

Hospice Care

What is hospice care?

Hospice focuses on caring, not curing and in most cases care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

How does hospice care work?

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 is 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 patient's personal physician;
- Hospice physician (or medical director);
- Nurses;
- Home health aides;
- Social workers;
- Clergy or other counselors
- Trained volunteers; and
- Speech, physical, and occupational therapists, if needed.

What services are provided?

Among its major responsibilities, the interdisciplinary hospice team:

- Manages the patient's pain and symptoms;
- Assists the patient with the emotional and psychosocial and spiritual aspects of dying;
- Provides needed drugs, medical supplies, and equipment;
- Coaches the family on how to care for the patient;
- Delivers special services like speech and physical therapy when needed;
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time; and
- Provides bereavement care and counseling to surviving family and friends.

Choosing a Hospice

There may be one hospice organization or several in your community. It is important to find out about the services that each hospice offers. If there are several hospices that serve your area, you may want to speak with some of them and/or ask your health care provider if they have recommendations for selecting a hospice. You may decide to request services from a particular hospice; be sure to communicate that request to your physician.

The National Hospice and Palliative Care Organization has developed some questions to help identify factors that may be important to you and your family when selecting a hospice.

Hospice FAQs

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 from hospice services. 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 is needed. By having these discussions in advance, patients are not forced into uncomfortable situations. Instead, patients can make an educated decision that includes the advice and input of family members and loved ones.

How does hospice care begin?

Typically, hospice care starts as soon as a formal request or a 'referral' is made by the patient's doctor. Often a hospice program representative will make an effort to visit the patient within 48 hours of that referral, providing the visit meets the needs and schedule of the patient and family/primary caregiver. Usually, hospice care is ready to begin within a day or two of the referral. However, in urgent situations, hospice services may begin sooner.

How does the hospice work to keep the patient comfortable?

Many patients may have pain and other serious symptoms as illness progresses. Hospice staff receives special training to care for all types of physical and emotional symptoms that cause pain, discomfort and distress. Because keeping the patient comfortable and pain-free is an important part of hospice care, many hospice programs have developed ways to measure how comfortable the patient is during the course of their stay in hospice. Hospice staff works 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. The care plan is reviewed frequently to make sure any changes and new goals are in the plan.

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

Hospice services can be provided to a terminally ill person wherever they live. This means a patient living in a nursing facility or long-term care facility can receive specialized visits from hospice nurses, home health aides, chaplains, social workers, and volunteers, in addition to other care and services provided by the nursing facility. The hospice and the nursing home will have a written agreement in place in order for the hospice to serve residents of the facility.

What happens if I cannot stay at home due to my increasing care need and require a different place to stay during my final phase of life?

A 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 stay where they usually live. These patients may require a different place to live during this phase of their life when they need extra care. However, care in these settings is not covered under the Medicare or Medicaid Hospice Benefit. It is best to find out, well before hospice may be needed, if insurance or any other payer covers this type of care or if patients/families will be responsible for payment.

Do state and federal reviewers inspect and evaluate hospices?

Yes. There are state licensure requirements that must be met by hospice programs in order for them to deliver care. In addition, hospices must comply with federal regulations in order to be approved for reimbursement under Medicare. Hospices must periodically undergo inspection to be sure they are meeting regulatory standards in order to maintain their license to operate and the certification that permits Medicare reimbursement.

How can I be sure that quality hospice care is provided?

Many hospices use tools to let them see how well they are doing in relation to quality hospice standards. In addition, most programs use family satisfaction surveys to get feedback on the performance of their programs. To help hospice programs in making sure they give quality care and service, the National Hospice and Palliative Care Organization has developed recommended standards entitled 'Standards of Practice for Hospice Programs' as one way of ensuring quality.

Resources

Choosing a Quality Hospice Worksheet

<http://www.momentsoflife.org/sites/default/files/public/moments/Choosing%20a%20Hospice.pdf>

Finding a Hospice

<https://www.nhpco.org/find-hospice>