



Hospice Care

What is 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

Hospice care focuses on quality rather than length of life. It 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.

The hospice philosophy accepts death as the final stage of life: it affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease, working to manage symptoms so that a person’s last days may be spent with dignity and quality, surrounded by their loved ones. It’s also family-centered – it includes the patient and the family in making decisions.

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 supportive or *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 loved ones, and your doctor decide together when hospice care should begin.

One of the problems with hospice is that it’s 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 leave hospice and go into active cancer treatment. 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.

Some doctors don’t bring up hospice, so the patient or family member might decide to start the conversation. If your treatment isn’t working anymore and you’ve run out of treatment options, you can ask your doctor or a member of your treatment team about hospice.

What does hospice care provide?

All hospices must provide certain services, but they tend to have different approaches to service, staffing patterns, and types of support services offered.

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 alert enough to enjoy the people around you and make important decisions.

To learn more, see our document called *Guide to Controlling Cancer Pain*.

Home care and inpatient care

Although most hospice care is centered in the home, there might be times when you need to be admitted to a hospital, extended-care facility, or an inpatient hospice center. Your home hospice team 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.

Spiritual care

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

Family meetings

Regularly scheduled family meetings, often led by the hospice nurse or social worker, keep family members informed about your condition and what to expect. Family meetings also give everyone a chance to share feelings, talk about what's happening and what's needed, and learn about death and the process of dying. Family members can get great support and stress relief through these meetings. Daily updates may also be given informally as the nurse or nursing assistant talks with you and your caregivers during routine visits.

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're having a problem, any time of the day or night. There's 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.

Respite care

For patients being cared for at home, hospice service may offer *respite care* to allow friends and family some time away from caregiving. Respite care can be given in up to 5-day periods of time, during which you are cared for either in the hospice facility or in beds that are set aside 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.

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 other contact, as well as through support groups. The hospice team can refer family members and caregiving 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, 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*.

Who provides hospice care?

Hospice care can be provided by independent hospices, or through programs based in hospitals, nursing homes, or other health care systems.

In most cases, an interdisciplinary health care team manages hospice care. Typically, the hospice doctor or medical director is in charge of your care, though your cancer doctor and/or primary care doctor can be involved, too. Doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers care for you and your family. Together, they give you and your loved ones complete palliative (supportive) care aimed at relieving symptoms and giving social, emotional, and spiritual support. Hospice care staff members are typically kind and caring. They communicate well, are good listeners, and want to work with families who are coping with a life-threatening illness. They are usually specially trained in the unique issues surrounding death and dying and provided with ongoing education and support to help with the emotional demands of the job.

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.

Where is hospice care given?

Hospice care is designed to be available 24 hours a day, 7 days a week. It can be given in the patient's home, a hospital, nursing home, or private hospice facility. Your doctor, hospital social worker, or discharge planner can be very helpful in deciding which hospice program is best for you and your family.

Home hospice care

Most people get hospice care at home. In fact, most of the hospice services provided in the US are given where the patient lives, which is usually a private residence. But people who live in places like residential facilities, assisted living, or nursing homes can get hospice care there, too.

Most home health agencies, as well as independently owned hospice programs, offer home hospice services. Although home hospice programs are staffed by nurses, doctors, and other professionals, the main 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 to provide much of the hands-on care.

It's important to know that home hospice may require that someone be home with you 24 hours a day, 7 days a week. 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, your family, and your caregivers 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 you at 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 needs or crises, home hospice programs have an on-call nurse who answers phone calls day and night, makes home visits, or sends out 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 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 that visits patients with advanced disease on any nursing unit. In other hospitals, the staff on the patient's unit will act as the hospice team.

Nursing home or long-term care facility-based hospices

Many nursing homes and other long-term care facilities have small hospice units. They might have specially trained nursing staff to care for hospice patients, or they might 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 don't 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 don't have 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.

Hospice care is paid for by Medicare, Medicaid in most states, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations. 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, an agency or facility must be approved by Medicare to provide hospice services. In this case, you pay nothing for hospice care, but you may have co-pays for prescriptions. You also have to pay a percentage of the bill for inpatient respite care. (Respite care is discussed in the section called "What does hospice care provide?")

To qualify for the Medicare hospice benefit, a doctor and the hospice medical director (also a doctor) must see the patient and certify that the patient has less than 6 months to live if the disease runs its normal course. The hospice benefit starts with 2 periods of 90 days each, then an unlimited number of 60-day periods. The doctor or nurse practitioner must re-certify the patient in a face-to-face visit before the third election period, then again before each benefit period after that. This means that the patient must be seen by their own doctor and the hospice doctor to be certified for the first 180 days of hospice care. After the first 180 days, the patient must be seen again to be re-certified every 60 days for as long as the patient is getting hospice care.

The patient signs a statement that says he or she understands the nature of the illness and hospice care, and that he or she wants to be admitted to hospice. By signing the statement, the patient chooses the Medicare hospice benefit for all care related to his or her cancer. The patient can still receive Medicare benefits for illnesses that aren't related to cancer. A family member may sign the statement if the patient is unable to do so.

If you're not sure how hospice might work for you, Medicare offers a one-time only hospice consultation. You can meet with a hospice medical director or hospice doctor to discuss your care options and treatment needs. You don't have to choose hospice care if you use this consultation service.

Medicaid coverage

Most states have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit.

Private insurance

Most private health 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 does not cover all costs, the patient and the family can hire hospice providers and pay for services out of pocket. Some hospices are able to provide services without charge if a patient has limited or no financial resources.

How do I find hospice care?

Since most communities have more than one hospice provider, you and your family will need to decide which agency you'll use for hospice services. Finding the hospice program that best meets your needs may take some research, but it's 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. 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. You may also find information and referral services 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 or search online for your state hospice organization.

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 can also help you find hospice services near you.

Choosing a hospice care program

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's 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. (Remember: Medicare will only pay for care given by agencies they've certified.)

Licensure

If your state requires it, is the program licensed? You can check with your state health department to find out. They're listed in the blue pages of your phone book or you can visit www.statelocalgov.net/50states-health.cfm.

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 the hospice work with each patient and family to apply policies or negotiate differences? If the hospice imposes conditions that don't feel comfortable, it may be a sign that it's not a good fit for you. If you're not sure whether you or your loved one qualifies for hospice – or whether you even want it – is someone from 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 person in charge of your care. 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 main (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

Will 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 by phone? 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's 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 and be sure to keep a copy. Check with your health insurance provider to find out what deductibles and co-pays to expect. For example, certain medicines and respite care may require a co-pay. What resources does the agency provide to help you find financial assistance if it's needed? Are payment plans available?

Telephone response

Does the agency have a 24-hour telephone number you can call when you have questions or problems? 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 call you back? Do they speak in plain, understandable language? What's 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 bad weather, a power failure, or a 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 allow 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'll also want to find out how the hospice would manage any new health problems that would be curable, such as a urinary tract infection or pneumonia. You may be more comfortable if they're able to treat these types of 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 a patient stay? What happens if the patient no longer needs inpatient care but can't go home? Can you tour the inpatient unit or residential facility? Which hospitals or nursing homes contract with the hospice for inpatient care? What kind of follow-up does the hospice provide for inpatients? Does the hospice provide as much nursing, social work, and aide care for each inpatient as it does for those at home?

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.

What if I don't like the hospice service I choose?

If you change your mind after choosing a hospice agency, you can change hospice providers. Check with your insurance company to be sure how to go about this without interrupting payments or services. They can tell you how to stop care with your first hospice agency and sign up with another one.

Deciding on hospice care

You and your loved ones are facing a difficult time. Hospice care is a way to get the help you all may need. Please remember that the American Cancer Society has 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

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

More about dealing with terminal illness

Nearing the End of Life (also in Spanish)

Advanced Cancer (also in Spanish)

Advance Directives

Talking With Your Doctor (also in Spanish)

Guide to Controlling Cancer Pain (also 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 in Spanish)

Listen With Your Heart (also in Spanish)

Family and Medical Leave Act (FMLA) (also in Spanish)

Home Care Agencies (also in Spanish)

Talking with children and other loved ones about cancer

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

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families

Coping Financially With the Loss of a Loved One: Financial Guidance for Families

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 in Spanish)

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

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

End of life and hospice information

Compassion and Choices

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

Website: 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; Multilingual line 1-877-658-8896

Website: www.nhpc.org

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

Hospice Education Institute

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

Website: 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

Website: www.hospicefoundation.org

Acts as an advocate for hospice care by offering public education and information; lists hospices by geographical area online at www.hospicedirectory.org

National Association for Home Care and Hospice Care (NAHC)

Website: www.nahc.org

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

Children’s Hospice International (CHI)

Website: www.chionline.org

Has an International Resource Directory which provides information on more than 1,500 programs around the world that care for children with life-threatening conditions and their families

For caregivers

Family and Medical Leave Act information from the US Department of Labor

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

TTY: 1-877-889-5627

Website: 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

Website: www.caregiver.org

Provides information and resources on long-term caregiving; searchable resource feature on their website provides information on publicly-funded and private caregiver support programs in each of the 50 states and the District of Columbia; also offers telecaregiving and other web learning programs for caregivers

Caregiver Action Network

Website: www.caregiveraction.org

Has helpful resources and stories about family caregivers, an online forum to get encouragement and advice, and trained volunteers who can help you find resources in your community

Finances and insurance coverage

Centers for Medicare & Medicaid Services (CMS)

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

TTY: 1-877-486-2048

Website: www.cms.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

Website: 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

Website: 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

Other resources for those exploring hospice care

National Association of Area Agencies on Aging (n4a)

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

Website: www.n4a.org

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

Joint Commission, The

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

Website: www.jointcommission.org

Provides information on accredited hospice agencies, including a “quality check” directory of hospices which gives information about the quality and safety of accredited organizations

Visiting Nurse Associations of America (VNAA)

Website: www.vnaa.org

Website 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

Website: www.aarp.org

Provides information on health care treatment, insurance benefits, and grief and loss; also offers information on caregiving at www.aarp.org/home-family/caregiving or call 1-877-333-5885

**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.

References

Center for Medicare Services. Medicare Hospice Benefits, August 2013. Accessed at www.medicare.gov/Pubs/pdf/02154.pdf on April 7, 2014.

Forman WB, Kitzes JA, Anderson RP, Sheehan DK. *Hospice and Palliative Care: Concepts and Practice*, 2nd ed. Boston: Jones and Bartlett Publishers, 2003.

Eyre, HJ, Morris, LB, Lange D. *Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment, and Recovery*, 2nd ed. Atlanta: American Cancer Society, 2002.

Amenta, M. Hospice Services: The Place of Hospice Care in Cancer Treatment. In McCorkle, Ruth, et. al., (eds). *Cancer Nursing: A Comprehensive Textbook*. 2nd ed. Philadelphia: Saunders, 1996. 1333-1344.

Hospice Directory. Hospice Myths and Realities. Accessed at www.hospicedirectory.org/cm/about/choosing/myths_facts on April 4, 2014.

National Hospice and Palliative Care Organization. *Living with an Illness*. Accessed at www.caringinfo.org/i4a/pages/index.cfm?pageid=3343 on April 4, 2014.

Wright AA, Katz IT. Letting Go of the Rope — Aggressive Treatment, Hospice Care, and Open Access. *N Engl J Med*. 2007;357(4):324-327.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org