

Hospice Care Guidance

When a patient has been diagnosed with a terminal illness, meaning the illness cannot be cured, it is time to explore end-of-life options. Hospice care is designed to control pain and other symptoms for terminally ill patients who have a life expectancy of 6 months or less.

The number of patients and families receiving hospice care has risen steadily over the years, and in 2012, about 1.5 million patients received care at 5,500 hospice care programs. More than 35% of patients receiving hospice care have a primary diagnosis of cancer; others have diagnoses such as dementia, heart disease, and lung disease. Special hospice programs exist for children with cancer or other diseases and for people with AIDS.

What is hospice care?

Hospice care provides the following services for patients with a terminal illness and, if the illness runs its usual course, a life expectancy of 6 months or less:

- **Basic medical care.** This care focuses on pain and symptom control.
- **Daily care.** This care includes help with bathing, dressing, and eating.
- **Round-the-clock access.** A member of the hospice care team is available 24 hours a day, 7 days a week.
- **Guidance.** The hospice care team provides assistance with the difficult issues of life completion and closure.
- **Respite care.** A member of the hospice care team can provide regular caregivers and family members a break, from a few hours to several days, depending on the program.
- **Counseling.** Hospice care team members provide psychological, emotional, and spiritual counseling.
- **Assistance with advance directive forms.** A *living will* allows a hospice patient to document his or her wishes at end-of-life when otherwise

unable to make medical decisions. A medical *power of attorney*, also known as a health care proxy, authorizes someone of the patient's choosing to make medical decisions on the patient's behalf.

- **Answers for questions about treatments received during hospice care.** These treatments are designed to relieve pain and other symptoms.
- **Bereavement services for family and friends.** Most programs provide at least 1 year of grief services after the death of a loved one.

How do I know if hospice care is right for me?

The decision to enroll in hospice care is an acknowledgement that you will shift your treatment goals from curing the illness to making the rest of your life as comfortable as possible. Being bed-ridden or in a hospital is not a requirement for hospice care. Regardless of your physical condition, hospice care is designed to keep you as comfortable, functional, and alert as possible. This deeply personal decision may be based on the following information:

- Your life expectancy is shortened due to a disease or illness
 - Treatment to cure the disease or prolong life is a burden rather than a benefit
 - You want to spend your remaining life as comfortable as possible in a setting of your own choosing
 - You want your family and friends involved in your care
 - You are a caregiver who wants your loved one with a terminal illness to die comfortably at home
- If you have decided to live as long as possible by any medical means necessary, hospice care may not be appropriate for you at this time.

What can I expect?

Throughout hospice care, an interdisciplinary team of health care providers comes together to care for

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the patient and his or her family. This team may include:

- Physicians
- Nurses
- Home health aides
- Therapists
- Bereavement counselors
- Spiritual counselors
- Volunteers
- Social workers

A family member or loved one will usually look after you much of the time. You may expect someone from your hospice care team to visit with you for about an hour, 1 or more times per week. A 24-hour hospice number is available for you to call if you have an emergency or get scared, and a nurse is usually able to come to your home any time of day or night. Your regular doctor can work with your hospice team and may remain involved in your care.

What questions should I ask?

All hospice programs should provide you with written materials outlining their services, eligibility rules, costs and payment procedures, employee job descriptions, and malpractice and liability insurance. Other questions you may want to ask include:

- **Accreditation.** Is the agency certified and licensed by a nationally recognized group, such as the Joint Commission?
- **Certification.** Is this hospice program certified by Medicare?
- **Licensure.** If your state requires it, is the program licensed? Visit <http://www.statelocalgov.net/50states-health.cfm> to access your state health department's requirements.
- **References.** Can the agency provide you references from professionals who have used this agency? Ask for names and telephone numbers, and check with the Better Business Bureau, your local Consumer Bureau, or the State Attorney General's office.
- **Care plan.** Does the agency create a care plan for

each new patient? Ask if you can look at a sample care plan.

- **Services.** How quickly can the agency start services? Does the hospice care program provide specialized services, such as pharmacists, dietitians, or family counselors?
- **Location.** Where does the agency provide care? Most people choose to receive hospice care at a personal residence, such as a private home, nursing home, or residential facility. Others receive care at an inpatient facility or an acute care hospital.
- **Emergency planning.** Does the agency have an emergency plan in place in case of bad weather, a power failure, or a natural disaster?
- **Patient's rights and responsibilities.** Ask to see a copy of the agency's rights and responsibilities information.
- **Personnel.** Are there references on file for the staff? Whom do you call if you have questions or complaints? What is the procedure for resolving issues?
- **Stopping care.** Check with your insurance company on how to change hospice agencies without interrupting payments or services.

For more information on hospice care, visit the National Hospice and Palliative Care Organization at <http://www.nhpc.org>.

Notes:
