



INFORMATION

Hospice Care

What is Hospice Care?

Hospice provides support and care for persons in the last phases of incurable diseases so that they may live as fully and comfortably as possible. Recognizing death as part of the normal process of living, hospice focuses on maintaining the quality of remaining life, neither hastening nor postponing the inevitable. Hospice exists in the hope and belief that through appropriate care — and the promotion of a caring community sensitive to their needs — patients and their families may be free to attain a degree of mental and spiritual preparation for death.

Most hospice programs provide care to terminally ill patients and supportive services to patients, their families, and significant others 24 hours a day, seven days a week, in both home and facility settings. During the last stages of illness, the dying process, and bereavement, physical, social, emotional, and spiritual care are provided by a medically directed interdisciplinary team consisting of patients, families, professionals, and volunteers.

Typically, when a patient, family member or caregiver contacts hospice care, the director of the center will call the patient's doctor to verify his condition. If all information is accurate, the hospice will proceed with caring for the patient. In any case, patients must have a terminal diagnosis to receive hospice care. When an individual who has no family desires hospice care there are two options:

- If the patient is able-bodied and independent, the hospice team will treat the patient in the home.
- If the patient is bed-ridden, the hospice team will send him or her to a hospice-operated, in-patient facility, or work with a nearby nursing home or hospital on a contractual basis to care for the patient. When home care is unavailable, hospices try to provide as close to a home-like setting as possible.

The Hospice Care Approach

The primary goal of hospice care is to manage and control pain and other symptoms and to ease the distress associated with terminal illnesses. Patients are fully involved in the decision-making process regarding how they would like their pain to be treated. A comprehensive plan is established in order to address as many concerns as possible. In the majority of cases, medication can be given orally, but if this is no longer possible, other routes of administration are available, even in the home setting.

Some of the fears hospice care addresses include:

- fear of pain related to the illness or the dying process
- fear of becoming a burden
- fear of being abandoned
- fear of financing the cost of a terminal illness

The hospice team of doctors, nurses, physical and occupational therapists, dietitians, social workers, psychologists, spiritual counselors, and volunteers provide support services such as administering medication, lending equipment, shopping, cleaning, and running errands for the patient. In most hospice settings, the staff can be reached 24 hours a day and will visit a patient when needed, night or day.

Availability of Hospice Care

Those seeking hospice care for a friend or relative can find a listing in their local telephone directory's yellow pages or through the National Hospice and Palliative Care Organization's website [<http://www.nhpco.org>]. However, most people find out about a particular hospice through a friend, neighbor, or family member who has experienced hospice care. Other ways to obtain information about hospice care are through a pastor, newspaper advertisements, and community club presentations (i.e., Kiwanis, Rotary, local library, and others).

More than 4,850 hospice programs exist in the United States. In addition to paid staff members, there are more than 550,000 volunteers.

How Hospice Prepares the Family

Here are some of the ways hospices help the families care for patients in the homes:

- The hospice staff helps to determine the realistic needs of the patient, such as a hospital bed, commode chair, or walker. The needs and wishes of the patient and the family are always given serious consideration.
- Hospice nurses serve as go-betweens for the patient and his or her doctor. The hospice team also teaches the family how to administer pain medications and other treatments.
- The hospice team helps the family to understand that the responsibility for the care of the patient needs to be shared by all family members.
- The hospice team encourages the family to surround themselves with a wider network of support from friends and church members.
- The hospice team encourages the family to reminisce and take time out for light-hearted moments. The family is also urged to express their feelings about what is happening.
- The hospice team supports the patient and family as they seek spiritual guidance during this difficult time.
- The hospice team prepares the family for the impending death e.g., what to expect as death approaches; whom to call first when the person passes away; and possibly what the patient may look like after death, etc. This enables the family to stay calmer with a greater sense of control.
- Volunteers work with the family in many ways such as giving them breaks and running errands for the family or the patient. Volunteers may also offer companionship to the patient, especially if he or she is in a facility.

- The hospice team may also help the family to plan the funeral (which volunteers and staff members often attend). Continuing psychological and spiritual counseling and support are usually available to the family for as long as they are needed.

The Cost of Hospice Care

Hospice care is the most cost-effective way of providing life-affirming care for a terminally ill person. In the U.S., the costs for care in a hospital or skilled nursing facility are far greater than the costs for care in a private hospice facility or for at-home hospice care, which is even less expensive. Hospice care is covered under Medicare, Medicaid (in some states), most private-insurance groups, and HMOs. Families may be asked to meet some uncovered costs. However, hospices rarely, if ever, turn down patients for financial reasons. Public and community support through donations, grants, memorial gifts and fund-raising events assist to help cover the cost of care.

How You Can Get Involved

Volunteers are a hospice's life-blood and keep the facility running in an efficient, caring manner. To become involved with hospice care:

- Contact your local hospice and find out how you can become a volunteer. Volunteers are fully trained by the hospice.
- Or, if you know a patient in your church, business, or neighborhood, you can assist the patient and their family on your own. Most hospices would be happy to provide general information to anyone wishing to help patients or their families.

Other practical suggestions:

- Listen
- Pray
- Write letters or thank-you notes for the patient
- Bake cookies for visitors
- Prepare a basket of teas and coffees
- Buy and/or wrap Christmas and birthday gifts
- Run errands
- Do the laundry and dishes
- Clean or vacuum the house
- Provide a meal (use disposable containers)
- Help take care of the lawn and weed flower beds
- Help write the patient's memoirs
- Send flowers
- Read to the patient
- Visit the patient to relieve caregiver
- Interview the family to determine needs

Patients and families needing help should ask for the specific help they need. Set up a sign up book for helpers and then recruit people to do the jobs. Stay concise and time limited, e.g. "Please bring dinner every Tuesday for the month of May" instead of "bring dinner sometime." The former is time-limited and well-defined and more volunteers will sign up under those conditions.

Additional Resources Available from Focus on the Family

Colorado Springs, CO 80995 • 719/531-5181

Item availability is subject to change. In such cases, our staff members would be pleased to help you find appropriate alternatives as they are able. Inclusion on this list does not necessarily constitute endorsement of material content or organizational viewpoint by Focus on the Family.

Resources

“Hope for the Seriously Ill” I-III (Dr. Margaret Cottle) • 5008477 •

In this broadcast recording, Dr. Margaret Cottle offers her expertise on hospice and palliative care for the terminally ill. She explains the difference between the two and shares valuable lessons she learned while caring for her dying mother.

“Eldercare”

- RL061 • \$Complimentary

This information sheet lists resources and referrals to organizations to assist caregivers in aiding the elderly.

“Resources for Senior Citizens”

- RL060 • \$Complimentary

This resource list offers suggested resources and referrals for senior citizens.

“Cancer Resources”

- RL059 • \$Complimentary

This information sheet lists helpful books, CDs and booklets, as well as referrals to organizations that deal with cancer.

Referrals

National Hospice and Palliative Care Organization (NHPCO)

1731 King Street, Suite 100

Alexandria, VA 22314

703/837-1500

800/658-8898

703/837-1233 — Fax

nhpco_info@nhpco.org — E-mail

<http://www.nhpco.org> — website