

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.

Volunteers

Trained volunteers bring comfort through companionship, music, reading, or simply being present.

They may also provide respite time so caregivers can rest and recharge.

Therapists (as needed)

Physical, occupational, or speech therapists may assist in maintaining comfort and mobility when appropriate.

All team members meet regularly to review and adjust your care plan — ensuring that every detail reflects your needs, your values, and your family's wishes.

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.

1. 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.

2. 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.

3. 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.

4. 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 to help you explore community grants, veteran benefits, or other funding options.


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.

 Hospice and Beyond Palliative Care Educational Handbook (Proofreading Continuation – Part 3)

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

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.

Our Role

Your hospice nurse or social worker can help you understand these documents, explain state requirements, and ensure your wishes are shared with all members of the care team. You may change your advance directives at any time. What matters most is that your voice guides your care, always.

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.

Hospice Providers Abuse, Neglect, and Exploitation Policy

At *Hospice & Beyond Palliative Care*, we are committed to upholding the dignity, safety, and wellbeing of every patient and family we serve. Abuse, neglect, or exploitation in any form—whether physical, emotional, financial, or verbal—is strictly prohibited and never tolerated. Every member of our care team is trained to recognize, report, and prevent any situation that could compromise a patient's safety or comfort.

Abuse includes any intentional harm or mistreatment of a patient. Neglect occurs when a caregiver fails to meet a patient's essential needs—such as food, comfort, hygiene, or medical attention. Exploitation refers to any misuse of a patient's trust, property, or finances. *Hospice & Beyond* maintains a zero-tolerance policy toward all three.

We encourage open communication. Patients, family members, and caregivers are urged to report any concern or suspicion immediately. Reports can be made confidentially without fear of retaliation. Every report is promptly investigated, and corrective actions are taken to ensure safety and accountability.

Our mission is to serve with compassion and integrity. That means every patient must feel respected, protected, and valued—always. At *Hospice & Beyond*, safeguarding our patients is not just a policy—it's a promise.

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

Proper medication management is essential for comfort, symptom control, and safety. At Hospice & Beyond Palliative Care, our team works closely with patients, families, and caregivers to ensure every medication is handled with care and precision.

All medications should be stored in their original containers with clear labels intact. Keep them in a cool, dry place, away from sunlight and moisture—never in the bathroom or near a kitchen sink. Always follow the instructions provided by your nurse or pharmacist. Do not adjust doses, mix medications, or share prescriptions without medical direction.

It's important to keep medications out of reach of children, pets, or visitors. For patients with cognitive changes, secure medications in a locked cabinet or box. A Hospice & Beyond nurse will assist in setting up a medication schedule and chart to help prevent missed or duplicate doses.

When medications are discontinued or expired, proper disposal is essential. Never flush medications or throw them in the trash. Instead, return them to our hospice nurse for safe disposal following state and federal guidelines.

By maintaining an organized, safe medication system, you not only protect your loved one's wellbeing—you also promote peace of mind in the caregiving environment.

-Infection Control in the Home Maintaining a clean, safe environment helps protect hospice patients from infections. At Hospice & Beyond, we take infection control seriously—because prevention is always better than cure.

Hand hygiene is the first and most important step. Caregivers and visitors should wash their hands with soap and water before and after every patient contact, meal preparation, or bathroom use. If soap and water are unavailable, alcohol-based sanitizer is a good alternative.

All wounds and medical devices, such as catheters or feeding tubes, must be cleaned and dressed as directed by the hospice nurse. Always use gloves when handling bodily fluids or soiled materials, and dispose of them safely afterward.

Keep the home well-ventilated and free of clutter. Change bed linens regularly and clean frequently touched surfaces—like doorknobs, phones, and tabletops—with disinfectant. Limit visitors who are sick or recently exposed to contagious illnesses.

At Hospice & Beyond, our team provides training on proper infection control techniques, ensuring the home remains a healing space. Compassion and cleanliness go hand in hand—protecting patients and preserving their comfort.

Medical Supplies and Disposal Guidelines: Every hospice patient requires specific medical supplies—bandages, gloves, syringes, oxygen equipment, or catheters. At Hospice & Beyond Palliative Care, we deliver and manage all supplies with precision, ensuring your loved one's needs are met safely and promptly.

Supplies should be stored in a clean, dry, and designated area—away from children and pets. Keep items in their original packaging until ready for use. Check expiration dates regularly, and notify our team if replacements are needed.

Used medical items—especially sharps like needles or lancets—must be disposed of in an approved sharps container. Never throw needles or syringes into household trash. When the container is full, contact Hospice & Beyond for proper disposal.

Soiled dressings, gloves, and other waste should be sealed in plastic bags and discarded according to your nurse's instructions. Our team can assist in setting up a simple disposal station in the home to maintain safety and organization.

We believe that caring for the environment is part of caring for people. Safe handling and disposal protect patients, caregivers, and the community from accidental harm or contamination—reflecting our promise of compassionate care beyond the bedside.

Emergency and Disaster Preparedness:

At Hospice & Beyond Palliative Care, preparedness is an act of protection and love. Emergencies such as severe weather, power outages, or natural disasters can occur without warning. Our goal is to ensure every patient, family, and caregiver remains safe, informed, and supported in any situation.

Each patient's care plan includes an emergency section with contact numbers, oxygen and medication lists, and step-by-step actions for critical situations. Keep this document in an easy-to-access location. Ensure all caregivers and family members know where it is stored.

If you use medical equipment that requires electricity—such as oxygen concentrators—identify backup power options or alternate equipment provided by our team. Keep flashlights, extra batteries, bottled water, and non-perishable food nearby.

During a community emergency, follow official instructions from local authorities. Our hospice team will maintain communication as conditions allow. We coordinate with emergency services to prioritize medically fragile patients and ensure continuity of care.

Safety begins with awareness and planning. Together, we stand ready to protect those in our care, no matter the circumstance.

My Pain Journal

Pain is personal, and every experience tells a story. The Hospice & Beyond Pain Journal helps patients and caregivers record details that guide our care team in providing the best possible comfort.

In this journal, patients or caregivers should note the time, location, and intensity of pain, using a scale from 0 (no pain) to 10 (worst pain). Record what may have triggered it—such as movement, meal, or medication changes—and what helps relieve it, like rest, massage, or prescribed medicine.

Patterns matter. Regularly tracking symptoms helps our nurses and physicians adjust treatments effectively. Some patients may also experience emotional or spiritual pain—these too are important to record.

This journal is not just a record—it's a conversation between you, your caregivers, and our team. It ensures that every ache, every discomfort, is seen and addressed with empathy.

At Hospice & Beyond, your comfort is our highest priority. By working together through awareness and documentation, we transform pain management into a partnership built on understanding and trust.

Call Hospice First

When changes occur in a patient's condition, families often feel uncertain about what to do. At Hospice & Beyond Palliative Care, our message is simple and vital: Call Hospice First.

Our team is available 24 hours a day, 7 days a week. Whether your loved one is experiencing shortness of breath, new pain, a fall, or a sudden decline, call us before dialing emergency services. Our clinicians are trained to handle most situations at home, preventing unnecessary hospital visits and maintaining comfort.

If death occurs, call Hospice & Beyond immediately. Do not call 911. Our team will guide you through every step with dignity, compassion, and respect for your loved one's wishes.

By calling hospice first, you allow our care team to respond quickly, provide relief, and support both patient and family with calm professionalism. You are never alone—help is always just one call away.

My Personal Health Calendar

The Hospice & Beyond Personal Health Calendar is designed to bring structure and clarity to the care journey. It serves as a simple, empowering tool for tracking daily health details, medication schedules, appointments, and emotional check-ins.

Each day, caregivers can record meals, hydration, mood changes, medication times, and vital signs if instructed. Weekly notes may include updates from visits, family reflections, or goals discussed with the care team.

This calendar helps identify trends—like improving appetite, changes in sleep, or new discomforts—allowing for quick and informed adjustments to the care plan. It also helps families stay connected, sharing updates among multiple caregivers with ease.

At Hospice & Beyond Palliative Care, we believe organization reduces stress and restores peace. A well-kept health calendar transforms care from overwhelming tasks into a rhythm of awareness and intention.

Every entry in this calendar reflects love in action—a record of care, consistency, and compassion.

Insurance and Financial Guidance

Hospice and Beyond Palliative Care is certified by Medicare and recognized by most private insurance and Medicaid programs.

Hospice care is typically covered 100% under the Medicare Hospice Benefit.

What's Included Under Coverage

- Physician and nursing services
- Home health aide and personal care
- Social work and counseling services
- Spiritual care
- Medications related to the terminal diagnosis
- Durable medical equipment and supplies
- 24-hour on-call services
- Bereavement counseling for families

Financial Counseling and Assistance

Our social workers help families understand coverage and any potential out-of-pocket costs. If a patient does not have insurance, we review payment options and available community resources.

We will never deny hospice care based solely on inability to pay.

Before You Pay Out of Pocket

Always consult your hospice nurse or social worker first.

Many items that appear to be “non-covered” may still be available through alternate programs, charitable funding, or state resources.

Common Myths and Facts

Myth: Hospice means giving up hope.

Fact: Hospice focuses on living fully and comfortably, not on giving up. Patients often live longer and more peacefully with hospice support.

Myth: Hospice care is only for the last few days of life.

Fact: Hospice can begin when a physician determines a life expectancy of six months or less — many patients receive months of supportive, meaningful care.

Myth: Hospice is a place you go to.

Fact: Hospice is a service, not a place. Most care happens right at home.

Myth: Choosing hospice means losing control.

Fact: Hospice empowers you to make informed decisions and stay in charge of your care plan.

Myth: Families can't contact hospice after hours.

Fact: Our team is available 24 hours a day, 7 days a week — every day of the year.

Duration and Recertification

Hospice eligibility is based on medical certification of a life expectancy of six months or less if the illness runs its normal course.

However, hospice care does not automatically end after six months.

If your physician and hospice team determine that continued hospice care is appropriate, recertification can extend services as long as needed.

Some patients even improve enough to discharge from hospice — they are always welcome to return when necessary.

Our philosophy is simple: hospice continues for as long as comfort, dignity, and support are needed.

Ethics, Compliance, and Non-Discrimination

Hospice and Beyond Palliative Care operates with transparency, respect, and full compliance with state and federal regulations.

We do not discriminate in the delivery of services based on race, color, national origin, religion, gender identity, age, disability, sexual orientation, or ability to pay.

We adhere to all privacy laws (HIPAA) and maintain strict confidentiality for every patient and family.

Our staff are trained regularly on ethical practice, patient rights, and professional boundaries. We encourage families to share feedback — we view it as a vital part of maintaining the highest quality of care.

If you have concerns, you can contact our administrator directly at any time, or file a grievance with the State Department of Health.

Your voice matters — and your trust is sacred to us.

Frequently Asked Questions (FAQs)

1. When should I consider hospice care?

When treatment is no longer effective or when comfort becomes the primary goal of care. The earlier hospice begins, the more support you and your family receive.

2. Who pays for hospice?

Medicare, Medicaid, and most private insurances cover hospice 100%. You should not receive a bill for covered services.

3. Can I keep my own doctor?

Yes. You may continue seeing your personal doctor in coordination with our hospice physician.

4. Where is hospice care provided?

Wherever you call home — private residence, assisted living, nursing home, or inpatient facility.

5. Can I change my mind about hospice?

Yes. You may stop hospice care at any time if you wish to resume curative treatment or for any reason.

6. How often will staff visit?

Visit frequency depends on your needs. Nurses usually visit weekly or more often if symptoms change. Aides, social workers, and chaplains visit as needed.

7. What if I need help at night or on weekends?

Hospice and Beyond provides 24/7 phone and on-call nursing support. You'll never be alone during an emergency.

8. Will hospice provide equipment and medications?

Yes, all medications, medical supplies, and durable equipment related to your diagnosis are provided and delivered to your home.

9. What if I live in a nursing home or assisted living?

Hospice works alongside facility staff to provide added layers of support and comfort.

10. What happens after my loved one passes away?

Our bereavement team will contact you to offer grief support, counseling, and ongoing resources for at least 13 months.

Community Resources and Support

Hospice and Beyond collaborates with community partners to connect families to additional help when needed.

We can refer you to:

- Local support groups
- Home meal programs
- Transportation services
- Veteran benefits
- Faith-based counseling
- Volunteer companionship programs

Ask your social worker for a personalized list of resources in your area.

Closing Message

You Are Not Alone.

Every day with Hospice and Beyond is about love, dignity, and comfort.

Whether you are a patient, family member, or caregiver, our promise is to walk with you — every moment, every step, with compassion and respect.

We are honored to serve you.

Contact Information

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