

A decision aid for Hospice Care for anyone considering hospice



You or a loved one have been diagnosed with a serious illness that might not be curable. Many people find this scary or confusing. Some people feel pressured to make decisions about end-of-life options. These feelings are normal.

It is important to know you have choices.

As you read this guide, we want you to think about:

- How and where you want to live the rest of your life
- Your hopes and fears
- Your values
- Your biggest questions



Throughout the guide we use the term “you”. But this guide is also for caregivers, loved ones, and anyone else helping someone make end-of-life decisions.

What are palliative care and hospice?

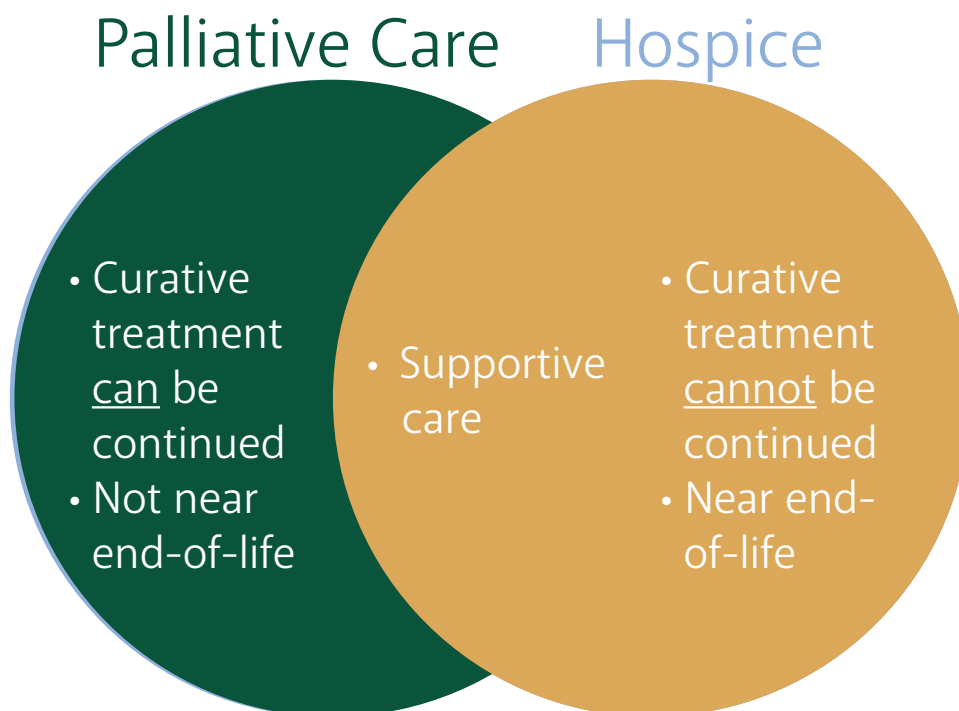
Understanding palliative care

Palliative care is medical care for people with serious illnesses. The goal of palliative care is symptom management, to provide comfort, and to improve the **quality of life**. Most people receiving palliative care can continue their curative treatments. Palliative care can be delivered in the hospital, at outpatient clinics, or at home. Not all hospitals have palliative care programs and not all insurances cover the cost of palliative care.



Understanding hospice

Hospice is a type of palliative care for people near the end of life. It is a treatment philosophy. Its goal is to deliver care that focuses on providing comfort to **seriously ill people** near the end of their life. Hospice does not cure disease but provides pain and symptom management along with emotional and spiritual support to patients and loved ones. Most hospice care is provided **at home**.

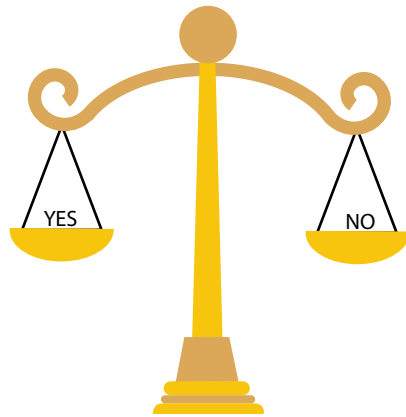


Is it the right time for hospice?

Hospice is not the right **choice** for everyone. If it is important to you to continue trying to cure your disease, hospice may not be right for you. However, if you do not want to continue curative treatment, it may be time for hospice. For many, this decision is difficult. This guide will help you think about your priorities so you can make decisions that are right for you.

Helping you make a decision

Now that you've learned about hospice services, the next two pages are meant to help you think about whether going into hospice now is right for you. **The choice is yours to make.**



Reasons other people have chosen either hospice or curative care



Curative Care

"I decided to stick with curative care because I want to keep trying aggressive treatment. My doctors say I probably have closer to 12 months to live and we may have to revisit this decision." - Steve



Hospice

"I chose to go into hospice because I was nearing the end of my life. I cared more about being comfortable and knew my illness couldn't be cured. It was important for me to die in my home and I didn't want my family to be stuck with a ton of medical bills. When I learned that hospice would also provide my family with support and bereavement, I knew this was the care that was right for me." - Bob

Helping you make a decision

The next few pages are meant to help you understand hospice and think about whether going into hospice now is right for you. **The choice is yours to make.**



What makes someone eligible for hospice?

The Medicare Hospice Benefit sets the standard for hospice eligibility. Medicare, Medicaid and private insurers can only pay for hospice care if a patient meets **3 eligibility criteria:**

1. My doctors and I agree that I have less than 6 months to live.

You can stay in hospice for longer than 6 months if needed.

2. I am ready to stop curative treatments and focus on being comfortable in what time I have left.

3. I am willing to sign a statement that I consent to hospice care.



If you are eligible for hospice, remember you have the choice of whether or not to enter hospice.

Where can I receive hospice care?

Hospice care center



Many hospices have care centers for people. Some care centers are equipped with private rooms for patients and families. Visits to care centers are temporary and are only to help stabilize symptoms. They are staffed 24 hours with trained medical staff to keep patients and loved ones comfortable.

Home

Most people receive hospice care at home. Hospice provides pain management, symptom control and emotional and spiritual support. Patients have access to trained medical staff (registered nurses, nurse practitioners, certified nursing assistants and physicians) 24 hours a day. Hospice will also provide some medical equipment such as hospital beds, wheelchairs, and other medical supplies.



Nursing Home

Hospice does not pay for expenses associated with nursing home care. However, hospice-eligible patients living in nursing homes can receive hospice care.

Who pays for hospice?

Paying for hospice is a big concern for many people thinking about hospice care as a treatment option. Medicare, Medicaid, and most private insurances pay for hospice services.

- ✓ Medicare
- ✓ Medicaid
- ✓ Private insurance

- All Medicare patients are eligible for the **Medicare Hospice Benefit**, which pays for most hospice-related expenses.
- Most other insurance companies, including Medicaid, cover hospice.
- It is important to remember that any hospice insurance benefits **only** pays for expenses related to your **hospice diagnosis** and care, but **does not** include any expenses related to nursing home care or secondary diagnoses.

Types of services the Medicare hospice benefit does and does not cover

	Medical Care	Support Services	Patient and Family Support
Hospice coverage MAY include	- 24 hour access to medical team - Pain management - Medical equipment • shower chair • hospital beds • wheelchairs	- Certified nursing assistants to help with personal care and activities - Some volunteer services may include massage, music, art, and pet therapy - Companionship	- Social work services - Spiritual care - Grief support • At least 12 months of bereavement support - Emotional support • Support groups • Respite care
Hospice coverage MAY NOT include	- Chemotherapy - Dialysis - Antiretroviral therapy - Emergency room visits - Room and board in nursing homes	- Visits to non-hospice doctors and nurses - Nursing home care	- Any support or therapy provided by non-hospice practitioners

Hospice myth versus fact

Myth	Fact
X If I live longer than 6 months, I am no longer eligible for hospice.	✔ You can stay in hospice for as long as your doctor believes you are showing decline.
X Hospice is where people go to die.	✔ Hospice is a treatment option for people with advanced illness who have decided curative treatment is no longer right for them. Hospice care does not aim to shorten or extend life.
X My spiritual, religious, or non faith-based practices are not allowed in hospice.	✔ Hospice is non-denominational and welcomes people with diverse religious and spiritual beliefs and cultures. These traditions are incorporated into individual care plans.
X I can continue curative treatments while in hospice.	✔ The hospice philosophy of care focuses on providing comfort to people. In most cases, patients must stop curative care before enrolling in hospice.
X If I choose hospice care, I'll have to leave my home.	✔ Most people get hospice care at home. But, you can still get hospice if you live in a nursing home or are in the hospital.
X Hospice care is not for my loved ones.	✔ Hospice care is for both patients and loved ones. Loved ones receive spiritual and emotional support and respite care. Loved ones are able to participate in designing a care plan for the patient.
X Once I enroll, I cannot leave hospice care.	✔ You can leave hospice and return to curative care if you choose.

Hospice Summary

We have provided you with some general information about hospice care. Below is a quick summary to help you make the best choice for you.

	Hospice	Curative Care
Treatment Philosophy	- Comfort - Pain management - Symptom management	- Curing disease
Payment	- Medicare - Private Insurance - Medicaid	- Different insurances pay for different treatments - Patients are responsible for co-pays and co-insurance
Medical Support	- Dedicated hospice doctors and nurses	- Any provider patient chooses
Social Support	- Social workers - Chaplains - Hospice care team	- Medical staff in hospital or ICU - Outpatient services?
Location	- Home - Nursing home - Hospital (rarely)	- Hospital - ICU - ER visits



What is the right choice for you?

What do you choose?

Ask yourself these questions to help think about your decision:

How do I want to live the rest of my life?

How important is it to me to die at home?

Am I ready to stop curative treatments?

What are my biggest fears about hospice care?

What questions and concerns do I still have?

Ready to make a choice? Write it down and your reasons below:

What are the trade-offs between hospice and curative care?

Hospice Care	Curative Care
- I want to stop curative treatment.	- I want to continue curative treatment.
- I prefer to stay at home.	- I am okay with being hospitalized.
- I am okay no longer seeing my specialist doctors.	- I want to continue seeing my specialist doctors.



Definitions

Palliative Care: Medical care for people with serious illnesses. The goal of palliative care is symptom management, to provide comfort, and to improve the quality of life.

Hospice: Hospice is a type of palliative care for people near the end of life. Its goal is to deliver care that focuses on providing comfort to seriously ill people near the end of their life.

Curative Care: Practices that treat patients with the intent of curing them, not just reducing their pain or stress. An example is chemotherapy, which seeks to cure cancer patients.

Hospice Care Center: Facilities that some hospices have to provide pain control and symptom management that cannot be provided at home. Stays in hospice care centers are usually short and end when the patients symptoms are stabilized.

Respite Care: Temporary institutional care of a dependent elderly, ill, or handicapped person, providing relief for their usual caregivers.

Medicare: The federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD).

Medicaid: A health care program that assists low-income families or individuals in paying for long-term medical and custodial care costs.

Comfort Care: Care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes.

Supportive Care: Prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.

For more information visit: www.patientdecisionaid.org



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