

Understanding Hospice Care

Hospice care is a program with services designed for people who are terminally ill and not expected to recover. Some people with terminal illnesses, such as AIDS, emphysema, heart failure, cancer, kidney disease, or Alzheimer disease may decide to use hospice care. There are special hospice programs for children who have cancer or other serious diseases and for people who have AIDS.

How do I know if hospice care is right for me?

The decision to be cared for by a hospice program is an acknowledgement that your treatment goals will shift from curing your condition to making the rest of your life as comfortable and high quality as possible.

You may decide to use hospice care if:

- Your life expectancy is shortened due to a disease or illness
- Treatment to cure the disease or prolong life is a burden rather than a benefit
- You want to spend your remaining life as comfortable as possible in a setting of your own choosing such as your home
- You want your family and friends involved in your care
- You are a caregiver who wants your loved one with a terminal illness to die comfortably at home

Not everyone who might benefit from hospice care receives it. Family members and doctors may find it difficult to acknowledge that a person is dying. Choosing hospice care means you've stopped trying to cure your illness and instead are focusing on comfort and quality of life. If you decide to remain in your home, your hospice team will prepare your caregivers for almost anything that could happen. You can still go to a hospital for any

medical care you may need. Your hospice team will work with you to arrange for any needed care. Being bedridden or in a hospital are not requirements for hospice care. Regardless of your physical condition, hospice care is designed to keep you as comfortable, functional, and alert as possible. Services may include help with bathing, dressing, and eating in addition to giving you medicine and treatment for all symptoms, including pain and anxiety.

Eligibility for most hospice programs rests on 2 criteria:

- You have a terminal illness.
- Your doctor has stated that, if your illness runs its normal course, your life expectancy is 6 months or less.

If you live longer than the expected 6 months, you can continue on hospice. Medicare and most Medicaid programs cover hospice services. Most private insurance programs offer a hospice benefit, and many hospice programs will research your medical coverage. Hospice care is not recommended for people who want to live as long as possible by any medical means.

What questions should I ask?

All hospice programs should give you written materials describing their services; explaining who provides the services; detailing eligibility, cost, and payment processes; and detailing the program's insurance and liability information. Other questions you may want to ask include:

- **Location.** Where are services provided? Can you remain in your home? Do you need to remain in a special inpatient hospice unit?
- **Services.** Do services provided include home visits, spiritual or religious counseling,

and household chores?

- **Care plan.** Who is responsible for specific duties? How often will each person in your hospice care team perform each duty?
- **Licensing and certification.** Is the plan Medicare-certified? Is the hospice program state-licensed?
- **References.** Do you know anyone who has used this program? Would they recommend this program to others?

What can I expect?

Oftentimes, hospice care is provided in your home. A family member or loved one will usually look after you much of the time. Someone from your hospice care team will probably visit you for about an hour, 1 or more times per week. A 24-hour hospice number is available for you to call if you have an emergency or get scared. A nurse is usually able to come to your home any time of day or night. You need not worry about losing touch with your regular doctor. He or she can work with your hospice team and remain involved in your care.

Hospice care provides:

- **Basic medical care.** This care focuses on pain and symptom control.
- **Round-the-clock access.** You can access a member of your hospice team 24 hours a day, 7 days a week.
- **Guidance.** Your hospice care team will provide you with assistance with the difficult issues of life completion and closure.
- **Respite care.** A break is provided for caregivers, family, and others who regularly care for you. This can range from a few hours a week to several days, depending on your hospice program.
- **Counseling.** Your hospice care team will assist you and your family with psychological, emotional, and spiritual issues.
- **Assistance with advance directive forms.** Your preferences regarding life support and

cardiopulmonary (kahr-dee-oh-puhl-mih-neh-ee) resuscitation (ree-suh-sih-tay-shun) (CPR) may be documented. Patients in hospice are usually not considered candidates for CPR, because successful CPR would lead to a counterproductive extension to a life that is ending.

- **Answers for questions about treatments received during hospice care.** These treatments are designed to relieve pain and other symptoms.
- **Help your family and friends through their grief after you die.** Most programs provide at least 1 year of bereavement services for family and friends after the death of a loved one.

To find more information about hospice care, log on to the website of the National Hospice and Palliative Care Organization, <http://www.nhpc.org>.

Notes:
