



# Patient Information

## Understanding Hospice Care

**W**hen a serious illness progresses to the point that medical treatment is no longer working or desired, *hospice* (**hahs**-pehs) care may be an option. Hospice care is a combination of services that focus on pain relief and symptom control for patients in the terminal stage of illness, as well as on social, spiritual, and emotional support for these patients and their loved ones. The goal of hospice care is to make the end of life as comfortable and meaningful as possible.

### Where can I receive hospice care?

Hospice care can be provided in a hospital, nursing home, or special hospice facility. In the United States, however, more than 90% of hospice care is provided in patients' own homes. In these cases, a family member or friend who is willing and able to look after the patient on a daily basis provides the bulk of the care, such as helping the patient to eat, bathe, and take medications. A hospice care team—including doctors; nurses; social workers; physical, occupational, and respiratory therapists; health aides; clergy members; and volunteers—is actively involved in and helps coordinate the patient's care, providing regular home visits and on-call support.

Even if a person receives hospice care primarily at home, there may be times when admission to a hospital or extended care facility is necessary for specialized care. In addition, the patient may be admitted to a hospice facility, nursing home, or hospital for a short period of time (usually five days) to give his or her

caregiver a break. This is known as *respite* (**res**-pit) care.

### What can I expect from hospice care?

All people who receive hospice care are treated *palliatively* (**pal**-yuh-tiv-lee), which means that treatment focuses on relieving the pain, symptoms, and stress of serious illness. Although palliative care can be provided in other settings along with treatments that attempt to cure the underlying disease, hospice care provides palliative care without curative treatments.

A wide range of medications can be used to relieve pain. For mild to moderate pain, *nonopioid* (**non-oh**-pee-oyd) medications—such as *acetaminophen* (uh-seet-uh-**min**-uh-fuhn) and *nonsteroidal anti-inflammatory* (**non-stuh-royd**-al an-tie-in-**flam**-uh-tor-ee) drugs—are commonly used. *Opioids* (**oh**-pee-oyds) are prescribed to treat moderate to severe pain and to ease shortness of breath and coughing. These drugs can be taken in pill form, absorbed through the skin with a patch, injected as a single dose, or pumped into the body continuously. *Adjuvant* (**ahj**-uh-vuhnt) medications are drugs that were originally developed to treat other problems, such as depression or seizures, but that have been found to relieve pain as well.

Although some medications used for pain (such as opioids) are strong, they can be used safely under proper medical supervision. The hospice team can help ensure that pain medication is prescribed, administered, and monitored appropriately. Along with medication, such treat-

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ments as relaxation, massage, and counseling can be used to manage pain.

For some people who experience problems swallowing or absorbing nutrients, artificial feeding and hydration may be considered as part of hospice care. These treatments can cause discomfort, however, and when death is very close, the treatments' disadvantages may outweigh their benefits. In such cases, simply treating the dry mouth and lips that result from dehydration can ensure a more comfortable end of life.

Hospice care team members prepare families to recognize signs of near death, including decreased consciousness, cool or discolored limbs, and irregular and noisy breathing. Laws for pronouncing death and contacting the proper officials vary from state to state, and the hospice and home care teams should discuss these matters early on. When families are grieving, a trained volunteer, clergy member, or professional counselor can support the surviving members through visits, phone calls, and letters. Family members also can be referred to support groups and mental health professionals.

### When is hospice care appropriate?

According to Medicare guidelines and those of most private insurance companies, coverage of hospice care requires an evaluation by a doctor that determines life expectancy to be less than six months. Medicare, private insurance, Medicaid (in 43 states), and the VA all cover hospice care when certain conditions are met. Some hospice programs offer services on a sliding scale for patients with limited incomes.

Hospice care works best when it is started early on. If the patient gets better

or the disease goes into remission, hospice care can be stopped and medical treatments aimed at curing the disease started. Likewise, hospice care can begin again if the disease is not responsive to such treatments.

### What else should I know about hospice care?

When making decisions about hospice care, the patient and his or her caregivers should review the options openly and thoroughly with one another, a doctor, and other professionals who can help to determine the best setting for care. And when selecting a hospice care facility outside of the home, it's important to ensure that the facility is nationally accredited, certified, and licensed and will meet the patient's personal needs.

Once the patient, caregivers, and doctor have made a decision about hospice care, a living will can be made. This written document states the medical wishes of the dying person, including who should make health care decisions for the patient in the event that he or she becomes unable to make them for himself or herself.

For more information about hospice care, visit the National Institutes of Health's hospice web page (<http://www.nlm.nih.gov/medlineplus/hospicecare.html>) and the web site of the National Hospice and Palliative Care Organization (<http://www.nhpc.org>). ●

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