Hospice Myths *and* Misconceptions

Dispelling hospice myths and misconceptions can help individuals and families choose to receive the quality end-of-life care that they deserve.

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St. Croix Hospice Chief Medical Officer
Andrew Mayo, M.D.

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Dispelling *hospice myths* and *misconceptions*

Hospice is a life affirming philosophy of care that promotes comfort and quality of life for those affected by a life limiting illness or disease. The concept of hospice care has been around since the early 1960s, but there are still a lot of misperceptions about what it is and what it entails.

Because of confusion around hospice care, it often goes underutilized by patients and their families. While in 2021, 1.71 million Medicare beneficiaries were enrolled in hospice care for one day or more, national statistics on the utilization of hospice suggest that a much higher population of people are eligible to receive hospice care than those who are using it. According to the most recent National Hospice and Palliative Care Organization (NHPCO) Facts and Figures Report, trends in recent years have shown that only about 50% of Medicare beneficiaries utilize the hospice benefit when they are eligible, and the median length of stay for a hospice patient in the United States is approximately 17 days, forgoing potentially months of care under the benefit.

The majority of both Medicare beneficiaries and hospice patients are over the age of 65 — an age group that is growing faster than the total population. According to the 2020 census, the 65 and older population in the United States grew five times faster than the total population from 1980 to 2020. The number of Americans ages 65 and older is projected to reach 94.7 million by 2060.

With an aging population comes an increase in the number of people needing help with their healthcare. Hospice can support the end-of-life journey, and it is important to clear up any misconceptions that might prevent patients and their caregivers from seeking this impactful benefit.

Common *hospice myths* and *misconceptions*

End-of-life care is often misunderstood.
Below we debunk some of the most common myths about hospice.

MYTH

Hospice means "giving up."

TRUTH

Hospice does not mean giving up.

Making the decision to enter hospice means the patient is shifting their priority toward a better quality of life. Instead of focusing on chasing a cure, hospice care helps patients live every day as best as possible in the time that is remaining. In some cases, increasing a patient's quality of life may actually help them live longer too. It is true that hospice becomes available to patients who have a life expectancy of six months or less. However, it is possible for patients to live longer than that.

There are several reasons hospice patients may live longer than six months. One is that hospice care may provide a level of comfort that prolongs a patient's initial life expectancy. With the shift toward pain and symptom management, hospice patients often start to feel better and experience less stress.

A widely cited 2007 report found that hospice patients live an average of 29 days longer than terminally ill patients who do not receive hospice.

Additionally, patients with a terminal diagnosis who begin hospice earlier have greater satisfaction with end-of-life, higher quality of life, fewer hospitalizations and lower medical costs. The right end-of-life care can also mean less stress and more quality time with loved ones.

Family members are often heavily involved in the benefits of hospice care— such as emotional, social and spiritual support —which extend to them as well. Hospice can help patients and their loved ones find deeper meaning at the end of life.

MYTH

Hospice is only for people in the final stages of dying.

TRUTH

Hospice providers can provide consultations to patients considering end-of-life care, but typically eligibility begins with a life expectancy of six months or less.

However, a patient can be eligible for care beyond six months as long as they continue to meet the medical requirements. Former President Carter recently set a powerful example of the hospice benefit by publicly choosing end-of-life care in 2023. At the time of this writing, President Carter has received hospice care for ten months, well past his initial six-month prognosis.

As demonstrated by President Carter, the earlier a patient enrolls in hospice, the more they will benefit from the services. Unfortunately, many people delay hospice care until their very last moments. In some cases, patients are admitted to hospice with only days or hours left to live. Starting hospice care earlier —once they have received the six months or less prognosis — means the patient can get the appropriate care to improve their quality of life.

MYTH

Hospice care is expensive.

TRUTH

Hospice usually has little to no out-of-pocket cost to the patient.

This is because hospice is usually paid for by Medicare, Medicaid or private insurance. Coverage often supports services, medication, supplies and visits from healthcare providers. The overwhelming majority of hospice patients are covered by Medicare.

For those patients not Medicare eligible, most private insurance companies and the Veterans Health Administration (VHA) provide coverage for hospice and end-of-life care, but each company has its own unique qualifications the patient needs to meet. Patients will have to review their insurance plan or ask their provider directly what coverage is available.

MYTH

Hospice care is a place.

TRUTH

Patients can receive hospice care wherever they are most comfortable. It is a service, not a place.

That means patients can receive care in the comfort of their own homes. They can also receive care in a nursing home or assisted living facility.

Medicare typically does not cover room and board if patients reside in a senior living setting (assisted living facility, skilled nursing facility, nursing home) and choose to receive hospice care. In very limited situations, patients may receive hospice as an inpatient service, meaning they are cared for in a hospital setting. This is an option for patients whose symptoms are too severe to be managed at home. The patient still receives the same level of care they would receive in a home setting, but they have access to licensed medical professionals around the clock, and in this instance, Medicare could pay for all of the cost.

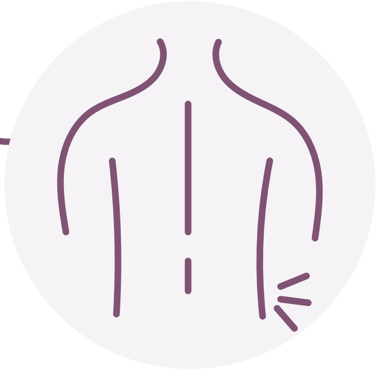
MYTH

If the patient isn't in pain, it's too soon for hospice.

TRUTH

Pain is not a requirement for hospice.

Some patients do not experience significant pain at the end of life. When patients do have pain, hospice care teams are very prepared to help. The doctors and nurses who oversee a patient's hospice care are trained to identify changes in a patient's decline, whether that is pain-related or otherwise, and they modify their care plan quickly and accordingly to accommodate the patient's ever-changing state at end of life.



MYTH

Hospice care is only for the elderly.

TRUTH

Younger people with life-limiting illnesses can also receive hospice care.

Patients in their 20s and 30s — or sometimes even younger — often choose to receive hospice care at home. This allows them to remain in a familiar environment close to friends and family. Others may choose to receive care at a hospital or hospice center.

Younger patients can continue to receive curative treatments along with hospice care. This is known as concurrent care and is a provision of the Affordable Care Act (ACA). The provision requires state Medicaid programs to pay for curative, life-prolonging treatment and hospice services for eligible patients under the age of 21. Concurrent care maintains the six-month prognosis but does not require patients to stop receiving treatment.

Pediatric hospice care also provides specialized emotional support for family members. Coping with the stress of having an ill child can be especially difficult. Pediatric hospice care teams can help families cope with grief. They can also provide developmentally appropriate support to any siblings.

MYTH

There is no hospice available in my area.

TRUTH

Less than one percent of Medicare beneficiaries live in an area where hospice is not available.

Primary care physicians and hospital discharge planners are often great resources who can provide recommendations on nearby hospice providers. Patients and families can also contact their state's hospice organization or the Department of Health or Social Services for information on hospice agencies that serve their community. Additionally, national resources such as the National Hospice and Palliative Care Organization and the National Association for Home Care and Hospice Care can support efforts to identify local hospices.

Other ways to find hospice agencies include searching the internet for "hospices near me" or contacting insurance.

MYTH

Hospice is only for the patient.

TRUTH

Family members of the patient also benefit from hospice.

Many family members act as caregivers, and when the patient enters hospice, they may still be involved in their care. One of the benefits of hospice is that it can be a source of support for family members. Caregiving can be extremely stressful, but hospice means the family is not doing it alone. Hospice involves a number of healthcare professionals, including nurses, social workers, counselors and more. This team can ease some of the workload on family caregivers.

The hospice care team can also provide emotional support and help prepare patients and their families for future decisions. Hospice care teams are patient advocates who support after-death financial plans, funeral wishes and other decisions that can be challenging to navigate alone.

MYTH

Hospice care ends after the patient’s death.

TRUTH

When a patient passes away, services do not end.

Bereavement support is an essential component of hospice. Support can include phone calls or in-person visits, grief support communications or referrals to support groups or counselors. Some hospice agencies provide bereavement support for up to 13 months after the death of a loved one.

* * *

MYTH

Patients cannot see their primary care doctors while on hospice care.

TRUTH

When a patient enters hospice, their primary care physician and other members of their healthcare team are welcomed and encouraged to remain engaged in their care.

The primary care physician often has a longstanding relationship with the patient and knows them well. That means they are in an ideal position to communicate the patient’s needs to the hospice team.

* * *

MYTH

It is the doctor’s responsibility to bring up hospice.

TRUTH

While a doctor can determine if a patient is medically eligible for hospice, patients and families can start the conversation about hospice when they perceive the end of life is imminent.

Letting the doctor know early on that hospice is an option when the time comes can ease the transition. Research has shown that hospice care is often started too late to maximize the benefit to the patient, so it is important for doctors to have the hospice conversation once it becomes clear that the patient may no longer benefit from curative treatment.

Patients and their caregivers can also reach out to hospice agencies on their own. Hospice agencies will meet patients and families wherever they call home and give a free hospice consultation to help determine whether hospice may be an appropriate next step.

MYTH

Patients cannot stop hospice once they enroll.

TRUTH

A patient can stop hospice at any time for any reason.

Patients do not have to remain in a hospice program once they are admitted. There are several reasons a patient might leave hospice. They may move out of the service area, or they might decide to try curative treatments again. Doing this without a doctor’s consent is known as “revoking” hospice. Some patients may revoke care at one hospice to transfer to another. For Medicare beneficiaries, revoking hospice also means that the patient is revoking services they may have received from the Medicare hospice benefit.

Patients can also be “de-certified,” meaning they are no longer deemed terminally ill. Sometimes medication adjustments, nutritional improvements and social interactions provided through hospice care can support recovery and extend life. If the patient recovers enough, their doctor may reevaluate their six-month prognosis. Hospice will be discontinued if the patient’s doctor believes they will live longer than six months. However, if the patient’s health begins to deteriorate, the doctor may reassess them. Once the patient meets eligibility requirements again, they can resume hospice.

MYTH

Hospice hastens death.

TRUTH

The main goal of hospice care is to manage a patient’s pain and symptoms and make the patient as comfortable as possible.

This does not mean that hospice providers are speeding up the death process. Instead, they are allowing natural death to occur as the disease runs its course. Any medications used during hospice are solely for the purpose of pain relief and symptom management.

Patients and their families are encouraged to engage in hospice care as soon as possible. Starting hospice early means the patient has more time for their condition to stabilize.

MYTH

Hospice provides 24-hour care.

TRUTH

Although hospice is available 24 hours a day, 7 days a week, care is based on intermittent visits by a team of physicians, nurses, aides, counselors and others.

If a patient requires round-the-clock care, the hospice agency will make that determination.

When is it time for *hospice?*

Although there are certain eligibility requirements patients must meet before they can enroll in hospice, the decision isn't always an easy one to make. There are a lot of hospice misconceptions that may discourage patients and their family members from seeking out care, but it is often the best choice. Hospice can help patients live out their final days in peace and comfort, surrounded by their loved ones.

Aside from meeting the eligibility requirements, some signs that might indicate that it's time for hospice include:

- Frequent hospitalizations or ER visits
- Frequent infections or wounds
- Inability to perform activities of daily living (bathing, dressing, feeding oneself, etc.)
- Increased uncontrolled pain
- Noticeable declines in health and comprehension

If any of these signs are present, requesting a hospice referral may be worth it.

Chief Medical Officer Dr. Andrew Mayo provides clinical direction for St. Croix Hospice, a nationally renowned, award-winning Midwest hospice organization. With nearly 30 years of experience practicing medicine, Dr. Mayo sets a company-wide precedent for exemplary patient care. For more information about St. Croix Hospice, please call 855-278-2764 or visit stcroixhospice.com.

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