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## Hospice Care

Hospice care provides compassionate care for people in the last phases of 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 provider.

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

*"You matter because of who you are. You matter to the last moment of your life, and we will do all we can , not only to help you die peacefully, but also to live until you die." -- Dame Cicely Saunders, founder of the first modern hospice*

Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

The hospice philosophy accepts death as the final stage of life: it affirms life, but does not try to hasten or postpone death. Hospice care treats the person and symptoms of the disease, rather than treating the disease itself. A team of professionals work together to manage symptoms so that a person's last days may be spent with dignity

and quality, surrounded by their loved ones. Hospice care is also family-centered – it includes the patient and the family in making decisions.

## **When should hospice care start?**

Hospice care is used when a disease, such as advanced cancer, gets to the point when treatment can no longer cure or control it. In general, hospice care should be used when a person is expected to live about 6 months or less if the illness runs its usual course. People with advanced cancer should have a discussion with their family members and doctor to decide together when hospice care should begin.

Studies show hospice care often is not started soon enough. Sometimes the doctor, patient, or family member will resist hospice because they think it means “giving up” or that there’s no hope. It’s important to know that you can leave hospice and go into active cancer treatment any time you want. But the hope that hospice brings is a quality life, making the best of each day during the last stages of advanced illness.

Some doctors don’t bring up hospice, so the patient or family member might decide to start the conversation. If your treatment isn’t working anymore and you’ve run out of treatment options, you might want to ask your doctor or a member of your cancer care team about hospice.

## **What does hospice care provide?**

All hospice providers must offer certain services. But they tend to have different approaches to service, staffing patterns, and types of support services offered.

### **Palliative care and symptom control**

Palliative care may also be called supportive care, symptom management, or comfort care. It can be given separately from hospice care (for example, while still in active cancer treatment), but it’s often a part of hospice care if cancer is no longer being treated because it has worsened. Palliative care does not treat the cancer itself. Instead, it’s used to prevent or treat symptoms and side effects as early as possible.

As part of hospice care, palliative care looks at how the cancer experience is affecting the whole person and help to relieve symptoms, pain, and stress. It gives patients options and allows them and their caregivers to take part in planning their care. It’s about assuring that all their care needs are addressed. The specialized professionals who are part of the palliative care team can help look for and manage mental, physical,

emotional, social, and spiritual issues that may come up.

The main goal of including palliative care into hospice services is to help patients be comfortable while allowing them to enjoy the last stage of life. This means that discomfort, pain, nausea, and other side effects are managed to make sure that you feel as good as possible, yet are alert enough to enjoy the people around you and make important decisions.

### **Home care and inpatient hospice care**

Although most hospice care is centered in the home, there might be times when you need to be in a hospital, extended-care facility, or an inpatient hospice center. Your home hospice team can arrange for inpatient care and will stay involved in your care and with your family. You can go back to in-home care when you and your family are ready.

### **Spiritual care**

Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet your specific needs. It might include helping you look at what death means to you, helping you say good-bye, or helping with a certain religious ceremony or ritual.

### **Family meetings**

Regularly scheduled meetings, often led by the hospice nurse or social worker, keep family members informed about your condition and what to expect. These meetings also give everyone a chance to share feelings, talk about what's happening and what's needed, and learn about death and the process of dying. Family members can get great support and stress relief through these meetings. Daily updates may also be given informally as the nurse or nursing assistant talks with you and your caregivers during routine visits.

### **Coordination of care**

The hospice team coordinates and supervises all care 7 days a week, 24 hours a day. This team is responsible for making sure that all involved services share information. This may include the inpatient facility, the doctor, and other community professionals, such as pharmacists, clergy, and funeral directors. You and your caregivers are encouraged to contact your hospice team if you're having a problem, any time of the day or night. There's always someone on call to help you with whatever may arise. Hospice care assures you and your family that you are not alone and can get help at

any time.

### **Respite care**

For patients being cared for at home, some hospice services offer respite care to allow friends and family some time away from caregiving. Respite care can be given in up to 5-day periods of time, during which the person with cancer is cared for either in the hospice facility or in beds that are set aside in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while you're cared for in an inpatient setting.

### **Bereavement care**

Bereavement is the period of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or other contact, as well as through support groups. The hospice team can refer family members and caregiving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death.

### **Is hospice care the same as palliative care?**

Hospice care and palliative care both aim to provide 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. But although hospice care often includes palliative care, they are not the same thing.

### **How they are different**

- When care is given: Hospice care is offered and provided for patients during their last phase of an incurable illness or near the end of life, such as in some people with advanced or metastatic cancer. Palliative care can be offered and provided at any stage of a serious illness.
- What other care can be given: Hospice care is provided when there is no active or curative treatment being given for the serious illness. "Treatment" during hospice care involves managing symptoms and side effects. Palliative care can be provided while the patient is receiving active treatment. In other words, it can be given at the same time as chemo, radiation, or immunotherapy for cancer.

- What the care team does: A hospice care team coordinates the majority of care for a patient, and communicates with the patient's medical care team. A palliative care team is separate from the patient's medical care team that's giving and managing treatment for the illness, but communicates with the medical care team.

You can learn more in [How and Where Is Palliative Care Provided and How Is It Paid for?](#)<sup>1</sup> and [How and Where Is Hospice Care Provided and How Is It Paid for?](#)

## Hyperlinks

1. [www.cancer.org/treatment/treatments-and-side-effects/palliative-care/who-provides-palliative-care.html](http://www.cancer.org/treatment/treatments-and-side-effects/palliative-care/who-provides-palliative-care.html)

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

### Who provides hospice care?

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

### The primary caregiver

When someone enters into hospice care, they are asked to pick someone to be their **primary caregiver**. Usually this is a family member or close friend. The primary caregiver works with the hospice team and patient to develop a care plan based on the patient's specific needs and preferences. The primary caregiver continues to be the main person to help make decisions for the patient throughout the length of hospice care.

For patients receiving in-home hospice care, the primary caregiver not only provides most of the physical care for the patient, but also helps with keeping records of symptoms and other problems. The primary caregiver can share the physical care responsibilities with other family members or hired caregivers, but takes responsibility for communication with the hospice team, and for scheduling caregivers in the home as needed.

For patients getting hospice care in a setting other than at home, the primary caregiver is considered to be a part of the hospice care team. The primary caregiver attends team meetings, helping to communicate the patient's needs and make care decisions.

If there is no family available to take on the primary caregiver role, the patient needs to work with the hospice team member who first comes to talk about services. They will also need to talk to their insurance company. There may or may not be other care setting options available, depending on insurance coverage and the types of hospice agencies or programs that are available.

## **The hospice team**

In most cases, an interdisciplinary health care team manages hospice care. This means there are many health care professionals involved in helping to manage the patient's care, based on each patient's needs and preferences. Typically, the hospice doctor or medical director is in charge of the patient's care, though the cancer doctor and/or primary care doctor can be involved, too. Doctors, nurses, social workers, counselors, dietitians, home health aides, clergy, therapists, and trained volunteers work together to help the patient and primary caregiver make decisions about the care that's needed. There will be regular reports, as well as family and care team meetings to evaluate the patient's status to be sure all the patient's needs are being addressed. Hospice care includes palliative care to relieve symptoms and give social, emotional, and spiritual support.

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 depending on the patient's needs and insurance coverage. For patients getting hospice care in places other than their home, regular visits or around-the-clock care may be options depending on the type of care setting, the needs of the patient, and insurance coverage.

Hospice care staff members are kind and caring. They communicate well, are good listeners, and want to support families during the last stage of an advanced illness. They're usually specially trained in the unique issues surrounding death and dying and are given ongoing education and support to help with the emotional demands of the job.

Hospice volunteers are a big part of the hospice team, too. They play an important role in planning and giving hospice care in the United States. Volunteers may be health professionals or lay people who provide services that range from hands-on personal care to working in the hospice office or fundraising.

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

Hospice agencies most often provide services in the patient's home. Hospice care can also be provided by free-standing or independent facilities specially designed to provide

hospice care, or through programs based in hospitals, nursing homes, assisted living centers, or other health care systems. Some hospice agencies offer both care in the home and care in an inpatient facility.

In any setting, hospice care is designed to be available 24 hours a day, 7 days a week. Your doctor, hospital social worker, case manager, or discharge planner can be helpful in deciding which type of hospice program is best for you and your family.

### **Home hospice care**

Most people get hospice care at home. People who live in places like residential facilities, certain types of assisted living, or nursing homes can get hospice care there, too. If hospice care is needed for a person living in one of these facilities, it may be considered in-home care since the facility is the patient's home. Health insurance coverage can vary on this.

Most hospice programs offer home hospice services. Although home hospice programs are staffed by nurses, doctors, and other professionals, the primary caregiver is usually a family member or friend who's responsible for around-the-clock supervision of the patient. For care given in the home, this person will need to be with the patient most of the time and will be trained to provide much of the hands-on care. For care given in another facility, a primary caregiver is still needed, but staff may help provide some of the physical care depending on the type of facility and insurance coverage for hospice services.

It's important to know that home hospice may require that someone be home with the patient 24 hours a day, 7 days a week. This may be a problem for people who live alone or whose partner or adult children have full-time jobs. But in most cases, creative scheduling and good team work among friends and loved ones can overcome this problem. Members of the hospice staff will visit regularly to check on the patient, family, and caregivers. They will make sure that any symptoms are under control and give any needed care and services.

Care begins when the patient is admitted to the hospice program, which generally means that a hospice team member visits you at home to learn about you and your needs. Sometimes they will visit you in the hospital if you have decided to receive hospice care but haven't yet been discharged home. Once at home or when care is set to start at home, your primary caregiver is responsible for physical care or for scheduling people to help with your care. The hospice team may be able to find volunteers to stay with the patient when needed, too. Hospice nursing visits are set up so that you can be re-evaluated regularly.



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

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

Many communities have inpatient hospice facilities. These may be operated by a hospice agency that also offers in-home care. Or, they can be free-standing, independently owned hospices that may or may not also offer in-home services. The free-standing hospice can be helpful to patients who don't have caregivers available at home or need around-the-clock physical care. Respite care (temporary care for times when the primary caregiver isn't available) may also be provided in some inpatient hospice facilities.

### **Hospital-based hospices**

Hospitals often have a hospice program. This gives patients and their families easy access to support services, and allows the patient to get around-the-clock care to help get control of symptoms. Some hospitals have a special hospice unit, while others use a hospice team that visits patients with advanced disease on any nursing unit. In other hospitals, the staff on the patient's unit will act as the hospice team. The patient returns to in-home hospice care when they are again comfortable.

### **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 specially trained nursing staff to care for hospice patients, or they might make arrangements with home health agencies or independent community-based hospices to provide care. This can be a good option for people who need hospice care but don't have someone to take care of them at home.

## **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>1</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>2</sup>.

- The coverage of hospice care by **Medicaid** is optional and varies by state. See [www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html](http://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html)<sup>3</sup>.

## Private insurance

Many work-based and private insurance plans provide at least some coverage for hospice care. It's best to check with your insurance company because there are different types of plans available that may or may not cover hospice services. There are also different ways a person can be considered eligible for hospice care and what costs are covered can vary based on the health plan you have.

## If you are uninsured

For people who are not insured, or who may not have full coverage for hospice services, some hospice organizations may 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 support staff who can help you with this, answer your questions, and help you get the care you need.

## Hyperlinks

1. [www.medicare.gov/coverage/hospice-care](http://www.medicare.gov/coverage/hospice-care)
2. [www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice\\_Care.asp](http://www.va.gov/GERIATRICS/Guide/LongTermCare/Hospice_Care.asp)
3. [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 provider or program that best meets your needs may take some time and searching, but it's time well spent. Most communities have more than one hospice provider. Your doctor, hospital discharge planner, or case manager can help you find them, but you and your family will need to decide which agency you'll use.

You and your family should look for hospice providers early in the care of your advanced illness, while you have the strength and ability to help make the decision. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage all need to be considered.

### Where to find hospice care providers

#### Local referrals

Your doctor or hospital discharge planner can help you find hospices in your area. Hospice care providers also are listed in the phone book. The American Cancer Society can provide information and referrals in some areas; call 1-800-227-2345 or [search online](#)<sup>1</sup>. Referral services may also be offered by an Agency on Aging or a local United Way chapter.

#### State resources

If your doctor or health care team does not provide you a list of hospice agencies in your area, you can contact your state's hospice organization or its department of health or social services to get a list of licensed agencies. The state health department oversees certification of hospice services. Certification allows them to get funding from Medicare and, in some states, also from Medicaid. Check your phone book for other resources in your area or search online for your state hospice organization.

## **National resources**

National organizations like the [National Hospice and Palliative Care Organization](#)<sup>2</sup>, or the [National Association for Home Care and Hospice Care](#)<sup>3</sup> can help you find hospice services near you.

## **Check your insurance coverage**

If you have a Medicare, Veteran's Administration, or Medicaid health plan, talk with your health care team about how you can get hospice benefits when they are needed. If you have a work-based or private insurance plan, check with your insurer to determine if you have hospice coverage. If you do, find out what options you may 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 a number of things you might want to ask about when deciding on a hospice program. Here are some ideas to get you started on a list of questions:

### **Is the agency reputable?**

#### ***Accreditation 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>4</sup>. The Joint Commission is an independent, not-for-profit organization that evaluates and accredits health care organizations and programs. It's an important resource in selecting quality health care services.

#### ***Approval and certification for Medicare***

It's best to be sure the hospice program is approved for Medicare participation. Medicare-certified programs have to meet approval for certain minimum

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.

### ***State licensure***

Check to see if your state requires a hospice provider or program to be licensed. You can check with your state health department to find out.

### ***References from professionals***

Consider finding out how many years the agency has been serving your community. Ask the agency to give you references from professionals – such as a hospital or community social workers – who have used them for other patients. Ask for names and telephone numbers. Consider talking with these people about their experiences with the hospice. Also, check with the Better Business Bureau, your local Consumer Bureau, or the State Attorney General's office.

### ***Patient's rights and responsibilities***

Ask to see a copy of the agency's patient's rights and responsibilities information. Ask them to explain anything you don't understand.

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

#### ***Ask for brochures and consumer information***

Be sure to ask if the hospice agency has written statements outlining services, eligibility rules, costs and payment procedures, employee job descriptions, and malpractice and liability insurance. Ask them to send you any brochures or other available information about their services.

#### ***What are the requirements for admission?***

Find out if the hospice provider or program works with each patient and family to apply policies or negotiate differences? If the hospice imposes conditions that don't feel comfortable, it may be a sign that it's not a good fit for you. If you're not sure whether you or your loved one qualifies for hospice – or whether you even want it – you may want to ask if there is someone from the agency willing to meet with you to help you talk through these concerns.

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

Hospice agencies should offer a care plan that is developed for each new patient. Consider asking if the plan is carefully and professionally developed with input from you and your family. The care plan should be written out and copies given to everyone involved. 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 a sample care plan.

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

Ask if the hospice requires you to have a primary caregiver as a condition of admission. If so, ask about responsibilities that are expected of the primary caregiver, such as if they or someone else needs to be with you all the time. 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 initial evaluation conducted?***

Usually a nurse, social worker, or case manager comes to talk to you about and evaluate the types of services you may need. Ask about where this is done and what the evaluation involves, including who should be present during the visit. It may be important to ask if the initial evaluation includes input from your family doctor and/or other professionals already involved in your care.

***What services are offered?***

Be sure to find out how quickly the hospice can start services. Some may have certain geographic service boundaries. You may want to ask if they offer specialized services such as rehabilitation therapists, pharmacists, dietitians, or family counselors when these could improve your comfort. If needed, find out if the hospice provides medical equipment or other items that might improve your quality of life.

***Who will be providing care?***

You may want to ask about references for home care staff, and if the agency trains, supervises, and monitor 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 whether the caregivers are licensed and bonded. Ask about who takes questions or complaints, and how issues are resolved.

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

One important aspect is how the agency handles payment and billing. Read the agreement carefully 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 to expect. 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***

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***

Something else to consider is 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 case of an emergency, you need to know whether the agency can still deliver services at your home.

### ***Limits on treatment***

During your first visit be sure to talk about all of the treatments you are currently getting. If you want to continue these things you must make it clear to the hospice provider. Some hospices will not cover things like dialysis, total parenteral nutrition (TPN, or intravenous feedings), blood transfusions, or certain drugs. But some hospices do allow you to add hospice care to your certain types of medical treatment. Find out how the hospice would handle your current treatments before committing to their services.

You'll also want to find out how the hospice would manage any 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 these types of questions about inpatient and respite care:

- Where is such care provided?
- What are the requirements for an inpatient admission?
- How long can a patient stay?
- What happens if the patient no longer needs inpatient care but can't go home?
- Can you tour the inpatient unit or residential facility?
- 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 as much nursing, social work, and aide care for each inpatient as it does for those at home?
- Does the agency explain your rights and responsibilities as a patient? Ask to see a copy of the agency's patient's rights and responsibilities information.

## Changing providers

Keep in mind if you don't like the hospice service you choose, you can change providers.

Check with your insurance company to be sure how to go about this 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. [www.cancer.org/treatment/support-programs-and-services.html](http://www.cancer.org/treatment/support-programs-and-services.html)
2. [www.nhpco.org/](http://www.nhpco.org/)
3. [www.nahc.org/](http://www.nahc.org/)
4. [www.jointcommission.org/](http://www.jointcommission.org/)

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## Questions to Ask Your Doctor About Hospice Care

If you are told your cancer has advanced, you may want to ask your doctor or health care team about hospice care. You should understand the expected benefits of hospice care, along with any restrictions for treatment or other services if you decide to start hospice care. Here are some general questions to consider asking. (For questions to ask when choosing a hospice service, see [Finding a Hospice Program](#).)

- Do you think it's time to consider hospice care? Why or why not?
- What will hospice offer me that you cannot?
- What will hospice not be able to offer me?
- Will I be in charge of the decisions that are made?
- Where do you recommend I receive hospice care?
- Do you think I need special equipment?
- Will you still be involved in my care if I decide to get hospice services?
- What's the next step?
- Should I contact hospice services?
- Do you have a recommended list of hospice providers?
- Is there a cost difference between hospice providers?
- What if I sign up for hospice then change my mind?
- What should I tell my family?

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