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# Hospice and Beyond Palliative Care



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

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,**

**Awau Omole**

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.



# 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.

01

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## 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

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## 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

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## 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

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## 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.

## 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.

# 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

## What Hospice Does Not Cover

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

- 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

### **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.

## 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.**

## 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.



## Safety, Support, and Essential Guidelines

### 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, and Essential Guidelines

## 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, and Essential Guidelines

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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 Essential Guidelines

## 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.







# Emergency and Disaster Preparedness and Essential Guidelines

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## 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.





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## **Pressure Ulcers (Bedsore)**

Pressure ulcers, also called bedsores, can develop when someone stays in one position for too long. They often appear on the heels, hips, tailbone, or elbows. In hospice care, our goal is to keep your skin healthy and prevent discomfort.

## **Protecting Your Skin with Comfort and Care**

### **Warning Signs**

- Changes in skin color or texture
- Swelling or tenderness
- Skin that feels warmer or cooler than nearby areas
- Redness or soreness that doesn't fade

### **Common Causes**

- Pressure from lying or sitting on hard surfaces (beds, wheelchairs)
- Moisture from sweat or incontinence
- Limited movement or muscle spasms

### **How to Help Prevent Pressure Ulcers**

- Change position regularly: Turn or shift at least every two hours.
- Use support surfaces: Special pads or mattresses can help relieve pressure.
- Keep skin clean and dry: Gently cleanse, pat dry, and use light moisturizer.
- Eat and drink well: Proper nutrition supports healthy skin.
- Check daily: Look for early changes and report any redness or pain right away.

### **When to Call the Nurse**

Your hospice nurse will routinely check the skin to detect early signs of pressure areas. If you notice any new redness, swelling, or open skin, contact your nurse immediately. Early attention leads to the best comfort and outcomes.

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## **Pain Management**

### *Comfort, Dignity, and Relief in Every Moment*

At Hospice and Beyond Palliative Care LLC, our goal is to ensure that every patient experiences comfort and dignity at all times. Pain management is a vital part of hospice care, helping patients live each day with the greatest possible ease and peace.

### **Understanding Pain**

Pain can be physical, emotional, or spiritual. It may come from illness, movement, anxiety, or other causes.

Everyone feels pain differently — that's why it's important to tell your hospice nurse or caregiver how you feel, even if the pain seems small.

### **How Hospice Manages Pain**

Your hospice team will assess and manage your pain through a personalized plan that may

include:

- Medications: Such as opioids and non-opioid medicines to relieve discomfort safely.
- Non-medication support: Relaxation, repositioning, massage, soft music, warm blankets, and emotional or spiritual care.
- Regular assessments: Nurses will check pain levels often and adjust medications as needed.
- 24/7 support: The hospice team is available anytime for pain or symptom changes.

### **What Patients and Families Can Do**

- Communicate openly: Let your nurse know if pain increases, changes, or becomes hard to manage.
- Keep a pain log: Note when and where pain occurs, and what helps.
- Follow the care plan: Take medications exactly as prescribed.
- Stay comfortable: Use pillows, gentle movements, or calming activities.
- Ask questions: Your comfort and understanding are our priority.

### **Our Promise**

Your comfort matters. The Hospice and Beyond team is dedicated to relieving pain with compassion, respect, and individualized care — ensuring that every life is honored and every moment is meaningful.

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## **Neglect and Exploitation**

### *Protecting Every Patient with Respect and Dignity*

At Hospice and Beyond Palliative Care LLC, every patient has the right to feel safe, respected, and protected. Our team is committed to ensuring that all individuals in our care are free from neglect, abuse, or exploitation of any kind.

### **What Is Neglect and Exploitation?**

- Neglect means failing to meet a person's basic needs, such as food, water, hygiene, medication, or comfort.
- Exploitation is taking advantage of someone for personal gain — this may include financial abuse, such as misusing a patient's money, property, or resources.
- Abuse can be physical, emotional, verbal, or sexual, and includes any behavior that causes harm, fear, or distress.

### **Warning Signs to Watch For**

- Unexplained injuries, bruises, or sudden behavior changes
- Poor hygiene, malnutrition, or unsafe living conditions
- Missing personal belongings, money, or medications
- Withdrawal, fearfulness, or anxiety around caregivers
- A caregiver restricting contact with family or hospice staff

### **How Hospice Helps Protect You**

Our hospice team is trained to recognize, report, and prevent all forms of abuse, neglect, or

exploitation.


We maintain strict confidentiality and act immediately to protect the patient's well-being.

### **What You Can Do**

- **Speak up:** If you suspect neglect or exploitation, tell your hospice nurse, social worker, or any member of our team immediately.
- **Stay observant:** Family and caregivers should watch for sudden changes in health, mood, or finances.
- **Know your rights:** Every patient has the right to be treated with respect, compassion, and honesty.

### **Reporting Concerns**

Hospice and Beyond Palliative Care LLC

 346-690-9032

 [beyondhospicehpcare@gmail.com](mailto:beyondhospicehpcare@gmail.com)

You may also contact Adult Protective Services (APS) or your state health department if you ever feel unsafe.

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### **Infection Control**

#### *Keeping Patients and Families Safe at Home*

At Hospice and Beyond Palliative Care LLC, infection control is an important part of keeping patients, families, and caregivers safe and comfortable. Many hospice patients receive care at home, where simple precautions can help prevent infections and promote a clean, healing environment.

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### **Why Infection Control Matters**

Infections can cause discomfort, delay recovery, or lead to complications. Because some patients have weaker immune systems, following good hygiene and care practices helps protect everyone in the home.

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### **Ways to Prevent Infection at Home**

#### **1. Hand Hygiene**

- Wash your hands often with soap and warm water for at least 20 seconds.
- Always wash before and after touching the patient, giving medication, handling food, or changing dressings.
- Use hand sanitizer when soap and water are not available.

#### **2. Clean Environment**

- Keep the patient's room clean, well-ventilated, and clutter-free.



- Wipe down commonly touched surfaces like doorknobs, tables, and remote controls daily.
- Change linens and towels regularly.

### **3. Safe Handling of Medical Supplies**

- Store medications and supplies in clean, dry areas away from pets or children.
- Dispose of used gloves, dressings, and materials in a covered trash container.
- Never reuse disposable items such as gloves or syringes.

### **4. Use of Personal Protective Equipment (PPE)**

- Caregivers should wear gloves when coming into contact with blood, body fluids, or open wounds.
- Masks may be used if the patient or caregiver has a cough, cold, or respiratory illness.

### **5. Wound and Skin Care**

- Follow the hospice nurse's instructions carefully when changing dressings.
- Keep wounds covered, clean, and dry unless directed otherwise.
- Report any redness, swelling, or drainage to the nurse immediately.

### **6. Food Safety**

- Wash fruits and vegetables thoroughly.
- Cook food to safe temperatures.
- Avoid leaving perishable foods at room temperature.

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### **When to Contact the Nurse**

Call your hospice nurse immediately if the patient develops:

- Fever, chills, or sweating
- New or increased pain
- Redness, warmth, or drainage from a wound
- Shortness of breath or unusual coughing
- Sudden confusion or weakness

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### **Our Commitment**

At Hospice and Beyond Palliative Care LLC, we believe infection control is an act of compassion.

By practicing good hygiene, maintaining a clean environment, and reporting early signs of infection, we ensure safety, comfort, and peace of mind for every patient and family.

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# Call Hospice First

## You Are Not Alone

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.

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## Contact Information



**Available 24/7**

**325-249-2748**



**Email Us**

[beyondhospicehpcare@gmail.com](mailto:beyondhospicehpcare@gmail.com)



**Visit Our Website**

[hospiceandbeyond.com](http://hospiceandbeyond.com)



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**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.**



## PAIN LOG

[illegible]

**Reference: Pain Scale Chart (0–10)**



[illegible]



## PAIN LOG

[illegible]

**Reference: Pain Scale Chart (0–10)**





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