

Hospice and Beyond Palliative Care

"A Legacy of Compassion – Honoring Every Life, Every Moment."



Dedication

Dedicated to families and caregivers who bring light to every moment. This handbook was created to honor your strength, your love, and the dignity of those you care for. May it guide, comfort, and empower you.

Welcome

Dear Patient and Family,

At Hospice and Beyond Palliative Care, our purpose is simple and unwavering: to surround you with expert care, steady guidance, and heartfelt companionship. Hospice is not about giving up—it's about focusing on what matters most: comfort, dignity, and connection. We partner with you to create a plan that reflects your values, beliefs, and goals for each day.

This handbook explains what hospice is, how it works, and who will be by your side. You'll learn what services are included, how your care team supports you, and how we empower families as essential partners in care. If family caregiving is limited or not available, our social worker can help you explore community resources and private options.

No matter where you call home, you are never alone. Our team is available 24/7 to answer questions, manage symptoms, and provide support. Thank you for trusting us during this tender time—we are honored to walk with you.

With compassion,

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Hospice and Beyond Palliative Care

Understanding Hospice Care

What is Hospice?

Hospice is specialized care for people with a life-limiting illness who prefer to focus on comfort and quality of life. Care is centered on relief of pain and symptoms, emotional and spiritual support, and preserving meaningful moments at home or wherever you live.

Hospice recognizes that the end of life is not just a medical event but a deeply personal, emotional, and spiritual journey. It provides comprehensive support for patients and families to live with dignity and peace in every remaining moment.

How is Hospice Different from Palliative Care?

Both hospice and palliative care focus on comfort and quality of life. Palliative care can begin at any point during a serious illness—even while receiving curative treatments. Hospice begins when a physician certifies that a patient's life expectancy is six months or less if the illness follows its usual course. At that point, the plan of care shifts from curative treatment to comfort-centered care.

Hospice care is not about giving up—it's about shifting focus to what truly matters: meaningful time, comfort, and peace.

Our Approach at Hospice and Beyond

At Hospice and Beyond, we surround the patient and family with a compassionate interdisciplinary team that includes a physician, nurse, hospice aide, social worker, chaplain, bereavement specialist, volunteers, and therapists as needed.

Together, we create an individualized plan of care that reflects your goals, values, and personal wishes. Our team provides 24/7 on-call support, education for caregivers, and guidance through physical, emotional, and spiritual needs.

We believe that every person deserves to live fully, even in their final stages of life — with comfort, dignity, and respect.

Family Caregiving is the Heart of Hospice

Family is central to the hospice experience. When loved ones are available, we teach and support them as partners in daily care. We guide them in symptom management, comfort techniques, emotional support, and communication with the care team.

If a primary caregiver is not available, our social worker will help explore options such as private-duty caregivers, community-based services, or respite programs. Before you pay out of pocket, we will help you understand what is covered and what resources are available to assist with your care plan.

Our goal is to make sure that no family feels alone or unsupported — every question matters, and every emotion is valid.

Settings of Care

Most hospice care takes place in the home or wherever the patient resides — including nursing homes, assisted living facilities, or group homes. When symptoms cannot be safely managed at home, short-term inpatient hospice care may be provided in a hospital or hospice facility. Respite care can also be arranged for a few days at a time to give family caregivers a much-needed rest while ensuring their loved one continues to receive quality care.

Your Interdisciplinary Care Team

Hospice care is not one person's work — it's a team effort built on compassion, communication, and expertise. At Hospice and Beyond, every patient and family receives care from a group of professionals who work together to meet physical, emotional, and spiritual needs.



Physician (Medical Director and Attending Doctor)

Our hospice physician oversees all aspects of your care plan. They collaborate closely with your personal physician (if you have one) to ensure your medical needs are met with comfort and dignity. They guide symptom control, adjust medications, and coordinate all treatment decisions to align with your goals.



Registered Nurse (Case Manager)

Your hospice nurse is your main clinical contact. They visit regularly to monitor symptoms, manage medications, educate caregivers, and ensure you are as comfortable as possible. The nurse also helps you and your family understand what to expect, explaining every change with empathy and clarity.



Hospice Aide

Hospice aides provide personal care such as bathing, grooming, and dressing. They help maintain dignity and cleanliness while offering companionship and emotional warmth.



Social Worker

Your social worker provides emotional support, helps with financial and legal resources, and guides you through community programs. They can help arrange private caregiver options if family members are not available, or connect you with respite programs and volunteer assistance. Social workers also help complete advance directives, explain coverage, and ensure no one faces this process alone.



Chaplain or Spiritual Counselor

The chaplain offers spiritual and emotional support regardless of faith or background. They help individuals and families find meaning, peace, and closure.



Bereavement Specialist

Our bereavement team provides grief support to families for up to 13 months after a loved one's passing. They offer phone check-ins, in-person visits, and group sessions to ensure no one grieves in isolation.

Levels of Hospice Care

Hospice and Beyond offers four levels of care as defined by Medicare and hospice regulations. Each level is designed to match your needs as they change.

01

Routine Home Care

This is the most common level of hospice care. Care is provided wherever the patient calls home — a private residence, nursing home, or assisted living facility. Visits from nurses, aides, social workers, and chaplains are scheduled regularly. Medications, medical supplies, and equipment related to the terminal diagnosis are delivered directly to you.

02

Continuous Home Care

This level is provided when symptoms become severe and require continuous nursing care for short periods. A nurse or hospice aide stays with the patient for extended hours (up to 24 hours if needed) to ensure pain and distress are well managed.

03

General Inpatient Care

If symptoms cannot be controlled at home, general inpatient care may be arranged in a hospital, hospice inpatient unit, or skilled nursing facility. The focus remains comfort and symptom control — the stay is temporary until the patient can safely return home.

04

Respite Care

Respite care offers short-term relief for family caregivers. The patient may stay in a hospice facility or contracted nursing home for up to five days while the caregiver rests, attends to personal needs, or travels. Respite care ensures families can continue caregiving with renewed energy and peace of mind.

What Hospice Covers

Hospice care under Medicare, Medicaid, or most private insurance plans covers a wide range of services. Hospice and Beyond ensures families understand what is included before care begins.

Services Covered Include:

- Physician and nursing care
- Medications related to the terminal diagnosis
- Medical equipment (such as hospital beds, oxygen, or wheelchairs)
- Medical supplies (gloves, dressings, hygiene items)
- Hospice aide and personal care visits
- Social work and counseling services
- Chaplain and spiritual care
- Volunteer services
- Bereavement counseling for families
- 24/7 on-call nurse availability

Family Care: The Heart of Coverage

Hospice assumes the primary caregiver is typically a family member or loved one. The hospice team supports, trains, and guides this caregiver throughout the journey. If a family caregiver is not available, hospice will still provide services, but additional private-duty help may be needed. Our social worker will assist in finding resources or community programs to minimize costs and prevent caregiver burnout.

What Hospice Does Not Cover

Hospice focuses on comfort, not cure — so some services are not included in hospice benefits.

Not Covered Under Hospice:

- Treatments intended to cure your illness (such as chemotherapy or radiation)
- Hospitalizations not arranged by the hospice team
- Emergency room visits for non-hospice related reasons
- Prescription drugs unrelated to your hospice diagnosis
- Room and board in a nursing home or assisted living facility (unless covered by another benefit)
- Ambulance trips not ordered by hospice
- Private-duty caregivers hired independently

Before You Pay Out of Pocket

Always check with the hospice nurse or social worker before purchasing medications, equipment, or supplies. In many cases, hospice can provide or arrange these at no cost. Our social worker is available

Patient and Family Rights

At Hospice and Beyond, every patient and family member has rights that are respected and protected. You have the right to:

- Receive compassionate, respectful care at all times.
- Be informed about your diagnosis and treatment options.
- Participate in decisions about your care.
- Request a change in hospice provider at any time.
- Receive care without discrimination based on race, religion, gender, age, disability, or financial status.
- Have privacy and confidentiality in all medical and personal matters.
- Receive pain and symptom control consistent with your wishes.
- Decline or discontinue hospice care at any time.
- File a complaint or grievance without fear of retaliation.

We honor your dignity and independence. Hospice and Beyond exists to serve you and your family with integrity and respect.

Advance Directives and Choices

Advance directives allow patients to express their wishes about medical treatment, comfort, and end-of-life decisions before a crisis occurs. At Hospice and Beyond, we encourage every patient and family to discuss and record these wishes clearly and early.

Types of Advance Directives

- **Living Will:** States what types of life-sustaining treatment you do or do not want (for example, mechanical ventilation or artificial feeding).
- **Medical Power of Attorney:** Names a person you trust to make healthcare decisions if you become unable to speak for yourself.
- **Do-Not-Resuscitate (DNR) Order:** Communicates your decision to forgo cardiopulmonary resuscitation if your heart or breathing stop.
- **Out-of-Hospital DNR:** Extends the same decision to emergency responders.

Bereavement and Emotional Support

Grief is the natural response to loss, and every journey through grief is unique. At Hospice and Beyond, our care does not end when life ends — we continue to support the family for up to 13 months following a loved one's passing.

Our Bereavement Program Includes:

Regular phone calls and letters of comfort

In-person visits and grief counseling

Support groups and community workshops

Memorial services and remembrance events

Educational materials for coping and healing

Our bereavement team listens without judgment, offering guidance and companionship as families adjust to a new normal. You are never expected to "move on," only to move forward with compassion and understanding.

Working Together with Families

Hospice is a partnership — between the care team, the patient, and the family. Families often tell us they feel closer, more peaceful, and more prepared after learning how to provide care and communicate openly with their loved one.

Our Commitment to Families

- We teach you how to manage comfort measures safely.
- We provide honest, compassionate communication about what to expect.
- We respect cultural and spiritual differences in how families cope.
- We encourage family meetings, especially when making difficult decisions.
- We remind you to care for yourself — rest, nutrition, and emotional support matter too.

When the journey feels heavy, remember: you do not carry it alone. Our hospice team walks beside you, guiding and lifting every step of the way.

Safety Guidelines and Resources

Oxygen Safety Tips

Many hospice patients depend on supplemental oxygen to improve comfort and breathing. While oxygen is safe when used correctly, it can become hazardous if not handled with care. At Hospice & Beyond, patient and family safety is our priority.

Oxygen supports life, but it also supports fire. It does not burn itself, but it makes other materials ignite more easily. Therefore, oxygen equipment should always be kept at least six feet away from open flames, candles, matches, gas stoves, or cigarettes. Absolutely no smoking should occur in any room where oxygen is being used.

Ensure all oxygen cylinders are stored upright, secured in a stand, and kept in well-ventilated areas. Avoid using petroleum-based products—like Vaseline—on the face or around the nose while using oxygen. Instead, use water-based lubricants as recommended by your nurse. Always check tubing for kinks or leaks, and never adjust flow settings without medical direction. When traveling, make sure oxygen is transported securely and upright.

At Hospice & Beyond, our staff will guide you step-by-step through safe oxygen use, ensuring comfort and peace of mind. Together, we create a home environment where breathing is not only easier—but safer.

Home Safety and Falls Risk

The home should be a place of peace and safety, especially during hospice care. However, falls remain one of the most common risks for patients with limited mobility or balance. At Hospice & Beyond, we focus on prevention—because every fall prevented is a step toward dignity and comfort preserved.

Our care team performs a detailed home safety assessment to identify potential hazards. We look for loose rugs, cluttered walkways, dim lighting, uneven floors, and unstable furniture. Small adjustments—like securing rugs, improving lighting, and installing grab bars—can make a major difference.

We also encourage families to ensure assistive devices such as walkers, wheelchairs, or canes are within easy reach and used consistently. Non-slip shoes and clear, unobstructed paths should always be maintained. Patients should be encouraged to move slowly when changing positions—from sitting to standing or from bed to chair—and to call for help when needed. Family caregivers can receive training from our team on safe transfer techniques.

At Hospice & Beyond, safety means more than avoiding injury—it means maintaining independence, confidence, and comfort in every step a patient takes.

Medication Safety, Storage, and Disposal Guidelines