

HOSPICE

A GROWING CONCEPT IN AMERICA

Hospice is not a place. Rather hospice is a philosophy of caring, providing palliative or comfort services to an individual who has reached the decision that the treatment options remaining for their condition may compromise their quality of life and their ability to live their last days as they wish.

Cicely Saunders introduced the hospice concept at St. Christopher's Hospice in England nearly 60 years ago. It was not until 1974 that the hospice movement reached America, beginning in New Haven, Connecticut. Since then, hospice is a growing concept in America. There are more than 5000 hospice programs in existence today. Most are small, free-standing programs, generally affiliated with nonprofit organizations.

Over 1.2 million patients received hospice services in 2005. In addition, that year, approximately one-third of all deaths in the United States were under the care of a hospice program.

HOSPICE CONCEPTS:

Many Americans still do not understand the concept of hospice and the services it provides to patients and their families. Important concepts are as follows.

- **Hospice affirms life and does not postpone or hasten death.**

Everyone's goal is to end his or her life comfortably. Most patients as they approach the end of life need both disease modifying and comfort enhancing treatments. While the hospice philosophy may support, in select circumstances, discontinuation of life-sustaining treatments, it opposes efforts to legitimize physician-assisted suicide.

- **Hospice focuses on an individual's quality of life. How that quality is measured is unique to each individual.**

The hospice patient may define the improvement to their quality of life as the management of pain. On the other hand, they may desire emotional and spiritual support.

With the assistance of hospice professionals and volunteers, individuals control the end-of-life choices that address their specific needs.

- **Patients and their families participate in making decisions regarding care issues. The patient's values, preferences, and outlook on life and death are respected and guide the care planning process.**

The individual patient's care plan is developed and revised, as necessary, by the interdisciplinary team.

The interdisciplinary team is composed of a broad spectrum of health care professionals as well as the patient and his/her family. All team members focus on meeting the needs of the hospice patient and their family.

The interdisciplinary team includes

- the patient and family,
- nurses – who specialize in pain management and symptom control
- social workers – who assist the family and patient with emotional concerns and access to supportive community services
- chaplains – who serve individuals of all faiths or of no religious faith, providing support and comfort whenever requested.
- bereavement counselors – who support the patient’s family and loved ones of all ages with support groups, and one-on-one counseling during the grieving process
- nurse’s aides – who provide personal care and assist with activities of daily living
- physicians – who oversee the medical services provided to each patient
- physical and occupational therapists – who help improve the patient’s quality of life
- nutritionists who assist patients with special food needs and
- volunteers – who are specially trained to provide companionship and support the patient and family meeting the every-day challenges of life.

The focus of the interdisciplinary team is broader than just the physical needs of the patient. The social, emotional and spiritual needs and desires of the patient are also part of the care planning process.

Social workers and counselors may help patients and families plan ahead for likely emergencies, provide resources to answer questions related to establishing a durable power of attorney for health care and assist with funeral planning.

Hospice is unusual in its use of volunteers. In 2005, there were an estimated 400,000 volunteers nationwide in hospice, representing 7% of all staff hours related to patient care. Most volunteers assist with direct patient care, but others may participate in fund raising activities or serve in an advisory position.

Strong bereavement support is also a cornerstone of hospice services. While all members of the interdisciplinary team help patients and families deal with feelings of loss and grief while the patient is on service, hospice is unique in its use of chaplains and providing extensive bereavement services for family and friends of the patient for thirteen months after the patient’s death.

- **Pain control is a core principle in hospice.**

The management of pain at all levels, whether emotional, spiritual or physical, is a focus of hospice. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity.

Physical pain can be managed with many options. There are many simple and complex pharmacological solutions available. Hospices may also use alternative methods to reduce physical pain such as massage therapy, music therapy and acupuncture. The distraction of a visit by a volunteer may also be helpful.

- **Hospice services cover many of the expenses related to the terminal disease.**

In general, hospices provide all medical appliances, medical supplies, drugs for pain management and drugs for symptoms related to the hospice diagnosis. The majority of these charges are covered for Medicare recipients. Individuals covered by insurance plans need to contact their carrier for specific hospice coverage guidelines.

- **Hospice services are delivered wherever the patient lives, whether at home, in an assisted living building or in a nursing facility.**

Research shows that more than 75% of all Americans would prefer to die at home, in comfortable and familiar surroundings, with friends and family beside them. Hospice patients are dying in the place they call “home” more often than patients are in the general population. Statistics show that 76% of hospice patients die in their private residence, an assisted living facility or in a nursing facility, whereas about 50% of the general population die in hospitals.

LEVELS OF CARE:

Hospice provides its services through four levels of care on an individual day basis.

- *Routine home care* is a day during which an individual is at home and not receiving other levels of care.
- *Continuous home care* is provided during a period of crisis in which a patient requires continuous care to achieve palliation or management of acute medical symptoms. A minimum of 8 hours of care during a 24-hour period is required. Nursing care must be provided for more than half of the period of care and must be provided by either a registered or a practical nurse.
- *Inpatient respite care* is a day during which the patient receives care in an approved facility on a short-term basis for respite. No more than five inpatient respite care days are a time are generally approved.
- *General inpatient care* is a day during which an individual receives general inpatient care in an approved facility for pain control or acute or chronic symptom management that cannot be managed in other settings.

All services are provided on a 24 hour/7 days a week basis by members of the interdisciplinary team regardless of where the patient lives.

SUGGESTED QUESTIONS:

When seeking a hospice provider for yourself or a family member, you might ask the following questions.

- Is this hospice program Medicare certified? Medicare certified agencies must meet minimum federal requirements for patient care services and management oversight.
- Is this hospice program licensed by the State? State license, while not required all States, also sets standards and requirements that the hospice must meet.
- Can you provide me information on the services you provide, the eligibility requirements for admission, and costs of service and payment options? Written information gives you a reference point for comparison between hospices and information on costs, payment, services and eligibility are an important consideration.
- Is the agency willing to make an assessment on you or your family member to determine whether the admission criteria are met? If the hospice appears to be too rigid in its policies, the hospice may not be a good fit.
- Does the hospice create a plan of care for each new patient? How are the patient and family involved in the process? Patients and their families should be involved in creating and revising, as necessary, the plan of treatment.
- How quickly can the hospice initiate services? Hospice services should be available 24 hours a day/7 days a week.
- Does the hospice provide all levels of care? The four levels of care are listed earlier in this article.

FINALLY:

Art Buchwald was recently a hospice patient. He may have summarized the concept of enjoying a quality of life until the end through hospice the best. In one of his articles, he said, "When you are in a hospice, people are very curious about you, about themselves and about how to deal with denial. I've had more than 2,000 letters, which I would never have received if I'd had a heart attack. So for just choosing a way to say goodbye, I now have a chance to relive every walk of my life and all the memories."

Sources: NHPCO, Cancer Support Center, JAMA articles