



Hospice and Palliative Care: Misconceptions and Realities

The Connecticut Association for Healthcare at Home encourages policies that support quality end-of-life care and advance-care planning. We must ensure that both chronically and terminally ill patients and their families have access to the full range of services available to them under the Medicare and Medicaid programs.

Here's the dilemma: Despite a rapidly aging population, Connecticut residents utilize hospice services less frequently than any other state. For those who do take advantage of hospice services, the average length of stay in hospice is only 47 days in Connecticut versus 67 days nationally—Connecticut ranks last in the country in length of stay.

How can hospice and palliative care services reduce suffering and allow people to die with dignity? We drew upon the expertise of the [National Hospice and Palliative Care Organization](#), the [Center to Advance Palliative Care](#), [Joanne Gould Kuntz, MD](#), Clinical Director of Palliative Services at UCONN Health Center and [Holly Bessoni-Lutz, RN, MSN](#), Hospice Program Director at [Interim Health Care](#).

Here are the primary misconceptions and realities about hospice and palliative care:

Misconception:

Hospice care is the same as palliative care.

Reality:

All hospice care is palliative care, but not all palliative care is hospice care.

Both hospice and palliative care are provided by an interdisciplinary team whose members include doctors, nurses, registered dietitians, pharmacists, and social workers. In both types of care the goal is to relieve suffering and improve quality of life for patients.

Although they share these same principles of comfort and holistic support, palliative care may be introduced much earlier in disease, ideally, at diagnosis.

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.



In comparison, hospice care is palliative care that may begin once the illness becomes life-limiting or terminal and has a prognosis of less than 6 months. When patients find that the burden of treatments aimed at prolonging life prove to be greater than the benefit, that is the time to consider and enroll in hospice. Hospice care focuses on caring, *not* curing.

Misconception:

Hospice is a place.

Reality:

Hospice is a philosophy of care that happens wherever the patient calls home.

More frequently, this is in a patient's own private residence, a nursing home, a freestanding hospice residence, an assisted living facility or a hospital. Again, hospice focuses on caring, not curing. In most cases, care is provided in the patient's home. In 2012, 41.5% of hospice patients remained in their own residence.

Misconceptions:

It's difficult to begin the process to receive hospice. Hospice is expensive.

Reality:

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.

Misconception:

Hospice means giving up.

Reality:

Hospice is *not* "giving up."

It is not a form of euthanasia or physician-assisted suicide.

Hospice focuses on living for however long that may be with a focus on the quality of life. It is all about setting *achievable* goals and respecting wishes.

Hospice care is the model for quality, compassionate care for people facing a life-limiting or terminal illness or injury. It uses a team 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 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.

Misconception:

The patient must have cancer to begin hospice.

Reality:

Non-cancer diagnoses outnumber cancer diagnoses.

63.1 percent of hospice admissions in 2012 were for non-cancer diagnoses. Today, cancer diagnoses account for less than half of all hospice admissions (36.9 percent). Currently, less than 25 percent of U.S. deaths are now caused by cancer, with the majority of deaths due to other terminal diseases. Some of the top non-cancer primary diagnoses for patients admitted to hospice in 2012 remained dementia (12.8 percent), heart disease (11.2 percent), and lung disease (8.2 percent).

Misconception:

To begin hospice services, the patient must be close to death.

Reality:

The Medicare Hospice Benefit was established in 1983 to provide Medicare beneficiaries with access to high-quality end-of-life care. A patient is eligible for hospice care if a physician determines that the patient has six months or less to live if the terminal illness runs its normal course. Patients must be re-assessed for eligibility at regular intervals, but there is no limit on the amount of time a patient can then spend under hospice care.

The hospice benefit was established with a six-month time frame in order to develop a trusting relationship with the patient and family and help them work through the end-of-life process. During this period, hospice workers need time to develop a relationship so that the individual and their family's physical, psychological, spiritual, and emotional concerns can be treated holistically.

Misconception:

Patients in hospice experience a high level of pain and discomfort before they die.

Reality:

Many patients may have pain and other serious symptoms as illness progresses. Hospice staff members receive special training to care for all types of physical and emotional symptoms that cause pain, discomfort and distress. Keeping the patient comfortable and pain-free is an important part of hospice care. Hospice staff works with the patient's physician to make sure that medication, therapies, and procedures are designed to achieve the goals outlined in the patient's care plan. The care plan is reviewed frequently to make sure any changes and new goals are in the plan.

Misconception:

The patient must give up all treatments related to the terminal illness before receiving hospice care.

Reality:

An interdisciplinary team and the patient's doctor evaluate each unique situation to determine and make recommendations related to the terminal diagnosis. Treatments such as chemotherapy, radiation therapy and physical therapy may be offered to help control symptoms and improve quality of life while receiving hospice care. Each patient is unique. **Patients are encouraged to consult their physician and hospice provider to discuss their individual situation.**

Misconception:

The patient must have set up a legal Do Not Resuscitate (DNR) in order to prevent medical personnel from administering any artificial life support in the event his/her lung or heart functions cease.

Reality:

Hospice does not discriminate its care based on a person's advance directive (or lack thereof.) An advance directive is a legal document that enables a person to plan for and communicate their end-of-life wishes in the event that they are unable to communicate. A goal of hospice care is to help the patient and their family understand the patient's prognosis and align the care provided with the goals and values of the patient. This may include placing limits on certain life prolonging or sustaining therapies such as CPR and mechanical ventilation.

Misconception:

The patient must give up their personal physician.

Reality:

Hospice works with the patient's primary doctor, along with the hospice medical director and an interdisciplinary hospice team.

Are you or a member of your family suffering from a chronic disease or terminal medical condition? Do you believe you could benefit from palliative or hospice services? [Click here](#) to access the Connecticut Association for Healthcare at Home's [searchable list of licensed hospice, palliative care and home health care agencies](#).