



Hospice Care

"You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

--Dame Cicely Saunders

What is hospice care?

In its earliest days, the concept of hospice was rooted in the centuries-old idea of offering a place of shelter and rest, or "hospitality" to weary and sick travelers on a long journey. In 1967, Dame Cicely Saunders at St. Christopher's Hospice in London first used the term "hospice" to describe specialized care for dying patients. Today, hospice care provides humane and compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

Hospice is a philosophy of care. The hospice philosophy or viewpoint accepts death as the final stage of life. The goal of hospice is to help patients live their last days as alert and pain-free as possible. Hospice care tries to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality rather than length of life. Hospice care is family-centered -- it includes the patient and the family in making decisions.

This care is planned to cover 24 hours a day, 7 days a week. Hospice care can be given in the patient's home, a hospital, nursing home, or private hospice facility. Most hospice care in the United States is given in the home, with family members or friends serving as the main hands-on caregivers. Because of this, a patient getting home hospice care must have a caregiver in the home with them 24 hours a day.

Hospice care is used when you can no longer be helped by curative treatment, and you are expected to live about 6 months or less if the illness runs its usual course. Hospice gives you *palliative care*, which is treatment to help relieve disease-related symptoms, but not cure the disease; its main purpose is to improve your quality of life. You, your family, and your doctor decide together when hospice care should begin.

One of the problems with hospice is that it is often not started soon enough. Sometimes the doctor, patient, or family member will resist hospice because he or she thinks it means you're "giving up", or that there's no hope. This is not true. If you get better or the cancer goes into remission, you can be taken out of the hospice program and go into active cancer treatment. You can go back to hospice care later, if needed. But the hope that hospice brings is the hope of a quality life, making the best of each day during the last stages of advanced illness.

Hospice care services

Many features of hospice care set it apart from other types of health care.

A team of professionals

In most cases, an interdisciplinary health care team manages hospice care. This means that many interacting disciplines work together. Doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers care for you and your family. Each of these people offers support based on their special areas of expertise. Together, they give you and your loved ones complete palliative care aimed at relieving symptoms and giving social, emotional, and spiritual support.

Pain and symptom control

The goal of pain and symptom control is to help you be comfortable while allowing you to stay in control of and enjoy your life. This means that discomfort, pain, and side effects are managed to make sure that you are as free of pain and symptoms as possible, yet still alert enough to enjoy the people around you and make important decisions. To learn more on this topic, please see our document, *Pain Control: A Guide for Those With Cancer and Their Loved Ones*.

Spiritual care

Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet your specific needs. It may include helping you look at what death means to you, helping you say good-bye, or helping with a certain religious ceremony or ritual.

Home care and inpatient care

Although hospice care can be centered in your home, you may need to be admitted to a hospital, extended-care facility, or a hospice inpatient facility. The hospice can arrange for inpatient care and will stay involved in your care and with your family. You can go back to in-home care when you and your family are ready.

Respite care

While you are in hospice, your family and caregivers may need some time away. Hospice service may offer them a break through *respite care*, which is often offered in up to 5-day periods. During this time you will be cared for either in the hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while you are cared for in an inpatient setting.

Family conferences

Regularly scheduled family conferences, often led by the hospice nurse or social worker, keep family members informed about your condition and what to expect. Family conferences also give you all a chance to share feelings, talk about what to expect and what is needed, and learn about death and the process of dying. Family members can find great support and stress relief through family conferences. Daily conferences may also be held informally as the nurse or nursing assistant talks with you and your caregivers during their routine visits.

Bereavement care

Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and care-giving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death. To learn more on this topic, please see our documents, *Coping With the Loss of a Loved One*, and *Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent*.

Volunteers

Hospice volunteers play an important role in planning and giving hospice care in the United States. Volunteers may be health professionals or lay people who provide services that range from hands-on care to working in the hospice office or fundraising.

Staff support

Hospice care staff members are kind and caring. They communicate well, are good listeners, and are interested in working with families who are coping with a life-threatening illness. They are usually specially trained in the unique issues surrounding death and dying. Yet, because the work can be emotionally draining, it is very important that support is available to help the staff with their own grief and stress. Ongoing education about the dying process is also an important part of staff support.

Coordination of care

The interdisciplinary team coordinates and supervises all care 7 days a week, 24 hours a day. This team is responsible for making sure that all involved services share information. This may include the inpatient facility, the home care agency, the doctor, and other community professionals, such as pharmacists, clergy, and funeral directors. You and your caregivers are encouraged to contact your hospice team if you are having a problem, any time of the day or night. There is always someone on call to help you with whatever may arise. Hospice care assures you and your family that you are not alone and help can be reached at any time.

Hospice care settings

Hospice care is defined not only by the services and care provided, but also by the setting in which these services are delivered. Hospice care may be provided in your home or in a special facility.

Most cancer patients choose to get hospice care at home. In fact, more than 90% of the hospice services provided in this country are based in patients' homes.

Before making a decision about the type of program that is best for you and your family, it is important to know all your options and what each requires. Your doctor, hospital social worker, or discharge planner can be very helpful in deciding which program is best for you and your family.

Home hospice care

Many, if not all, of the home health agencies in your community, as well as independently owned hospice programs, will offer home hospice services. Although a nurse, doctor, and other professionals staff the home hospice program, the primary caregiver is the key team member. The primary caregiver is usually a family member or friend who is responsible for around-the-clock supervision of the patient. This person is with the patient most of the time and is trained by the nurse to provide much of the hands-on care.

It is important to know that home hospice may require that someone be home with you at all times. This may be a problem if you live alone, or if your partner or adult children have full-time jobs. But creative scheduling and good team work among your friends and loved ones can overcome this problem. Members of the hospice staff will visit regularly to check on you and your family and give needed care and services.

Care begins when you are admitted to the hospice program, which generally means that a hospice team member visits the home to learn about you and your needs. Return visits are set up so that your needs can be re-evaluated regularly. To handle around-the-clock patient needs or crises, home hospice programs have an on-call nurse who answers phone calls day and night, makes home visits, or sends the team member you may need between scheduled visits. Medicare-certified hospices must provide nursing, pharmacy, and doctor services around the clock.

Hospital-based hospices

Hospitals that treat seriously ill patients often have a hospice program. This arrangement allows patients and their families easy access to support services and health care professionals. Some hospitals have a special hospice unit, while others use a hospice team of caregivers who visit patients with advanced disease on any nursing unit. In other hospitals, the staff on the patient's unit will act as the hospice team.

Long-term care facility-based hospices

Many nursing homes and other long-term care facilities have small hospice units. They may have a specially trained nursing staff to care for hospice patients, or they may make arrangements with home health agencies or independent community-based hospices to provide care. This can be a good option for patients who want hospice care but do not have primary caregivers to take care of them at home.

Independently owned hospices

Many communities have free-standing, independently owned hospices that feature inpatient care buildings as well as home care hospice services. As with long-term care facility hospice programs, the free-standing hospice can benefit patients who do not have primary caregivers available at home.

Who pays for hospice care?

Home hospice care usually costs less than care in hospitals, nursing homes, or other institutional settings. This is because less high-cost technology is used and family and friends provide most of the care at home.

Medicare, Medicaid in most states, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations pay for hospice care. Also, community contributions, memorial donations, and foundation gifts allow many hospices to give free services to patients who can't afford payment. Some programs charge patients according to their ability to pay.

Medicare hospice

To get payment from Medicare, the agency must be approved by Medicare to provide hospice services.

To qualify for the Medicare hospice benefit, a doctor and the hospice medical director (also a doctor) must certify that the patient has less than 6 months to live if the disease runs its normal course. The doctor must re-certify the patient at the beginning of each benefit period (2 periods of 90 days each, then an unlimited number of 60-day periods). The patient signs a statement that says he or she understands the nature of the illness and of hospice care, and that he or she wants to be admitted to hospice. By signing the

statement, the patient declines Medicare Part A and instead chooses the Medicare hospice benefit for all care related to his or her cancer. The patient can still receive Medicare benefits for other illnesses. A family member may sign the statement if the patient is unable to do so.

Medicaid coverage

In 1986, laws were passed to allow the states to develop coverage for hospice programs. Most states have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit.

Private insurance

Most private insurance companies include hospice care as a benefit. Be sure to ask about your insurance coverage, not only for hospice, but also for home care.

Private pay

If insurance coverage is not available or is not enough to cover all costs, the patient and the family can hire hospice providers and pay for services out of pocket. Some hospices provide services without charge if a patient has limited or no financial resources.

How do I find hospice care?

Finding the hospice program that meets your needs may take some research, but it will be time well spent. You and your family should do this early in your care while you have the strength and ability to take part in the decision. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage all need to be considered. Most communities have more than one hospice provider you can choose from. Here are some things to think about as you start your search:

Local resources

Your doctor or hospital discharge planner can help you find hospices in your area. Hospice care providers also are listed in the phone book. Your community may have information and referral services available through your American Cancer Society, an Agency on Aging, a local United Way chapter, the Visiting Nurse Association, or your place of worship.

State resources

You may contact your state's hospice organization or its department of health or social services to get a list of licensed agencies. The state health department oversees certification of hospice services. Certification makes them able to get funding from

Medicare and, in some states, also from Medicaid. Check the blue pages of your phone book for other resources in your area.

National resources

National organizations that deal with hospice care accreditation, treatment, and patient advocacy are listed in the "To learn more" section at the end of this document. Some of them also tell you which hospices are near you.

What questions should I ask about hospice care?

There are a number of things you might want to ask about when deciding on a hospice program. We will review some of them here.

Accreditation

Is the agency accredited (certified and licensed) by a nationally recognized group, such as the Joint Commission? The Joint Commission is an independent, not-for-profit organization that evaluates and accredits health care organizations and programs. It is an important resource in selecting quality health care services.

Certification

Is this hospice program certified by Medicare? Medicare-certified programs have to meet at least minimum requirements for patient care and management.

Licensure

If your state requires it, is the program licensed?

Consumer information

Does the agency have written statements outlining services, eligibility rules, costs and payment procedures, employee job descriptions, and malpractice and liability insurance? Ask them to send you any brochures or other available information about their services.

References

How many years has the agency been serving your community? Can the agency give you references from professionals -- such as a hospital or community social workers -- who have used this agency? Ask for names and telephone numbers. A good agency will give you these if you ask for them. Talk with these people about their experiences with the hospice. Also, check with the Better Business Bureau, your local Consumer Bureau, or the State Attorney General's office.

Admissions

How well does hospice work with each patient and family to apply policies or negotiate differences? If the hospice imposes conditions that do not feel comfortable, it may be a sign that it is not a good fit for you. If you are not sure whether you or your loved one qualifies for hospice -- or whether you even want it -- is the agency willing to meet with you to help you talk through these concerns?

Care plan

Does the agency create a care plan for each new patient? Is the plan carefully and professionally developed with input from you and your family? Is the care plan written out and are copies given to everyone involved? Check to see if it lists specific duties, work hours/days, and the name and telephone number of the supervisor in charge. Will the care plan be updated as your needs change? Ask if you can look at a sample care plan.

Primary caregiver

Does the hospice require you to have a primary caregiver as a condition of admission? What responsibilities are expected of the primary caregiver? Will someone need to be with you all the time? What help can the hospice offer to organize and assist the family's efforts? For example, can the hospice help you fill in around job schedules, travel plans, or other responsibilities? If you live alone, what other options can the hospice suggest?

Initial evaluation

Does a nurse, social worker, or therapist come to you to talk about and evaluate the types of services you may need? Is this done in your home, rather than over the telephone? Does it highlight what you can do for yourself? Does it include input from your family doctor and/or other professionals already involved in your care? Are other members of your family included in this visit?

Personnel

Are there references on file for home care staff? Ask how many references the agency requires for each staff member who gives home care (2 or more should be required). Does the agency train, supervise, and monitor its caregivers? Ask how often the agency sends a supervisor to the patient's home to review the care being given to the patient. Ask whether the caregivers are licensed and bonded. Who do you call if you have questions or complaints? What is the procedure for resolving issues?

Costs

How does the agency handle payment and billing? Get all financial arrangements -- costs, payment procedures, and billing -- in writing. Read the agreement carefully before

signing. Be sure to keep a copy. What resources does the agency provide to help you find financial assistance if it is needed? Are standard payment plan options available?

Telephone response

Does the agency have a 24-hour telephone number you can call when you have questions? How does the hospice respond to calls? Does the telephone staff seem caring, patient, and competent from the first contact, even if they need to return your call? Do they speak in plain, understandable language? What is the procedure for making and resolving complaints?

How did the hospice respond when you first contacted them? How a hospice responds to your first call for help may be a good sign of the kind of care to expect.

Emergency planning

Does the agency have an emergency plan in place in case of a power failure or natural disaster? You can ask to see a copy of the plan. In case of an emergency, you need to know whether the agency can still deliver services at your home.

Services

How quickly can the hospice start services? What are its geographic service boundaries? Does the hospice offer specialized services such as rehabilitation therapists, pharmacists, dietitians, or family counselors when these could improve your comfort? If needed, does the hospice provide medical equipment or other items that might improve your quality of life?

Limits on treatment

During your first visit be sure to talk about all of the treatments you are currently getting. If you want to continue these things you must make it clear to the hospice provider. Some hospices will not cover things like dialysis, total parenteral nutrition (TPN, or intravenous feedings), blood transfusions, or certain drugs. But some hospices, most often the bigger ones, do offer open-access care which allows you to add hospice care to your current medical treatment. Still, this is not always an option. Find out how the hospice would handle your current treatments before committing to their services.

You may also want to find out how the hospice would manage it if you should get a health problem that is curable, such as a urinary tract infection or pneumonia. Even though they cannot cure your cancer, you may be more comfortable if they are able to treat these smaller problems.

Inpatient care

What are the policies about inpatient care? Where is such care provided? What are the requirements for an inpatient admission? How long can the patient stay? What happens if

the patient no longer needs inpatient care but cannot go home? Can you tour the inpatient unit or residential facility? Which hospitals contract with the hospice for inpatient care? What kind of follow-up does the hospice provide for inpatients? Do nursing homes contract with the hospice? Does the hospice provide as much nursing, social work, and aide care for each patient in the nursing home as it does in the home setting?

Patient's rights and responsibilities

Does the agency explain your rights and responsibilities as a patient? Ask to see a copy of the agency's patient's rights and responsibilities information.

Deciding on hospice care

You and your loved ones are facing a sensitive and difficult time. Hospice care is a way to get the help you all may need. Please remember that there are also professional cancer information specialists who are ready to talk with you about your concerns. They are available 24 hours a day, 7 days per week at our National Cancer Information Center. You can speak to one of them by calling 1-800-227-2345.

To learn more

More information from your American Cancer Society

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345, or read on our Web site, www.cancer.org.

More about dealing with terminal illness

Nearing the End of Life

Advanced Cancer (also available in Spanish)

Advance Directives

Talking With Your Doctor (also available in Spanish)

Pain Control: A Guide for Those With Cancer and Their Loved Ones (also available in Spanish)

For caregivers and loved ones of the person with cancer

What it Takes to Be a Caregiver

What You Need to Know as a Cancer Caregiver

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also available in Spanish)

Listen With Your Heart (also available in Spanish)

Family and Medical Leave Act (FMLA)

Home Care Agencies (also available in Spanish)

Talking with children and other loved ones about cancer

Talking With Friends and Relatives About Your Cancer (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness

Financial and insurance issues

Health Insurance and Financial Assistance for the Cancer Patient (also available in Spanish)

Financial Guidance for Cancer Survivors and Their Families: Advanced Illness

Financial Guidance for Families: Coping Financially With The Loss Of A Loved One

Bereavement

Helping Children When a Family Member Has Cancer: When a Child Has Lost a Parent

Coping With the Loss of a Loved One (also available in Spanish)

Books

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

Cancer in the Family: Helping Children Cope With a Parent's Illness

When the Focus Is On Care: Palliative Care and Cancer

National organizations and Web sites*

Along with the American Cancer Society, other sources of information and support include:

Compassion and Choices

Toll-free number: 1-800-247-7421

Web site: www.compassionandchoices.org

For local referrals to pain specialists, hospice programs, and other resources; offers patients assistance in completing living wills and advance directives, and in talking to families, friends, and health care providers about health care wishes

National Hospice and Palliative Care Organization (NHPCO)

Toll-free number: 1-800-658-8898; in Spanish 1-877-658-8896

Web site: www.nhpco.org

Provides information about hospice programs in your area; also publishes information for consumers and has frequently asked questions on their Web site

City of Hope Pain/Palliative Care Resource Center (COHPPRC)

Telephone number: 626-256-4673, extension 63829

Web site: www.prc.coh.org

Has information on palliative care and pain management, as well as educational programs on death and dying

Hospice Education Institute

Toll-free number: 1-800-331-1620

Web site: www.hospiceworld.org

Offers information about caring for the dying and the bereaved; maintains a directory of hospice and palliative care programs in the United States; and provides general information about good hospice care

Hospice Foundation of America (HFA)

Toll-free number: 1-800-854-3402

Web site: www.hospicefoundation.org

Acts as an advocate for hospice care by conducting public education and information; lists hospices by geographical area, which is available at www.hospicedirectory.org

Hospice Net

Web site: www.hospicenet.org

Provides information and support to patients facing life-threatening illnesses and to their families and friends; also can help find a local hospice

National Association for Home Care and Hospice Care (NAHC)

Web site: www.nahc.org

Provides a state-by-state database of phone numbers for state home care, including Visiting Nurse Associations and hospice agencies (choose “agency locator”); offers information on how to choose a home care agency or a hospice

Family and Medical Leave Act

Toll-free number: 1-866-487-9243

TTY: 1-877-889-5627

Web site: <http://www.dol.gov/whd/fmla/index.htm>

Has information on the Family and Medical Leave Act of 1993 (FMLA), which helps people keep jobs and health insurance while taking time off to care for themselves or loved ones

Family Caregiver Alliance

Toll-free number: 1-800-445-8106

Web site: www.caregiver.org

Provides information and resources on long-term caregiving; searchable resource feature on their Web site provides information on publicly-funded and private caregiver support programs in each of the 50 states and the District of Columbia

National Family Caregivers Association (NFCA)

Toll-free number: 1-800-896-3650

Web site: www.thefamilycaregiver.org

Quarterly newsletter offers can-do advice, helpful resources and stories about family caregivers, and a bereavement kit for when members are no longer caregivers, to help them deal with their loss and move on with their lives

Centers for Medicare & Medicaid Services (CMS) – HHS

Toll-free number: 1-877-267-4227

TTY: 1-877-486-2048

Web site: www.cms.hhs.gov (or for just Medicare info: www.medicare.gov)

Answers questions about how to apply for Medicare, Medicaid, disability, or survivor benefits, and also answers questions about coverage for all Medicare recipients

Medicare Rights Center (MRC)

Toll-free number: 1-800-333-4114

Web site: www.medicarerights.org

Basic information and explanations of Medicare rights and benefits

Social Security Administration (SSA)

Toll-free number: 1-800-772-1213

TTY: 1-800-325-0778

Web site: www.socialsecurity.gov

Has general information, qualification criteria, and information about how to apply for program benefits (such as Social Security Disability Income and Supplemental Security Income if you cannot work). Makes referrals to local SSA and Medicare/Medicaid offices

National Association of Area Agencies on Aging (n4a)

Toll-free number: 1-800-677-1116

Web site: www.n4a.org

To find agencies with local resources for older people with cancer, see their online Eldercare Locator

Joint Commission

Toll-free number: 1-800-994-6610 (to file a complaint about an accredited organization)

or program)

Web site: www.jointcommission.org

Provides information on accredited hospice agencies, including a "quality check" directory of hospices

Visiting Nurse Associations of America (VNAA)

Web site: www.vnaa.org

Web site can link you to one of their member Visiting Nurse Association office in your area. Local VNAs offer services including skilled nursing and mental health care, hospice care, and home health care

AARP

Toll-free number: 1-888-687-2277

Web site: www.aarp.org

Provides information on health care treatment, insurance benefits, caregiving, and grief and loss

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for cancer-related information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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