliative care might help.

Most health plans, including Medicare and Medicaid, will pay for palliative care just as they pay for many other medical services. But unlike hospice care, there is no Medicare benefit that pays just for palliative care.

For more information, see the Center to Advance Palliative Care at www.capc.org.

Hospice Care

This part of the guide gives answers to many questions family caregivers ask about hospice.



In hospice care, the patient and family are treated as the unit of care.

When should we start thinking about hospice care?

- ▶ When there are no more treatment options to cure your family member's disease, hospice becomes an option. With hospice, the focus is on comfort and quality of life.
- ▶ Hospice may be the best option when you and your family member decide that treatment meant to cure is not worth its side effects, pain, and suffering.
- ▶ It helps to make the choice for hospice sooner rather than later. Many people delay since it marks a turning point in your family member's care. This means that many patients receive hospice care for only a short period of time. Some patients and caregivers fear that choosing hospice means that nothing more can be done. But this is not the case. In fact, hospice patients often receive a lot of services to help improve their quality of life.

Who decides about hospice care?

As the family caregiver, you and your family member are the ones to decide about seeking hospice care. Many people find that it helps to make this choice only after talking with other family members, doctors, and caregivers. You must freely make the choice – meaning that no one can force you to accept hospice care.

Your doctor may be the first one to suggest hospice care. Or you may be the first to mention it. Please do not be afraid to talk about hospice. Some doctors do not like talking about hospice as they feel it is a sign of failure. Other doctors do not mention hospice because they wrongly believe that they cannot continue to be involved in the patient's care. Once in a while, a doctor may criticize family caregivers for asking about hospice. If this happens, ask why and then get a second opinion from another doctor.

Sometimes a doctor and a hospice program do not agree on who should get hospice care. This may occur when a patient does not have a clearly defined illness or "terminal condition." If this

happens, ask the doctor to explain why he or she believes your family member is eligible and why the hospice did not accept the patient. You can also try another hospice.

Once the decision is made for hospice care, a doctor must sign an order requesting it.

What if my family member cannot help make the choice?



Even if you are the one most responsible for your family member's care, it helps to talk with your whole family about whether to start hospice.

- ▶ If your family member is too ill, unconscious, confused, or unable to speak, then you as the family caregiver may be the one to decide about hospice care. It helps if you have discussed this ahead of time with your family member. If not, you need to decide based on what your family member has said in the past or what you know about what he or she would want.
- ▶ Sometimes family members strongly disagree with each other. If so, ask the doctor or a social worker to meet with your family so you all can learn more about your family member's illness and chance for recovery.

An advance directive is a very important legal document that can help. It is a way for patients to appoint someone to speak on their behalf if they no longer can speak for themselves. This person is known as a substitute decision maker or health care proxy. To learn more about advance directives, go to http://www.nextstepincare.org/Caregiver_Home/Advance_Directives/

What services are included in hospice care?

Services vary but include:

- ▶ Care from a team of trained doctors, nurses, social worker, chaplain, home care aides and other health care providers.
- ▶ The team may also include physical and occupational therapists.
- ▶ Access to the hospice team by phone 24 hours a day, 7 days a week.



Hospice care does not include treatments and medications that are aimed to cure. Some programs offer more expensive comfort measures, equipment, or support and care because they have charity donations or special agreements with certain health insurance plans.

- ▶ Medication to relieve nausea, pain, shortness of breath, agitation, and other symptoms.
- ▶ Medical supplies and equipment, such as a hospital bed or wheelchair.
- ▶ Family support. This includes emotional support as well as teaching how to do certain health care tasks such as giving injections and changing dressings.
- ▶ A short stay in the hospital if the patient's symptoms are too difficult to manage at home.
- ▶ Short-term respite care – time off for family caregivers.
- ▶ Volunteers to provide companionship for the patient.
- ▶ Bereavement counseling to family caregivers for a year after the patient's death.

Who pays for hospice care?

- ▶ If the patient has Medicare Part A coverage, the Medicare Hospice Benefit pays for most direct patient services listed in this guide including professional fees, medical equipment, and medication. Hospice patients can keep getting Medicare benefits to treat health problems other than the terminal illness.
- ▶ Most private health insurance plans pay for hospice and follow Medicare guidelines.
- ▶ Although not required, most state Medicaid programs pay for hospice services. You should check this to make sure. You may need to pay a small co-payment (co-pay) for some hospice services, such as some drugs and respite services.

How should I choose a hospice?

Hospices are not all the same. Some are large and some are small. Some are run by nonprofit agencies, others by corporations. You may have many hospices to choose from or just one. You can find out about hospices in your area by asking a doctor, hospital, state hospice organization, or health department, or by going to www.hospicedirectory.org and other websites. Make sure you check several sources to get a complete list.

Here are some questions you may want to ask before choosing a hospice:

- ▶ Is the hospice certified by Medicare? This means that the hospice meets state and federal guidelines.
- ▶ Can I speak with hospice staff 24 hours a day, 7 days a week? Is there a specific nurse or case manager I need to contact?
- ▶ How does the hospice manage medical emergencies, such as difficulty breathing or severe pain?
- ▶ How does the hospice manage complaints?
- ▶ How much and what kind of equipment will the hospice provide?
- ▶ What are the hospice policies about:
 - ▶ Giving pain medication, antibiotics, chemotherapy to relieve symptoms, radiation therapy, anti-nausea medication, and blood transfusions?
 - ▶ Using mechanical ventilator support (breathing tubes)?
 - ▶ Taking out implanted heart devices (pacemakers)?



The first few days of hospice care can be very busy and perhaps confusing. It takes a while to get to know the new team, understand who will be coming and when, and what your role is as a family caregiver.

What happens once hospice services begin?

- ▶ A hospice staff member will set up a meeting with you after your family member has been referred for hospice. This meeting is a time for you and your family member to ask questions and confirm if hospice is the right choice. If so, you will be asked to sign consent forms. The hospice team then begins working with your family member within 1 to 2 days.
- ▶ If your family member had services from a home care agency, you may miss some staff with whom you had a good relationship. This is a common reaction to working with a new team.



Calling 911 is often not a good idea because ambulance rides or emergency department visits can be uncomfortable for your family member and are not always helpful.



Let the hospice team know if your family has any special religious, cultural, or other practices that may affect patient care.

- ▶ You may have to make some changes to the home such as moving furniture to make room for new hospice equipment.
- ▶ You will be assigned a hospice nurse. He or she will be your main contact and will visit regularly. The hospice team may also include therapists and a part-time aide or homemaker. You can keep working with other aides or helpers you pay for on your own. The hospice team will review your family member's care on a regular basis. This is a time to see if there have been any changes in your family member's medical condition and prognosis. Based on this review, hospice care may go on for more than 6 months if your family member still meets Medicare's hospice guidelines.
- ▶ Hospice staff will talk with you about what to do in a medical emergency. Most often, this means calling the 24-hour hospice number rather than 911. This can be a difficult change if you are used to calling for an ambulance to take your family member to the hospital.
- ▶ When you call the 24-hour hospice number, the staff can help you decide what to do in a medical emergency. Maybe your family member is now at the end of his or her life and would be more comfortable at home. Or perhaps the hospital is the best place to manage his or her symptoms. If your family member does need to go to the hospital, the hospice nurse can assist with the admission and may be able to help you avoid the emergency room.

What if we want to stop hospice care?

Hospice care is voluntary. This means that you and your family member can leave the hospice program for any reason, for example, if he or she is getting better. Later on, you can again start working with the same or another hospice program.

What if hospice stops working with our family member?

On rare occasions, a hospice program will discharge (stop providing services to) a patient. This can happen if the patient gets better and no longer meets the 6-month prognosis. A hospice program may also discharge a patient if the home environment is not safe or the family refuses to cooperate with



Every hospice has its own medical director who oversees patient care. Many patients can also have their own primary care doctors involved in hospice care. If so, both the doctor and medical director need to work together.

the hospice rules. Hospice programs cannot discharge patients because their care is too expensive or inconvenient.

Patients and families can find it upsetting to be discharged from hospice. After all, you have come to rely on the team of hospice nurses, aides, and social workers. If your family member is discharged, the hospice team may help set up other home health services or move to a different level of care, such as a long-term care facility (nursing home).

How will hospice affect me, the caregiver?

Hospice is different from other types of care. You may have more help than you are used to. This can be both good and bad. It can be good in that others take over certain caregiving tasks and you may have more time for yourself. But it may feel like a loss when others take on tasks you are used to doing. It helps to talk about these changes with your hospice team.

Hospice teams recognize you as the primary caregiver for the person who is ill. The hospice team will teach you and others how to care for your family member at home.

You may have to learn new tasks and accept a plan of care that is different from before. You will also be offered bereavement services for a year after the death of your family member.

Hospice provides a level of care that is difficult to obtain in other settings at a time when your family member needs special care. But it also requires a lot from you and your family. Think about your family member's values, your own abilities, and what hospice provides. If you choose hospice, you will be better prepared for this important transition.



With some exceptions, usually during the last few days of life, hospice care does not provide around-the-clock nursing or personal care. This means that family members or hired caregivers provide most of the care.

Hospice and palliative care: A comparison

	Palliative Care	Hospice Care
Goals	To assess and treat the patient’s pain and other physical, psychosocial, and spiritual problems.	To keep the patient comfortable, as free as possible from pain and symptoms, and allow him or her to maintain a good quality of life for the time remaining. Hospice accepts death as an inevitable outcome for a patient with a terminal (end-stage) illness. In hospice, both the patient and family are the focus of care.
Patients	Palliative care accepts patients who have complicated or advanced medical disease. There is no time limit in terms of life expectancy – patients may or may not be dying. Patients can get treatments intended to cure. They also can participate in research studies.	Hospice only accepts patients who are near the “end of life” (meaning they have a terminal illness) and are likely to die within 6 months if the disease runs its normal course.
Where care occurs	Palliative care is usually given in hospitals. Sometimes it takes place at nursing homes or assisted living facilities. Palliative care at home is possible but not readily available.	Most hospice care happens at home, although it can also be given in other settings as well, such as the hospital, nursing home, or assisted living facility.
Who provides the care	Palliative care is a medical subspecialty. This means that doctors and nurses who practice palliative care have extra training about ways to manage symptoms. They work with a team of other professionals.	Hospice care is a team approach, led by doctors and nurses with special training. Specialists may provide spiritual, psychosocial and other care. Hospice care may require a lot of time and effort from the family.
Paying for services	There is no special insurance benefit for palliative care. The patient’s health insurance generally covers palliative care services.	Hospice is a Medicare (federally funded) program. Many state Medicaid plans and private health insurance plans pay for hospice. A patient who chooses the Medicare hospice benefit agrees to give up treatments meant to cure disease. This is in return for other types of support and supplies.