



FREQUENTLY ASKED QUESTIONS

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.

Will I be the only hospice patient that the hospice staff serves?

Every hospice patient has access to a hospice volunteer, registered nurse, social worker, home health aide, and chaplain (also known as the interdisciplinary team). For each patient and family, the interdisciplinary team writes a care plan with the patient/family that is used to make sure the patient and family receive the care they need from the team. Typically, full-time registered nurses provide care to about a dozen different families. Social workers usually work with about twice the number of patients/families as nurses. If needed, home health aides, who provide personal care to the patient, will visit most frequently.

All visits, however, are based on the patient and family needs as described in the care plan and the condition of the patient during the course of illness. The frequency of volunteers and spiritual care is often dependent upon the family request and the availability of these services. Travel requirements and other factors may cause some variation in how many patients each hospice staff serves.

Is hospice available after hours?

Hospice care 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.

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.

What role does the hospice volunteer serve?

Hospice volunteers 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, and lending emotional support and companionship to patients and family members.

Because hospice volunteers spend time in patients' and families' homes, each hospice program generally has an application and interview process to assure the person is right for this type of volunteer work. In addition, hospice programs have an organized training program for their patient care volunteers. Areas covered by these training programs often include understanding hospice, confidentiality, working with families, listening skills, signs and symptoms of approaching death, loss and grief and bereavement support.

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.

There are also voluntary accreditation organizations that evaluate hospice programs to protect consumers. These organizations survey hospices to see whether they are providing care that meets defined quality 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 that hospice program. A hospice program may volunteer to obtain accreditation from one of these organizations.

Quick Facts About Hospice

Inpatient options are available in assisted living, nursing, hospital and dedicated hospice facilities.

The most common complaint about hospice is that patients did not enroll soon enough for them and their families to benefit from the full spectrum of care.

Hospice admission under the Medicare Benefit requires that the person's physician and the hospice medical director determine that the person is unlikely to live longer than 6 months if his or her illness is allowed to run its natural course. Admission under the benefit also requires that the person forego any treatments intended for cure of the illness.