

# Frequently Asked Hospice Questions

## 1. When should a decision about entering a Hospice program be made—and who should make it?

At any time during a life-limiting illness, it's appropriate to discuss all of a patient's care options, including hospice. By law the decision belongs to the patient. Understandably, most people are uncomfortable with the idea of stopping an all-out effort to "beat" their disease. Hospice staff members are highly sensitive to these concerns and are always available to discuss them with the patient, family and physician.

## 2. Should I wait for our physician to raise the possibility of hospice, or should I raise it first?

The patient and family should feel free to discuss hospice care at any time with their physician, other healthcare professionals, clergy or friends.

## 3. What if our physician doesn't know about hospice?

Most physicians know about hospice. If your physician wants more information, it is available from the American Academy of Hospice and Palliative Medicine, medical societies, state hospice organizations, local hospices, or the National Hospice and Palliative Care Organization Helpline, 1-800-658-8898. In addition, physicians and all others can also obtain information on Hospice from the American Cancer Society, the American Association of Retired Persons and the Social Security Administration.

## 4. Can a hospice patient who shows signs of recovery be returned to regular medical treatment?

Certainly. If improvement in the condition occurs and the disease seems to be in remission, the patient can be discharged from hospice and return to aggressive therapy or go on about his or her daily life. If a discharged patient should later need to return to hospice care, Medicare and most private insurance will allow additional coverage for this purpose.

## 5. What does the hospice admission progress involve?

One of the first things hospice will do is contact the patient's physician to make sure he or she aggress that hospice care is appropriate for this patient at this time. (Hospices may have medical staff available to help patients who have no physician.) The patient will also be asked to sign consent and insurance forms. These are similar to forms patients sign when they enter the hospital. The so called "hospice election form" says that the patient understands that the care is palliative (that is, aimed at pain relief and symptom control) rather than curative. It also outlines the services available. The form Medicare patients sign also tells how election Medicare hospice benefit affects other Medicare coverage for a terminal illness.

## 6. Is there any special equipment or changes I have to make in my home before hospice care begins?

Your hospice provider will assess your needs, recommend any necessary equipment, and help make arrangements to obtain it. Often the need for equipment is minimal at first and increases as the disease progresses. In general, hospice will assist in any way it can make home care as convenient, clean and safe as possible.

## 7. How many family members or friends does it take to care for a patient at home?

There's no set number. One of the first things a hospice team will do is prepare an individual care plan that will, among other things, address the amount to care-giving a person needs. Hospice staff visits regularly and are always accessible to answer questions and provide support.

# 8. Must someone be with the patient at all times?

In the early weeks of care, it's usually not necessary for someone to be with the patient all the times. Later, however, since one of the most common fears of patients is the fear of dying alone, hospice generally recommends someone be there continuously. While family and friends must be relied on to give most of the care, hospices do provide volunteers to assist with errands and provide a break and time away for major caregivers.

## 9. How difficult is caring for a loved one at home?

It's never easy and sometimes can be quite hard. At the end of a long, progressive illness, nights especially can be very long, lonely and scary. So, hospices have staff available around the clock to consult with the family and to make night visits as appropriate.

# 10. What specific assistance does hospice provide home-based patients?

Hospice patients are cared for by a team of doctors, nurses, social workers, counselors, home health aids, clergy, therapists, and volunteers—and each provides assistance based on his or her area of expertise. In addition, hospices help provide medications, supplies, equipment, hospital services and additional helpers in the home, as appropriate.

## 11. Does hospice do anything to make death come sooner?

Hospices do nothing either to speed up or to slow down the dying process. Just as doctors and mid-wives lend support and expertise during the time of child birth, so hospice provides its presence and specialized knowledge during the dying process.

## 12. Is the home the only place hospice care can be delivered?

No. Although most hospice services are delivered in a personal residence, some patients live in nursing homes or hospice centers.

## 13. How does hospice "manage pain"?

Hospice nurses and doctors are up-to-date on the latest medications and devices for pain and symptom relief. In addition, physical and occupational therapist assist patients to be as mobile and self-sufficient as possible, and they are often joined by specialists schooled in music therapy, art therapy, diet counseling, and other therapies. Hospice believes that emotional and spiritual pain are just as real and in need of attention as physical pain, so it addresses these as well.

## 14. What is hospice's success rate in battling pain?

Very high. Using some combination of medications, counseling and therapies, most patients can attain a level of comfort that is acceptable to them.

## 15. Will medications prevent the patient from being able to talk or know what's happening?

Usually not. It is the goal of hospice to help patients be as comfortable and alert as they desire. By constantly consulting with the patient, hospices have been very successful in reaching this goal.

## 16. Is hospice affiliated with any religious organization?

Hospice care is not an off-shoot of any religion. While some religious organizations have started hospices (sometimes in connection with their hospitals), these serve a broad community and do not require patients to adhere to any particular set of beliefs.

## 17. Is hospice care covered by insurance?

Hospice coverage is widely available. It is provided by Medicare nationwide, by Medicaid in some 42 states, and by most private health insurance policies. To be sure of coverage, families should, of course, check with their employer or health insurance provider.

## 18. If the patient is not covered by Medicare or any other health insurance, will hospice still provide care?

The first thing hospice will do is assist families in finding out whether the patient is eligible for any coverage they may not be aware of. Barring this, most hospices will provide care for those who cannot pay, using money raised from the community or from memorial or foundation gifts.

## 19. Does hospice provide any help to the family after the patient dies?

Hospice provides continuing contact and support for the family and friends for at least a year following the death of a loved one. Most hospices also sponsor bereavement and support groups for anyone in the community who has experienced the death of a family member, a friend or a loved one.

## 20. If the patient is eligible for Medicare, will there be any additional expenses to be paid?

Medicare covers all services and supplies related to the terminal illness for the hospice patient. In some hospices, the patient may be required to pay a 5% or \$5 "co-payment" on medication and a 5% co-payment for respite care. You should find out about any co-payment when choosing a hospice.

For more information on hospice services please call:



1-855-542-7267 toll free