Hospice and Palliative Care

Quality of Life at the End of Life

For many seriously ill patients, hospice and palliative care offers a more dignified and comfortable alternative to spending your final months in the impersonal environment of a hospital. Palliative medicine helps patients manage pain while hospice provides special care to improve quality of life for both the patient and their family. Seeking hospice and palliative care isn't about giving up hope or hastening death, but rather a way to get the most appropriate care in the last phase of life.

What is hospice and palliative care?

Although death is a natural part of life, the thought of dying understandably still frightens many people. You may imagine pain and loneliness, spending your final days in the cold, sterile environment of a hospital far from family, friends and all that you know and love. However, hospice care represents a compassionate approach to end-of-life care, enhancing the quality of remaining life and enabling you to live as fully and as comfortably as possible.

Hospice is traditionally an option for people whose life expectancy is six months or less, and involves palliative care (pain and symptom relief) rather than ongoing curative measures, enabling you to live your last days to the fullest, with purpose, dignity, grace, and support. While some hospitals, nursing homes, and other health care facilities provide hospice care onsite, in most cases hospice is provided in the patient's own home. This enables you to spend your final days in a familiar, comfortable environment, surrounded by your loved ones who can focus more fully on you with the support of hospice staff.

The term "palliative care" refers to any care that alleviates symptoms, even if there is hope of a cure by other means. It is an approach that focuses on the relief of pain, symptoms, and emotional stress brought on by serious illness. Your disease doesn't have to be terminal for you to qualify for palliative care and, in the U.S., many palliative treatments are covered by Medicare. In some cases, palliative treatments may be used to alleviate the side effects of curative treatment, such as relieving the nausea associated with chemotherapy, which may help you tolerate more aggressive or longer-term treatment.

Talking about hospice and end-of-life issues

For many in Western society, death remains a taboo subject. Consequently, many patients and their families remain reluctant to even discuss the possibility of hospice care or palliative care. While most people would prefer to die in their own homes, the norm is still for terminally ill patients to die in hospital, receiving treatment that is either unwanted or ineffective. Their loved ones usually have only limited access and often miss sharing their last moments of life.

Some families who do choose hospice care often do so only for the last few days of life, and later regret not having more time saying goodbye to their loved one. To ensure that your family understands your wishes, it's important for anyone with a life-limiting illness to learn all they can about hospice and palliative care and discuss their feelings with loved ones before a medical crisis strikes. When your loved ones are clear about your preferences for treatment, they're free to devote their energy to care and compassion.

Legal planning for the future

If you became unable to direct your own medical care because of illness, legal documents such as a Living Will, Power of Attorney, or Advanced Directive can set forth your wishes for future health care so your family members are all clear on your preferences. Laws differ between states, so consult a lawyer or see the Resources section below to learn about your state's laws. For more information on legal planning, see Advance Health Care Directives and Living Wills (/articles/aging-well/advanced-health-care-directives-and-living-wills.htm).

How hospice and palliative care works

Hospice care focuses on all aspects of a patient's life and well-being: physical, social, emotional, and spiritual. There is no age restriction; anyone in the late stages of life is eligible for hospice services. While specific hospice services around the world differ in the amenities they provide, most include a hospice interdisciplinary team, or IDT, that includes the patient's physician, a hospice doctor, a case manager, registered nurses and licensed practical nurses, a counselor, a dietician, therapist, pharmacologist, social workers, a minister, and various trained volunteers.

The hospice team develops a care plan tailored to a patient's individual need for pain management and symptom relief, and provides all the necessary palliative drugs and therapies, medical supplies, and equipment. Typically, hospice care is provided at home and a family member acts as the primary caregiver, supervised by professional medical staff. Hospice IDT members make regular visits to assess the patient and provide additional care and services, such as speech and physical therapy, therapeutic massage, or dietary assistance. Certified home health aides may also be deployed for help with bathing and other personal care services. Hospice staff remains on-call 24 hours a day, seven days a week.

A hospice IDT also provides emotional and spiritual support according to the needs, wishes, and beliefs of the patient. Emotional and spiritual support is also provided to the person's loved ones as well, including grief counseling.

The benefits of hospice and palliative care

Research published in the Journal of Pain and Symptom Management found that terminally-ill patients who received hospice care lived on average 29 days longer than those who did not opt for hospice near the end of life.

Source: *National Hospice and Palliative Care Organization*

Hospice care providers offer specialized knowledge and support at the end of life just as obstetricians and midwives lend support and expertise at the start of life. Hospice can reduce anxiety in both the terminally ill patient and his or her family by helping them make the most of the time remaining and achieve some level of acceptance.

When terminally ill patients, who are often already in a weakened physical and mental state, make the decision to receive hospice and palliative care instead of continued curative treatment, they avoid the dangers of over-treatment. In-home care from a hospice

IDT often means the patient receives greater monitoring than he or she would in a hospital. In addition to focusing on the physical health and comfort of a patient, hospice care also focuses on the emotional needs and spiritual well-being of the terminally ill and their loved ones.

Since a hospice program offers substantial support and training for family caregivers, it also helps many patients feel less of a burden to their loved ones.

Misconceptions about Hospice and Palliative Care	
Misconception	Reality
Hospice makes death come sooner.	Hospice neither hastens nor postpones dying. The aim is to improve the quality of remaining life so patients can enjoy time with family and friends and experience a natural, pain-free death. In some cases, hospice care can extend life.
Hospice is giving up hope; it's better to fight for life.	Most terminally ill patients experience less anxiety by refocusing hope on what might be realistically achieved in the time remaining. If continuing uncomfortable and painful curative treatment for an illness is fruitless, hospice patients benefit more from having their symptoms treated instead.
A hospice patient who shows signs of recovery can't return to regular medical treatment.	If a patient's condition improves, they can be discharged from hospice and return to curative treatment, or resume their daily lives. If need be, they can later return to hospice care.
A hospice patient can't change his or her mind and return to curative treatment even if their prognosis hasn't changed.	A patient can go on and off hospice care as needed—or if they change their mind and decide to return to curative treatment. They may also enter hospital for certain types of treatment if it involves improving their quality of life.

Misconceptions about Hospice and Palliative Care	
Hospice care is limited to a maximum of six months.	In the U.S., many insurance companies, as well as the Medicare Hospice Benefit, require that a terminally ill patient has a prognosis of six months or less to start hospice, but a terminally-ill patient can receive hospice care for as long as necessary.

A guide to hospice care services

Hospice care services are typically structured according to the needs and wishes of each patient and his or her family. These may change over time and during the three different stages of care:

- The last phases of an illness
- The dying process
- The bereavement period

Depending on the patient's circumstances and stage of care, a hospice interdisciplinary team (IDT) may provide any combination of the following services:

Nursing Care. Registered nurses monitor your symptoms and medication, and help educate both you and your family about what's happening. The nurse is also the link between you, your family, and the physician.

Social Services. A social worker counsels and advises you and family members, and acts as your community advocate, making sure you have access to the resources you need.

Physician Services. Your doctor approves the plan of care and works with the hospice team. In a full hospice program, a hospice medical director is available to the attending physician, patient, and hospice care team as a consultant and resource.

Spiritual Support and Counseling. Clergy and other spiritual counselors are available to visit you and provide spiritual support at home. Spiritual care is a personal process, and may include helping you explore what death means to you, resolving "unfinished business," saying goodbye to loved ones, and performing a specific religious ceremony or ritual.

Home Health Aides and Homemaker Services. Home health aides provide personal care such as bathing, shaving, and nail care. Homemakers may be available for light housekeeping and meal preparation.

Trained Volunteer Support. Caring volunteers have long been the backbone of hospice. They're available to listen, offer you and your family compassionate support, and assist with everyday tasks such as shopping, babysitting, and carpooling.

Physical, Occupational, and Speech Therapies. These hospice specialists can help you develop new ways to perform tasks that may have become difficult due to illness, such as walking, dressing, or feeding yourself.

Respite Care. Respite care gives your family a break from the intensity of caregiving. Your brief inpatient stay in a hospice facility provides a "breather" for caregivers.

Inpatient Care. By the same token, even if you are being cared for at home, there may be times when you'll need to be admitted to a hospital, extended-care facility, or a hospice inpatient facility. Sometimes medical intervention will be recommended to ease the dying process (for example, an IV drip with pain medication), requiring round-the-clock nursing care. Thus, a facility may be a better choice. Your hospice team will arrange for inpatient care, and remain involved in your treatment and with your family.

Bereavement Support. Bereavement is the time of mourning we all experience following a loss. The hospice care team will work with surviving family members to help them through the grieving process. Support may include a trained volunteer or counselor visiting your family at specific periods during the first year, as well as phone calls, letters, and support groups. The hospice will refer survivors to medical or other professional care if necessary.

Who is eligible for hospice care?

If your doctor has certified your prognosis as not longer than six months, you are eligible for hospice. This applies to anyone of any age, with any type of illness. As well as cancer patients, people with ALS, kidney disease, and Alzheimer's disease, for example, can also benefit greatly from hospice care. Alzheimer's disease, in particular, is often overlooked for hospice referral because of its slow progression. People with Alzheimer's are usually referred to hospice when they are in the final stages of the illness, which can be very helpful to family members even if the person can no longer communicate.

You can receive hospice care in a nursing home if the nursing home agrees to allow the hospice staff to provide the primary care. Hospice pays for all of the medications and equipment needed in the nursing home. If you're in a Board and Care facility, the B&C must obtain a waiver from licensing to have someone from hospice at the facility.

When is it time for hospice and palliative care?

It's **not** time for hospice care and palliative instead of curative treatment if you are currently benefiting from treatments intended to cure your illness. For some terminally ill patients, though, there comes a point when treatment is no longer working. Continued attempts at treatment may even be harmful, or in some cases treatment might provide another few weeks or months of life, but will make you feel too ill to enjoy that time. While hope for a full recovery may be gone, there is still hope for as much quality time as possible to spend with loved ones, as well as hope for a dignified, pain-free death.

There isn't a single specific point in an illness when a person should ask about hospice and palliative care; it very much depends on the individual. The following are signs that you may want to explore options with hospice care:

1. You've made multiple trips to the emergency room, your condition has been stabilized, but your illness continues to progress significantly, affecting your quality of life.
2. You've been admitted to the hospital several times within the last year with the same or worsening symptoms.
3. You wish to remain at home, rather than spend time in the hospital.
4. You have decided to stop receiving treatments for your disease.

How to choose a hospice care service

Finding a hospice care service

- Ask your doctor what hospice programs are available in your community.
- Contact your hospital's social worker, discharge planner, or a care manager, any of whom should be able to recommend local hospice providers and facilities.
- Consult with friends who have used hospice services in the past for their loved ones.
- Visit the international searchable databases in the Resources section below.

Tips for selecting hospice care providers

People are sometimes reluctant to question doctors or other medical professionals about their care. Yet what is more important than the quality of care you will receive during this final phase of life? When you and your family are choosing your hospice team, be sure to ask about:

- The hospice's patient-to-caregiver ratios for each hospice discipline.
- Average frequency of home hospice visits.
- Response time and procedures followed for after-hours questions and concerns.
- Continuity of care (i.e., having the same care providers over time).

Also, ask whether the hospice will develop a written treatment plan that is given to all service providers for smooth coordination of care. You and your family members should receive copies of the care plan as well, listing specific duties, work days and hours, and the contact information for the hospice care supervisor.

Questions to ask a hospice care service

Some other questions to ask when considering a hospice care program:

- Is the program accredited by a nationally recognized accrediting body, such as the Joint Commission on Accreditation of Healthcare Organizations? This means that the organization has voluntarily sought accreditation and is committed to providing quality care.
- Is this hospice program Medicare certified? Medicare certified programs have met federal minimum requirements for patient care and management.
- If applicable, is the program licensed by the state? Are caregivers licensed and bonded?
- Can the program provide references from professionals, such as a hospital or community social workers? Talk with these people about their experiences.
- How flexible is this hospice in applying its policies to each patient or negotiating over differences? If the hospice imposes conditions that do not feel comfortable, that may be a sign that it’s not a good fit.
- Is a care plan carefully developed for each patient and their family? Does a nurse, social worker or therapist conduct a preliminary evaluation of the types of services needed in the patient’s home?
- How much responsibility is expected of the family caregiver? What help can the hospice offer with filling in around job schedules, travel plans, or other responsibilities?
- What are the program’s policies regarding inpatient care? Where is such care provided?

- Is there a 24-hour telephone number you can call with questions? Try it to see how the hospice responds to your first call.

Adapted from: *Hospice Net*

Paying for hospice and palliative care

Hospice care generally costs less than inpatient care in a hospital, nursing home, or other facility. This is because with home hospice, you pay only for the specific care that you need. In addition, volunteers may be able to provide many services at little or no cost, such as telephone support, friendly visits, meal preparation, and running errands.

In the U.S., Medicare, Medicaid, and most private insurance plans cover hospice services. Medicare regulations require that your hospice care be provided at home, with only short stays in an inpatient facility.

In order to qualify for the Medicare hospice benefit:

- Your physician must re-certify you at the beginning of each benefit period (two periods of 90 days each, one of 30 days, and an indefinite fourth period).
- You must sign an elective statement indicating that you understand the nature of your illness or condition, and of hospice care. By signing the statement, you surrender your right to other Medicare benefits related to your illness. (A family member may sign the election statement for you if you are unable to do so.)

While patients usually pay out-of-pocket for any services not covered by insurance (known as a co-payment), hospice services are generally provided without charge if you have limited or nonexistent financial resources. If you are unable to pay, most hospices will provide for you using funds raised from community donations and charitable foundations.

Related HelpGuide articles

- Late Stage and End-of-Life Care: (/articles/caregiving/late-stage-and-end-of-life-care.htm) Caregiving in the Final Stages of Life
- Saying Goodbye: (/harvard/saying-goodbye.htm) Coping With a Loved One's Terminal Illness
- When a Loved One is Terminally Ill: (/harvard/dealing-with-a-loved-ones-serious-illness.htm) Talking About Death and Making End-of-Life Decisions

- Coping with Grief and Loss: (/articles/grief-loss/coping-with-grief-and-loss.htm) Understanding the Grieving Process and Learning to Heal
- Caregiver Stress and Burnout: (/articles/stress/caregiving-stress-and-burnout.htm) Tips for Regaining Your Energy, Optimism, and Hope
- Family Caregiving: (/articles/caregiving/caregiving-support-and-help.htm) Tips for Making Family Caregiving Easier and More Rewarding

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