



Hospice Care

A Guide for Families

WHAT IS HOSPICE CARE?

Hospice programs are available to help terminally ill individuals live their remaining days with dignity. These programs can assist the family (or other designated caregiver) in making the patient as comfortable as possible, and assistance is available around the clock, seven days a week.

Hospice is primarily a concept of care, not a specific place of care. Hospice care usually is provided in the patient's home. It also can be made available at a special hospice residence. Hospice is a combination of services designed to address not only the physical needs of patients, but also the psychosocial needs of patients, their loved ones.

Hospice combines pain control, symptom management and emotional and spiritual support. Seniors and their families participate fully in the health care provided. The hospice team develops a care plan to address each patient's individual needs. The hospice care team usually includes:

The terminally ill patient and his or her family caregiver(s):

- Doctor
- Nurses
- Home health aides
- Clergy or other spiritual counselors (e.g., minister, priest, rabbi)
- Social workers
- Volunteers (if needed, and trained to perform specific tasks)
- Occupational, physical, and/or speech therapists (if needed).

WHEN IS HOSPICE CARE APPROPRIATE?

As with many end-of-life decisions, the choice to enroll in a hospice care program is a deeply personal thing. It depends almost as much on the patient's philosophy of living and spiritual beliefs as it does on his or her physical condition and the concerns of family members. The following case study shows how one patient decided that hospice care was what she wanted and why it was right for her:

Case Study

Lynda was 57 years old when she was diagnosed with liver cancer. In spite of the best medical treatment her doctors could provide, her cancer proved incurable. Although the prospect of dying frightened her, Lynda wanted to receive professional assistance to prepare herself and her family for her death.

She realized that she wanted to be cared for at home by her sister, Sara. The local hospice service made the arrangements so that this would be possible. Hospice staff made sure that Lynda's family would have the equipment they needed, and trained Sara in how to administer medications to relieve Lynda's pain.

The hospice program also sent a registered nurse to the house to oversee Lynda's care, and the nurse consulted with a doctor to make sure Lynda was as comfortable as she could be during her final weeks. In addition, the hospice service sent a personal care attendant to bathe Lynda twice a week, and a social worker and a clergyman to provide spiritual and grief counseling for Lynda and Sara.

Lynda lived the last six weeks of her life at home before she passed away surrounded by Sara and the rest of her family.

HOW CAN I PAY FOR HOSPICE CARE?

Medicare, private health insurance, and Medicaid (in 43 states) cover hospice care for patients who meet eligibility criteria. Private insurance and veterans' benefits also may cover hospice care under certain conditions. In addition, some hospice programs offer health care services on a sliding fee scale basis for patients with limited income and resources. To get help with your Medicare questions, call 1-800-MEDICARE (1-800-633-4227, TTY/TDD: 1-877-486-2048 for the speech and hearing impaired) or look on the Internet at www.medicare.gov. Additional information about how to pay for hospice care can be found at the [Public Policy Institute of the AARP](#)

WHERE CAN I LEARN MORE ABOUT HOSPICE CARE?

Seniors and caregivers may order a copy of the *National Hospice Foundation's* consumer brochure by calling 1-800-646-6460 from 9 am to 5 pm, EST, Monday through Friday. The e-mail address is info@nhpco.org and the postal address is: National Hospice Foundation; 1700 Diagonal Road, Suite 625; Alexandria, VA 22314. <http://www.hospiceinfo.org/>.

Another resource is the *Hospice Foundation of America*, which can be reached by calling 1-800-854-3402 or by visiting the organization's website at <http://www.hospicefoundation.org/>. The postal address is: Hospice Foundation of America; 2001 S St., NW; Suite 300; Washington, DC 20009.

The Hospice Association of America provides information about hospice programs and how terminally ill patients and their families can find hospice services in their area. Call 202-546-4759 or visit the association's website at <http://www.hospice-america.org/>. The postal address is: Hospice Association of America; 228 Seventh St., SE; Washington, DC 20003.

Hospice Net at <http://www.hospicenet.org/> is one more website where you can get information about how to find a hospice that is right for you. The e-mail address is comments@hospicenet.org and the postal address is: Hospice Net, 401 Bowling Ave., Suite 51, Nashville, TN 37205-5124

To find out more about hospice programs where you live, you can contact your local aging information and assistance provider or area agency on aging (AAA). *The Eldercare Locator*, a public service of the Administration on Aging (at 1-800-677-1116 or <http://www.eldercare.gov>) can help connect you to these agencies.

OTHER FAMILY COUNSELING AND SUPPORT SERVICES

Seniors and family caregivers facing end-of-life decisions often must deal with very difficult issues of grief and loss—both before and after their loved one dies.

In addition, they may have practical concerns about their legal rights and how to pay the bills now that an important member of the household is gone.

To help families prepare for a loved one's death (and to support them afterwards), the following organizations offer resources that address everything from family counseling to financial planning:

Americans for Better Care of the Dying was founded in 1997 to help ensure that every terminally ill patient can count on good end-of-life care. It publishes several books on how to deal with mortality (death) and what health care alternatives (including hospice care) are available for seniors. The group can be reached by calling 1-212-895-2660 or visiting its website at: <http://www.abcd-caring.org/>

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy. They have facts sheets available on a variety of topics including end-of-life issues. The fact sheets are available on the organization's website at: <http://www.caregiver.org/>

Last Acts is a national coalition of organizations engaged in an campaign to improve care for people who are dying and their families. Last Acts has developed a number of publications and resources to assist professionals and caregivers, including the Last Acts Consumer/Family Resources for Caregivers guide. You can find out more about Last Acts by its website at: <http://www.lastacts.org/>

Since 1994, *GriefNet.org* has helped family members mourn the loss of a loved one. By visiting the organization's website at: <http://www.rivendell.org/>

Widowed Persons Service that is managed by the Elderplan. The Widowed Persons Service offers free support, companionship, and social activities for anyone who has recently lost a spouse. It can be reached by calling 1-718-921-7909 from 8 am to 7 p.m., EST, Monday through Friday, or by visiting the program website at: <http://www.elderplan.org/free/widowedperson.htm>

Hearing-impaired seniors should call toll-free at TTY 1-800-610-6303 for more information.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov