

HOSPICE CARE

A Consumer's Guide to Selecting
a Hospice Program



Caring Connections
a program of the
National Hospice and Palliative Care Organization

Hospice

It's About How You LIVE

*One of our greatest fears is dying alone
in a sterile, impersonal surrounding.*

*We don't want to be hooked up to tubes,
and cut off from our family,
friends, and loved ones, and things that are familiar.*

We also fear dying in pain.

*We would prefer, if possible,
to spend our final phase of life at home —
pain-free and alert as possible — surrounded by
the people and things we love.*

*An end-of-life care option that provides
dying patients and their loved ones with
comfort, compassion, and dignity does exist.*

It's called hospice.

*This brochure will help you learn more about hospice
so you and your loved ones can make an
educated decision about end-of-life care.*

*It contains information on what hospice is,
what services are provided, and the key
questions to ask when selecting a hospice program.*

*The brochure will help you choose a hospice program
that best suits your needs and wishes,
as well as those of your loved ones.*



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How did hospice begin in America?

The modern-day American hospice movement began in 1974 with establishment of the Connecticut Hospice in New Haven. It was founded on the model of care best identified with Dame Cicely Saunders, MD, who opened her now-famous Saint Christopher's Hospice in 1967 in Sydenham, England. This center became the model for comprehensive whole person and family care at the end of life. Hospice programs have been at the forefront of efforts in America to involve and include families in providing quality end-of-life care.



What is hospice?

Considered to be the model for quality, compassionate care at the end-of-life, hospice involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is extended to the patient's loved ones, as well. At the center of hospice is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

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The focus is on caring, not curing and, in most cases, care is provided in the patient's home. Hospice also is provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness.

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff are on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The team usually consists of:

- ◆ The person receiving care
- ◆ The person's family/caregiver
- ◆ The person's personal physician and/or hospice physician (or medical director)
- ◆ Nurses
- ◆ Home health aides
- ◆ Social workers
- ◆ Counselors and spiritual caregivers
- ◆ Trained volunteers
- ◆ Other professionals, such as speech, physical, and occupational therapists, as needed

The plan also outlines the medical and support services required such as nursing care, personal care (*dressing, bathing, etc.*), social services, physician visits, counseling, and homemaker services. It also identifies the medical equipment, tests, procedures, medication and treatments necessary to provide high-quality comfort care.



How do I go about choosing a hospice?

“How do I decide if hospice is the appropriate care choice for me?”

“How do I choose among different hospice programs?”

“Are all hospices the same?”

“If there is only one hospice program in my community, how do I determine if it is a good one?”

These are common questions for patients and loved ones facing life-threatening illnesses. Determining if a hospice is right for you may best be learned from interviewing different hospices and talking to those you trust who are familiar with hospice programs in your area. Resources for information about hospice in your community include:

- ◆ Physicians, nurses, and other healthcare professionals
- ◆ Social workers, clergy, and other counselors
- ◆ Friends or neighbors who have had direct experience with hospice care
- ◆ Local or state Office on Aging or senior centers
- ◆ Various medical and health-related Internet sites
- ◆ Your local yellow pages or directory information

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 the web site at www.nhpc.org.

Next, call or visit the hospice providers on your list. Talk with hospice personnel to find out what services are available from individual programs in the community. A “Question Checklist” is provided at the end of this brochure. This checklist should be useful in evaluating the different types of care and services each hospice provides.

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What kind of services should I expect from a hospice?

Hospice services are available to patients with life-limiting illnesses who can no longer benefit from curative treatment and usually have a life expectancy of six months or less, as determined by a physician. Hospice services typically include:

- ◆ Physician services for the medical direction of the patient's care, provided by either the patient's personal physician or a physician affiliated with a hospice program
- ◆ Regular home care visits by registered nurses and licensed practical nurses to monitor the patient's condition and to provide appropriate care and maintain patient comfort
- ◆ Home health aide and homemaker services, attending to the patient's personal needs
- ◆ Chaplain services for the patient and/or loved ones
- ◆ Social work and counseling services
- ◆ Bereavement counseling to help patients and their loved ones with grief and loss
- ◆ Medical equipment (*i.e.*, hospital beds)
- ◆ Medical supplies (*i.e.*, bandages and catheters)
- ◆ Medications for symptom control and pain relief
- ◆ Volunteer support to assist loved ones
- ◆ Physical, speech, and occupational therapy
- ◆ Dietary counseling



How does hospice care begin?

Typically, hospice care starts as soon as a formal request or "referral" is made by the patient's doctor. Often a hospice program representative will make an effort to visit the patient on the day the referral is made, providing the visit meets the needs and schedule of the patient and family/caregiver. Usually, care is ready to begin within a day or two of a referral. However, in urgent situations, service may begin sooner.



What kind of support is available to the family/caregiver?

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In many cases, family members are the patient's primary caregivers. Additionally, 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 about the primary caregiver's priorities. They will also 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, including family members who live at a distance, about the patient's condition; and the provision of volunteers to assist with patient and family needs.



Counseling services for the patient and loved ones are an important part of hospice. After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, and support groups. Individual counseling may be offered by the hospice or the hospice may make a referral to a community resource.



What role does the physician play?

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It is important to find out what the role of the patient's primary doctor will be once the patient begins receiving hospice care. Most often, hospice patients can choose to have their personal doctor involved in the medical care. Both the patient's physician and the hospice medical director may work together to coordinate the patient's medical care, especially when symptoms are difficult to manage. Regardless, a physician's involvement is important to ensure quality hospice care. The hospice medical director is also available to answer questions you may have regarding hospice medical care.

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What role does the hospice volunteer serve?

Hospice volunteers enhance quality of life and help reduce the burden of caregiving. They are generally available to provide different types of support to patients and their loved ones including running errands, preparing light meals, staying with a patient to give family members a break, lending emotional support and companionship to patients and family members, and helping out with light housekeeping.

Because hospice volunteers spend time in patients' and families' homes, it is important for a hospice program to have some type of application and interview process. In addition, hospice programs should have an organized training program for their patient care volunteers. Areas covered by these training programs often include confidentiality, listening skills, signs and symptoms of approaching death, working with families, loss and grief, and bereavement support.



How does hospice work to keep the patient comfortable?

Many patients experience pain and other distressing symptoms as illness progresses. Hospice staff receive special training to effectively anticipate, assess, treat, and prevent all types of physical symptoms that cause discomfort and distress. Because symptom management, especially pain, is such an important component of hospice, many hospice programs have developed ways to measure how well they do in this area through surveys and studies. Hospice staff work with the patient's physician to make sure that medication, therapies, and procedures are designed to achieve the goals outlined in the patient's care plan. That plan is evaluated frequently to reflect changes and new goals.



Is hospice available after hours?

Hospice is available "on-call" after the administrative office has closed, seven days a week, 24 hours a day. Most hospices have nurses available to respond to a call for help within minutes, if necessary. Some hospice programs have chaplains and social workers on call, as well.

Understand how hospice can help no matter where a person lives.



Can I be cared for by hospice if I reside in a nursing home or other type of long-term care facility?

Hospice services can be provided to a person whose place of residence is a nursing home. This means the patient receives specialized visits from hospice nurses, home health aides, chaplains, social workers, and volunteers, in addition to other care and services provided by the nursing home. The hospice and the nursing home should have a written agreement in place in order for hospice to serve residents.



What happens if I cannot stay at home due to my increasing care needs and require an alternate place to stay during my final phase of life?

A small, but growing, number of hospice programs have their own hospice facilities or have arrangements with freestanding “hospice houses,” hospitals, or inpatient residential centers to care for patients who cannot reside in a private residence. It is best to find out in advance whether insurance covers this type of care and how the hospice arranges for payment.



How do I ensure that quality hospice care is provided?

Many hospices use tools to evaluate how well they are doing in relation to quality hospice standards. In addition, most programs conduct family satisfaction surveys to get feedback on the performance of their programs. To assist hospice programs in these efforts, the



National Hospice and Palliative Care Organization has developed recommended standards — entitled “*Standards of Practice for Hospice Programs*” — as one means of self- and field-evaluation.

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Do state and federal reviewers inspect and evaluate hospices?

There are federal, state, and professional organizations that evaluate hospice programs to protect consumers. These organizations survey hospices to see whether they are providing care that meets defined standards. These reviews consider the customary practices of the hospice, such as policies and procedures, medical records, personal records, evaluation studies, and in many cases also include visits to patients and families currently under care of the hospice. As you research different hospice programs, ask hospice representatives to share the survey report with you and to answer any questions you may have about this complex document.



How do I pay for hospice?

Medicare, private health insurance, and Medicaid (in 43 states) cover hospice care for patients who meet eligibility criteria. As with any healthcare program, there may be “co-pays” and deductibles that families pay to receive care. Many hospices also rely on community support for donations. While each hospice has its own policies concerning payment for care, it is a tradition of hospice care to offer services based upon need, rather than the ability to pay. *(For more information about the Medicare Hospice Benefit, the services it covers, and eligibility requirements, refer to the Caring Connections brochure, “Hospice Care and the Medicare Hospice Benefit.”)*



When is the right time to ask about hospice?

Now is the best time to learn more about hospice and ask questions about what to expect. Although end-of-life care may be difficult to discuss, it is best for family members to share their wishes long before it becomes a concern. This can greatly reduce stress when the time for hospice becomes apparent. By having these discussions in advance, patients aren't forced into uncomfortable situations. Instead, they can make an educated decision that includes the advice and input of loved ones. *(To learn more about having a conversation about hospice, refer to the Caring Connections brochure, “Communicating Your End-of-Life Wishes.”)*

QUESTION CHECKLIST

Here is a list of questions to help you select the hospice program best able to meet your needs.

Patient's Needs and Wishes:

- ◆ How does the hospice staff, working with the patient and loved ones, honor the patient's wishes?

Family Involvement and Support:

- ◆ How are family caregivers given the information and training they need to care for the patient at home?
- ◆ What services does the hospice offer to help the patient and loved ones deal with grief and loss?
- ◆ Is respite care (relief for the caregiver), including inpatient, available?
- ◆ Are loved ones told what to expect in the dying process and what happens after the patient's death?
- ◆ What bereavement services are available after the patient dies?

Physician Role:

- ◆ What is the role of the patient's physician once hospice care begins?
- ◆ How will the hospice physician oversee the patient's care and work with the patient's doctor?

Staffing:

- ◆ How many patients at any one time are assigned to each hospice staff member who will be caring for the patient?

Volunteers:

- ◆ What services do volunteers offer?
- ◆ What screening and type of training do hospice volunteers receive before they are placed with patients and families?

Hospitals and Other Inpatient Options:

- ◆ How does the hospice work with hospitals and other facilities during the course of the patient's stay?
- ◆ What will happen if care cannot be managed at home?

Nursing Home Residents and Other Residential Care Settings:

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

Comfort and Pain Management:

- ◆ Does the hospice staff regularly discuss and routinely evaluate pain control and symptom management with patients and families?
- ◆ How quickly does the hospice staff respond to requests for additional pain medication?
- ◆ What specialty or expanded programs does hospice offer?
- ◆ How does the hospice meet the spiritual and emotional needs of the patient and family?

After-Hours Care:

- ◆ How quickly does the hospice respond to after-hour emergencies?
- ◆ How are calls and visits handled when death occurs?
- ◆ Are other services, such as chaplain or social worker, available after-hours?

Quality:

- ◆ What measures does the hospice use to ensure quality?
- ◆ Does the hospice program follow the National Hospice and Palliative Care Organization's "*Standards of Practice for Hospice Programs*"?
- ◆ Do hospice professionals have special credentials in their areas?

Surveys and Inspections:

- ◆ Is the hospice program certified, licensed, and reviewed by the state (if state licensure applies) or the federal government?
- ◆ What other kind of accreditation or certification does the hospice program or its staff have?

Paying for Hospice Care:

- ◆ Are all of the costs of hospice care covered by the patient's health insurance?
- ◆ What services will the patient have to pay for out-of-pocket? Are any services provided at no charge?



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For more information, or to locate a hospice
in your area, contact Caring Connections:

www.caringinfo.org ♦ caringinfo@nhpco.org

HelpLine 800.658.8898

Multilingual Line 877.658.8896

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