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 the quality of life rather than its length. 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. Hospice care is 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 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 symptoms, but not cure the disease. Its main purpose is to improve your quality of life. You, your family members, and your doctor decide when hospice care should begin.

Hospice often is not started soon enough. Sometimes the doctor, patient, or family member will resist hospice because they think it means “giving up” or that there’s no hope. This is not true. You can leave hospice and go into active cancer treatment any time you want. But the hope that hospice brings is 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 might want to ask your doctor or a member of your cancer care 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, nausea, and other side effects are managed to make sure that you feel as good as possible, yet are alert enough to enjoy the people around you and make important decisions.

**Home care and inpatient care**

Although most hospice care is centered in the home, there might be times when you need to be in 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 meetings, often led by the hospice nurse or social worker, keep family members informed about your condition and what to expect. These 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 hospice 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 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 can get help at any time.
**Respite care**

For patients being cared for at home, some hospice services 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 the person with cancer is 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’re cared for in an inpatient setting.

**Bereavement care**

Bereavement is the period 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.

**References**


**Who provides and pays for hospice care?**

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

**The hospice team**

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 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’re usually specially trained in the unique issues surrounding death and
dying and given 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 type of
hospice program is best for you and your family.

Home hospice care

Most people get hospice care at home. People who live in places like residential facil ities,
assisted living, or nursing homes can get hospice care there, too.

Most hospice programs offer home hospice services. Although home hospice programs
are staffed by nurses, doctors, and other professionals, the main caregiver is a family
member or friend who’s 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 in most cases, 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. They
will make sure that any symptoms you have are under control and give any 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 you 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 often have a hospice program. This gives patients and their families easy access
to support services, and allows the patient to get around-the-clock care to help get control
of symptoms. 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. The patient returns to home hospice care when they are again comfortable.

**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 24-hour care. This can be a good option for patients who want hospice care but don’t have someone 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 or need around-the-clock care.

**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 often 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.

Nearly all hospices have financial support staff who can help you with this, answer your questions, and help you get the care you need.

**References**


How do I find a hospice program?

Finding the hospice program that best meets your needs may take some research, but it’s time well spent. Since most communities have more than one hospice provider, you and your family will need to decide which agency you’ll use.

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, or a local United Way chapter.

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:

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 where you live. 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 like the National Hospice and Palliative Care Organization, or the National Association for Home Care and Hospice Care can help you find hospice services near you.
What to look for in a hospice program

There are a number of things you might want to ask about when deciding on a hospice program. Here are some ideas to get you started on a list of questions:

**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.

**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 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 it 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 any time 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 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 do allow you to add hospice care to your current medical treatment. 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

You might want to ask these types of questions 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 program, 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.

References


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