



What is Hospice:

*The Definitive Guide for
You and Your Family*



What is Hospice Care?

For many, hospice is a foreign topic of discussion, and in most cases, is not one that is easy to broach. It can be confusing, with so many hospice care companies available, and the emotions it brings are enough to make the conversation stop before it even begins.

Learning more about what hospice care is and the benefits it can offer can be very helpful at any stage of care. To help start the conversation, we've broken down the benefits of hospice care, provided common signs, symptoms, and diagnoses that may indicate hospice services are needed, and explained the importance of learning about hospice care prior to obtaining services.

So, what is hospice care? Hospice is care that is focused on quality of life and comfort, rather than cure. It is individualized, comprehensive care designed to meet the physical, social, emotional, and spiritual needs of the individual and their family. Hospice does not necessarily mean that death is imminent. Sometimes, people are able to have hospice for many months or even years. Many times, hospice care supports families with the challenges of caring for a loved one from practical, planning details to the emotional difficulties.

What are some diagnoses that may need hospice care down the road? Collectively speaking, hospice care can be needed for diagnoses that are in the end stages. These can include terminal cancers, heart disease or failure, renal failure, neuromuscular diseases, and respiratory diseases, among others.

What are signs and symptoms that can also be red flags for hospice care? Some signs include adult failure to thrive, multiple hospitalizations, weight loss, significant confusion, or mental decline, as well as difficulty breathing.

Why should hospice care be discussed early on? Educating yourself and your family members about hospice care is important for a variety of reasons. First and foremost, your preparation removes confusion and the emotional aspect of decision-making. Furthermore, after taking time to understand hospice care and explore local options, you and your family will have peace of mind and reassurance that when the time arrives, hospice care will be the right decision.



Disease-Specific Indicators

The individual may be eligible if their diagnosis has advanced according to any of the following:

Alzheimer's, dementia, or stroke with at least one of the following:

- Weight loss of 10% or more in the last 6 months
- Difficulty swallowing/eating
- Bowel and bladder incontinence
- Unable to walk/dress without assistance
- Decubiti
- Frequent urinary tract infections
- Recurrent pneumonia
- Impaired communication/cognition
- Dependent in all activities of daily living
- Bed-bound
- Garbled speech

Cancer with at least one of the following:

- Poor prognosis
- Metastatic or progressing in spite of treatment
- Refusal of further treatment

Cardiac:

- NYHA Class IV
- EF 20% or less
- End-stage CHF/cardiomyopathy
- Symptoms resistant to treatment

Pulmonary:

- End-stage COPD
- Disabling dyspnea at rest
- Oxygen-dependent
- Recurrent infections

Hepatic:

- Hepatic encephalopathy
- Ascites, jaundice
- Advancing cirrhosis

Renal:

- Late Stage IV
- Dialysis refusal
- Progressively worsening uremia
- Hepatorenal syndrome

Neuromuscular:

- End-stage ALS/MD/Parkinson's
- Unable to walk
- Declines ventilation

CVA (Cerebrovascular accident [stroke]):

- Significant CVA
- Declining in clinical/functional status
- Comatose, increasing complications

HIV/AIDS:

- Antiviral therapy failure
- Encephalopathy
- Kaposi's Sarcoma
- Lymphoproliferative malignancy

Patient declining or stopping dialysis for Parkinson's Disease with at least one of the following:

- Difficulty swallowing
- Decline in speech
- Progression from independent ambulation to wheelchair or bed-bound status

Stages of Hospice Care

Transitioning a loved one to hospice care can be a difficult and emotionally draining process. One of the biggest aspects that can make things overwhelming is educating yourself on which level of hospice care your loved one needs.

The Four Levels Of Hospice Care

At Wesley Hospice, we provide four levels of hospice care and work with our patients and their families to create a comprehensive, individualized care plan. Below, we've outlined a more in-depth overview of each level of care we offer.

1

Level One: Routine Home Care

Routine home care is the basic type of hospice care. It is for patients who have had a doctor identify that hospice services are needed. With routine care, hospice staff visits patients on a set schedule to provide comfort and to address the physical, emotional, and spiritual needs of not only the patients but also of their caregivers.

2

Level Two: Continuous Care

Continuous care is provided for periods of crisis. It is composed primarily of nursing care that is used to help achieve palliation or management of acute medical symptoms such as:

- Pain
- Nausea
- Vomiting
- Terminal restlessness/agitation
- Respiratory distress

Continuous care is often used in the final days of life when these symptoms may be unmanageable. This type of care is usually for longer lengths of time each day and typically is centered around direct nursing care and hospice aide care to continue managing the patient's uncontrollable pain symptoms.



3

Level Three: General In-Patient Care

This type of care is usually for longer lengths of time each day and is typically centered around direct nursing care and hospice aide care so your loved one will have the ability to remain comfortable.

4

Level Four: Respite Care

Respite care is offered in a skilled nursing facility and is designed to give short-term relief for families and caregivers. Respite care is offered for up to five consecutive days at a time and is a wonderful option for caregivers who may be going on vacation, need a break, or who want to begin introducing a facility to their loved one so they are able to engage with others while receiving support.





How to Talk About Hospice

Not wanting to talk about end-of-life care is common. Many people are opposed to talking about things as serious as death and will avoid the topic altogether. Unfortunately, this means that talking about hospice care is often delayed until the individual in need of care is at a level of crisis.

Have the Conversation Before Crisis

There are many ways to start the conversation regarding hospice preferences that will be a guide in the decision making process. Knowing how to start the conversation can help ensure that a person's wishes have been taken into consideration. It is critical to learn about the different care options and communicate with your loved one before cognitive and/or physical impairment prevents an individual from making their own decisions for care. Unrevealed care goals can delay hospice access due to the misconceptions that hospice can bring which results in utilizing hospice care as a last resort rather than using hospice to support an individual's quality of life.

Benefits of the Discussion

- Your family member or spouse is empowered to make decisions
- Family members know what the person wants
- It prevents confusion/hurt feelings/arguments amongst family members
- A plan now prevents stress and chaos when a crisis occurs
- The person needing hospice care will feel heard and valued

Families delay having this conversation despite the many logical reasons they can benefit from discussing it in advance.



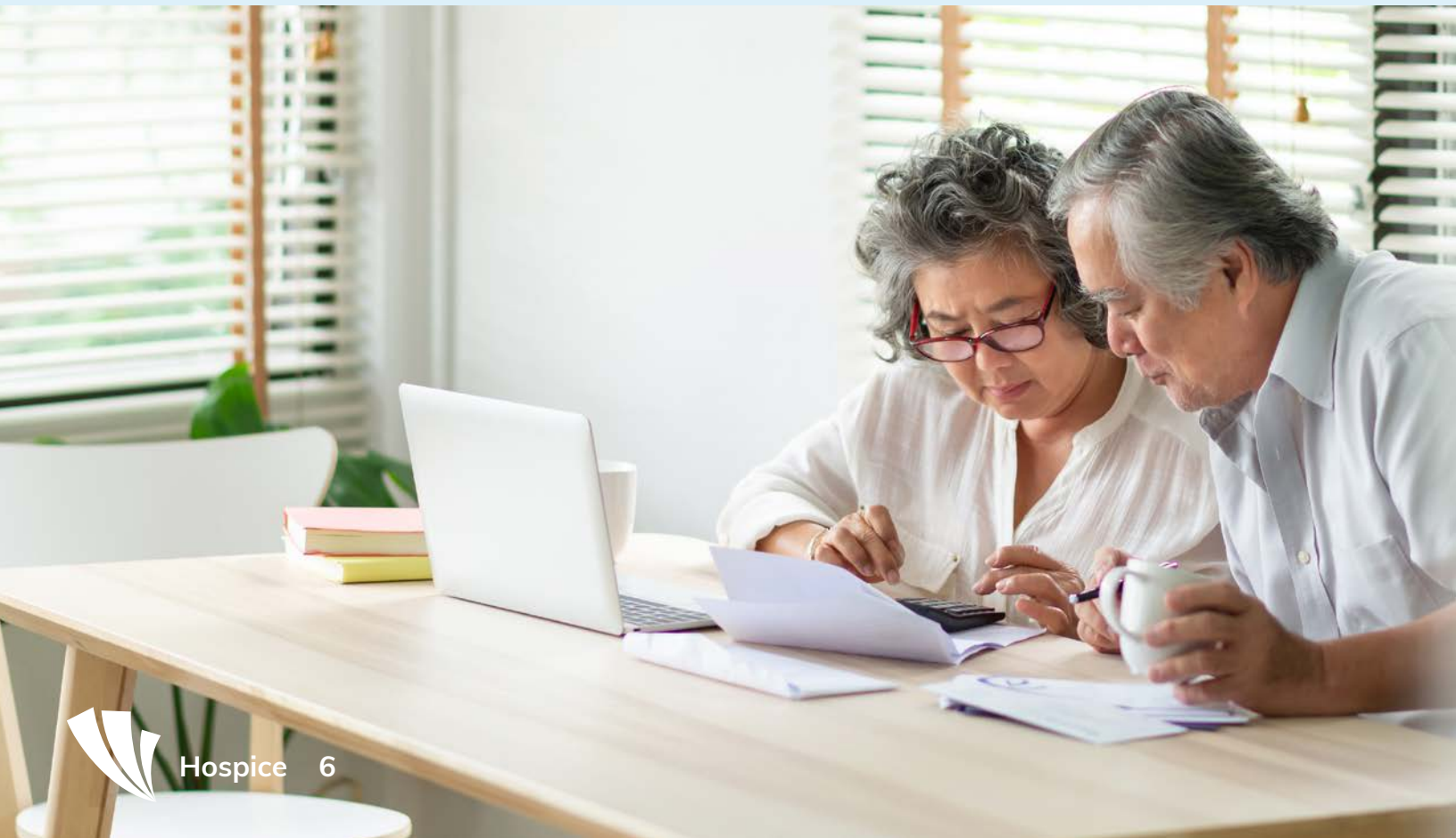
Items to Consider when Preparing for the Future

It's easy to get overwhelmed with everything to consider when planning for hospice care. You should focus on several documents to help you better prepare for the future. Your living will specifies what kinds of treatment and care you would or would not want in order to sustain life. Your durable power of attorney authorizes someone you trust to act as your representative and make medical decisions for you if you cannot make them for yourself. These are healthcare documents and do not include financial, estate, or business concerns. Advance directives are only useful if they are completed before a health crisis and are available when you are unable to speak for yourself.

Everything you will want to think about when making your plan:

- Legal documents
- Will
- Advanced directives (living will)
- Durable power of attorney finances
- Durable power of attorney healthcare
- Finances
- The complexity of distributing monetary gifts
- The details surrounding hiring in-home care
- Living arrangements
- Where do you want to be treated
- What kinds of treatments do you want to receive
- Under what conditions do you want to receive them
- Who should speak for you should you not be able
- Funeral and burial arrangement
- What kind of funeral do you want
- Where do you want your funeral to be held
- Do you want a viewing
- How do you want to be buried or cremated

A growing number of physicians support patients receiving hospice care early in order to have a better quality of life. The longer symptoms are managed, the more the patient will be able to do.





Medicare and Hospice

As of the date of this publication, the Medicare Hospice Benefit covers hospice costs for the vast majority of patients in the United States.

Medicare also covers health costs not related to terminal illness, though you or the patient could be responsible for co-pays and deductibles. Call 1-800-MEDICARE or visit [medicare.gov](https://www.medicare.gov) for more information about applying for Medicare coverage.

Common Hospice Services

Hospice offers a wide range of services to patients and their families. Services include:

- Medical equipment, supplies, and comfort medications
- 24/7 access to our hospice team
- Home visits by hospice nurse
- Hospice aide visits to assist with personal care
- Pain and symptom management
- Counseling and spiritual support for patients and caregivers
- Grief support and bereavement services
- Volunteer services, including hair services, pet and music companions, massage therapy, and caregiver relief

A Typical Hospice Team

Many hospice teams include:

- RN Case Manager
- Hospice Aides
- Social Worker
- Spiritual Counselor
- Administrative and Support Staff
- Medical Director
- Volunteer Coordinator
- Bereavement Coordinator
- Volunteers
- Chaplain



The Simple Facts

Eligibility:

The patient's physician and our hospice Medical Director must certify that the patient has a life expectancy of six months or less if the disease progression was to run its normal course.

Who Pays:

Hospice is covered 100% by Medicare and Medicaid and is a benefit of most private insurances.

Where is Care Provided:

Hospice comes to wherever you call home, including a family residence, an assisted living facility, a skilled care facility, an in-patient unit, or a hospital.

When Should You Call:

It is time to call Wesley Hospice when you or your loved one experiences an advancement in a life-limiting illness, which may include:

- An increase in pain, nausea, and/or breathing distress
- Repeated hospitalizations or trips to the emergency room
- Failure to "bounce back" after medical setbacks
- Decrease in function, requiring assistance with walking, eating, bathing, dressing, and/or personal hygiene
- Decrease in alertness
- Significant decrease in appetite and weight loss

Bereavement Services

Bereavement services are available to assist the patient's family through spiritual and or grief support during this emotionally difficult time. Bereavement services can be resources to the patient's family for a period of at least 13 months following the loved one's death. Bereavement support may consist of the following: regular mailings that provide emotional support, phone contacts and counseling visits, hospice-sponsored support groups, and access to informational grief and bereavement materials.

At some point, all of us experience the loss of someone important in our lives. Dealing effectively and positively with grief caused by such a loss is central to a healthy and fulfilling life. Wesley Hospice provides ongoing bereavement follow-up to family members and friends for 13 months.



FAQ

Are hospice staff available 24/7?

Yes, the staff is available to you at all hours to keep you cared for and comfortable.

Does hospice stop services if the individual lives longer than 6 months?

No, as long as the patient continues to meet eligibility for hospice services, they may continue to use the program.

Is hospice available to people with non-life-threatening cancer?

No, hospice is meant for those actively receiving treatment for life-threatening conditions.

Are hospice services typically covered by health insurance?

Yes.

Does hospice provide grief support?

Yes, hospice provides bereavement services, which can include grief counseling to the patient's family up to 13 months after the passing of their loved one.

Can hospice be provided in a retirement community?

Yes, hospice can be provided wherever the patient calls home. This includes, retirement communities, assisted living and long-term care facilities, as well as residential homes.

Is hospice care only for those who have a few days to live?

No, hospice is appropriate for anyone with a life-limiting illness and a life expectancy of 6 months or less.

Does hospice speed up the dying process?

No, hospice does not speed up, nor does it slow down the dying process. The goal of hospice is to manage and alleviate symptoms and provide comfort.

Can hospice care be provided at home?

Yes, many communities offer hospice at home.

Is hospice only available to people over 65?

No, hospice can be provided to anyone who has been diagnosed with a life-limiting illness and is no longer seeking curative treatment. The focus of hospice is comfort and symptom management.





Life Enriching Communities owns and operates six senior living communities (CCRCs):

CINCINNATI AREA

- Twin Towers, College Hill: 513-853-2000
- Twin Lakes, Montgomery: 513-247-1300

CLEVELAND AREA

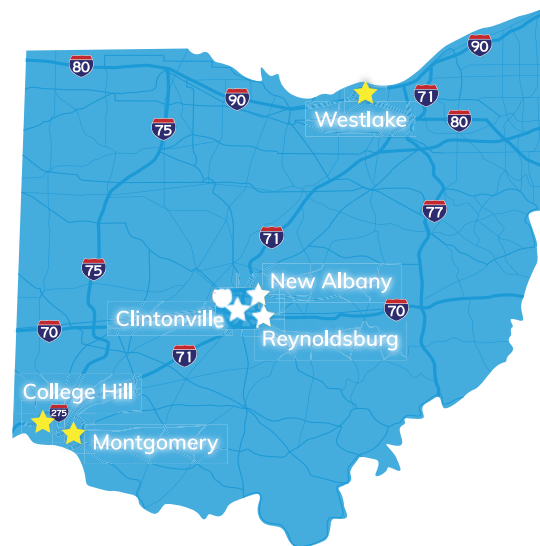
- Concord Reserve, Westlake: 440-961-3700

COLUMBUS AREA

- Wesley Glen, Columbus: 614-888-7492
- Wesley Ridge, Reynoldsburg: 614-759-0023
- Wesley Woods, New Albany: 614-656-4100
- Wesley Hospice, a Life Enriching Communities (LEC) program: 614-451-6700

Confident Living is a continuing care at home program offered by Life Enriching Communities (LEC) in Cincinnati, designed to help people navigate their options so they can live independently in their own homes.

- 513-719-3522



Life Enriching Communities is affiliated with the West Ohio Conference of the United Methodist Church and welcomes people of all faiths. We do not discriminate and we provide free assistance in your native language, if needed. Find our complete non-discrimination policy at www.LEC.org.