

THE TRUTH ABOUT  
**HOSPICE**

A Guide for Family Caregivers





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# The Truth About Hospice

Let's face it. Death is a difficult topic. No one wants to think about it. Few are willing to talk about it. But we'll all deal with it, eventually. Many will go through the final days with an elderly parent, family member or friend. Some will need to manage the details from afar.

But end of life doesn't need to be so daunting or depressing or dreaded. It can be full of life-affirming moments of compassionate care. Advance planning is key to making sure a loved one's final days are as comfortable and organized as possible. However, even if you've already started down that road with a loved one or friend, and don't know where you're headed, it's not too late to get the information you need to help make smart decisions.

Among the most difficult aspects of hospice care are the pre-conceived ideas about end of life. There are many myths surrounding hospice. There's also fear. Facing the truth head on and taking action could be the best course for you and your loved ones.

In this guide, we'll address several of the myths about hospice, and hopefully give you or someone you're caring for a clearer view of the road ahead.



**51%** of those surveyed reported talking to close family or friends about their end-of-life care.

*BMC Palliative Care* <https://bmcpalliatcare.biomedcentral.com>

## Myth 1

### **Hospice is the place to go when there is “nothing else to be done.”**

In a nutshell, hospice is not always the last resort for the dying, and neither hastens nor postpones death. Instead, this concept of care affirms life and faces dying as a normal part of living. It's a holistic approach for families that creates a unique care plan with the individual and loved ones at the center of attention.

Hospice not only provides an individual with medical care, pain management, and emotional and spiritual support, but offers support for the family throughout their loved one's illness and typically for at least a year following that individual's death.

Hospice care focuses on helping to improve the quality of life and helps an individual live with dignity during the time that is left. Its goal is to help people complete life's journey with comfort, dignity and companionship. Symptom management is a major focus of hospice care. Relief and comfort are the goals when there is no definitive cure for the illness.

Statistics show that 80 percent of hospice care is provided in the patient's home, family member's home and in nursing homes. Inpatient hospice facilities are also sometimes available to assist with caregiving.

Even though the family and loved ones typically provide support to the individual during hospice, a team of hospice professionals – led by a physician – work together to provide the best possible care and meet the needs of the patient and loved ones.



# 51.5 %

of hospice deaths occur  
in the home.

*NHPCO Facts and Figures*

<https://www.nhpc.org/wp-content/uploads/NHPCO-Facts-Figures-2020-edition.pdf>

In conjunction with hospice, you may hear the term palliative care. Some may use this care term interchangeably with hospice. However, hospice care and palliative care are not the same.

## Palliative Care

Palliative care can best be described as pain relieving or comfort care. People of any age can receive palliative care for serious illness whether it's life-threatening, a chronic condition or a life-limiting illness. The goal of palliative care is to help improve symptoms, and relieve pain and stress from these conditions.

Palliative care aims to provide relief from symptoms such as pain, shortness of breath, nausea and other distressing indicators. This care can be applied early in the course of illness, with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.

Palliative care can start at the diagnosis, and occur in addition to and simultaneously with care designed to cure or prolong life. Depending on the situation, palliative care may be covered by insurance, paid privately and may be difficult to access. Many times individuals need to ask for the services. All hospice care is palliative, but not all palliative care is hospice care. The major difference between the two types of care is the prognosis of the illness and the goals of the person receiving the care.

You should always ask questions, such as:

- ? "What are my options?"
- ? "How will I feel with that treatment?"
- ? "What is the likely outcome with or without treatment? "
- ? "When should we consider palliative care?"

## The Difference Between Palliative Care and Hospice Care

Mary's 80-year-old mother, Fran, hadn't been feeling well for weeks. A trip to her family doctor and a series of tests pointed to an infected gallbladder. However, when doctors performed surgery to remove the gallbladder, they made another discovery. Surgeons found widespread cancer, and removed as much as they could. After surgery, they gave Fran and her family the bad news.

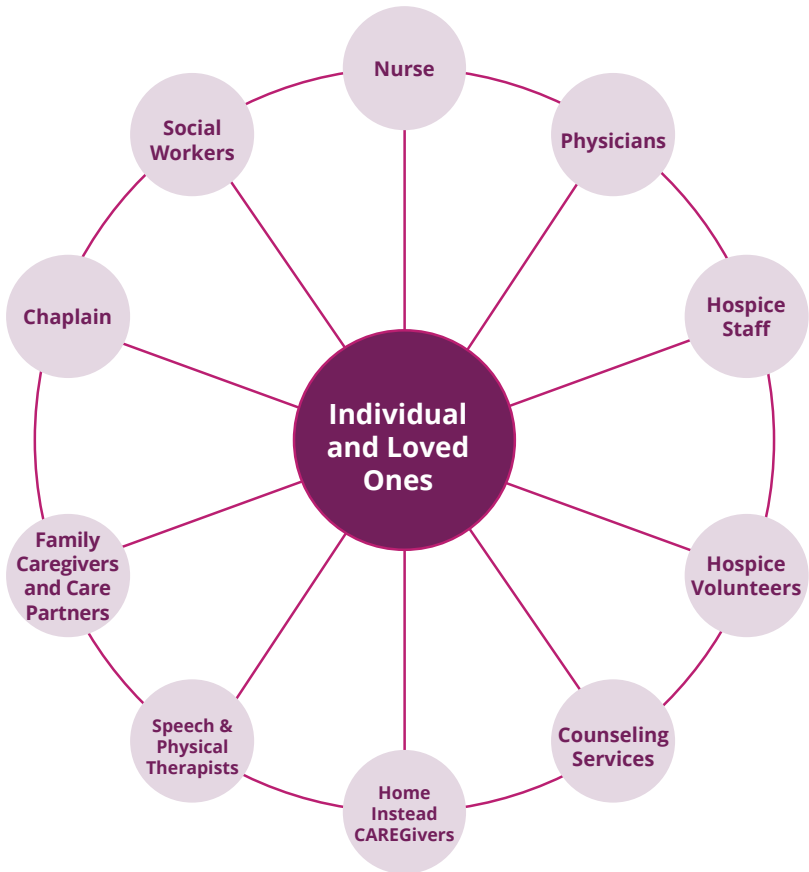
Understandably, Fran wanted to do everything to try to cure the cancer. At this point in her care, Fran's goal was a cure. So Fran's doctors needed to strike a balance between comfort and steps to help achieve a cure (hospitalizations, tests, office visits and interventions such as chemotherapy, radiation and surgery). This approach is considered "curative" and "palliative."

Four months later, Fran's medical team concluded that further intervention had little to no chance of curing her cancer. Fran had reached a "tipping point" where the burdens of this approach outweighed any benefits. At this point, it made sense to Fran and her family to change their focus from the cure approach entirely to comfort, maximizing the quality and well-being of her remaining time. She was now ready to embrace the hospice philosophy.

## Myth 2

### As a family caregiver or care partner, I am all alone on my journey.

Although family members and loved ones serve as the primary caregivers for their loved ones, you are never alone. You have an expert team to call upon when you need assistance.





A team approach can help families make the most of their time together. A hospice team typically includes the following members:

### **Physician**

An ongoing role of the physician(s) generally is to manage the patient's symptoms and pain. This involves regular evaluation of comfort and modification of medication as pain and other symptoms may increase.

### **Family Caregiver and Care Partners**

The family caregiver(s) and care partners(s) are supported by the hospice team but they also play a role in caring for the individual. This care could include bathing, toileting, grooming, assistance with eating and medication management. However, other members of the team can help and support the caregivers and care partners, such as hiring a professional Home Instead® CAREGiver<sup>SM</sup>.

### **Nurses**

The main role of a hospice nurse is to ensure quality of life during their remaining days. They are responsible for speaking with patients to help them understand their pain parameters, manage medication and manage through any crisis. Nurses on the core hospice team also educate family members, teaching them techniques for personal care and ways to help keep their loved one comfortable.

### **Social Workers**

Once an individual decides to use hospice care, social workers provide information and help coordinate community services such as additional home care or government benefits.

### **Chaplain**

A chaplain provides spiritual support to the person on hospice and his/her loved ones.

### **Hospice Volunteers**

Volunteers help by providing the patient with support and companionship.

## **Hospice Staff**

A hospice staff member, such as a home health aide, is available on an intermittent basis, usually one time a week, for assistance with tasks such as bathing.

## **Professional Caregivers**

Outside caregivers from in-home care companies are available to help as well. They can provide care with activities of daily living and instrumental activities of daily living such as personal care, meal preparation and light housekeeping, along with companionship. They can also provide respite help if the family needs time away or has an outside commitment. A caregiver also can support the family by providing their loved one assistance with medication management and hospice care.

## **Speech/Physical Therapist**

While not part of the core hospice team, a person on hospice may need the assistance of a speech therapist to show him or her techniques to communicate with family members and caregivers. A physical therapist may help a hospice patient learn to move with a disability or a new device.

## *Myth 3*

## **You can't keep your own doctor if you enter hospice.**

Hospice physicians work closely with the doctor of choice to determine a plan of care. Someone on hospice need never lose a personal physician. However, that individual will typically gain a hospice provider as part of the care team. Sometimes family physicians prefer that patients work with hospice physicians.

## Myth 4

### **Hospice care is more expensive.**

Studies have shown hospice care to be less expensive than conventional care during the last six months of life. Less high-cost technology is used, and family, loved ones, friends and volunteers provide an estimated 90 percent of the day-to-day patient care at home.

Additionally, patients eligible for Medicare or Medicaid generally pay fewer out-of-pocket expenses related to their hospice care. Many private insurers also cover some or most hospice-related expenses.

According to Medicare.gov, people who meet all of the following conditions are eligible to receive Medicare hospice care benefits if:

- The person is eligible for Medicare Part A (Hospital Insurance),
- The person's doctor certifies he or she is terminally ill and expected to have six months or less to live (recertification is required every six months),
- The person accepts palliative care (for comfort) instead of care to cure his or her illness,
- The person signs an agreement choosing hospice care instead of routine Medicare-covered benefits for his or her illness

## Medicare Hospice Benefit

According to [Medicare.gov](https://www.medicare.gov), hospice benefits can include:

- Physician services
- Nursing and medical services
- DME or medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Drugs for symptom control or pain relief (may need to pay a small copayment)
- Hospice aide and homemaker services
- Social worker services
- Dietary counseling
- Grief and loss counseling for the hospice patient and their loved ones
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care
- Physical and occupational therapy; speech-language pathology services\*

Any other Medicare-covered services needed to manage pain and other symptoms related to the terminal illness, as recommended by the hospice team.

*\* Costs of these services would fall under a per diem reimbursement. A hospice program may agree to a physical therapy or speech consult only, not a series of therapy sessions.*

## What Medicare Does Not Cover When Hospice Care is Chosen

These services may not be covered when hospice care is chosen:

- Treatment intended to cure a terminal illness
- Prescription drugs to cure illness (rather than for symptom control or pain relief -- for example, chemotherapy)
- Care from any hospice provider that was not set up by the hospice medical team
- Room and board. (Medicare doesn't cover room and board no matter where hospice care is provided)
- Care in an emergency room, inpatient facility care, or ambulance transportation, unless it's arranged by a hospice team member or is unrelated to the terminal illness

## Myth 5

### **Hospice means death is imminent.**

Hospice care is a process that can be as unique as the individual. Hospice care is generally for a person with a prognosis of six months or less to live. With Medicare, hospice care is given in benefit periods. Eligible persons can get hospice care for two 90-day periods, followed by an unlimited number of 60-day periods. At the start of each period, the hospice medical doctor or other hospice doctor must certify the person is terminally ill so he or she can continue the hospice care.

At any time, a person can stop his or her hospice care.

## Myth 6

### **We shouldn't tell Mom she is dying or has exhausted all treatment options.**

It's important to be honest with a loved one and to remember that people with a life-limiting illness do have a choice. They can continue treatment to try and combat their illness or they can discontinue treatment and seek comfort care. When they discontinue treatment, they may choose to enter into hospice care, which is designed to help control the pain and manage the symptoms associated with the illness.

This often means they move from a hospital to a home setting or from a hospital to a long-term care facility or hospice facility. They must weigh several factors when they make their decision. Deciding what to do can be a process.

Hospice care can make someone feel as though others have given up hope on him or her. Reassure a family member or loved one that is not the case. Hospice care is not about giving up hope, but changing the focus from continued treatment to comfort and quality. In fact, some individuals do improve on hospice care for a time. When it is time to go, though, hospice can help someone die with dignity.

Here are some conversation starters that could help you and your family member work through these issues:



*“Many older adults don’t want to utilize the resources of a facility because they want to remain independent.”*

*“Mom, I wish we had a treatment that could take all this away, but we don’t. I think we should focus on the things that will enable you to have the best quality of life for the longest period of time.”*

*“What do you think? Do you feel like you’re on your final journey?”*

*“Did you understand what the doctor said? Can I go over that with you?”*

*“Do you have questions about what this means?”*

*“The doctor has suggested hospice care. I think this sounds like a great way to make you more comfortable. Would you like to learn more? I think I would. We can have someone come in and talk with us about hospice. How does that sound?”*

*“After we learn more, you can decide what you’d like to do.”*

*“I’ll be with you every step of the way, Mom. We’ll face this together.”*

## The Family Caregiver and Care Partner

As we’ve already discussed, the family caregiver or care partner plays an integral role in hospice and often serves as the primary caretaker for a family member or loved one. Having to care for a family member or loved one during this time can be physically and emotionally exhausting. The dying process can bring intense emotions that require exceptional coping skills. These emotions can change daily and even hourly as the end nears.

Take time to adjust so that you are comfortable in this new role. Some people never become fully comfortable and feel guilty when they cannot do it. Hospice is typically set up for you and your loved one to be the primary caregivers, so if this role is overwhelming or you don’t have enough support, there is help. It’s also a good time to pull the family together and determine everyone’s roles. Hold regular family conferences and make sure to keep the lines of communication open.

Here are some key roles and challenges of the family caregiver or care partner:

**Hands-on caregiving:** Taking care of the physical needs of a loved one will be a big part of the job. You could be called on to help your family member or loved one maintain hygiene habits and proper nutrition, alleviate or resolve sleeping issues and provide pain control. Nursing staff can help teach common caregiving techniques based on the family caregiver or care partner's ability.

**Decision-making:** Caregivers may be called on to take over daily decisions for their loved ones. This could become more difficult if a family member or loved one becomes mentally impaired or has dementia. If that's the case, try to put yourself in your loved one's shoes before the illness and think about what that individual would want.

**Withstanding the ups and downs:** Caring for a loved one on hospice creates emotional upheavals. Anger is a normal and common reaction to such a situation. There is always room for hope. For their loved ones, caregivers can hope for a life without pain and discomfort or a meaningful time with family and friends.

**Maintaining Balance:** A family caregiver or care partner's well-being is crucial. Make a point of getting out of the house periodically.

**Striving for Quality:** Make sure your loved one is treated with dignity and respect, and strive for quality and independence. A set routine can help all of you.

**Communicating:** Create an atmosphere of give and take. Include your loved one in choices about his or her medical treatment. Be sure to include other family members and loved ones as well, understanding the role they will play. Try to convey to other family members what you need.

**Getting extra support:** Remember, you can't be an effective family caregiver or care partner if you don't have the help you need. Look to other family and friends who could help, or seek respite assistance through a home care company. Don't feel guilty about asking for help and for going through varied emotions that can be part of the end-of-life process.

## The Role of Home Care

It's easy for a family caregiver or care partner to become overwhelmed. While hospice care can provide much-needed support to the hospice patient, it is important to understand that the hospice provider will not have a hospice team member there on a daily basis. This means that family caregivers and care partners are relied on to provide personal care and everyday tasks such as meal preparation, housekeeping and errands. These duties may add more stress to the lives of family caregivers. That's where a professional caregiving company could help.

While professional caregiving support is typically private pay, just a few hours a day or week could mean so much to hospice patients and their families. Professional caregivers can pick up where the hospice team and other medical services end by providing personal care, light housekeeping, meal preparation, medication reminders and errands.

Make sure that the home care company you're working with is trained in hospice support. One important role that a home care company can play is that of companionship. It may be difficult to be with a loved one all of the time. That's where a home care professional can step in, providing valuable support and comfort to the individual on hospice, their families and loved ones.

Wherever you or a loved one may be on life's journey, take comfort that others have traveled this road and are there to help.



# Resources

For additional information and resources about hospice, check out the following:

- Home Care Hospice Support  
[HomeInstead.com](http://HomeInstead.com)
- National Hospice and Palliative Care Organization (NHPCO)  
[nhpco.org](http://nhpco.org)
- Hospice Foundation of America  
[hospicefoundation.org](http://hospicefoundation.org)
- Canadian Hospice Palliative Care Association (CHPCA)  
[chpca.ca](http://chpca.ca)
- Medicare Hospice Information  
[medicare.gov/coverage/hospice-care](http://medicare.gov/coverage/hospice-care)

## Books

- Final Gifts - *Maggie Callahan and Patricia Kelley*
- The Four Things that Matter Most - *Dr. Ira Byock*

For more information, contact your local Home Instead office.

*All Content provided herein is information of a general nature and does not address the circumstances of any particular individual or entity. Nothing provided herein constitutes professional legal, medical and/or financial advice, nor does any information herein constitute a comprehensive or complete statement of the matters discussed or the law relating there to.*

## About Home Instead

Founded in 1994 in Omaha, Nebraska, the Home Instead® franchise network provides personalized care, support and education to enhance the lives of aging adults and their families. Today, the network is the world's leading provider of in-home care services for older adults, with more than 1,200 independently owned and operated franchises that provide more than 90 million hours of care annually throughout the United States and the world. Local Home Instead offices employ approximately 100,000 CAREGivers<sup>SM</sup> worldwide who provide basic support services that enable older adults to live safely and comfortably in their own homes for as long as possible. Home Instead franchise owners partner with clients and their family members to help meet varied individual needs. Services span the care continuum – from providing personal care to specialized Alzheimer's care and hospice support. Also available are family caregiver education and support resources. Home Instead, Inc., is a subsidiary of Honor Technology, Inc.

**For a free no-obligation consultation, contact a franchise office near you by visiting [HomeInstead.com](http://HomeInstead.com).**





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