

c h o o s i n g



a

consumer's

guide

Hospice



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The thought that you or someone you love is dying can be devastating.

It may seem that there is nothing more you can do.

But in fact much can be done and Hospice can help.

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what is *Hospice*?

The term “hospice” originated in medieval times when it was used to describe a place of shelter and rest for weary or sick travelers on long journeys. The modern hospice movement began in 1967 when Dr. Cicely Saunders, a British physician, established St. Christopher’s Hospice near London. Her program included a team of professional caregivers for each patient, and was the first to combine compassionate care for the dying, which hospice has always offered, with modern pain and symptom control techniques.

Today hospice care is for the patient whose illness is no longer responding to aggressive curative therapies. Hospice addresses all the symptoms of the disease with special emphasis on controlling the patient’s pain and discomfort. Hospice also deals with the emotional, social, and spiritual impact of the disease on the patient, and the patient’s family and significant others.

A hospice team consists of physicians, nurses, aides, social workers, spiritual caregivers, counselors, therapists, and volunteers: all of whom are specially trained to provide pain and symptom management for the patient and support for the family. The patient and family make up the core of the hospice team and are at the center of all decision making.

The goal of all hospice programs is to improve the quality of the patient’s last days and weeks of life by offering comfort and dignity.

To do this, the hospice conducts an evaluation of the patient’s physical condition, pain, support system, and environment. Because each patient’s/family’s needs are unique, a hospice team works with the patient and family to develop a personalized care plan. The delivery of the plan by an interdisciplinary team distinguishes hospice care from ordinary home care.

The hospice brings this caring team right to the patient’s home, be it a house, apartment, nursing home, assisted living setting, or residential hospice.

Family members are encouraged to participate in the care by visiting regularly, bringing favorite music or food, and by providing as much hands-on support as is comfortable, such as feeding, bathing, reading favorite books, or just being present.

When care is delivered in the patient’s house or apartment the hospice provides instruction, assistance, and support for the family. When hospice care is delivered in a facility, much attention is paid to making the environment and care planning as patient-friendly as possible.

Always, the focus is on controlling pain, managing symptoms, and providing comfort, dignity, and quality of life.

Support

why choose *Hospice*?

Approximately 885,000 people in the United States were cared for by hospice programs in 2002 and the number grows annually. The reasons vary, but those generally identified are simple:

Hospice does not seek to lengthen life nor hasten death, but instead to focus on quality of life.

Hospice workers provide the patient and family with information and opportunities to participate in the decision making process, and focus the care on symptom management, comfort, dignity, and quality of life.

Hospice staff and volunteers assist with all the traditional physical care tasks, such as bathing, managing pain medications, arranging medical equipment, and therapies. The staff and volunteers also do things as simple as provide back rubs, assist with household chores, help put financial matters in order, talk openly about feelings, arrange transportation to doctor appointments, and help family members cope.

Care for the terminally ill in the home generally provides patients more privacy and control of their environment, such as when to eat, what to eat, when to bathe, when to have company, visits with pets, etc. It is also more convenient for family and friends to visit the patient at home.

Many hospice facilities provide this same control and comfort for hospice patients and their significant others.

Data shows that care in the home is less costly than care in a hospital.

The family receives bereavement care for at least one year.

The patient, family, and/or physician can initiate an information/referral call or visit as soon as a terminal disease is diagnosed, or at the same time a patient decides to move from a treatment plan focused on curing the disease to a plan focused on providing comfort and pain relief.

Hospice services

Before providing care, a hospice clinician, the patient's personal physician(s), and the hospice physician confer on the patient's disease history, current physical systems, and life expectancy.

A hospice representative meets with the patient and family to discuss the hospice philosophy of care, services available, pain and comfort levels, expectations, Advanced Directives, the support system available, financial and insurance resources, medications, and equipment needs. Patients are asked to sign an informed consent for care. From the information gathered, a "plan of care" is developed. As the patient's condition changes, this plan is regularly reviewed and revised.

The plan of care provides the hospice staff, the patient, and the family with details about what services and support visits (nurse, social worker, aide, counselor, spiritual care, and volunteer) to expect, in addition to what medications, therapies, supplies, and equipment will be used. It also outlines what training the patient and family can expect and how they will participate in the care.

Caregivers are generally asked to provide a safe, comfortable environment, help with feeding, bathing, turning, and giving medications. Caregivers are also advised to alert the hospice of any changes in the patient's condition.

Additionally, the plan of care includes bereavement service needs, for hospice also provides support for caregivers following the patient's death.

interesting facts

The patient and family is the “unit of care.” Family is defined as relatives, a life partner, and any friends patients view as part of their support network.

Whenever possible, patients are cared for in their own, or a family member’s, home.

Volunteers who receive special training take an active role in providing care and support for patients and families and hospice functions. Approximately 400,000 people volunteer for hospice annually.

Hospice staff is available by telephone to provide support 24 hours a day.

In 2002, 50% of hospice patients had a cancer diagnosis. Heart disease, dementia, lung, kidney, and liver disease accounted for 30%, with AIDS and other diseases making up the balance.

There are more than 3,200 hospices in the United States and Puerto Rico.

who regulates Hospice care

Most states require hospices to be licensed. The Centers for Medicare and Medicaid Services (CMS) certify hospices that provide Medicare covered services. Medicaid certification is offered in 45 states and the District of Columbia.

The Joint Commission for Accreditation of Health Care Organizations accredits hospices.

Hospice

when selecting a Hospice, ask...

- Does the hospice serve your area?
- Is the hospice licensed (where applicable) and Medicare/Medicaid certified?
- Does the hospice provide the services you want/need?
- What does that hospice expect from you and your caregiver support system?
- Will your insurance plan work with the hospice?
- Does the hospice have a support program for caregivers?
- Where is needed inpatient or respite care provided?
- Is the hospice’s position on resuscitation, hydration, and antibiotics consistent with yours?
- What out-of-pocket expenses should you anticipate?
- Is there a sliding scale payment plan for services not covered by insurance?



how to find a Hospice in *your* area:

Ask your physician. Check the yellow pages under "Hospice." On the Internet visit - www.hospicefoundation.org or www.nhpco.org/custom/directory. Call Hospice Foundation of America at 1-800-854-3402 or call the National Hospice and Palliative Care Organization at 1-800-658-8898.

who *pays* for Hospice care?

Medicare has a Hospice Benefit for patients with a prognosis of six months or less if the disease runs its normal course. The Medicare Benefit is covered for longer than six months if the patient is re-certified as being terminally ill.

This benefit covers all the services, medications, and equipment related to the terminal illness. These include: physician direction, intermittent nursing services, home health aides and homemakers, social workers, spiritual caregivers, volunteers, physical, occupational, and speech therapists, medications for pain and symptom management, medical supplies and equipment, short term inpatient care for crisis management and respite care, continuous home care in times of crisis, and bereavement services for the family up to a year following the patient's death. In certain cases, such as equipment and pharmacy, a small co-payment may be applied.

- 45 states and the District of Columbia offer Medicaid covered hospice services.
- Most insurance plans and managed care plans cover hospice.
- Hospice services are covered under Tricare, the health benefits program for the military.
- A patient receiving the Medicare Hospice Benefit will continue their regular Medicare coverage for other illnesses, diseases, or care.

Hospice Foundation of America

Hospice Foundation of America (HFA) is a grassroots, non-profit organization that acts as an advocate for the hospice concept of care by training health care workers and the families they serve on issues related to terminal illness and loss, providing information to the public about end-of-life care, and supporting programs designed to encourage the extension of hospice care to persons of all ages and illnesses.

Hospice Foundation of America offers programs and publications that assist caregivers to serve the terminally ill and their grieving loved ones:

- Distance learning and continuing education for health care professionals is offered through Hospice College of America, a subsidiary of Hospice Foundation of America
- The Living With Grief® teleconference series, which provides free bereavement education and assistance to over 100,000 professionals and lay people annually through North America
- Journeys, a monthly newsletter that offers support for those coping with loss
- Training programs for clergy in ministering to families in medical crises
- "Clergy to Clergy," an audiotape series designed to help clergy minister more effectively to others
- Resources for the military and civilian communities to help them respond to loss
- Opportunities for the chronically and terminally ill to tell the stories of their lives through A Guide for Recalling and Telling Your Life Story
- The Living With Grief textbook series
- Information and guidance to companies on handling grief in the workplace

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