

Getting Started with Hospice: A Guide for Family Members

Making the decision to put a loved one in hospice care is challenging and can be devastating, but it is also important for an impacted individual to be able to have assistance when he or she is struggling with a life-limiting illness.

Deciding when to start hospice care is never an easy choice, as it represents that the afflicted individual may never fully recover. However, it can also be one of the most important decisions made for that loved one.

Many hospice care teams are extremely experienced and dedicated to helping individuals suffering from a life-limiting illness. They have been specially trained to serve in these situations and are sensitive to a patient's emotional, physical, and spiritual needs.

A hospice care team is usually made up of a team of family members, counselors, social workers, doctors, nurse practitioners and nurses, physical and occupational therapists, hospice aides, homemakers, volunteers, and speech-language pathologists, depending on the patient's condition. A hospice doctor may also be included as part of the medical team.

Family caregivers and health workers are the ones who should make the decision whether to put a patient in hospice care. This decision is a big one, and it can be helpful to speak to doctors, caregivers, and other family members before this decision is made. Keep in mind that individuals in the position of making this decision must be able to make this choice freely. No other person should force you to accept hospice care.

It is possible that a patient's family members may be the first ones to suggest hospice care or it could be recommended by the doctor. In certain situations, doctors or family members may feel uncomfortable speaking about hospice care because it might be viewed as a sign of failure. This critical decision might seem overwhelming at the time, but it may be the best way to allow a patient to obtain pain relief at home.



Where a Patient Can Get Hospice Care

Hospices allow family members and the affected patient to stay together in the comfort of their own home, unless care is needed from an inpatient facility. If the hospice team determines that inpatient care is necessary, they will make the appropriate arrangements for a loved one's stay. The hospice team investigates the situation and the impacted person's medical needs prior to establishing the appropriate type of care.

Wherever possible, family members often want to allow an impacted patient to be able to receive hospice care at home. This can be much more comforting for a loved one who is more at ease in his or her own surroundings.

Hospice care can make a tremendous difference in an affected patient's treatment and quality of life when that individual is suffering from kidney failure, respiratory disease, heart disease, cancer, or any other serious and life-limiting illness. Hospice care is a special form of medical treatment that allows patients to feel relief from symptoms, emotional distress, pain, and other issues associated with a serious illness or that illness's treatment, including chemotherapy. Hospice care goes much farther than simple comfort care.

It is important to consider hospice care for an affected patient when there are no additional treatment options available to cure that family member's disease. The focus in hospice care is quality of life and comfort.

Hospice care may also be the best solution when a family member decides that treatment for their particular life-limiting illness is not worth the disadvantages involved, which may include pain, suffering, and other side effects.

It often helps to make the decision to select hospice care sooner rather than later. Although it can be difficult to come to this conclusion, as the family members and other loved ones may not want to accept this turning point in a loved one's care, hospice care can be an important form of support during a challenging time.



Who is Eligible for Hospice Care?

Hospice care is available for individuals who have a life expectancy of six months or less if the disease were to run its normal course. If a patient lived longer than six months, he or she may still be eligible to receive hospice care as long as the hospice doctor recertifies the patient's status of having a life expectancy of six months or less.

Under a Medicare program, patients are eligible to switch providers only once during each benefit period, and they can obtain hospice care for two 90-day benefit periods. After that time, the patient may be eligible for hospice care for an unlimited number of 60-day benefit periods as well. When each period restarts, the hospice medical director or other hospice doctor has to recertify that the patient has a life expectancy of six months or less in order to continue hospice care.

Hospice care is a highly personal decision. It can be difficult to accept that it's the only option when a physician suggests it. Take some time to absorb this situation and determine whether or not hospice care could help the afflicted loved one get some relief, particularly relating to pain.

Individuals who have received a diagnosis that may qualify them for hospice care may already be coping with significant pain, and having the treatment and care opportunities provided by an experienced hospice team can help to relieve stress and concern for everyone involved. While this is an emotionally charged decision, and some family members may continue to hope for a full recovery, hospice care provides a valuable and critical support system for families in their time of need.

Identifying a Hospice Care Program

There are several important questions to consider when selecting a hospice care program for a loved one with a life expectancy of six months or less. These include:

- •Does the provider train caregivers for at-home care?
- •How will existing doctors work with one provided by hospice?
- •How does hospice staff respond to emergencies that occur after hours?
- •What services are provided by hospice volunteers?
- •Will the hospice staff meet regularly with family members to discuss care options?
- •Is the hospice provider licensed and certified by the state or federal government? Speaking with a representative from the hospice care facility can help put family members' minds at ease during this challenging time.



What about other Conditions?

Where Medicaid Health Plans and Medicare Advantage Plans Fit into Hospice Care? Once hospice care has been selected, paying for hospice care with health benefits like Medicare or Medicaid should cover everything needed for the affected patient. Original Medicare covers all Medicare-associated services obtained while in hospice care, even if the patient was previously on a Medicare Advantage plan or another Medicare health plan, if the plan covers services that are not covered by the original Medicare plan. The patient's new plan will cover extra services so long as the patient continues to pay the premium.

What about other Conditions?

In the majority of cases, hospice care covers all care-related concerns, except in very rare situations. This means that the patient should not have to go outside of the hospice services to obtain appropriate medical care. The hospice benefits should cover everything that the patient needs after he or she enters hospice care.

Speaking with the members of the hospice care team at the outset of the engagement is important for identifying the comprehensive needs of the patient and determining the most appropriate care schedule. During a difficult time, the right care team makes all the difference. Most hospice care teams will take the time to explain the full range of their services so that everyone is on the same page.

What about Stopping Hospice Care?

In the event that a patient's illness goes into remission or his or her health improves, the individual may no longer need hospice care. Patients always have the right to stop hospice care at any time.

Family members may choose to stop hospice care, and, if so, they will be asked to sign a form that includes the date that the care will end. No forms regarding stopping hospice care should be offered at the time that a patient begins the hospice service.



Will the Hospice Staff Only Serve One Patient at a Time?

Every hospice patient has access to a hospice care team. Typically, the members of this team provide care to multiple families. All visits, however, are based on the individual patient's needs and the family's needs as described in the overall care plan. The frequency of volunteer visits and number of volunteers is dependent upon the availability of these services as well as the family's requests.

How Does Hospice Help to Make a Patient More Comfortable?

Hospice staff receives special training to care for all kinds of emotional and physical symptoms that cause distress, pain, and discomfort. The patient may be struggling with many different types of pain, but hospice staff is trained to make the patient as comfortable and as pain free as possible throughout the service.

Hospice volunteers typically provide different types of support to patients and loved ones including preparation of light meals, staying with patients to give family members a break, running errands, and lending companionship and emotional support to patients and family members.

Make sure family members always evaluate a hospice care team prior to selecting that team to work with a patient.