



Embracing Our Dying

A Project of the California Catholic Conference

An Explanation of Hospice and Palliative Care

Source: [National Hospice and Palliative Care Organization website](#)

Hospice: A Historical Perspective

The term “hospice” (from the same linguistic root as “hospitality”) can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey. The name was first applied to specialized care for dying patients in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice—St. Christopher’s Hospice—in a residential suburb of London.

Saunders introduced the idea of specialized care for the dying to the United States during a 1963 visit with Yale University. Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care. This lecture launched the following chain of events, which resulted in the development of hospice care as we know it today.

Palliative Care

Palliative care is treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual’s needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual’s values and symptoms. The individual’s choices and decisions regarding care are paramount and must be followed.

—from the National Hospice and Palliative Care Organization’s *Standards of Practice for Hospice Programs*

Hospice care

Hospice care is a family-centered approach that includes, at a minimum, a team of doctors, nurses, social workers, counselors, and trained volunteers. They work collaboratively focusing on the dying patient’s needs, be they physical, psychological, or spiritual. The goal is to help keep the patient as pain-free and lucid as possible, with loved ones nearby until death.

Below is a list of services available to Medicare hospice recipients.

- Physician services for the medical direction of the patient’s care
- Regular home visits by registered nurses and licensed practical nurses
- Home health aides and homemakers for services such as dressing and bathing
- Social work and counseling
- Medical equipment such as hospital beds
- Medical supplies such as bandages and catheters
- Drugs for symptom control and pain relief
- Volunteer support to assist patients and loved ones
- Physical therapy, speech therapy, occupational therapy, and dietary counseling

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What is Hospice and Palliative Care?

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual's needs must be continually assessed and treatment options should be explored and evaluated in the context of the individual's values and symptoms. Palliative care, ideally, would segue into hospice care as the illness progresses.

How does hospice care work?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The team usually consists of:

- The patient's personal physician
- Hospice physician (or medical director)
- Nurses Home health aides;
- Social workers
- Clergy or other counselors
- Trained volunteers, and
- Speech, physical, and occupational therapists, if needed

What services are provided?

Among its major responsibilities, the interdisciplinary hospice team:

- Manages the patient's pain and symptoms
- Assists the patient with the emotional and psychosocial and spiritual aspects of dying
- Provides needed drugs, medical supplies, and equipment
- Coaches the family on how to care for the patient
- Delivers special services like speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time, and
- Provides bereavement care and counseling to surviving family and friends.

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Who qualifies for hospice care?

Hospice care is for any person who has a life-threatening or terminal illness. Most reimbursement sources require a prognosis of six months or less if the illness runs its normal course. Patients with both cancer and non-cancer illnesses are eligible to receive hospice care. All hospices consider the patient and family together as the unit of care.

Medicare Hospice Benefit (Medicaid Hospice Benefit mirrors the federal benefit)

More than 90 percent of hospices in the United States are certified by Medicare. Medicare defines a set of hospice core services, which many hospices surpass through voluntary, community-based efforts.

The Medicare Hospice Benefit, initiated in 1983, is covered under Medicare Part A (hospital insurance). Medicare beneficiaries who choose hospice care receive a full scope of non-curative medical and support services for their terminal illness. Hospice care also supports the family and loved ones of the patient through a variety of services, enhancing the value of the Medicare Hospice Benefit.

The Medicare Hospice Benefit provides for:

- Physician services
- Nursing care
- Medical appliances and supplies
- Drugs for symptom management and pain relief
- Short-term inpatient and respite care
- Homemaker and home health aide services
- Counseling
- Social work service
- Spiritual care
- Volunteer participation
- Bereavement services

Who is Eligible?

Medicare/Medicaid has three key eligibility criteria:

- The patient's doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with a life expectancy of six months or less, if the disease runs its normal course;
- The patient chooses to receive hospice care rather than curative treatments for their illness; and
- The patient enrolls in a Medicare-approved hospice program.

Payment for Hospice:

- Medicare pays the hospice program a *per diem* rate that is intended to cover virtually all expenses related to addressing the patient's terminal illness.
- Because patients require differing intensities of care during the course of their disease, the Medicare Hospice Benefit affords patients four levels of care to meet their needs: Routine Home Care, Continuous Home Care, Inpatient Respite Care, and General Inpatient Care.
- 96 percent of hospice care is provided at the routine home care level for adults which is reimbursed at approximately \$114 per day.

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- The Hospice Benefit rates have increased annually based on the Hospital Market Basket Index. With the advent of costly new drugs and treatments like palliative radiation, the average cost to hospices has risen much faster than the hospice benefit reimbursement rates.
- Hospices that are Medicare-certified must offer all services required to palliate the terminal illness, even if the patient is not covered by Medicare and does not have the ability to pay.

Special Considerations related to Hospice Care for Infants and Children

- High degree of variability between hospice programs in their ability to care for sick infants and children with a range of diagnoses: from a clinical perspective and financial. Most lack pediatric and neonatal experienced clinical staff- nursing, social worker, chaplain and physician/ medical director. Special needs for pediatric care from pharmacy, infusion services, 24/7 coverage for pediatric patients.
- Variability of type of services offered/ covered: home infusions for antibiotics, blood products, opioids, TPN, tube feedings. Apnea monitor, special chairs etc.
- Do Not Resuscitate status: some programs require DNR status as a requirement for admission which is rarely if ever acceptable terms for enrollment for help for parents.
- Lack of options for inpatient level of care under hospice benefit due to hospice reimbursement rates. Disincentive for Children's facilities to admit for so low a rate.
- Current perspective of hospice= **No Hope; "we are giving up" no more treatment = No more care.**
- The SIX MONTH PROGNOSIS REQUIREMENT HAS CREATED A PERILOUSLY HIGH EMOTIONAL AND COGNITIVE HURDLE FOR BOTH PARENTS AND PROFESSIONALS ALIKE.
- Forgoing all curative and life prolonging therapies or interventions is an enormous leap of acceptance many can not or will not make immediately upon signing up. Concurrent models would allow child to receive optimal treatment for their condition with the best features of hospice: coordination of care, expertise in pain and symptom management that strives to prevent and treat symptoms prevent crisis and re-admissions, care for all family involved, communication among providers is maintained and supported for one plan of care.

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