

## Hospice: The Basics

### What is Hospice?

Hospice is not a physical place or location a patient is sent to, rather it is a philosophy that a patient and his/her family embrace and follow. The word hospice comes from the Latin word "hospitium" which means guesthouse. It originally stems from the medieval custom of hosting religious pilgrims who were sick and weary from their travels, or wounded during their pilgrimage, by providing them with rest and comfort on their journey. It was not until the 1960's that a British physician, Dr. Cicely Saunders, began the modern hospice idea and founded St. Christopher's hospice near London. A contemporary hospice offers a complete and comprehensive program of care to patients and their families.

Hospice is a philosophy of care that focuses on providing the best possible quality of life for patients faced with a terminal illness. Some may think of hospice as "giving up", however, hospice is really a change in the focus of care, from further life-extending cancer treatments and tests, to measures that will enhance the person's quality of life, such as relief of pain and other symptoms. A hospice team works with the entire family to provide emotional and spiritual support, as well as bereavement support after a patient passes on. Hospice attempts to make the most of every day and to teach that death is a normal part of life.

### How does hospice work?

Hospice care is provided by a team, which includes a physician, nurses, social workers, counselors, chaplains, case managers and trained volunteers. The care they provide focuses on the needs of the patient and his/her family. The patient's oncology team initially sets up hospice care, which can occur in a patient's home or at an inpatient facility.

A physician, who specializes in symptom management, oversees the patient's care. When care is provided in a home, nurses make regular visits to assess and manage the patient's needs, communicating with the doctor and hospice team regarding the patient's condition and other needs. Home health care providers can be arranged to help patients with self-hygiene. Case managers can arrange for medical supplies to be delivered to the patients' home, such as, a hospital bed, portable toilet, walker, wheelchair, etc. Counselors and social workers not only provide support to the patient, but the entire family, who are coping with the patient's illness, dying, and death. When care is provided in an inpatient facility, the entire team is available as needed, with nursing care present around the clock.

### When is the right time to consider hospice?

Hospice is appropriate at any time when the goals of care have changed from curative therapy to palliation of symptoms; it is not only "end-of-life" care. The decision to start hospice is a very personal one and should be discussed with your healthcare

team, family, and friends. Ideally, the concept of hospice should be presented while the patient is able to express opinions and wishes, though this is not always the case. The patient, the family, or the physician can request hospice information or a referral visit from the hospice team at any time, when the focus of treatment is shifting from aggressive treatment to one of maintaining comfort and providing symptom relief. Patients should understand that embracing hospice does not mean that you, the doctor or your oncology team has "given up". Your physician still has an active role in the hospice process and in ensuring your comfort and good quality of life.

Hospice is reserved for patients who have a limited life expectancy – most insurers require a healthcare provider to state that the patient's life expectancy is six months or less. However, if the patient lives more than 6 months, they will not be "kicked out" of hospice. At that time, their healthcare team can discuss if hospice is still appropriate for them and, if so, again state that the patient has a six-month life expectancy.

## What is the cost of hospice?

Most health care plans offer some type of hospice benefit. Patients over age 65 qualify for the Medicare Hospice Benefit in the United States and Medicare covers most aspects of hospice care. For those younger than 65, many private health plans do have some type of hospice provision. You may need to review your policy, call your insurance company or meet with a social worker to determine the coverage provided on your plan. Medicaid covers hospice care in nearly all states. Even if patients do not have hospice coverage, many hospices will still provide care for people. Typically, hospices have a financial specialist on staff to answer questions about receiving financial assistance, which may come from donations, grants or other community fundraisers.

## What are some common misconceptions about hospice?

*Hospice may hasten death.* Hospice neither speeds up nor puts off a person's death. Hospice provides an individualized service to the patient and his/her family so that everyone can prepare for the inevitable death and that it may be dignified and noble. Hospice care focuses on improving or maintaining a good quality of life during the final phase of life.

*Once I sign up, I can never get treatment for my cancer again.* Another misconception is that a patient cannot decide to stop receiving hospice services once enrolled. Should a patient's condition improve and/or the patient decides to pursue further treatment, such as a clinical trial or a new treatment, the patient can be discharged from hospice.

*I am not of a certain religion, so I cannot participate.* Some believe that hospice is affiliated with certain religious beliefs. Actually, hospice is not associated with any particular religion. It simply provides medical, emotional, spiritual, and psychological care in a manner most beneficial to the patient and his or her own beliefs. Hospice services would never interfere with any patient's religious convictions or beliefs. All patients are encouraged to seek out and freely practice their faith and spirituality. Therefore, if desired, evoking the participation of one's own clergy is also welcomed.

*I have to wait for my healthcare provider to offer hospice.* The patient or their family members can bring hospice into the discussion at any time. Some healthcare providers may hesitate to bring up hospice, for fear that the patient will not be open to the idea. If the patient is interested in learning more about hospice options, they should not hesitate to discuss this with the healthcare team.

## Does hospice provide help for caregivers/family?

Hospice agencies understand that caregivers' needs are often overlooked in everyone's focus on the patient. The same



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emotional and spiritual support that is offered to patients is available to their caregivers. Some hospices provide respite care for caregivers, which provides a temporary break that can be essential in terms of relieving stress, restoring energy, and promoting balance in his/her life. In turn, providing some relief of the physical and emotional distress associated with caring for a loved one, allows the caregiver to provide better care for the patient. The caregiver can work with the hospice to arrange for in-home care or a skilled nursing facility to care for the hospice patient. The breaks could be for a few hours or a few days. In addition, there are support groups for caregivers that one may find beneficial.

Caregiver grief and emotional distress does not end with the death of the ill. For this reason, hospices can provide continued support for caregivers for as long as a full year following the death of a loved one. Most hospices organize bereavement and support groups for anyone who experienced such a loss, regardless if your loved one was a patient in their care. Furthermore, some hospices can provide assistance in financial planning for a funeral. Bereaved family members are often ill equipped to organize funeral arrangements and hospice volunteers can provide assistance in these negotiations.

#### **Additional links to resources for caregivers:**

- [Hospice Foundation of America](#)
- [Cancer Support Community](#)

#### **Resources about Hospice Care:**

- [Hospice Foundation of America](#)
- [Caring Connections](#) (a program of the National Hospice and Palliative Care Organization)
- [American Cancer Society](#)