

What is Hospice?

Hospice is:

- Medical care for people with an anticipated life expectancy of 6 months or less, when cure isn't an option, and the focus shifts to symptom management and quality of life.
- An interdisciplinary team of professionals trained to address physical, psychosocial, and spiritual needs of the person; the team also supports family members and other intimate unpaid caregivers.
- Specialty care that is person-centered, stressing coordination of care, clarification of goals of care, and communication.
- Provided primarily where a person lives, whether that is a private residence, nursing home, or community living arrangement, allowing the patient to be with important objects, memories, and family.
- Care that includes periodic visits to the patient and family caregivers by hospice team members. Hospice providers are available 24 hours a day, 7 days a week to respond if patient or caregiver concerns arise.
- The only medical care that includes bereavement care, which is available during the illness and for more than a year after the death for the family/intimate network.
- A Medicare benefit; to which all Medicare enrollees have a right. Hospice care also is covered by most private health insurance at varying levels, and in almost every state, by Medicaid.

Hospice is *not*:

- Focused on curative therapies or medical intervention designed to prolong life.
- A replacement for nursing home care or other residential care.
- 24/7 care, in the majority of cases.
- Care that hastens death.

What services does hospice provide?

Most hospices follow Medicare requirements to provide the following services, as necessary, to manage the primary illness for which someone receives hospice care:

- Time and services of the care team, including visits to the patient's location by the hospice physician, nurse, medical social worker, home health aide, and chaplain/spiritual adviser
- Medication for symptom control, including pain relief
- Medical equipment like a hospital bed, wheelchairs or walkers, and medical supplies such as oxygen, bandages, and catheters

- Physical and occupational therapy*
- Speech-language pathology services*
- Dietary counseling*
- Any other Medicare-covered services needed to manage pain and other symptoms related to the terminal illness, as recommended by the hospice team
- Short-term inpatient care (e.g. when adequate pain and symptom management cannot be achieved in the home setting)
- Short-term respite care for family caregivers (e.g. temporary relief from caregiving to avoid or address “caregiver burnout”)
- Grief and loss counseling for the patient and loved ones, who may experience anticipatory grief. Grief counseling is provided to family members for up to 13 months after a death.

*Access to these services is determined on a case-by-case basis depending on assessment of hospice team, goals of care as established by the hospice team, and disease progression and symptom burden.

What's not included in hospice care?

- Treatment, including prescription drugs, intended to *cure* a terminal illness or other illness unrelated to the terminal diagnosis unless the other illness is causing increased symptom burden.
- Prescription drugs and supplies prescribed to *treat* an illness or condition unrelated to the diagnosis that qualifies the person for hospice.
- Room and board in a nursing home or hospice residential facility.
- Care in an emergency room, inpatient facility care or ambulance transportation, unless it is ordered by or arranged by the hospice team.

Who can receive hospice care?

- Adults with a terminal illness and lifetime prognosis of 6 months or less are eligible for hospice care.
- Hospice care is also available for children and adolescents. Rules and regulations regarding hospice services and coverage for children are different from those utilized in the adult population.
- Common diagnoses of those who receive hospice care include, but are not limited to: cancer, heart disease, dementia, Parkinson’s disease, lung disease, stroke, chronic kidney disease, cirrhosis, and Lou Gehrig’s disease (ALS).

Where is hospice care provided?

Hospice care comes to the patient wherever they may be.

- Hospice services are provided where a patient lives, which may be their private residence or that of a loved one, an assisted living center, nursing home, or in some cases, in a hospital.
- Some hospices have their own long-term residential centers where services are provided. When hospice care is provided at a residential center, the patient/family remains responsible for the costs associated with the residence, as they would for any other home.
- If a patient needs 24/7 care, hospices may transport the patient to a special inpatient facility for a short period of time to manage symptoms, with the goal of returning the patient to their home.

When is it time for hospice?

A person does not have to be bedridden or in their final days of life to receive hospice care. It is most beneficial when the patient and family can receive care early to take advantage of the many benefits hospice care can offer. It can be used for months, as long as medical eligibility is met.

Hospice should be considered when:

- There is a significant decline in physical and/or cognitive status despite medical treatment. This may include increased pain or other symptoms, substantial weight loss, extreme fatigue, shortness of breath, or weakness.
- The goal is to live more comfortably and forego the often physically debilitating treatments that have been unsuccessful in curing or halting a life-threatening illness.
- Life expectancy is 6 months or less, according to physicians.
- The person is in the end stage of Alzheimer's or dementia.

How does someone initiate hospice care?

Many individuals and families could benefit from hospice care but are unaware of how to access hospice services. Some are afraid to discuss it, some wait for a physician to suggest it, and some don't know that they can initiate hospice care on their own, as long as eligibility criteria are met.

At Hospice Foundation of America, we hear from many individuals and families who tell us they wish they had known about and used hospice services earlier.

It's important to let healthcare providers know that hospice care is a preference and not to wait for them to raise the topic.

To qualify for hospice services:

- A hospice physician and a second physician (often the individual's attending physician or specialist) must certify that the patient meets specific medical eligibility criteria indicating that an individual's life expectancy is 6 months or less if the illness or condition runs its typical course. These established criteria vary by illness and condition.
- Typically, referral to hospice care begins with the attending/specialist physician knowledgeable about the person's medical history, and hospice eligibility is confirmed by the hospice physician.
- Self and family referral is possible (the person and/or family may contact hospice directly), but eligibility must be confirmed by physicians prior to receiving care.

If a physician does not agree to refer for hospice care or if the individual has not seen a physician for many years, the person may still be eligible for hospice care and they, or their family members, may reach out to a local hospice provider for more information on the admission process.

Who pays for hospice care?

- Most hospice patients are eligible for [Medicare](#), which covers all aspects of hospice care and services. There is no deductible for hospice services although there may be a very small co-payment for prescriptions and for respite care. In most states, [Medicaid](#) offers similar coverage.
- Many health insurance plans obtained privately, such as through an employer or on a state or the national exchange, offer a hospice benefit but the extent to which they cover hospice care and services may differ from Medicare as well as from one another.
- Military families have hospice coverage through [Tricare](#).
- The Veterans Health Administration offers hospice services and contracts with local community hospice providers. Any veteran with the VHA Standard Medical Benefits Package is eligible and there is no co-pay.
- Hospices accept private payment, referred to as "self-pay."

What other requirements are important to know?

Caregiving in Private Home Setting

In a private home setting, receiving hospice generally requires a family caregiver(s) or another caregiver who may be a friend or someone who is hired to provide caregiving services. Read more about hospice caregiving [here](#).

Length of Stay

There are strict federal rules that hospices must abide by that address length of stay in hospice and who is eligible. Possible changes to care may occur due to:

- *Extensions:* Hospice care is given in benefit periods: two 90-day periods followed by an unlimited number of 60-day periods. Although medical eligibility generally relies on the physician's opinion that the patient's life expectancy is 6 months or less, neither the patient nor the physician is penalized if the patient lives longer than 6 months. The patient can be re-certified for hospice care, provided medical eligibility is validated.
- *Discharge:* If a patient's condition stabilizes or improves sufficiently, they may no longer meet medical eligibility for hospice services. At that time, the patient is "discharged" from the hospice program and their Medicare benefits revert to the coverage they had before electing hospice care.
- *Revocation:* Sometimes hospice patients may choose to pursue curative therapies such as entering a clinical study for a new medication or procedure. In order to do so, the patient must withdraw their selection of hospice care, called "revocation."

Patients who are discharged, as well as any who choose to leave hospice care, can re-enroll at any time provided they meet the medical eligibility criteria.