

Understanding Hospice

What Families Need to Know

A clear, compassionate guide to understanding hospice care — what it is, who it serves, and what your family can expect.

Key takeaway: Hospice is not about giving up. It is a philosophy of care focused on comfort, dignity, and quality of life for people with a life-limiting illness.

1. What Hospice IS

Hospice is comfort-focused care for people who have a life-limiting illness. It is not giving up — it is a shift in focus from trying to cure the disease to making sure the person is as comfortable as possible.

Hospice is a philosophy of care, not a place. Most hospice care happens right at home — in your living room, in your bedroom, wherever the person is most comfortable. It can also be provided in nursing homes, assisted living facilities, or dedicated hospice centers.

The hospice team wraps around the patient and the family, providing medical care, emotional support, spiritual guidance, and practical help. The goal is the best quality of life possible for whatever time remains.

Hospice means:

- Comfort and dignity come first
- Pain and symptoms are actively managed
- The whole person is cared for — body, mind, and spirit
- The family receives support too

2. What Hospice IS NOT

Hospice is NOT "giving up hope." Hope simply changes shape. Instead of hoping for a cure, families hope for comfort, peace, meaningful time together, and a gentle passing.

Hospice is NOT only for the last few days. Many people benefit from hospice for weeks or months. The earlier you start, the more support you receive.

Hospice is NOT only for cancer. Hospice serves people with heart failure, COPD, dementia, ALS, kidney disease, liver disease, and many other conditions.

Hospice is NOT just for the elderly. People of any age, including children, can receive hospice care.

Hospice does NOT hasten death. Research consistently shows that hospice patients often live as long as or longer than those who do not receive hospice.

You CAN leave hospice. Choosing hospice is not a one-way door. You can revoke hospice at any time and return to curative treatment.

Important

If anyone tells you hospice means "there's nothing more we can do," that is not accurate. Hospice means there is a great deal we can do — the focus simply shifts to comfort and quality of life.

3. The 4 Levels of Hospice Care

Medicare defines four distinct levels of hospice care. Your hospice team will determine which level is appropriate based on the patient's current needs.

Routine Home Care

This is the most common level. The hospice team makes regular visits to the home (or facility) — typically a nurse several times a week, an aide for personal care, and other team members as needed. Between visits, you have 24/7 access to the on-call nurse by phone.

Continuous Home Care

When a patient experiences a medical crisis (such as severe uncontrolled pain, acute anxiety, or respiratory distress), hospice can provide 8 to 24 hours of continuous nursing care in the home. This is short-term and designed to get symptoms back under control.

General Inpatient Care (GIP)

If symptoms cannot be managed at home, the patient may be transferred to a hospital, hospice inpatient unit, or skilled nursing facility for short-term, intensive symptom management. The goal is to stabilize symptoms so the patient can return home.

Respite Care

Caregiving is exhausting. Respite care allows the patient to stay in a Medicare-approved facility for up to 5 days so that the primary caregiver can rest. This benefit can be used more than once.

You do not need to ask for these levels yourself. Your hospice team will recommend the right level of care. But knowing they exist helps you understand your options and advocate for your loved one.

4. Your Hospice Team

Hospice care is delivered by an interdisciplinary team. Each member plays a specific role:

Hospice Physician Medical Director — Oversees the overall plan of care, works with the patient's own doctor, certifies hospice eligibility, and adjusts medications.

Registered Nurse (RN) / Case Manager — Your primary clinical contact. Manages symptoms, administers medications, educates the family on what to expect, and coordinates care. Available 24/7 by phone.

Social Worker — Helps with emotional support, advance directive planning, insurance and financial questions, community resources, and family dynamics.

Chaplain / Spiritual Counselor — Provides spiritual support regardless of faith tradition (or no faith). Helps with existential concerns, legacy work, and end-of-life meaning.

Certified Nursing Assistant (CNA) / Home Health Aide — Assists with bathing, grooming, dressing, light housekeeping, and companionship. Usually visits 2–3 times per week.

Volunteers — Provide companionship, run errands, sit with the patient so caregivers can rest, and offer other non-medical support.

Bereavement Counselor — Supports the family for up to 13 months after the patient's death through calls, visits, mailings, and support groups.

5. What Hospice Covers

Under the Medicare Hospice Benefit, hospice covers a wide range of services and supplies related to the terminal diagnosis at little or no cost to the family:

- Medications related to the hospice diagnosis (pain medications, anti-nausea drugs, anxiety medications, etc.)
- Durable medical equipment — hospital bed, wheelchair, walker, bedside commode, oxygen equipment
- Medical supplies — gloves, wound care supplies, incontinence pads, syringes
- 24/7 on-call nurse — a nurse is always available by phone, day or night
- Respite care — up to 5 days of inpatient care to give caregivers a break
- Bereavement support — grief counseling for the family for 13 months after the death
- All team visits — nursing, social work, chaplain, aide, and volunteer visits

Note: Hospice does not cover treatments aimed at curing the terminal illness, room and board in a nursing home (unless for respite or GIP), or medications unrelated to the hospice diagnosis. Your regular Medicare or insurance continues to cover those.

6. How to Qualify for Hospice

To qualify for the Medicare Hospice Benefit, a physician must certify that the patient has a life expectancy of 6 months or less, "if the disease runs its normal course."

This does not mean the person will die in exactly 6 months. It is a medical estimate, not a countdown. Many patients live longer than 6 months on hospice — and that is perfectly fine.

Hospice eligibility is reviewed periodically. If the patient is still eligible after 6 months, they can be re-certified and continue receiving hospice care. There is no maximum time limit as long as the patient continues to meet the criteria.

Who can refer someone to hospice? Anyone can make a referral — the patient's doctor, a family member, the patient themselves, a hospital discharge planner, or a friend. You do not need to wait for a doctor to bring it up.

7. Your Rights

As a hospice patient or family caregiver, you have important rights:

- You can leave hospice at any time. You are never locked in. If you want to pursue curative treatment again, you can revoke hospice and return later if needed.
 - You can change hospice providers. If you are not satisfied with your hospice agency, you have the right to transfer to a different one.
 - You can request a different nurse or aide. If you are not comfortable with a particular team member, you can ask for someone else.
 - You have the right to pain management. Adequate pain control is a fundamental right. If your loved one's pain is not being managed, speak up — and keep speaking up.
 - You have the right to be informed. The hospice team should explain the plan of care, answer your questions honestly, and include you in decisions.
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Sources

1. Medicare.gov — Medicare Hospice Benefits — <https://www.medicare.gov/coverage/hospice-care>
2. National Hospice and Palliative Care Organization (NHPCO) — <https://www.nhpc.org/hospice-care-overview/>
3. National Institute on Aging (NIA) — <https://www.nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care>
4. CaringInfo (NHPCO) — <https://www.caringinfo.org/types-of-care/hospice-care/>
5. CMS Medicare Hospice Benefits — <https://www.cms.gov/medicare/payment/hospice>

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Evidence-based resources for families navigating end of life