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## Hospice Care

Hospice care gives people comfort and support in the last phases of an incurable disease so that they may live as fully and comfortably as possible. Learn what's included in hospice care, what to expect, and how to find the right hospice program.

- [What Is Hospice Care?](#)
- [Where Is Hospice Care Provided and How Is It Paid For?](#)
- [Finding a Hospice Program](#)

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## What Is Hospice Care?

Hospice care focuses on a person's quality of life as they near the end of life. Hospice treats the person and the symptoms of cancer, rather than the cancer itself. A team of health care professionals work together to manage symptoms, distress, and spiritual issues. Hospice care is family-centered and includes the person with cancer and loved ones in making decisions and planning care.

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## When should hospice care start?

Hospice care can be started when a person's cancer can no longer be controlled and they are expected to live no more than 6 months. Hospice can help make a person's quality of life the best possible during their last few months, weeks, or days.

Studies show that many times hospice isn't started as soon as it could be. This might be because:

- The doctor, patient, or family member thinks hospice means "giving up" or that there's no hope.
- Some people with cancer don't want to stop treatment, as they hope that it will still work.
- Some doctors or other cancer care team members don't suggest hospice.

Suggesting that a person with cancer consider hospice doesn't mean that the cancer care team is giving up. Bringing up hospice shows that they think the time has come to focus on managing symptoms and quality of life. Hospice can provide services that the cancer care team is not able to.

Don't be afraid to ask your cancer care team if you or a loved one would like to know more about hospice. It is important for you to know all your options.

## What is palliative care?

[Palliative care](#)<sup>1</sup> is also called supportive care, symptom management, or comfort care. It can be given along with treatment to people who are not in hospice care, but also is an important part of hospice care. Palliative care does not treat the cancer itself. It's used to prevent or treat symptoms and side effects as early as possible.

When palliative care is included in hospice, it can help manage discomfort, pain, nausea, and other side effects so that the person with cancer feels as good as possible and alert enough to enjoy the people around them.

Palliative care is given by a team that looks for and helps manage mental, physical, emotional, social, and spiritual issues that may come up. It tells the person with cancer and their caregivers the options and includes them in any decision making. It's about making sure that all care needs are addressed.

## How are hospice and palliative care different?

Hospice and palliative care both try to provide a better quality of life and relief from symptoms and side effects for people with a serious illness. Both have special care teams that address a person's physical, emotional, mental, social, and spiritual needs. Hospice care often includes palliative care, but they are not the same thing.

- Hospice care is given when a person's cancer cannot be controlled by cancer treatment. Hospice focuses on managing symptoms and side effects. Hospice care is given to people during their last 6 months of life.
- Palliative care can be given at **any time** during a serious illness such as cancer. Palliative care can be provided while the person with cancer **is receiving treatment** to cure or control their cancer. In other words, it can be given at the same time as chemo, radiation, immunotherapy, or other treatments for cancer.

What the care teams do:

- A hospice team coordinates most of the care during a person's last 6 months of life.
- A palliative care team works with the the person's cancer care team to help manage their symptoms and treatment side effects.

## Home care and inpatient hospice care

Hospice care is most often given in the home. But for some people, being at home isn't possible. So hospice care can also be given in a hospital, extended-care facility, or inpatient hospice.

Some people who would like to be at home need more intense care for a while. If that is the case, the home hospice team can arrange for inpatient care. The hospice team will stay involved in your care and you might be able to go back to home hospice when you and your caregiver are ready.

## Spiritual care

Each person with cancer can have different spiritual needs and religious beliefs. The hospice team will take the time to understand your needs. Hospice teams often include a spiritual care provider, such as a chaplain.

The hospice team will make sure you get the support you need. This might mean helping you think about what death means to you, help you say good-bye to loved ones, or help with a certain religious ceremony or ritual. If you would like to speak with a

religious leader from a certain religion, they can help arrange that for you as well.

### **Family meetings**

A hospice nurse or social worker can set up family meetings to keep people informed about how you are doing and what to expect. These meetings can give everyone a chance to share feelings, talk about what's going on and what's needed, and learn about death and the process of dying.

These meetings can also give support to caregivers, family members, and other loved ones and help lower their stress. Between meetings, the hospice staff may also give updates if there are changes.

### **Coordination of care**

The hospice team will manage all care for the person with cancer. They make sure that everyone who is giving care talks with each other and organizes their services. This might include the oncologist, hospice doctor, an inpatient facility, pharmacists, clergy, or funeral directors.

You and your caregivers should contact your hospice team if you're having a problem. They have someone on hand any time of the day or night. Hospice care makes sure that you and your loved ones know that you are not alone and can get help at any time.

### **Respite care**

Being a caregiver can be tiring and stressful. Many caregivers need a break to rest up and take care of themselves so they can continue to care for their loved one. Some hospices offer respite care. This lets caregivers and other loved ones step away from caregiving for a while.

Respite care can last as long as 5 days. During that time, the person with cancer is cared for either in the hospice facility or in beds that are set aside in nursing homes or hospitals. After the respite, the person with cancer will go back home with the caregiver.

### **Bereavement care**

Bereavement is the time a person feels sadness after losing a loved one. The hospice team works with people who have lost a loved one to help them through the grieving process. A trained volunteer, clergy member, or counselor can support caregivers, family members and other loved ones through visits, phone calls, or other contact, as

well as through support groups. The hospice team can refer family members, caregivers, and friends to other support if needed. Bereavement services are often offered for about a year after the person with cancer dies.

## Questions to ask your doctor about hospice care

If you are told that your cancer can no longer be controlled, you may want to ask your doctor or cancer care team about hospice care. You should know the benefits of hospice care, and any restrictions for treatment or other services. Here are some questions to consider asking:

- Do you think it's time to think about hospice? Why or why not?
- What will hospice offer me that you cannot?
- What will hospice not be able to offer me?
- Will I still be able to make decisions about my care?
- Where do you suggest I get hospice care?
- Do you think I will need special equipment?
- Will you still be involved in my care if I decide to get hospice services?
- What's the next step?
- Can someone help me contact hospices?
- Are there certain hospice providers you suggest?
- Is there a cost difference in hospice providers?
- What if I sign up for hospice then change my mind?
- What should I tell my family?
- What should I do if I have an emergency while I'm getting hospice care?

## Hyperlinks

1. [www.cancer.org/cancer/managing-cancer/palliative-care.html](http://www.cancer.org/cancer/managing-cancer/palliative-care.html)

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## Where Is Hospice Care Provided and How Is It Paid For?

No matter where it is given, hospice care is meant to be available 24 hours a day, 7 days a week. Your doctor, hospital social worker, case manager, or discharge planner can help you decide which type of hospice program is best for you and your loved ones.

- [Who provides hospice care?](#)
- [The primary caregiver](#)
- [The hospice team](#)
- [Where is hospice care given?](#)
- [Who pays for hospice care?](#)

## Who provides hospice care?

Hospice care is given by a hospice program or provider. The hospice program's team of professionals will work with the primary caregiver (usually a family member) to provide care and support 24 hours a day, 7 days a week.

## The primary caregiver

Every person who gets hospice care must have a [primary caregiver](#)<sup>1</sup>. This is often a family member or close friend. This caregiver will work with the hospice team and person with cancer to develop a care plan based on the person with cancer's specific needs and preferences. The primary caregiver will help make decisions with or for the person getting hospice care.

For people getting home hospice care in their home, the primary caregiver not only provides most of the physical care for the patient, but helps keep records of symptoms and other problems. Other people, such as other family members or hired caregivers, can help with physical care, but the primary caregiver is in charge of talking with the hospice team. They are also responsible for making sure that other caregivers are in the home, as needed.

For people getting hospice care in a setting other than at home, the primary caregiver is still part of the hospice care team. The caregiver attends team meetings, communicates about the patient's needs, and helps make care decisions.

If the person with cancer doesn't have someone who can be the primary caregiver, they should talk with the hospice team about other options. Options may depend on insurance and hospice agencies or programs in the area.

## The hospice team

The hospice team has many health care professionals to help manage the needs of the individual with cancer. The hospice team will often include:

- A hospice doctor or medical director who will often work with the person's cancer or primary care doctor
- Hospice nurses
- Social workers
- Counselors or therapists

- Dietitians
- Home health aides
- Clergy, chaplain, or other spiritual leaders
- Trained volunteers

Staff who work in hospice are trained in the special issues related to death and dying.

The hospice team will hold meetings and report regularly with the person with cancer, their caregiver and loved ones. The meetings are to review how the person in hospice is doing and to make sure that all their needs are being met. This includes symptom relief and social, emotional, and spiritual support.

## **Where is hospice care given?**

Hospice care can be given in many settings. This might include a person's home, a free-standing hospice facility, or through hospice programs in hospitals, nursing homes, assisted living centers, or other health care settings.

### **Home hospice care**

Most people get hospice care at home. For patients receiving in-home hospice care, the hospice nurses make regular visits and are always available by phone 24 hours a day, 7 days a week. Other members of the hospice team may also visit based on the patient's needs and insurance coverage.

People who live in places like residential facilities, certain types of assisted living, or nursing homes can often get hospice care there. This might be called in-home care since the facility is the patient's home. A primary caregiver is still needed, but staff at the facility may help provide some of the physical care depending on the type of facility and insurance coverage for hospice services.

### ***Caregiving in home hospice***

Home hospice often requires that someone be home with the patient 24 hours a day, 7 days a week. This will be the primary caregiver who will be trained to give much of the hands-on care. But the primary caregiver might need some help with this.

Finding someone who can be in the home around the clock might be a challenge. This is especially true for people who live alone or whose partner or adult children have full-time jobs. But creative [scheduling and teamwork](#)<sup>2</sup> among friends and loved ones can



help deal with this. The hospice team may be able to find volunteers to stay with the patient when needed as well.

*Members of the hospice staff will visit regularly to check on the person in hospice and their caregivers and loved ones. They will make sure that any symptoms are under control and give any needed care or services. How does home hospice get set up?*

Once the decision has been made to start hospice care, a hospice team member visits the person with cancer and their loved ones. During this visit, a plan to address care needs will be decided on together. Then the hospice team will arrange for any services that are needed. Then hospice nursing visits are set up to see how the person in hospice is doing. This allows for ongoing updates to the plan to address care needs as they often change.

To handle around-the-clock needs or crises, home hospice programs have a nurse who answers phone calls day and night, makes home visits, or sends out the team members you may need between scheduled visits. Medicare-certified hospices must provide nursing, pharmacy, and doctor services around the clock.

In an emergency, call hospice before calling 911 or going to the hospital. The hospice team will tell you what to do and set things up (such as calling 911), if needed.

If the person in hospice goes to the hospital or emergency room without first setting things up through hospice, hospice benefits might be put at risk and the person in hospice may be asked to pay for the visit or hospital stay.

### **Inpatient or free-standing hospices**

Many communities have free-standing hospices. These facilities provide hospice care in an inpatient setting but are different from hospitals. They include the same services as other types of hospice, but can also provide a higher level of support if symptoms can't be managed well enough in a home-setting.

The free-standing hospice might be helpful to people who don't have caregivers available at home or need around-the-clock physical care. They might also be able to give respite care when the primary caregiver isn't available for a period of time.

### **Nursing home or long-term care facility-based hospices**

Many nursing homes and other long-term care facilities have small hospice units. They might have nursing and other staff trained to care for people in hospice. Or they might work with hospice agencies in the local area to provide care. These can be a good option for people who need hospice care but don't have someone to take care of them at home.

### **Hospital-based hospices**

Some hospitals have hospice programs. This gives people in hospice and their loved ones easy access to support services and around-the-clock care to help control symptoms. Some hospitals have a special hospice unit, while others use a hospice team that visits people in hospice on any nursing unit. In other hospitals, the staff on the inpatient unit will act as the hospice team.

## **Who pays for hospice care?**

### **Government programs**

- Medicare covers hospice care costs through the Medicare Hospice Benefit. See [www.medicare.gov/coverage/hospice-care](http://www.medicare.gov/coverage/hospice-care)<sup>3</sup>.
- Veterans' Administration (VA) benefits also cover hospice care. See [www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice\\_Care.asp](http://www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice_Care.asp)<sup>4</sup>.
- Medicaid hospice coverage is different in each state. See [www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html](http://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html)<sup>5</sup>.

### **Private insurance**

Many work-based and private insurance plans provide some coverage for hospice care. Check with your insurance company to find out whether your plan covers hospice services and in what settings (where). Each insurance plan has its own criteria that people need to meet to be in hospice. You should also check to see what is covered.

### **If you are not insured or your insurance doesn't cover the full cost of hospice**

Some hospice providers offer care at no cost or at a reduced rate based on your ability to pay. They can often do this because of donations, grants, or other sources. Nearly all hospices have financial staff members who can help you with this, answer your questions, and help you get the care you need.

## Hyperlinks

1. [www.cancer.org/cancer/caregivers/what-a-caregiver-does/who-and-what-are-caregivers.html](http://www.cancer.org/cancer/caregivers/what-a-caregiver-does/who-and-what-are-caregivers.html)
2. [www.cancer.org/cancer/caregivers/what-a-caregiver-does/making-decisions.html](http://www.cancer.org/cancer/caregivers/what-a-caregiver-does/making-decisions.html)
3. [www.medicare.gov/coverage/hospice-care](http://www.medicare.gov/coverage/hospice-care)
4. [www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice\\_Care.asp](http://www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice_Care.asp)
5. [www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html](http://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html)

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# Finding a Hospice Program

Finding the hospice program that best meets your needs may take some time. Most areas have more than one hospice option. Your doctor, hospital discharge planner, nurse navigator, or case manager can help you find them. But you, your caregiver, and loved ones will need to decide which hospice is best for you.

- [How to find hospice care providers](#)
- [What to look for in a hospice program](#)
- [Is the agency a good fit for your needs?](#)
- [Changing hospice provider](#)

Start looking for hospice programs soon after you find out that your cancer can no longer be controlled. That way you will have time to think about your options and be able to help make the decision. Look for information about quality of care, what services they offer, staff training and expertise, and insurance coverage.

## How to find hospice care providers

### Local and state resources

Your doctor, navigator, case manager, social worker, or hospital discharge planner can often help you find hospices in your area. Hospice care providers also are listed in the phone book.

There are some local and state resources that might be able to help you find hospices in your area.

- Your local [Agency on Aging](#)<sup>1</sup>
- Your state's [hospice association](#)<sup>2</sup>
- Your [state department of health](#)<sup>3</sup>

### National resources

Organizations like the [National Hospice and Palliative Care Organization](#)<sup>4</sup>, or the [National Association for Home Care and Hospice Care](#)<sup>5</sup> can help you find hospice services near you.

## Check your insurance coverage

If you have insurance through Medicare, Medicaid or the Veteran's Administration, talk with your cancer care team about how you can get hospice benefits when they are needed.

If you have a private insurance plan, check with your insurer to determine if you have hospice coverage. If you do, find out what options you have, including any preferred hospice providers. Doing this ahead of time can save some stress later.

## What to look for in a hospice program

There are many things to look at in choosing the best hospice to meet your needs. First, you'll want to talk with your cancer care team and decide what services you'll need. Then you can look for hospice programs that offer those services. Here are some of the things you might ask about a home care agency.

### Is the hospice provider accredited by a nationally recognized group?

Check to see if an agency is accredited (certified and licensed) by a nationally recognized group, such as

- The [Joint Commission](#)<sup>6</sup>
- [Accreditation Commission for Health Care \(ACHC\)](#)<sup>7</sup>
- [Community Health Accreditation Partner \(CHAP\)](#)<sup>8</sup>

### Is the hospice provider approved and certified for Medicare?

Medicare-certified programs must meet set requirements for patient care and management. Many non-Medicare health plans follow Medicare's guidance on approval and certification. Payment for hospice services may depend on the program's approval or certification so check to be sure.

### Is the hospice provider licensed in your state?

You can check with your [state health department](#)<sup>9</sup> to find out if your state requires a hospice provider or program to be licensed.

### Will health care professionals recommend the program?

Consider finding out how many years the hospice program has been serving your community. Ask them to give you references from professionals – such as hospital staff or social workers – who have sent other people to them. Also, check with the [Better Business Bureau](#)<sup>10</sup>, your local Consumer Bureau, or the [State Attorneys General's office](#)<sup>11</sup>.

## **Is the agency a good fit for your needs?**

### **Ask for information**

Ask if the hospice has written information about the services they offer, who can be in their hospice, costs and how payments are made, what staff they have, and malpractice and liability insurance. Ask them to send you any brochures or other information about their services.

### **What services are offered?**

Most hospices offer similar services. Ask if you think you would need more specific services, such as those provided by physical therapists, pharmacists, dietitians, or family counselors. If needed, find out if the hospice provides medical equipment or other items that might improve your quality of life.

### **Is a primary caregiver required?**

Ask if the hospice requires you to have a primary caregiver and if someone needs to be with you all the time. Also ask what the primary caregiver will be expected to do. You may want to ask if the hospice can fill in to help with care around job schedules, travel plans, or other responsibilities. Or, if you live alone, ask what other options the hospice suggests.

### **How is the first evaluation done?**

Usually a nurse, social worker, or case manager comes to give you information about hospice and see what type of services you might need. Ask where this will be done, what the evaluation involves, and who should be there during the visit. You might also want to ask if your family or cancer care team will be involved in planning your care.

### **How are care plans created?**

Hospice providers should offer a care plan for each person who starts hospice. Ask how

the plan is developed and if you and your family will be able to give input. The care plan should list specific duties, work hours/days, and the name and telephone number of the person in charge of your care. The care plan should also be updated as your needs change. You can ask to see an example of a care plan.

### **Who will provide your care?**

You might want to ask about references for home care staff, and if the agency trains, supervises, and monitors its staff, caregivers, and volunteers. Ask how often the agency sends a supervisor to the patient's home to review the care being given to the patient. Ask if the caregivers are licensed and bonded. Ask who takes questions or complaints, and how issues are resolved.

### **How is payment handled?**

Find out how the hospice handles payment and billing. Read any agreement before signing it and be sure to keep a copy. Check with your health insurance provider to find out if there are any deductibles and co-pays. For example, certain medicines and respite care may require a co-pay. Ask about resources the agency provides to help you find financial assistance if it's needed.

### **Communication with the hospice provider**

The agency should have a 24-hour telephone number you can call any time you have questions or problems. Ask about the procedure for calling for problems, and for making and resolving concerns or complaints. How a hospice responds to your first call to ask about services may be a good sign of the kind of care to expect.

### **Emergency planning**

Ask if the agency has an emergency plan in case of bad weather, a power failure, or a natural disaster. You can ask to see a copy of the plan. In an emergency, you need to know if the hospice provider can still deliver services to your home.

### **Limits on treatment**

During your first visit, be sure to talk about the treatments you are currently getting. Talk to the hospice provider if you would like to continue any of them.

Some hospices (and insurance plans) will not cover things like dialysis, intravenous feedings, blood transfusions, and certain medicines. Some hospices do allow certain

medical treatments to continue, but this will likely depend on your insurance coverage as well. Find out how the hospice would handle your current treatments before committing to their services.

You'll also want to find out what the hospice would do if you developed new health problems that would be curable, such as a urinary tract infection or pneumonia. You may be more comfortable if they're able to treat these types of problems.

### **Inpatient or respite care**

Even if you plan to get hospice care at home, you might need inpatient or respite care at some point. You might want to ask questions about inpatient and respite care before deciding on a hospice provider.

Can hospital or respite care be provided?

What are the requirements for an inpatient admission?

How long can a patient stay in a hospital before it affects their hospice benefits?

What happens if the patient no longer needs inpatient care but can't go home?

Which hospitals or nursing homes contract with the hospice for inpatient care?

What kind of follow-up does the hospice provide for inpatients?

Does the hospice provide nursing, social work, and aide care during respite care or an inpatient stay?

### **Changing hospice provider**

If you don't like the hospice service you choose, you can change providers.

Check with your first insurance company to be sure that you can make this change without interrupting payments or services. They can tell you how to stop care with your first hospice agency and sign up with another one.



## Hyperlinks

1. <http://palliativedoctors.org/hospice/program>
2. [hospicefoundation.org/Hospice-Directory](https://hospicefoundation.org/Hospice-Directory)
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