

# Hospice Care



Care and Choice at the End of Life

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**Compassion & Choices** is the nation's oldest, largest and most active nonprofit working to improve care and expand options for the end of life.

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## What Is Hospice?

Hospice is a service that provides compassionate medical care at the end of life. The goal is to maintain or improve quality of life for someone whose illness, disease or condition is unlikely to be cured. Each patient's individualized care plan is designed to address the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care also offers practical support for the caregiver(s) during the illness and grief support after the death. For those who have an appropriate medical referral, the cost of hospice care is usually covered by Medicare, Medicaid or a 3rd party insurance.

## What Does a Hospice Provider Do?

Based on an individual's needs, hospice care is provided by a team of healthcare professionals and volunteers who work to provide comfort to patients who are in the terminal phase of an illness and are no longer seeking life-prolonging treatment. Members of the team generally include a registered nurse, a physician, a social worker, a spiritual counselor, healthcare aides and trained volunteers.

The patient's primary care physician or other doctor makes the referral for hospice care following a determination that the patient will most likely die of their disease within six months or less. The hospice team provides comfort care, which focuses on achieving the best quality of life through aggressive symptom management aimed at relieving pain and suffering. They also provide psychosocial and spiritual comfort and support as desired by the patient or by significant others. The patient and family are considered the unit of care.

Hospice is almost always provided in the patient's home, but arrangements can be made for hospice services to be provided wherever the patient is most comfortable, for example, in the home of a family member or friend. Hospice can generally arrange to place a healthcare aide in the home for several hours a day. It is important to note that the patient and family can ask for as little or as much support as they want or need.

Hospice services are also provided in dedicated hospice facilities, skilled nursing facilities (SNF), assisted living facilities, hospitals and long-term care facilities.

## What Kind of Services Are Available for the Family and/or Caregivers?

In many cases, family members are the patient's primary caregivers. Hospice recognizes that loved ones have their own special needs for support. As a relationship with the hospice begins, hospice staff will want to know how best to support the patient and family during this time. Support can take many different forms, including visits with the patient and family members; telephone calls to loved ones about the patient's condition; and the provision of volunteers to assist with patient and family needs.

## How Does a Hospice Referral Happen?

It is often the case that a physician will tell their patient that their disease has progressed to the point where they know of no further treatments to try to help them. At this point, the physician will write a referral for hospice care. A patient may also decide to stop any further treatment and allow the dying process to take its course. It is a person's right to choose this path, as unwanted or unnecessary treatment can be harsh and debilitating, and severely affect one's quality of life. If that is the case and you have not already discussed your interest in hospice care with your physician, we suggest that you do so.

In the event that your physician is reluctant to refer you to hospice in a timely manner, many hospices will provide a free in-home evaluation to determine whether your medical condition merits hospice care. If the hospice providers agree that you are now eligible for their services, the hospice physician will contact your primary care physician to obtain your medical history and will provide for your care. You can contact any hospice in your community to make arrangements for this assessment.

The following are a few ways you can start the conversation with your physician:

*I want to talk with you about how I can maintain control of my life as my illness progresses. I appreciate all you have done to help me fight this disease, but I have come to a place where I want to redirect my remaining energy. The quality of my life is much more important to me than the number of days I have left. I believe it is time to talk about a referral to hospice and comfort care only.*

*I want my pain to be kept under control, and I want to be kept comfortable until my death — even if this means I might sleep all of the time. I am no longer interested in traditional or experimental procedures designed to prolong my life. At this time, I am seeking only one thing: the peace of mind that comes with knowing hospice will be available to me at the time of my choosing.*

## Finding and Selecting a Hospice

Many communities have numerous hospice providers, and you should be able to find one that is aligned with your end-of-life values. It's important to choose a hospice that is a good fit for your priorities and beliefs, one that will honor your end-of-life care preferences. Some hospices will support you in the full range of end-of-life options such as palliative sedation, voluntarily stopping eating and drinking, and medical aid in dying, while others will not.

You can begin learning about different hospices in your community even if you have not yet received a referral:

- » Ask friends or family who have had experiences with hospices in your community for advice. A personal recommendation is a good place to begin.
- » Ask your referring physician if they prefer a particular hospice and why. This does not mean you have to choose that one.
- » Some healthcare systems have policies that could prevent your healthcare providers from supporting you with the full range of end-of-life options (e.g. medical aid in dying, voluntarily stopping eating and drinking (VSED), palliative sedation). If end-of-life options are important to you, ask how the hospice will be able to support you with these options.
- » Some insurance companies pay for only a particular hospice. When you contact a hospice, ask whether they take your insurance.
- » In addition, you can contact the National Hospice and Palliative Care Organization (NHPCO), which represents most hospice programs in the United States. To find an NHPCO member hospice, call NHPCO's HelpLine at 1.800.658.8898 or visit [NHPCO.org](https://www.nhpc.org).

Once you've found a hospice, call and ask to speak to an intake person. Make sure to take notes. Explain your current medical situation, tell them where you live, and ask questions from the list below that are important to you.

### THINGS TO CONSIDER WHEN SELECTING A HOSPICE

*Listen for concern, kindness and thoughtful responses.*

#### **Patient care**

- » How will the hospice staff work with me and my loved ones, and honor my wishes?
- » How are family caregivers provided the information and training they need to care for me at home?
- » Is respite care (relief for the caregiver) readily available?
- » Are loved ones told what to expect in the dying process and what happens after I die?
- » If I decide to voluntarily stop eating and drinking as I near death, will hospice support me and my family in that process?

- » If my suffering can't be controlled, will hospice provide palliative sedation to keep me unconscious and comfortable until I die?
- » If I live in an authorized state for medical aid in dying, will hospice support me and my family in that process?
- » What will happen if care cannot be managed at home?
- » What bereavement services are available for my family after I die?

### **Physician role**

- » What is the role of my physician once hospice care begins?
- » Can I still see my own physician if I want to?
- » How will the hospice physician oversee my care and work with my doctor?

### **Volunteers**

- » What services do volunteers offer?

### **Nursing home residents and other residential care settings (if applicable)**

- » How does the hospice provide services for residents in different care settings?

### **Comfort and pain management**

- » Will the hospice staff regularly discuss and routinely evaluate pain control and symptom management with me and my family?
- » How quickly does the hospice staff respond to requests for additional pain medication? What is the process for that?
- » In the event that the usual doses of oral pain medications are not sufficient to relieve acute distress, is palliative sedation, or total sedation, an option? (*Palliative sedation is the medical procedure of intravenous pain medication given to the point of constant deep sleep until death occurs. Some hospices may need to transfer the patient to a healthcare facility in order to provide this service.*)
- » How will you meet the spiritual and emotional needs of me and my family?

### **After-hours care**

- » How quickly does the hospice respond to after-hours emergencies?
- » How are calls and visits handled when death occurs?
- » What is your weekend and night coverage? (There should be a nurse available by phone 24 hours a day, seven days a week.)
- » Are other resources, such as a chaplain or social worker, available after hours?

## Paying for hospice care

- » Are all of the costs of hospice care covered by my health insurance?
- » What services will we have to pay for out of pocket? Are any services provided at no charge?

## Making the decision

After you have completed your search, compare the notes you have taken. If you are able, talk with a friend or family member, and seek their input. Do not hesitate to call a hospice back if you need clarification or have lingering questions. These are the people who will play a vital role in the last months and days of your life. You want to feel confident that you will be in good hands and treated competently, respectfully and compassionately.

## What happens once you have selected a hospice

- » A nurse and/or social worker will come to your home and complete an intake interview. This visit may last more than an hour. Make sure any friends or family who will be involved in your care are present.
- » **Take care of yourself.** The interview consists of many questions and forms to sign. Depending on how you feel that day, it may be exhausting. If you become too weak or tired to pay attention, ask to have them return the next day. Remember, you are in charge of your care.
- » If you have a preference for a male or female nurse, let them know.
- » When you meet your nurse for the first time, describe any special needs or concerns you have. Try to let your caregivers know what you want. Do you like to be kept informed? Are you uncomfortable discussing your feelings? Do you have any specific fears about pain or memories of difficult deaths that others have experienced? Are there family issues that are contributing to your stress? The better informed your hospice providers are about your unique concerns, the better able they will be to meet your needs.
- » Read through the hospice materials you are given. Make sure everyone involved in your care reads them. Don't hesitate to ask questions when your nurse visits, or call the hospice in-between visits if questions arise that trouble you.
- » **You are in charge.** If you want the nurse or other members of the hospice team (social workers, spiritual counselors, volunteers or aides) to visit more or less frequently, let them know. If you are uncomfortable with the nurse who has been assigned to you, call the hospice and ask to speak with the nursing supervisor. Explain your concerns and explore whether another nurse can be assigned to your care.
- » If you find that the hospice you have chosen is not being responsive to your needs, even though you have brought a matter to their attention, you may always "fire" them and find a new one. (This rarely is necessary, but it is certainly an option to consider.) Check with your insurance provider regarding this possibility.

## **If a medical crisis develops**

Because you are now a hospice patient, the response to life-threatening situations may differ from what would happen in an earlier stage of your illness. For instance:

- » Hospice should always be called before calling 911, and they will discuss this with you. Make sure anyone staying in the home knows this. Post the hospice number near every phone. Discuss with your hospice nurse what should be done in the event of a medical problem like a fall or a suspected broken bone.
- » Hospice will provide you with an out-of-hospital do-not-resuscitate order form (DNR and/or POLST/MOST). If emergency services are accidentally called to your home, this document will inform them that they are not legally bound to perform CPR or resuscitation efforts.