



CHOOSING HOSPICE CARE

“My only regret about my father’s death is that we didn’t know about hospice sooner. He was so much happier at home than in the hospital and with the help of the hospice professionals, he could remain at home.”

— Lisa, 48 year-old-daughter

It is common to feel overwhelmed about making health care decisions when you are facing a terminal or life threatening illness. Receiving information about end-of-life health care choices can help guide these difficult decisions. One of the options that is available and is utilized by thousands of people facing imminent death each year is hospice care.

What is “Hospice Care”?

Hospice Care is an approach to assisting patients and managing disease at the end-of-life. The primary focus of hospice care is on improving the quality of a person’s life so that the person is alert and pain-free as the end-of-life approaches. This type of care does not prolong life or attempt to cure the illness. It does not quicken death either. Hospice care allows dying to take its natural course while placing the emphasis on being comfortable during the last months, weeks, and days of life.

The hospice concept promotes togetherness with family and other loved ones while focusing on finding enjoyment and pleasure in each day. Hospice programs provide end-of-life physical, supportive and emotional care for the individual by a team of professionals and volunteers. Hospice encourages each person to choose the type of care he/she wants, in the setting he/she prefers, whether home, hospice facility, nursing home, or hospital.

What Services Does Hospice Provide?

Hospice care not only focuses on the person’s physical well being, but also on the family’s emotional, spiritual, and social needs. The providers of this care offer a positive approach to coping with all the feelings that

accompany the dying process. Hospice programs vary in the specific kinds of services provided, but generally hospice care includes:

- **Emotional Support /Spiritual Guidance.** Hospice care providers help the patient come to terms with his/her own death at a pace that is comfortable for that particular person. They can also assist patients in preparing for important moments such as saying final goodbyes, mending broken relationships, completing a last will and testament, making memorial/funeral plans, and distributing personal belongings.
- **Medical Care.** Physician visits, skilled nursing services, and home health aides are available to assist with controlling pain and relieving symptoms from the illness along with providing overall physical care to keep the patient as comfortable as possible.
- **Family Support.** Some hospice programs provide respite care for family caregivers, offering them rest from their care-giving responsibilities for a brief period of time. Hospice workers also provide training and guidance for family members in the care of the patient, e.g. administering medication and changing dressings. Many hospice programs continue providing grief counseling and support to loved ones for up to one year after death.
- **Volunteer Services.** Hospice volunteers lend a helping hand by doing household chores, running errands, helping with personal assistance like bathing and dressing, and providing support, guidance and companionship to the patient and the family.

Who Provides Hospice Care?

Hospice uses a team approach to address the patient's needs as well as the needs of family members. An interdisciplinary health care team composed of physicians, nurses, aides, social workers, clergy and/or volunteers provide guidance and care along the way. A quality hospice care plan can usually be tailored specifically to each patient's needs and desires.

When Should I Use Hospice Care?

Hospice is appropriate for anyone with a terminal illness. Most hospice programs require a patient to have less than six months to live in order for them to utilize the services they provide. Your doctor does need to certify that it is his/her medical opinion at the time the order is written that your

prognosis is approximately six months or less. Everyone involved in this process knows these are only opinions, albeit educated ones, and hospice services can continue if you live past the six months. If your life does continue beyond six months, your doctor will need to re-certify your need for hospice care in order to continue receiving hospice health care benefits.

How Might I Feel When Considering Hospice Care?

Coming to terms with the likelihood of a limited life expectancy is an individualized process. It is common to feel a range of distressing emotions when first diagnosed with an illness or disease that may likely result in death within a relatively short time span, or when dealing with an illness that has progressed to its final stages. These emotions can include anxiety, fear, sadness, depression, hopelessness, and/or anger. These emotions influence an individual's response to hospice care.

Other things can also affect a person's reaction to hospice care. They include a person's age, values, spirituality, purpose in living, and relationships with family and friends. In addition, determining life expectancy is not an accurate science, and no one can tell for certain how a person's end-of-life situation will unfold. Thus, the pace at which people consider hospice care an option differs widely. Some people are quick to embrace it, while others may take longer to find their way to hospice care. Others still may never do so.

How Do I Connect to a Hospice Program?

Many communities in the United States have access to a hospice program, either as part of a local hospital or as a separate organization/agency. Your primary care provider may be able to refer you to a hospice program. If not, please refer to the resource section at the end of this handout, to find a local hospice program in your area. You do not have to be a health care provider to contact a hospice program. However, no matter how hospice is contacted, a doctor is needed to request hospice care in order for you to receive services.

How Do I Choose a Hospice Program?

Hospice programs vary. Thus a program that is well-suited for some patients may not suit the needs and desires of others. In addition, the services, hours, staff, volunteers, costs, and programs can vary from hospice to hospice. When exploring hospice programs, visit or call several

different hospice providers and inquire about the philosophy, the services provided, and cost.

How Do I Pay for Hospice?

Most private insurance plans, HMOs, and other managed care organizations include hospice care as a benefit. For those who are Medicare eligible, Medicare will cover hospice care related to a terminal illness no matter where hospice is provided, including the hospital, home, or other location. The Medicare hospice benefit eliminates the burden of paper work, as families are not required to submit claims or pay bills. Patients will receive all durable medical equipment and medications through their hospice Medicare benefit. If a patient receiving Medicare hospice services chooses to return to conventional treatment after accepting hospice care, the patient can return to regular Medicare coverage instead of the Medicare hospice coverage at any time.

Most states provide Medicaid for hospice patients. To find out what your state's Medicaid coverage is call the Center for Medicare and Medicaid
Phone: 1-877-267-2323

Those without insurance, Medicare, or Medicaid, or those who cannot afford hospice care for whatever reason, should know that many hospice organizations will not deny someone service. Charitable donations help hospice programs provide services to those in need.

Where To Get Help

National Resources

American Hospice Foundation. This national foundation's mission is to improve access to quality hospice care through public education, professional training, and consumer advocacy. Helpful articles for patients and loved ones are available on the site.

Phone: 1-202-223-0204. Web site: www.americanhospice.org

Hospice Association of America (HAA). An affiliate of the National Association for Home Care and Hospice Care (NAHC), this agency offers general information about hospice, including consumer guides.
Phone: 1-202- 546-4759. Web site: www.nahc.org/HAA/consumer.html

Hospice Foundation of America. This national foundation's Web site defines the hospice concept, offers tips to locate hospice services, lists

questions to ask a hospice representative when selecting a hospice, and has a section of stories from people who have personally experienced hospice services. A free brochure, “*Choosing Hospice*” can be ordered by phone or online.

Phone: 1-800-854-3402. Web site: www.hospicefoundation.org

HospiceLink. HospiceLink helps people seeking information and education about hospice care, and makes referrals to hospices in all 50 states. There is no charge for any HospiceLink service. Phone: 1-800-331-1620.

Hospice Net. This internet only organization offers articles regarding end-of-life issues and locates hospice programs. Web site: www.hospicenet.org

National Hospice and Palliative Care Organization (NHPCO). This membership organization’s Web site offers information on the hospice philosophy and tips for selecting a hospice. It also identifies keys to quality care, provides a national hospice directory, and has a useful FAQ section. In addition, it has valuable Consumer Guides.

Phone: 1-800-658-8898. Web site: www.nhpc.org

Hospice Payment Options: Medicare and Medicaid Coverage

Medicare. This agency offers a free brochure, “Medicare Hospice Benefits” that covers eligibility, benefits, how to choose a hospice program, and where you can get more help. Phone: 1-800-633-4227.

Web site: www.medicare.gov/Publications/Pubs/pdf/02154.pdf

Medicaid. The New York State Medicaid program provides hospice care. Call the New York State Medicaid Hotline, 1-800-541-2831. In New York City, residents can also call the Human Resources Administration toll free at 1-877-472-8411. Web site: www.cms.hhs.gov

New York State Resources

Hospice and Palliative Care Association of New York State. Provides end-of- life care resources in New York State. Select “Find a Hospice Program” section. Phone: 1-518-446-1483. Web site: www.hpcanys.org

This resource provides brief, general information about this health care topic. It does not take the place of specific instructions you receive from your health care providers. For answers to other questions consult your physician or other health care provider.

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HANDOUTS AVAILABLE ON

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