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Patient and Family Guide

Hospice Care Training



EmpathHealth.org

Here for the Full Life

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A Message from Our President



As President and CEO of Empath Health, I want to extend my heartfelt gratitude to you for entrusting us with the care of your loved one. It's a privilege to be part of this journey with you, and I speak on behalf of the entire Empath team when I say that our commitment to providing compassionate, dedicated care is unwavering.

I understand that the past few days have likely brought a lot of new information your way. Transitioning to hospice care is a significant step, and we recognize that it can sometimes be a lot to process. Our goal is to support you and your loved one with clarity and compassion every step of the way. Please know that every question, observation, and concern you have is important to us. We encourage you to reach out to any member of your care team at any time—we are here for you.

Each patient's journey is unique, and so is the care we provide. Your loved one's Plan of Care is thoughtfully crafted to meet their specific needs, and we consider it an honor to walk alongside you during this precious time. While our care teams bring a wealth of experience, we fully appreciate that this may be your first experience with hospice. Our focus is on working together to meet the physical, emotional, and spiritual needs of your loved one, while also being there for you. Your expectations and hopes are central to the care we provide, and we are here to listen to and support you in every way possible.

Your feedback is invaluable to us. After our services conclude, you may receive a survey inviting you to share your thoughts on the care provided. We deeply appreciate your insights, as they help us continually improve and recognize the team members who made a difference in your journey. However, you don't have to wait for the survey—we welcome you to share your feedback at any time. At Empath Health, our mission is to honor and serve every person in our care, and your voice is vital in helping us achieve that.

Yours in Mission,

Jonathan D. Fleece
President & CEO Empath Health

Please scan the QR code to share your thoughts about the Full Life Care we provide.

Who We Are

Vision

Redefine healthcare as Full Life Care.

Mission

Unified in empathy, we serve our communities through extraordinary Full Life Care for All.

Values

At Empath Health, we hold ourselves to an intrinsic set of values that guides our everyday actions. Each, an expression of the empathy we find essential. Each, a pathway to achieving real, human connection. Each, a demonstration of our heartfelt compassion for the full lives we serve and those we serve alongside.

Eternally Hopeful

We are dedicated to being a source of inspiration in people's lives by offering renewed empowerment through choice, ongoing encouragement through positivity and personal dignity through the respect deserving of every stage in life.

Profoundly Helpful

We are here to provide unwavering support to ALL people, through every moment possible, with the same level of attention, understanding and insight fundamental to the great outcomes we strive to provide to everyone we serve.

Lovingly Truthful

We are here to offer guidance, by listening with open minds, engaging with open arms and enlightening with the genuine, open and honest communication essential to building understanding, trust and ultimately, peace of mind.

Confidently Skillful

We provide the finest quality care available by insisting on a level of medical expertise that's unrivaled, a level of excellence that's unheard of and a belief in our mission and ourselves that's undeniable.

Courageously Impactful

We always strive to make a difference in every life we touch by embracing every opportunity to advocate for people's needs, adapt to meet life's challenges and innovate to continue a history of leading healthcare forward.

When You Should Call

You may wonder when it's appropriate to reach out to your hospice team with a concern. There are several key indicators that signal it's time to call us. Even if your specific question or concern isn't listed below, please don't hesitate to reach out—day or night, weekends or holidays. We are here for you.

Here are some examples of when it's important to call:

Always Call if You

- Fall - even if minor
- Are considering going to the hospital or calling 911
- Change locations (e.g. hospital to home, nursing center to home, home to hospital, etc.)
- Are considering scheduling any doctor's appointments, treatments, or filling any prescriptions.

Difficulties With

- Breathing
- Clearing throat
- Sleeping or staying awake
- Urination
- Diarrhea, constipation or no bowel movement in three days
- Worrying

New or Increased

- Pain
- Shortness of breath
- Bleeding
- Nausea/vomiting
- Confusion
- Anxiety/restlessness
- Feelings of being sad or overwhelmed
- Fever
- Chills
- Sweating
- Coughing
- Weakness
- Skin sores/broken areas
- Swelling (e.g. legs, arms, abdomen, etc.)

Changes In

- Ability to eat or drink
- Desire to eat or drink

Have Questions Related to

- Medical equipment
- Treatments
- Expected deliveries or visits
- Advanced care planning (help with a living will, health care surrogate, etc.)
- Additional caregiving services (information on private hire, respite care, assisted living/nursing facility care)

Contact Information for Your Community Hospice Program

Empath Health's hospice programs have been dedicated to faithfully serving communities across Florida for many years. Please refer to the contact numbers below to reach the hospice team serving your area. **We are available 24/7 to support you.**

Hospice Programs	
Empath Hospice (Polk, Hardee, Highlands)	**(855) 843-3935**
Hospice of Marion County	**(352) 873-7400**
Suncoast Hospice (Pinellas County)	**(727) 467-7423**
Suncoast Hospice of Hillsborough	**(813) 651-7300**
Tidewell Hospice (Charlotte, DeSoto, Manatee, Sarasota)	**(941) 552-5900**
Trustbridge Hospice (Palm Beach and Broward)	**(888) 441-4040**
Emergency Line (All Programs)	**(888) 855-2838**

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I.
How We Can Help

Essential Information for Those Who Come to Hospice Near the End

While hospice typically provides support for six months or less, there are instances where admission occurs during more advanced stages of illness. If you find yourself in this situation, we understand that things are moving swiftly, and it's crucial to have key information right from the start.



It's important to realize that you now have a dedicated team to assist you through this challenging time, and Empath Health possesses the resources and expertise to manage distressing symptoms and ensure you receive necessary support. If you're feeling alone, sad, or in pain, don't hesitate to reach out to your hospice team for **24/7** support.

Shortly after admission to an Empath Health hospice program, you'll be assigned a nurse, a social worker, physician, certified nursing assistant, chaplain, pharmacist, therapist, grief counselor and volunteer. These team members are vital contacts who can connect you with essential resources. They aim to understand your family's needs and priorities, assisting with care setting decisions, medication and equipment deliveries, clarifying care options and expectations, and providing referrals to additional information as outlined in this guide.

Remember, you're not alone; we're here for you. Our goal is to be as present and helpful as needed, adapting to your situation to provide the support you require.

Our focus remains on hope.



Facing a Life-Limiting Illness

This guide is designed to provide you with a clear understanding of hospice care, what you can anticipate in the coming days and weeks, and how we can support both you and your family. The insights shared here are beneficial for individuals managing illness and their caregivers alike. If there's anything you'd like further clarification on or if you have questions, please don't hesitate to reach out. We are committed to being here for you.

Our focus remains on hope—hope for a fulfilling life, even amidst the challenges of serious illness.

Our Specialty Is Supporting People Through this Time in Life

Just as specialists help with allergies or broken bones, your hospice team consists of experts trained to support individuals with life-limiting illnesses. We understand that this experience is unique and can bring about many questions and concerns. It's normal to feel overwhelmed.

Remember, you have a diverse team of dedicated professionals here to help you manage the physical, social, emotional, and spiritual aspects of this journey, empowering you and your loved ones to make the most of your time together.

Living Your Full Life

At first, it may seem impossible to live a full life while dealing with serious illness. However, this time can also be filled with opportunities to experience meaning, purpose, growth, connection, joy, and peace. Empath Health is devoted to providing comprehensive care that supports your full life and helps you discover your personal sources of strength, hope, and comfort. We're here for all dimensions of your well-being and for the aspects of life most dear to you. Illness can remind us of the preciousness of life and the importance of cherishing each moment. We understand that every day is a gift.

Honoring and Respecting Who You Are and What is Important to You

Your hospice team honors and respects your individuality by actively listening to your preferences, involving you in decision-making, and tailoring care to align with your values and priorities. We are committed to ensuring everyone receives fair treatment, has equal access to quality care, and feels respected and valued. We believe that open communication and a deep understanding of your experience are crucial for fostering a trusting and collaborative relationship between you and your hospice team.

II.
Hospice Care Is Different

Your Healthcare Experience So Far – Traditional Medicine

In traditional medicine, the primary aim is to cure the illness and prolong life. This approach typically involves diagnosing and treating diseases through tests, medical and surgical interventions, and various therapies. The focus is on the disease, often employing aggressive treatments, especially for serious illnesses. Care is usually provided in hospitals, clinics, or outpatient settings, where patients often play a more passive role, following the doctor's recommendations with less involvement in decision-making. The scope of traditional medicine is generally narrower, concentrating on the physical aspects of illness without a holistic approach to the person's emotional, social, and spiritual needs.

Receiving a Life-limiting Diagnosis

When facing a life-limiting diagnosis, the primary aim shifts from cure to comfort. There are many considerations about living with the illness, its impact on your family and friends, and your faith and beliefs. Although there may not be a pathway to cure your illness, there is so much that can be done to support you and your family during this time. Choosing hospice is not about giving up; it is about focusing on the kind of care that will enable you to live your full life for as long as possible.



The Hospice Approach to Care

The approach to care at Empath Health is centered around supporting a person's full life and honoring what is most important to them, especially as they face the end-of-life. Here's how this philosophy is put into practice:

Patient-Centered Goals: Care is tailored to your preferences, values, and goals. This means respecting your decisions and wishes regarding treatment, living arrangements, and other aspects of care. You are in charge, guiding us on what is most important to you.

Holistic Approach: Our hospice provides comprehensive care that addresses not only physical symptoms but also the emotional, social, and spiritual needs of both you and your family.

Quality of Life Focus: Our primary goal is to enhance your quality of life. This includes managing pain and other distressing symptoms, providing comfort, and helping you live as fully and comfortably as possible in your remaining time.

Family Support: We extend our support to your family, offering respite care, counseling, and bereavement services to help them cope with the emotional and practical challenges of the end-of-life journey.

Choosing hospice is not about giving up.



Interdisciplinary Team: A team of professionals, including doctors, nurses, certified nurse assistants, social workers, chaplains, and volunteers, work together to provide comprehensive care tailored to your and your family's needs.

Respect for the Individual: We respect the dignity and uniqueness of each person, providing care that honors your life, beliefs, and choices.

Communication and Coordination: We maintain open communication with you and your family, ensuring you are fully informed and involved in care decisions. Our hospice team also coordinates with other healthcare providers to ensure a seamless, integrated approach.

By focusing on what's most important to you and supporting a full life in the face of a life-limiting illness, hospice helps you and your family navigate this challenging time with dignity, respect, and compassion.

III.
Beginning Your Hospice Experience: What to Expect



Being admitted into an Empath hospice program begins with a dedicated flurry of activity. Our goal is to ensure you have all the equipment, medication, and support necessary to focus on living your fullest life.

Visits from Your Care Team

During the first week, you may receive several visits from members of your care team. These visits allow us to fully assess your needs and stabilize symptoms. Together, we create a plan of care tailored to the needs, goals, and traditions of each patient and family. Future visits from hospice team members will be scheduled according to this plan. You will know whom to expect and when. Our team members are skilled, compassionate, and knowledgeable, ready to provide answers to your questions. Feel free to ask about anything on your mind.



Delivery of Medications, Equipment and Supplies

In most cases, all medications, equipment, and supplies related to your hospice diagnosis will be delivered directly to your place of residence. Medications and supplies will be replenished as needed. The purpose and use of each medication or piece of equipment will be thoroughly explained. If you aren't clear about something, please ask questions. We want to ensure you understand and are comfortable with everything provided.

We create a plan of care tailored to the needs.

Support for Caregivers

Caring for someone with a life-limiting illness can be challenging, even for those experienced in healthcare. It's natural to feel uncertain and overwhelmed at times. Please know we are here for you. The well-being of our patients and their caregivers is important to us. Share any concerns about your caregiving responsibilities and how they are impacting you. As the needs of your loved one change, we will educate and prepare you so you understand what is happening and know what to expect. If you feel sad, tired, or overwhelmed with your caregiving responsibilities, you can count on your team to provide the support and resources you need.

For those in Independent, Assisted Living or Nursing Homes

If you are living in an independent living, assisted living, or skilled nursing facility, your hospice team works closely with facility staff to provide the needed care and resources.

IV.
Who Provides Hospice Care

Your Team

Compassionate, skilled, and experienced, the members of your hospice team are dedicated to providing personalized care that honors dignity and humanity. Recognizing that everyone's needs are different, we work with you to create a customized plan of care, which is regularly reevaluated as needs change. Your individual plan of care may include the following professionals:

Physicians and Advance Practice Registered Nurses (APRN) – These professionals oversee medical and clinical decisions. When medically necessary, the physician may evaluate the patient.

Registered Nurses (RN) and Licensed Practical Nurses (LPN) - They manage the patient's care, including home visits. They provide medical care, administer medications, assess changing needs, educate caregivers, offer emotional support to the patient and family, and serve as a direct line of communication between the family and the hospice team.

Certified Nurse Assistants (CNA) - They visit the patient regularly, assisting with personal care such as bathing, skin care, dressing, and feeding. They can also assist with daily living activities and may even prepare light meals for the patient.

Social Workers - These professionals provide emotional support to patients and families, helping them navigate the challenges of serious illness. They connect patients and families with essential community resources, provide counseling services, and assist with advance directives, living wills, healthcare surrogate information, and complex billing systems.

Spiritual Care Chaplains – They offer support to people of all faiths, as well as those who do not affiliate with any faith tradition. Chaplains help you connect with your source of strength and peace, make sense of your experience, and provide a calm, caring presence. They can also help you connect with your faith community for any ritual or sacramental needs.

Providing personalized care that honors dignity and humanity.

Volunteers – Volunteers assist the patient and family in numerous ways, such as sitting with the patient to give family members a break, running errands, or even helping care for the family pet.

Therapies – Your hospice team may determine that you could benefit from additional support from therapists, including physical, occupational, speech, respiratory, and music therapists. These professionals work to ensure your symptoms are well managed, helping you live your best life under the circumstances.

Bereavement Counselor – They create a safe atmosphere where those who have experienced a loss can begin to heal and grow. Our experienced bereavement counselors provide individual and group counseling for children, teens, and adults.



V.
Helping You to Live Your Full Life: Your Plan of Care

The Driving Question: What is Most Important to You?

Hospice care at Empath Health is dedicated to helping you live your fullest life, and you are the expert on what that means for you. That's why your hospice team always asks, "What is most important to you?" Our goal is to provide the support and resources you need so that your illness doesn't prevent you from experiencing life to its fullest. We are here to ensure you can focus on what truly matters to you.



Support For Your Full Life

What does a full life look like for you? This question may require some reflection. At this time in your life, what is most important to you may have changed. Imagining what this means can help you work with your hospice team to make that vision a reality, ensuring your time is spent doing the things and being with the people that matter most to you. Here are some considerations for creating that full-life vision:

Feeling as Good Physically as You Can
Effective pain and symptom control is a priority, enabling you to engage more fully in activities you enjoy and spend quality time with family and friends without the burden of discomfort.

Processing What this Means to You
Being admitted to hospice can cause you to reflect on your life. Your hospice team helps you redefine your hopes, find new sources of meaning, and cope with your feelings.

Being Supported by Family and Friends
Share with your hospice team the family members and friends who are closest to you, so we can support their involvement. Your social worker and chaplain can also help address relationships where there may be challenges or a need for healing or reconciliation.



Having Peace of Mind and Feeling Connected Spiritually
Whether you are religious or not, living with life-limiting illness can be frightening and isolating. It's important to draw on inner resources to feel more peaceful and connected. Your chaplain is here to walk alongside you and help connect you with what brings you meaning and comfort.

Engaging in Meaningful Activities
Participate in activities that bring joy and meaning, whether it's listening to favorite music, enjoying nature, or spending time with family and friends.

Making Sure Nothing is Left Undone or Unsaid
This is an opportunity to reflect on your roles and relationships and ensure you feel a sense of resolution and closure.

Here to ensure you can focus on what truly matters to you.

Creating and updating your Plan of Care

Your Plan of Care is a personalized outline designed to support your physical, emotional, social, and spiritual needs. It is created through conversations with your nurse, social worker, and chaplain, all of whom take their direction from you. This plan will evolve and adapt as your circumstances change. When you achieve a goal or identify a new priority, continue to communicate with your team so your Plan of Care always reflects the support you need.

After the first week, the plan of care may start to feel routine, at least for a while. It will change as your needs change. Since everyone's journey is unique, no one can say for certain what's to come. However, we can say the moments remaining hold many opportunities to share memories, make amends, deepen relationships, express love and hope, and simply be together. We can also say for certain that your hospice team will be with you every step of the way, bringing hope for a fulfilling life even as the journey nears completion.

VI.
Making Sure Your Wishes Are Honored

As your illness progresses, there may come a time when you no longer have the energy or focus to make all the decisions about your care. To ensure your wishes are respected and honored, it's important to communicate them clearly to your family and your hospice team. At Empath Health, we recognize your fundamental right to make informed decisions about your healthcare, including the right to choose or refuse treatment or services.



Advance Directives

Advance directives are legal documents that outline your preferences for medical care. These documents serve as a guide for healthcare providers, family, and friends who are caring for you, ensuring that your preferences are respected at every stage of your illness. Examples include:

- Living Will
- Health Care Surrogate
- Durable Power of Attorney for Health Care
- Do Not Resuscitate Order

Importance of Advance Directives

Advance directives are an essential component of healthcare planning because they provide clarity and guidance during challenging times. They help ensure your healthcare preferences are known and honored, reduce the burden on family members by making your wishes clear, and assist healthcare providers in delivering care that aligns with your values and desires.

Legal Requirements and Implementation

While no one is required to prepare advance directives, all healthcare providers in Florida are mandated by law to make patients and families aware of them. Empath Health supports your right to make treatment choices that are right for you. All advance directives must be fully executed (complete with signatures, dates, and appropriate court stamps as applicable) for Empath Health to honor and follow them. Copies of these documents are required to be placed in your medical record.

Advance directives can be revoked or amended by you at any time, as long as you have decisional capacity. Documentation of any changes must be obtained and placed in your medical record. It is the responsibility of you and/or your family to inform Empath Health of any changes to ensure your medical record reflects your current wishes. An advance directive executed in another state in compliance with the law of that state or of Florida is valid and will be honored in Florida.

Empath Health is here to support you in making treatment choices that honor your wishes and provide peace of mind for you and your loved ones.

Living Will

A living will is a legal document or verbal statement outlining your care preferences if you can no longer communicate your healthcare wishes and are suffering from an end-stage condition, a terminal condition, or are in a persistent vegetative state. A living will can:

- Indicate a health care surrogate, a person to carry out your wishes.
- Clarify the types of life-prolonging procedures you desire or do not desire, including the circumstances under which procedures should be chosen, withheld, or withdrawn.
- Discuss other important issues to you, such as the role of religious preferences in end-of-life decisions.

A living will should be signed, dated, and witnessed by two people, one of whom is neither a spouse nor a blood relative. Discuss your wishes with family and your personal physician so your living will can become a part of your permanent medical record. Florida law does not require an attorney to draft a living will, nor does it require notarization.

Empath Health supports your right to make treatment choices that are right for you

We understand the importance of informed decision-making in healthcare



Designation of Healthcare Surrogate

A designation of health care surrogate is a document that names another person as your representative to make healthcare decisions and receive health information when you are unable to do so. You may specify whether the authority of the health care surrogate is exercisable immediately, without the necessity for a determination of incapacity, or only upon such a determination. You can also include instructions about any treatment you do or do not want and designate an alternate surrogate.

Durable Power of Attorney for Health Care

Similar to the designation of health care surrogate, the Durable Power of Attorney for Health Care allows you to appoint another person to make healthcare decisions on your behalf when you are unable to do so. Either the designation of a health care surrogate or the durable power of attorney for healthcare is required to identify who will make these decisions for you.

Do Not Resuscitate Order

A Do Not Resuscitate Order (DNR or DNRO) is a doctor's order instructing paramedics and emergency room doctors not to perform CPR in the event of cardiac or respiratory arrest. DNRs are typically used by individuals with an end-stage disease, terminal condition, or in a persistent vegetative state. The DNR must be printed on yellow paper, as required by the Florida Department of Health. DNRs printed on any other color, even if using the exact form from the Florida Department of Health, may not be honored by paramedics or emergency medical personnel.

Empath Health is committed to empowering patients and families with comprehensive information, resources, and support regarding advance care planning. We understand the importance of informed decision-making in healthcare and are dedicated to ensuring that every individual we serve has access to the necessary tools and support to make their preferences known. As you consider your options for treatment and care, your care team can connect you with staff and resources to help you share what is most important.

Hard Choices for Loving People

The compassionate guide, *Hard Choices for Loving People,* assists patients and families with end-of-life medical decisions. Topics covered include:

- **Setting Goals for Medical Care:** Thoughtfully considering your healthcare goals before making decisions.
- **Common Medical Treatment Decisions:** Understanding options for treatments such as CPR, feeding tubes, dialysis, pacemakers, and more.
- **Emotional and Spiritual Concerns:** Addressing the emotional and spiritual aspects of end-of-life care for people of any faith tradition or none at all.

This guide is designed to provide clarity and comfort, helping you navigate these challenging decisions with compassion and understanding.

VII.
When The End Draws Near

This chapter provides insights into what to expect as illness progresses and death approaches. Having this knowledge can help both the person receiving care and their caregivers feel more prepared, normalizing aspects of the process that may seem unfamiliar. Reviewing this information with your nurse, social worker, or chaplain can offer additional support and answer any questions you might have.

Approaching death is an intensely personal and unique experience that varies greatly from one individual to another. People often die as they have lived—reflecting their personal values, attitudes, and the essence of who they are. The process of dying, much like living, is influenced by an individual's personality, life experiences, and coping mechanisms. Some may face their final days with acceptance and tranquility, while others may struggle with fear and unresolved issues.

Understanding this can help us approach the end-of-life journey with empathy, respect, and an open heart, recognizing the individual needs and wishes of the dying person. It underscores the importance of providing personalized care and support that honors the person's life and legacy, allowing for a death that is as meaningful and peaceful as possible.

As a person nears the end of their life, it can be a profoundly emotional and challenging time for both the patient and their family members. Understanding what to expect can provide some measure of comfort and preparation for what lies ahead. Here is a brief overview of what families might expect during this time.





Physical Changes: As a person nears the end of their life, their body will undergo several physical changes. These can include increased sleepiness, changes in breathing patterns, decreased appetite and fluid intake, and a gradual decline in bodily functions. The skin may become cooler and paler, and the person may experience periods of confusion or disorientation.

Emotional and Spiritual Responses: It is not uncommon for individuals to experience a wide range of emotions as they approach the end of their life, including fear, anger, sadness, or acceptance. Some may wish to discuss their life, legacy, or beliefs about what comes after death. These conversations can be important for both the patient and their families, providing a chance for closure and peace.

Care Needs: As the body weakens, the need for care increases. This may involve help with daily activities, managing symptoms and pain, and providing emotional support. Hospice services can be invaluable during this time, offering medical, emotional, and spiritual support tailored to the patient's needs and wishes.

Communication: Open and honest communication between the patient, family members, and healthcare providers is crucial. Discussing preferences for end-of-life care, including any measures the patient does or does not want to prolong life, ensures that the patient's wishes are respected and can help reduce stress and uncertainty for everyone involved.

Saying Goodbye: As difficult as it may be, saying goodbye is an important step. It provides an opportunity for everyone to express their love, forgiveness, and final wishes. These moments can be deeply meaningful and provide comfort to both the patient and their family.

After Death: Following the death of a family member, there will be practical matters to address, such as funeral arrangements and managing the person's estate. Grieving is a deeply personal process, and everyone experiences it differently. It is important for family members to allow themselves to grieve and to seek support when needed.

Empath Health is here to support you through every stage of this journey, ensuring that your loved one's final days are filled with dignity, compassion, and respect.

Food and Fluids

Navigating the final days of a person's life is never easy, but understanding what to expect can help families provide comfort, make informed decisions, and cherish the time they have left together.

When someone you are caring for is nearing the end of their life, the instinct to nurture and provide comfort through food and fluids is a natural response. However, the process of dying is fundamentally different from other stages of illness, and the body's ability to process food and fluids changes significantly as organ function declines. As difficult as it may be to witness, this shift is a natural part of the dying process.

In the final stages of life, the body's systems begin to shut down, and the need for food and fluids decreases. The digestive system slows, making it difficult for the body to process foods and liquids. Providing food and fluids can sometimes cause discomfort, such as nausea, bloating, and respiratory problems if fluids accumulate in the lungs.

Healthcare professionals often focus on ensuring the comfort of the dying person, which might mean shifting from trying to nourish the body to providing mouth care and keeping the lips and mouth moist. This approach is based on the understanding that forcing food or fluids can lead to discomfort and is not beneficial in the final stages of life.

It is important for families to discuss these issues with healthcare providers, who can offer guidance on the best ways to support the patient's comfort during this time. Your hospice team is particularly skilled in managing the symptoms and challenges arising at the end-of-life, including decisions about nutrition and hydration. They can provide valuable support and information to help families navigate these complex and emotional decisions, ensuring the focus remains on the quality of life and dignity of the individual.

Our bodies possess intrinsic knowledge and capability to manage their needs at various stages of life. As individuals approach the end of their life, bodily functions begin to decline, and the need for sustenance decreases. Understanding this natural progression towards the end-of-life can help caregivers make compassionate care decisions that honor the natural process of dying. It emphasizes the importance of palliative care in providing dignity and comfort, supporting the body's natural journey in its final stages.

Restlessness and Agitation

Restlessness and agitation at the end-of-life, often referred to as terminal restlessness or terminal agitation, is a common phenomenon that can be distressing for both the patient and caregivers. It is characterized by symptoms such as physical restlessness, emotional distress, confusion, and sometimes agitation or aggression. Several factors can contribute to restlessness and agitation at the end-of-life, including:

- **Physical Discomfort:** Pain, constipation, urinary retention, or other physical ailments can lead to restlessness.
- **Medication Side Effects:** Reactions to or withdrawal from medications may cause agitation.
- **Metabolic Imbalances:** Changes in electrolyte levels, dehydration, or kidney failure can lead to confusion and restlessness.
- **Neurological Factors:** Brain metastases, strokes, or other neurological changes can cause disorientation and agitation.
- **Psychological Factors:** Anxiety, depression, or unresolved emotional issues can manifest as restlessness.

Understanding that restlessness and agitation can be part of the dying process is crucial for caregivers. It is important to approach these situations with compassion, patience, and understanding. Management strategies often focus on identifying and treating any reversible causes, such as pain, urinary retention, or constipation, and ensuring the patient's environment is calm, comfortable, and familiar.

Non-medication approaches, such as providing reassurance, reducing environmental stimuli, and using gentle touch or soothing music, can be very effective. In some cases, medication may be necessary to relieve distress and ensure comfort. Your hospice care team can offer guidance and support in managing these symptoms effectively.

Our team of experienced professionals works collaboratively to assess and address the unique needs of each patient experiencing terminal agitation. We prioritize a holistic approach, considering physical, emotional, and spiritual factors that may contribute to a patient's distress. By focusing on the overall well-being of the patient, we strive to provide a peaceful and comforting environment during this challenging time.

We strive to provide a peaceful and comforting environment

Secretions

Terminal secretions, often referred to as the "death rattle," describe the sound that sometimes occurs when a person is near death, typically in the last hours or days of life. This sound is caused by the accumulation of secretions in the throat and airways, as the individual is no longer able to effectively swallow or clear these secretions due to a decrease in reflexive actions as the body prepares for death.

Characteristics of Terminal Secretions:

- **Sound:** The sound can vary but is often described as a gurgling, rattling, or crackling noise heard during breathing when air passes through the accumulated secretions.
- **Timing**: It tends to occur in the final hours or days of life and can last for varying amounts of time.
- **Consciousness**: Typically, the person experiencing the death rattle is not conscious or aware of the sound, and it is believed not to cause them discomfort. However, it can be distressing for family members and caregivers to hear.

Management Strategies

The primary goal in managing terminal secretions is to ensure comfort for the dying person and provide support and reassurance to family members and caregivers. Here are some strategies:

- **Positioning:** Gently repositioning the person, such as turning their head to the side or elevating the head of the bed, can help facilitate the drainage of secretions.
- **Medications:** Anticholinergic medications can be administered to reduce the production of secretions, thereby decreasing the noise.
- **Suctioning:** While sometimes considered, suctioning is generally avoided as it can be invasive and uncomfortable, and it may not be effective in reducing the sound.
- **Hydration:** Managing the intake of fluids can be considered to decrease the production of secretions, but this is approached with care to ensure the comfort of the individual.

At Empath, our team is dedicated to ensuring the comfort and dignity of your loved one during this time. We provide compassionate support and practical solutions to help manage terminal secretions, allowing families to focus on being present and cherishing their remaining moments together.



Withdrawal

Withdrawal at the end-of-life is not just a physical decline but also a decrease in social interaction and interest in activities once enjoyed. This process is a natural part of the dying experience, reflecting both the body's diminishing energy reserves and an inward focus on the psychological and spiritual aspects of transitioning from life to death.

During this time, individuals may speak less, show little interest in communicating, and prefer solitude or the presence of only a few close family members or friends. This withdrawal can also manifest as a reduced interest in food and drink, as their body begins to conserve energy and prepare for the final stages of life. It is as if the person is gradually letting go of the physical world to focus on their inner experience, which can be a deeply personal and introspective process.

For caregivers, observing this withdrawal can be challenging, evoking feelings of sadness, helplessness, and grief. However, understanding that this behavior is a normal part of the dying process can help provide the right support. It is important to respect the dying person's need for peace and quiet, offering comfort through presence, touch, and words of love and reassurance, even if the response is limited. This respectful acknowledgment of their need to withdraw can be an invaluable gift of love and understanding in their final days.

At Empath, we recognize the importance of supporting both the individual and their loved ones during this deeply personal time. Our team is here to offer guidance, compassion, and reassurance, ensuring that the final stages of life are met with dignity and peace.

Emotional and Spiritual Response

At the end-of-life, individuals often embark on a profound and deeply personal journey that encompasses a range of emotional and spiritual responses. This period can bring about a reflective review of one's life, evoking feelings of peace, acceptance, regret, or a desire for reconciliation. Some may find comfort in their faith or spiritual beliefs, seeing this time as a transition to an afterlife or a return to the spiritual essence of the universe. Others may grapple with existential questions, seeking meaning and purpose in their life experiences and relationships.

Emotional responses can vary widely from person to person, influenced by their life history, relationships, spiritual beliefs, and their process of coming to terms with mortality. It is not uncommon for individuals to express a need to resolve unfinished business, make amends, express forgiveness, or share love and gratitude with those close to them. These interactions can be deeply healing for both the dying person and their family, offering a sense of closure and peace.

Spiritually, this time may be marked by a deepening of faith for some, while others may question their beliefs or find new spiritual understanding. Spiritual care, including support from faith leaders, chaplains, or spiritual counselors, can provide immense comfort, allowing individuals to explore these thoughts and feelings in a safe and supportive environment.

Recognizing and honoring this emotional and spiritual journey is crucial for family members and friends. Offering presence, listening with empathy, and providing support through this deeply personal transition underscores the importance of dignity, respect, and compassion, affirming the individual's experiences and feelings as they navigate this final phase of life.

Empath Health believes that supporting the emotional and spiritual well-being of someone at the end-of-life is crucial. Our social workers and chaplains can support you through:

- **Active Listening:** Offering a compassionate ear, allowing the person to express fears, hopes, and reflections without judgment.
- **Spiritual Care:** Engaging spiritual care providers, like chaplains or spiritual counselors, who can offer guidance and support in line with the person's beliefs.
- **Creating Legacy Projects:** Helping the individual create something meaningful, like a video, letter, or art project, can provide comfort to both the person dying and their family and friends.
- **Encouraging Open Conversations:** Facilitating discussions about feelings, beliefs, and end-of-life wishes can provide emotional relief and ensure that the person's values are respected.

Empath is committed to providing comprehensive support that honors the emotional and spiritual journey of each individual, ensuring that their final days are filled with peace, dignity, and meaningful connection.

Dream-Like Experiences

Dream-like experiences at the end-of-life, often referred to as end-of-life dreams and visions (ELDVs), are phenomena that many individuals encounter as they approach death. These experiences can include vivid dreams, visions of deceased loved ones, or seeing places others cannot. Research and anecdotal evidence suggest that ELDVs are relatively common and can hold significant meaning for the dying person, often providing comfort, reassurance, and a sense of peace or reconciliation with approaching death.

Characteristics of End-of-Life Dreams and Visions:

- **Content:** The content of these dreams and visions can vary widely but often includes reunions with deceased loved ones, seeing religious figures, or reliving meaningful life events.
- **Realness:** Many people describe these experiences as exceptionally vivid and more real than a typical dream.
- **Timing:** ELDVs tend to occur more frequently as death approaches and can happen while the individual is awake, half-asleep, or in a state in between.
- **Emotional Impact:** These experiences often have a profound emotional impact, providing comfort, easing fear of death, and helping to reconcile unresolved issues.



The interpretation of ELDVs can vary greatly depending on cultural, religious, and personal beliefs. For some, these experiences are seen as spiritual or religious occurrences, offering evidence of an afterlife or a transition to another existence. For others, they may be understood in psychological terms, as a way for the mind to process the end-of-life and find peace.

Regardless of the interpretation, the significance of ELDVs in providing comfort and meaning to the dying process cannot be understated. These experiences can help individuals feel less isolated by reaffirming connections with loved ones who have passed away or by providing a sense of being loved and supported as they approach death.

Supporting Individuals Experiencing ELDVs:

- **Listening Openly:** Encourage sharing these experiences without judgment or dismissal. Acknowledging the reality and importance of these experiences for the individual is key.
- **Providing Reassurance:** Reassure them that these experiences are common and can be a meaningful part of the dying process.
- **Facilitating Comfort:** Ensuring that they feel safe and comfortable sharing their experiences can help them process and find meaning in their ELDVs.
- **Documenting Experiences:** For those interested, documenting these dreams and visions can be valuable for the individual and their families, offering comfort and memories to cherish.

Understanding and respecting the significance of end-of-life dreams and visions is an important aspect of providing holistic care at the end-of-life. Recognizing these experiences as meaningful and potentially beneficial can enhance the quality of care and support given to individuals as they approach the end of their lives. At Empath Health, we are committed to honoring these experiences and providing compassionate care that embraces the full spectrum of the human experience.



Caregiver Role

The role of a caregiver at the end-of-life is both profoundly important and deeply challenging, encompassing a wide spectrum of responsibilities that cater to the physical, emotional, and spiritual needs of the dying person. Caregivers often provide day-to-day care, manage medication, assist with mobility, and ensure comfort through pain management and symptom relief. Beyond these tangible tasks, perhaps their most significant role lies in offering emotional support—being present, listening, and providing companionship during this vulnerable time.

Caregivers also function as advocates, navigating the healthcare system, communicating with medical professionals, and making critical decisions that align with the dying person's wishes and values. They play a crucial part in creating a peaceful environment, one that respects the preferences and dignity of the person nearing the end of their life.

The emotional toll on caregivers cannot be understated. They may experience a range of emotions, including grief, sadness, frustration, and exhaustion, often while trying to balance their own life's demands. Support for caregivers is vital, including access to respite care, counseling, and support groups, to help them manage the stress and emotional burden of caregiving.

Ultimately, caregivers at the end-of-life provide a bridge between the medical and the personal, ensuring the final days of the dying person are as comfortable and meaningful as possible. Their role is a testament to the strength of human connection, compassion, and the profound impact of providing care and comfort at life's end.

Empath and your care team support our caregivers through providing:

Emotional Support:

- **Peer Support Groups:** Joining a support group offers caregivers a sense of community, understanding, and shared experience that is invaluable.
- **Counseling:** Hospice social work and counseling services can help caregivers process their feelings, cope with stress, and navigate the complexities of grief and loss.
- **Respite Care:** Taking regular breaks is essential. Respite care services can provide temporary relief, allowing caregivers to rest and recharge. Ask your care team about the respite benefit available through the Hospice Medicare Benefit.

Educational Support:

- **End-of-Life Care Training:** Our RNs can provide training and education about what to expect and how to manage symptoms, empowering caregivers to feel more competent and confident in their role.
- **Resource Information:** Access to information about the practical aspects of caregiving, such as managing medications, nutritional support, and understanding legal and financial issues, is crucial.

Physical Support:

- **Certified Nursing Assistant Services:** CNAs can assist with the physical demands of caregiving, such as bathing, dressing, and mobility.
- **Medical Equipment and Supplies:** Ensuring caregivers have the necessary equipment and supplies to provide care safely and effectively is important.



Social Support:

- **Community Resources:** Our social workers and counselors can refer and connect you with local community resources, such as meal delivery services, transportation assistance, and volunteer help, to alleviate some of the logistical burdens on caregivers.
- **Family and Friends:** A network of family and friends who can share in caregiving responsibilities, offer emotional support, or simply provide a listening ear is invaluable.

At Empath, we recognize the immense dedication and love that caregivers provide, and we are committed to supporting them every step of the way. Our goal is to ensure that caregivers have the resources, support, and respite they need to continue their vital role with strength and compassion.

Identifying Caregiver Burnout

Caregiver burnout is a state of physical, emotional, and mental exhaustion that can occur when caring for a loved one becomes overwhelming. Recognizing the signs is crucial for taking proactive steps to address it. Symptoms may include:

- **Feeling Overwhelmed or Constantly Worried:** Persistent anxiety about caregiving tasks and the well-being of your loved one.
- **Feeling Tired Most of the Time:** Chronic fatigue that doesn't improve with rest.
- **Changes in Sleep Patterns:** Difficulty falling asleep, staying asleep, or sleeping too much.
- **Significant Weight Changes:** Gaining or losing a substantial amount of weight without trying.
- **Loss of Interest in Activities:** No longer finding joy in activities that were once enjoyable.
- **Irritability or Anger:** Becoming easily frustrated or angry, even over small things.
- **Feelings of Sadness or Hopelessness:** Persistent feelings of sadness, depression, or a sense of hopelessness.
- **Physical Symptoms:** Experiencing headaches, stomachaches, or other chronic pains without a clear medical cause.

Utilizing hospice support as a caregiver is a critical step in ensuring both the patient's and your own well-being during the end-of-life journey. Engaging with hospice means you are not alone; you have a team of compassionate professionals by your side, offering support, guidance, and care every step of the way. It is about ensuring the best possible quality of life for the patient while also taking care of yourself as a caregiver.

How Empath Can Help:

- **Emotional Support:** Access to counseling and support groups to help process feelings and cope with stress.
- **Respite Care:** Temporary relief services that allow caregivers to rest and recharge.
- **Educational Resources:** Training and information on managing symptoms, medications, and other caregiving tasks.
- **Physical Support:** Assistance with daily activities and access to necessary medical equipment and supplies.
- **Community Connections:** Referrals to local resources such as meal delivery services, transportation assistance, and volunteer help.

We understand the challenges of caregiving and are dedicated to providing the support you need to continue your vital role with strength and compassion. Recognizing and addressing caregiver burnout is essential for maintaining your health and well-being, allowing you to provide the best possible care for your loved one.



Saying Goodbye

Saying goodbye to someone at the end-of-life is one of the most profound and emotional experiences anyone can go through. It involves confronting the reality of loss while expressing love, forgiveness, gratitude, and sometimes unresolved feelings. Here are some considerations and approaches to help navigate this difficult time:

Express Your Feelings:

- **Love and Appreciation:** Share how much they mean to you. Reminisce about cherished memories, express gratitude for the time spent together, and acknowledge the impact they have had on your life. This can be comforting for both of you.
- **Forgiveness:** This can be a time for forgiveness around any unresolved issues. Apologizing or offering forgiveness for past conflicts can bring peace to both parties.
- **Goodbye:** Saying goodbye is a deeply personal moment. It doesn't have to be elaborate; it needs to be sincere. For some, it might simply be saying, "I love you, goodbye."

Be Present:

- **Physical Presence:** If possible, being physically present can be very comforting. Holding hands, gentle touch, or just sitting quietly next to them can convey support and love.
- **Virtual Presence:** If you cannot be there physically, sending a letter, recording a message, or arranging a video call with the help of caregivers can also be meaningful.

Include Others:

- **Family and Friends:** Encourage other family members and friends to share their goodbyes and expressions of love. This can be coordinated to ensure it is not overwhelming for the patient.
- **Children and Grandchildren:** Drawings or letters from children and grandchildren can add a layer of personal and heartfelt sentiment.

Use Music or Readings:

- **Favorite Music:** Playing their favorite pieces of music can create a soothing atmosphere.
- **Cherished Readings:** Reading passages from beloved books or sharing poems can be a meaningful way to connect, especially when words are hard to find.

Spiritual or Religious Rites:

- **Engage in Rituals:** If the patient is spiritual or religious, participating in prayers, rituals, or other spiritual practices they value can be comforting and meaningful.

Create a Peaceful Environment:

- **Serene Atmosphere:** Make the space around the patient peaceful and comforting. Soft lighting, comfortable bedding, and minimizing any distressing noise can help create a serene environment.



Saying goodbye is an act of love and courage

Seek Support:

- **Emotional Support:** Saying goodbye is emotionally taxing. Lean on friends, family, or professional support to process your feelings. Bereavement groups, counselors, or spiritual advisors can offer guidance and support during this time.

Remember, it is Your Goodbye:

- **Personal Process:** There is no right or wrong way to say goodbye. It is a deeply personal process that reflects your relationship with the person who is dying. Trust your instincts about what feels right for you and them.

Saying goodbye is an act of love and courage. It acknowledges the importance of your relationship and the difficulty of parting. While it is heart-wrenching, it can also be a moment of profound connection, offering solace and peace to all as you navigate this final journey together. We are here to support you through every step of this journey, ensuring that your goodbyes are as meaningful and comforting as possible.

The Rally

An energy surge at the end-of-life, often referred to as "terminal lucidity" or a "rally" before death, is a phenomenon where patients with severe, chronic, or terminal illnesses experience a temporary improvement in physical and cognitive abilities. This unexpected change can include increased energy, clarity of mind, and emotional expression, typically occurring days or hours before death. Contributing factors include:

- **Physiological Changes:** Some researchers speculate that changes in the body's metabolism or alterations in brain function as the body prepares for death might temporarily improve symptoms or cognitive function.
- **Medication Adjustments:** Changes in medication regimes, either intentional reductions or the body's decreased ability to metabolize drugs, may lead to a temporary improvement in symptoms.
- **Psychological and Spiritual Factors:** Psychological or spiritual factors may play a role, with individuals mustering their remaining energy for a final goodbye or to resolve unfinished business.

Observations and Effects:

- **Improved Interaction:** Patients may become more interactive, wanting to talk with family and friends, share memories, or express thoughts and feelings they were previously unable to articulate.
- **Emotional Closeness:** This period can be precious for loved ones, offering an unexpected opportunity for closure, reconciliation, and expressing love and forgiveness.
- **Increased Physical Activity:** Some individuals may show a surprising surge in physical energy, asking for food after days of little or no intake, sitting up in bed, or even attempting to get out of bed.



Preparing for and Responding to an Energy Surge:

- **Embrace the Moment:** Recognize this time as a potential gift, but also prepare emotionally for the likelihood that it is a sign of impending death.
- **Express Love and Forgiveness:** Use this time for meaningful conversations, expressing love, forgiveness, and saying goodbye.
- **Document Wishes:** If the patient is lucid and has not previously been able to express their end-of-life wishes, this may be an opportunity to discuss and document their preferences.
- **Seek Support:** Healthcare professionals, including hospice and palliative care teams, can provide guidance on navigating this period and offer support for both the patient and family members.

It is important to understand that an energy surge does not necessarily indicate a turn toward recovery but rather is a common part of the dying process. Embracing this time can provide comfort and closure for both the patient and their families.

The most important thing is to create a peaceful, soothing atmosphere

When Death Occurs

We cannot predict the exact moment of death. People can hover between life and death for hours or even days, and it is easy to miss the final moment. Some individuals may choose to die when no one else is in the room, possibly due to their private nature or a desire to spare their families distress. Others might wait for a specific person to arrive or for a meaningful date to pass. The most important thing is to create a peaceful, soothing atmosphere and to express everything you want them to know, even if they cannot respond.

Have a Plan Before the Death Occurs:

- **Choose a Funeral Home in Advance:** Provide the name to the hospice nurse, social worker, or chaplain to make things easier when the time comes.
- **Consider Making Arrangements in Advance:** It is better to make choices at a less stressful time than at the last minute. Your hospice social worker or chaplain can guide and assist you.
- **Make a List of People to Notify:** Include their phone numbers.
- **Consider Writing an Obituary:** If you wish to have one published.
- **Locate Important Papers:** Such as insurance, investments, etc.

When death occurs, it happens quickly. Even if you have never been present at a death, you will likely recognize the moment. Sometimes, the person will give several outward breaths as the heart and lungs stop. Others may give one long exhale followed by a long pause before another intake of breath, which may be repeated several times before breathing stops entirely.

Indicators of death may include:

- No pulse (heartbeat).
- No breathing.
- No response to voice or touch.
- Skin tone may become pale or waxy.
- Facial expression may change or loosen and eyes may remain open.

At the Time of Death:

Your Empath Health hospice team is here to assist you.

- **Do Not Call 911 or the Police:** Our nurses have the authority to pronounce death.

Your Hospice Team Will:

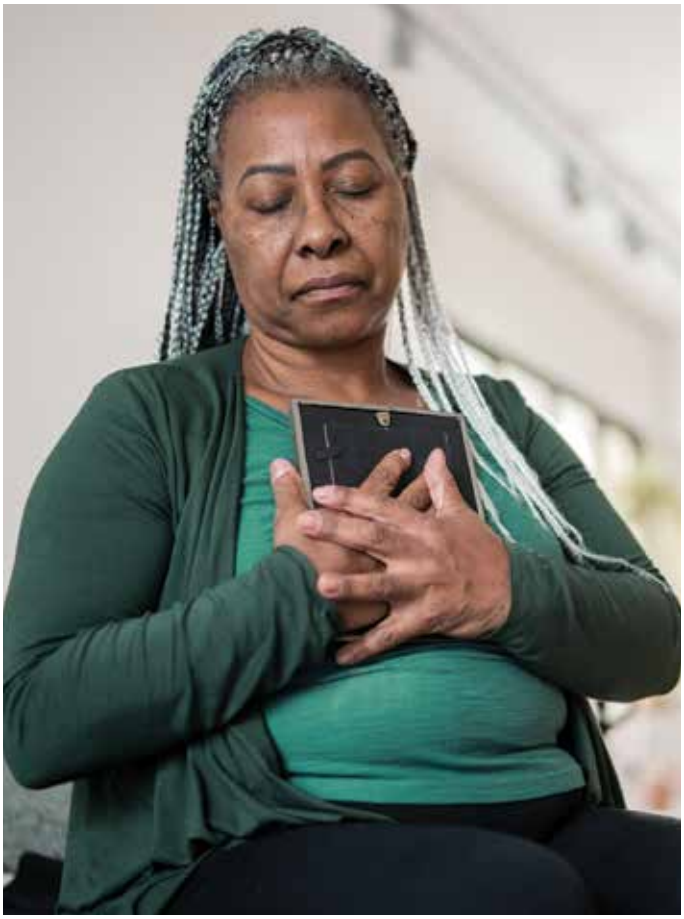
- Notify the physician.
- Contact the funeral home.
- Provide needed support.
- Arrange to have equipment picked up.

It is advisable to lower the head and foot of the bed to a flat position. If you would like to provide personal care, such as washing and dressing the body before the funeral home arrives, you may do so with assistance from your hospice team.

We hope that your hospice care team, along with the information in this guide, eases some of the uncertainty and anxiety about dying. Know we are here for you whenever needed. Our goal is to support you throughout this journey.

VIII.
Support for Grieving Family & Friends

At Empath Health, we are deeply committed to walking alongside those who are grieving, offering the support, resources, and compassion needed to navigate the journey of loss. We believe in the resilience of the human spirit and the capacity for healing, even in the face of profound sorrow, and we are here to support individuals in finding their path.



You Are Already Grieving:

A common misconception is that grieving only begins after someone we care about dies. In reality, grieving starts at the moment you receive a life-limiting diagnosis. There is always hope that the person who is sick will defy the odds and live longer than expected. However, this is also when we begin to anticipate not only the final loss at the time of death but also all the losses that occur along the way as the illness progresses. Both the person receiving the diagnosis and those who care for them experience anticipatory grief as part of this journey.

Grief is Different for Everyone:

Another misconception is that there is a right and a wrong way to grieve. You may think grief must be expressed with tears and deep sadness, or that it is never appropriate to laugh or feel joy. The way we experience and express our grief is also shaped by our family and culture.

You might not feel tearful when others do, or you may find yourself crying all the time. You may feel uncomfortable with public displays of emotion or still feel broken and vulnerable long after others expect you to resume normal activities. It's important to remember that your experience of grief is unique. While loss is something we all share, how we grieve is deeply personal.

Allow Yourself to Feel Your Grief:

There is often a tendency to push grief away or ignore it, hoping it will disappear. This only prolongs the grieving process, and feelings kept inside can burst through in unpredictable and sometimes unhealthy ways. As difficult as it may be, we need to feel our feelings and give ourselves time to come to terms with what they mean for us.

Empath Health offers support to help you navigate these emotions and find your way through grief. We provide:

- **Counseling and Support Groups:** Professional counseling and peer support groups can provide a safe space to express your feelings and connect with others who understand what you're going through.
- **Educational Resources:** Information and resources to help you understand the grieving process and find healthy ways to cope.
- **Community Connections:** Links to community resources and services that can offer additional support.

Grieving is a natural and necessary process, and we are here to support you every step of the way. At Empath, we honor your unique journey through grief and offer our heartfelt compassion and care.

You Do Not Have to Carry This Alone

Grief can feel incredibly isolating, especially when those around you don't share your circumstances. It might seem like no one truly understands what you're going through. However, you don't have to bear this burden alone. Your hospice team is here to connect you with resources and support. Talking to people who understand and appreciate your experience can provide invaluable comfort. Our Empath hospice bereavement services are designed to help you cope with and integrate your feelings of grief, ensuring you have the support you need every step of the way.

Empath Hospice Bereavement Services Include:

- **Individual Counseling:** The social worker/counselor on your team is someone you can talk to and share your feelings with throughout your hospice journey. After the death occurs, bereavement counselors can provide individual counseling support for up to 13 months.
- **Support Groups:** There are few things more affirming and helpful than being with others who have gone through similar experiences and are dealing with similar challenges. Your hospice offers ongoing support groups for grieving individuals. It can be validating and healing to hear each other's stories and support one another through difficult times.

- **Phone Calls & Mailings:** Your hospice team will periodically check in to see how you are doing. Use these check-ins as an opportunity to pause, remember, reflect, and reach out if there is something we can do to support you. You will also receive periodic mailings with information on support groups, memorial services, and other resources to assist you on your healing journey.

The Importance of Closure Rituals

Your decisions about funerals and memorial services may be influenced by your faith community. If you are not part of a faith community, there is still immense value in marking this milestone in a meaningful way. Your hospice team includes spiritual care chaplains who can assist families in creating gatherings and services to honor and remember the deceased in ways that are significant to you. The simple act of gathering, remembering, and honoring is a powerful part of the healing process.

Other activities can also promote a sense of closure. You may want to write a letter to the deceased if there are things you still need to express. Visiting a place that was significant to them, sitting quietly, or setting a place for them at a family gathering to share cherished memories can be very meaningful. Your hospice counselor and chaplain can be a great resource for finding ways to honor and remember your loved one.

At Empath Health, we are committed to walking alongside you through your grief, offering the support, resources, and compassion you need to navigate this difficult journey. You do not have to carry this alone—we are here for you.

Support for Grieving Children

Children need clear, simple, and honest answers to help them cope with loss and grief. They thrive when given information and support appropriate for their age and development. Too much information can confuse them and create anxiety. It's important to ask children questions to determine what they already know or believe and to encourage open dialogue.

Begin at the Child's Level:

- **Understand Developmental Stages:** Be aware of the child's developmental level and how it affects their reasoning and understanding.
- **Tell the Truth:** Honesty fosters trust and security. Involving children in the situation and letting them know what is happening can be very supportive and lead to improved coping skills.

Be Guided by the Child's Questions:

- **Create a Safe Environment:** Ensure the child feels safe and secure to ask questions.
- **Clarify Questions:** Take time to understand what the child is asking.
- **Express Feelings:** Provide opportunities for the child to express their feelings.
- **Encourage Emotional Expression:** Help the child identify and express feelings related to the death, memories of loved ones, and hopes for the future.

Encourage Feedback:

- **Develop a Plan:** Ensure the child's needs are met.
- **Maintain Routine:** Keep the child's daily routine as normal as possible.
- **Provide Reassurance:** Children need love, care, honesty, consistency, and structure.
- **Dedicated Time:** Set aside uninterrupted time to listen to the child and reassure them that you have plenty of time for their concerns.

There are many creative ways to help children express their feelings. Most children respond positively to warm, loving adults who listen to their feelings and provide a safe, nurturing environment.

Creative Methods for Expression:

- **Books and Storytelling:** Use literature to help children understand different endings to stories, including those specific to death and dying.
- **Art:** Encourage children to draw pictures that express their feelings, such as how they are feeling now, their family, or the funeral.
- **Music and Puppetry:** These can help children retell their story, particularly useful with young children.

Additional Tips:

- **Ask and Listen:** Ask children what they know and what they want to know. Don't assume.
- **Be Honest:** Be truthful about the reasons for your tears and sadness.
- **Focus on Reality:** Children's vivid imaginations can create answers far worse than reality.
- **Make Time for Them:** Dedicate time specifically for them.
- **Observe Play:** Watch their play for clues about how they are feeling.
- **Expect Variability:** Understand that expressions of their feelings will come and go depending on many factors, including age and attention span.

By providing a supportive and understanding environment, you can help children navigate their grief and find healthy ways to express their emotions.

We are committed to walking alongside you

IX.

What Can I Do to Support Hospice Care in My Community?

Volunteer Opportunities

Many who have received the compassionate support of their hospice team feel a desire to give back, expressing their gratitude for the life-changing care provided by Empath Health. Volunteering time and talents to a local hospice program is a meaningful way to make a difference.

From the very beginning, volunteers recognized the need for hospice care in their communities and took action to make it happen. Today, our volunteers continue to provide a wide range of services that profoundly enhance our community impact.

The primary requirement for becoming a volunteer with an Empath Health hospice program is a helping heart. Our volunteer coordinators will assist in finding the role that best fits you and provide the necessary training to become an integral part of hospice care in your community.





Volunteer Contributions:

Volunteers are vital to not-for-profit healthcare organizations like Empath Health. They provide countless hours of service that represent millions of dollars in value. Common hospice-related volunteer tasks include:

- **Running Errands:** Assisting with everyday tasks for patients and their families.
- **Delivering Meals:** Ensuring patients receive nutritious meals.
- **Providing Companionship:** Spending time with patients, offering comfort and company.
- **Sitting with Patients:** Being present with patients at the end-of-life.
- **Making Phone Calls:** Checking in with patients and families.
- **Veteran Volunteers:** Conducting special pinning ceremonies to honor fellow military members.



Additional Volunteer Opportunities:

- **Resale Shops:** Assisting in Empath Health's resale shops.
- **Administrative Tasks:** Helping with office duties.
- **Event Planning:** Organizing charitable events.
- **Special Therapies:** Providing pet visits, aromatherapy, or massage therapy.
- **Grief and Bereavement Services:** Supporting those dealing with loss.

Joining our volunteer team is a rewarding way to make a significant impact in your community and honor the care you or your loved ones have received. For more information about volunteering, call your local hospice or visit **EmpathVolunteers.org.**

Supporting Empath Health's Mission

Family members often ask how they can show their gratitude for the exceptional care provided by Empath Health; here are three essential reasons why your support is crucial in helping us fulfill our mission:

1. **Philanthropic Dependence:** Unlike hospitals, Empath Health does not receive federal or state funding to cover the costs of treating indigent patients. We rely on philanthropic support to provide millions of dollars in uncompensated care each year, ensuring everyone receives services regardless of financial means. This care is free and supported by donations to Empath Health's foundations.
2. **Comprehensive Services:** Empath Health is committed to offering a wide range of services tailored to individual needs, many of which are not covered by insurance. Therapies such as massage, music, and pet therapy are prescribed as alternatives to pain or anxiety medications. Grief and bereavement counseling for caregivers and family members is available well beyond the death of a loved one.
3. **Innovation and Evolution:** Empath Health continually evolves to meet the needs of patients and families through innovative programs and services, all funded exclusively through philanthropic support.

Ways to Support Empath Health:

- **Annual Giving:** Contributions can be used where the need is greatest or directed to a specific program or location.
- **Memorials:** Request donations be directed to your hospice foundation in lieu of flowers; or, make a donation in memory of a friend or loved one.
- **Planned Giving:** Contributions through wills and trusts, annuities, retirement plans, and paid-up life insurance policies.
- **Resale Shop Donations:** Donate gently used clothing, furniture, and household items to hospice resale shops (not available in all Empath communities).
- **Stock:** Receive the same income tax deduction for a stock gift as for a cash gift and possibly avoid capital gains taxes.
- **Tangible Property:** Donate real estate and other valuable items.
- **Third-Party Special Events:** Host an event to benefit Empath Health.

Visit **EmpathHealth.org/Foundations** to connect with the Empath foundation closest to you. Your support helps Empath Health deliver exceptional care while honoring the memory of your loved one. Thank you for considering these meaningful ways to give back.

Our Foundations

Hospice of Marion County Foundation

Hospice of Marion County Foundation supports the patients and families of HMC regardless of their ability to pay. It also funds programs and services that take care above and beyond basic hospice care.

(352) 291-5143
HospiceOfMarion.org/Donate

Suncoast Hospice Foundation

Suncoast Hospice Foundation supports the patients, clients, participants and family members of Empath Health and its entire nonprofit network of integrated care. Empath Health cares for anyone facing chronic or advanced illness or who is grieving the loss of a loved one. We help patients live as comfortably and meaningfully as possible and offer assistance to their families and caregivers along the way.

(727) 523-2441
SuncoastHospiceFoundation.org/Donate

Tidewell Foundation

The Tidewell Foundation provides philanthropic support to Tidewell Hospice and affiliate companies. Charitable contributions to the Tidewell Foundation sustain and grow the critically important programs and services provided through the not-for-profit mission of Tidewell Hospice.

(941) 552-7546
TidewellFoundation.org

Trustbridge Foundation

Trustbridge Foundation, formerly Hospice of Palm Beach/Broward County Foundation and Hospice by the Sea Foundation is the philanthropic arm of Trustbridge. The Foundation is dedicated to raising funds to support the unfunded patient programs and services offered by Trustbridge, which are not covered by Medicare, Medicaid or private insurance.

(561) 848-5200
Trustbridge.com/Foundation

Visit **EmpathHealth.org/Foundations** to connect with the Empath foundation closest to you. Your support helps Empath Health deliver exceptional care while honoring the memory of your loved one. Thank you for considering these meaningful ways to give back.

APPENDIX 1.

Everything You Need to Know About Hospice

Who Is Eligible for Hospice Care?

Hospice care is a special kind of care that is focused on supporting the physical, emotional, social, and spiritual needs of the patient and anyone the patient identifies as their family. The focus is on comfort rather than cure, so those who seek to be admitted to a hospice program are people who have received the diagnosis of a life-limiting illness with a prognosis of six months or less

How Hospice Care is Paid For

First, it is important to know that no person who needs hospice care in Empath Health's coverage area is turned away because of inability to pay. There are many ways Empath's hospice care is paid for. Medicare and Medicaid along with most major insurance companies and managed care providers offer coverage for hospice services. People may also pay out of pocket for services to the extent that they are able. Through the generous financial support of your community, your nonprofit Empath hospice offers care to all regardless of their ability to pay. If at any time you have questions about billing, payments, or reimbursement, please do not hesitate to ask your care team.

Medicare & Medicaid: What are the Hospice Medicare and Hospice Medicaid benefits?

The Hospice Medicare Benefit is a federal benefit that helps to pay for eligible hospice care and services.

How do I know if I have Hospice Medicare and/or Medicaid?

Everyone who is eligible for traditional Medicare and/or Medicaid is eligible for the Hospice Medicare and/or Medicaid benefit if they meet certain end-stage, disease related conditions. You or your legal representative must sign an election form to start using your Hospice Medicare and/or Medicaid benefit. Neither can be started without your permission.

May I have both Hospice Medicare and/or Medicaid and Traditional Medicare and/or Medicaid?

Your Hospice Medicare and/or Medicaid benefit only covers those services, hospitalizations, equipment, treatments, and medications that are related to your hospice diagnosis and part of the plan of care. Your traditional benefit continues to cover your unrelated healthcare needs as it did prior to your admission to hospice.

How will a hospital or doctor know which type of Medicare or Medicaid to bill?

This is where we need your help. It is very important that your Empath Hospice care team is notified as soon as you do anything new that affects your care. With timely and correct information, we can communicate with you and your health care providers to ensure that you have optimal access to your Medicare or Medicaid benefits. If you go to the hospital, to a new doctor, a nursing home, or plan to start a new treatment, it's very important that you let your team know right away.

What are my responsibilities as a Medicare or Medicaid beneficiary?

At Empath Health, we are committed to coordinating your care in the best manner possible to ensure your needs are met with compassion and excellence and in a timely manner. For us to do that, we need your help. It is your responsibility to notify Empath Health any time you go to the hospital, plan for, or receive a new treatment, change your location of care, or consult a new health care practitioner. Including your care team in the planning process will help us better meet your needs and ensure that you have the fullest spectrum of Medicare or Medicaid benefits available to you.

What if I go to the hospital or receive treatment without letting Empath Health know?

Our commitment to your care includes being committed to using the Hospice Medicare/ Medicaid benefit according to laws and regulations. Therefore, it is possible that we may not be able to cover the cost of services that you receive without our knowledge or involvement. If anything new happens with your care, call your hospice care team. We are grateful for the opportunity to be a partner in your care.

What if my hospice care is paid for by another source?

It's still very important that your Empath hospice care team is informed and involved in every aspect of your care. Your team wants to support you in accessing and coordinating the care that feels right to you.

How can I learn more about how the Hospice Medicare and Medicaid benefits work?

Start by asking your Empath Hospice care team. Your social worker or counselor is familiar with how reimbursement for hospice care works and can help you find the information you need. Periodically, the Center for Medicare and Medicaid Services sends beneficiaries a statement called a Medicare Summary Notice. This notice provides a snapshot of Medicare's reimbursement for hospice services for a specific period. It is not a bill. If you receive a Medicare Summary Notice and have any questions, your care team will be happy to review it with you.

Patient Rights & Responsibilities

Patients have the right to be informed of their rights and obligations before hospice care begins. Consistent with Florida law, the patient's family/representative may exercise the patient's rights when the patient is unable to do so. Empath Hospice wishes to protect and promote the rights of their patients.

Florida Patient Bill of Rights & Responsibilities

Florida law requires that your healthcare provider or healthcare facility recognize your rights while you are receiving medical care and that you respect the healthcare provider's or healthcare facility's right to expect certain behavior on the part of patients. You may request a copy of the full text of this law from your healthcare provider or healthcare facility. A summary of your rights and responsibilities follows:

1. A patient has the right to be treated with courtesy and respect, with appreciation of his or her individual dignity, and with protection of his or her need for privacy.
2. A patient has the right to a prompt and reasonable response to questions and requests.
3. A patient has the right to know who is providing medical services and who is responsible for his or her care.
4. A patient has the right to know what patient support services are available, including whether an interpreter is available if he or she does not speak English.
5. A patient has the right to bring any person of his or her choosing to the patient-accessible areas of the health care facility or provider's office to accompany the patient while the patient is receiving inpatient or outpatient treatment or is consulting with his or her health care provider, unless doing so would risk the safety or health of the patient, other patients, or staff of the facility or office or cannot be reasonably accommodated by the facility or provider.
6. A patient has the right to know what rules and regulations apply to his or her conduct.
7. A patient has the right to be given, by the healthcare provider, information concerning diagnosis, planned course of treatment, alternatives, risks, and prognosis.
8. A patient has the right to refuse any treatment, except as otherwise provided by law.
9. A patient has the right to be given, upon request, full information and necessary counseling on the availability of known financial resources for his or her care.

10. A patient who is eligible for Medicare has the right to know, upon request and in advance of treatment, whether the healthcare provider or healthcare facility accepts the Medicare assignment rate.
11. A patient has the right to receive, upon request, prior to treatment, a reasonable estimate of charges for medical care.
12. A patient has the right to receive a copy of a reasonably clear and understandable itemized bill and, upon request, to have the charges explained.
13. A patient has the right to impartial access to medical treatment or accommodations, regardless of race, national origin, religion, physical handicap, or source of payment.
14. A patient has the right to treatment for any emergency medical condition that will deteriorate from failure to provide treatment.
15. A patient has the right to know if medical treatment is for purposes of experimental research and to give his or her consent or refusal to participate in such experimental research.
16. A patient has the right to express grievances regarding any violation of his or her rights, as stated in Florida law, through the grievance procedure of the healthcare provider or healthcare facility that served him or her and to the appropriate state licensing agency.
17. A patient is responsible for providing to the healthcare provider, to the best of his or her knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations, medications, and other matters relating to his or her health.
18. A patient is responsible for reporting unexpected changes in his or her condition to the healthcare provider.
19. A patient is responsible for reporting to the healthcare provider whether he or she comprehends a contemplated course of action and what is expected of him or her.
20. A patient is responsible for following the treatment plan recommended by the healthcare provider.
21. A patient is responsible for keeping appointments and, when he or she is unable to do so for any reason, for notifying the healthcare provider or healthcare facility.
22. A patient is responsible for his or her actions if he or she refuses treatment or does not follow the healthcare provider's instructions.
23. A patient is responsible for assuring that the financial obligations of his or her healthcare are fulfilled as promptly as possible.
24. A patient is responsible for following healthcare facility rules and regulations affecting patient care and conduct.

As An Empath Hospice Patient You Can Expect to

- Exercise your rights as a patient of Empath Health.
- Have your property and person treated with respect; voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for your property by anyone who is furnishing services on behalf of Empath Health
- Exercise your rights without being subjected to discrimination or reprisal.
- Receive effective pain management and symptom control from Empath Health for conditions related to your hospice diagnosis.
- Be involved in developing your hospice plan of care.
- Refuse care or treatment.
- Choose your attending physician.
- Have a confidential clinical record; access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164.
- Be free from mistreatment, neglect or verbal, mental, sexual, and physical abuse including injuries of unknown source and misappropriation of patient property.
- Receive information about the services covered under your hospice benefit.
- Receive information about the scope of services that Empath Health will provide and specific limitations on those services.

Levels of Care

Depending on what your care needs are, we may need to change your "level of care." Hospice has four levels of care.

Routine Home Care

This is the standard and most common level of care provided by the primary hospice care team wherever a patient calls home (i.e., private residence, assisted living facility, nursing facility, etc.) Frequency and duration of staff visits will vary depending on the changing needs of the patient.

Crisis Care

Crisis Care may be provided for a limited period when unmanaged symptoms require increased nurse monitoring and collaboration to achieve patient comfort. This level of care can consist of bedside nursing shifts (up to 24 hours a day), more frequent nursing visits or both. Once symptoms are managed or the acute crisis has subsided, the patient returns to a routine level of care.

General Inpatient Care (GIP)

GIP care is most often provided in a hospice care center, or at times, a local hospital. This level of care is reserved for patients with symptoms that cannot be feasibly managed in another care setting. Once the hospice care team determines those symptoms are controlled (as defined by regulatory guidelines), insurance providers will no longer cover a GIP level of care. The hospice care team will assist a patient and/or family to arrange for transfer to their previous residence or a more appropriate care setting.

Respite Care

Whereas the other three levels of care focus on the needs of the patient, respite care is designed with the caregiver in mind. When a caregiver needs a break or a rest from caregiving responsibilities, Medicare or Medicaid will provide for up to five days of respite care in an approved facility (such as a hospice care center or nursing facility). This benefit may not be covered by other insurance providers.

Nondiscrimination and Accessibility Requirement

Discrimination is Against the Law

Empath Health, including all of its subsidiaries, complies with applicable Federal civil rights laws and does not discriminate based on race, color, national origin, age, disability, or sex (consistent with the scope of sex discrimination described at 45 CFR § 92.101(a)(2)). Empath Health does not exclude people or treat them less favorably because of race, color, national origin, age, disability, or sex.

Empath Health:

- Provides people with disabilities reasonable modifications and free appropriate auxiliary aids and services to communicate effectively with colleagues, such as:
  - Qualified sign language interpreters
  - Written information in other formats (large print, audio, accessible electronic formats, etc.).
- Provides free language assistance services to people whose primary language is not English, which may include:
  - Qualified interpreters
  - Information written in other languages

If you need reasonable modifications, appropriate auxiliary aids and services, or language assistance services, or you believe that Empath Health has failed to provide these services or discriminated in another way based on race, color, national origin, age, disability, or sex, you can file a grievance with:

Civil Rights Coordinator
6310 Capital Dr., Suite 200
Lakewood Ranch, FL. 34202
ComplianceConnection@EmpathHealth.org
(727) 467-7423

You can file a grievance in person, by mail, or email. If you need help filing a grievance, the Civil Rights Coordinator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at **https://ocrportal.hhs.gov/ocr/portal/lobby.jsf** or by mail or phone at:

U.S. Department of Health & Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
800-868-1019 | **800-537-7697 (TDD)**

Complaint forms are available at **http://www.hhs.gov/ocr/office/file/index.html**

Medical Privacy Under the Health Insurance Portability and Accountability Act (HIPAA)

Empath Health protects your medical information and your rights regarding your own medical records. We are dedicated to protecting your right to privacy of your medical information, while providing the highest quality medical care. We want you to be aware of regulations that affect how we use and disclose your medical information, and the rights you have regarding your medical records. Privacy rules adopted as part of the federal Health Insurance Portability and Accountability Act (HIPAA) establish standards for the release of medical information that personally identifies you.

Authorization/Release of Medical Records

Empath Health is not allowed to discuss your care with anyone besides you and/or your legal representative unless you tell us it is okay to do so.

Requests for copies of your medical record require an authorization form to be filled out and signed by an authorized individual. While on service, authorized individuals include:

- The patient
- The patient's legal representative (Healthcare Surrogate, Medical Power of Attorney, Proxy)

In Florida, hospice records have an extra layer of confidentiality to them and can only be released in certain circumstances once an individual is deceased. Those circumstances are:

- To the personal representative who has been appointed by the court
- To the executor/personal representative named in a Last Will & Testament, or
- By court order

No other individuals will be permitted to obtain copies of the medical record unless a valid authorization is on file. It is recommended that if you want anyone to have access to your medical records, you complete an authorization form while on service. You are not required to sign an authorization form and we will not deny treatment if you elect not to sign one.

Empath-Stratum, Inc. DBA Empath Health

Notice of Privacy Practices

Empath Health offers a variety of services and programs in its continuum of care through its various subsidiaries and wholly controlled affiliated companies. This Notice of Privacy Practices applies to all of such services and programs including, but not limited to, Empath Partners in Care, Empath LIFE, Suncoast Hospice, Tidewell Hospice, Hospice of Marion County, Trustbridge, Hospice of Palm Beach County, Hospice by the Sea, Harbor Palliative Care Services, Empath Home Health, Empath Personal Care, Empath Therapies, Empath Community Health, Empath Grief Care, and Empath Medical Services. This joint Notice of Privacy Practices describes how Empath Health may use and disclose/share your health information and how you can get access to this information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). **Please review it carefully.**

YOUR RIGHTS

When it comes to your health information, under federal law, you have certain rights. This section explains what your rights are and some of our responsibilities to help you.

Get an electronic or paper copy of your medical record	• You and/or your legal representative have the right to inspect and obtain a copy of your health information, including billing records. To see or obtain a copy, please contact the Health Information Management department. • Empath Health will make a reasonable effort to provide access to your protected health information in the form or producible in the form or format you request. Your record will be provided in either standard electronic format or if you do not want this form or format, a readable hard copy form. • We will provide a copy of your health information within 14 days of your request. We may charge a reasonable, cost-based fee for copying, postage, labor and supplies.
Ask us to correct your medical record	• You and/or your legal representative have the right to request Empath Health to amend your records. You can ask us to correct health information about you that you think is incorrect or incomplete. To make this type of request, please submit your request in writing to the HIPAA Privacy Officer and explain why the amendment is necessary. • We may say "no" to your request, but we'll tell you why in writing within 30 days.
Request confidential communications	• You and/or your legal representative have the right to request confidential communications. Empath Health will not request that you provide any reasons for your request. ○ *Example: you can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address.* • We will say "yes" to all reasonable requests. • To make this type of request, please submit your request in writing to the HIPAA Privacy Officer.
Request restrictions, ask us to limit what we use or disclose	• You and/or your legal representative have the right to request that Empath Health place additional restrictions on our use or disclosure of your health information. Empath Health is not required to agree to these additional restrictions, but if we do, we will abide by the agreement (except in emergency) or if it would affect your care. • In the event you pay out-of-pocket and in full for services rendered, you may request that Empath Health not disclose your health information with your health plan. ○ We will say "yes" unless a law requires us to disclose that information. • To request restrictions, you must make your request in writing to the HIPAA Privacy Officer. In your request, please include (1) the information that you want to restrict; (2) how you want to restrict the information (for example, restricting use to this office, only restricting disclosure to persons outside this office or restricting both); and

Original Effective Date: April 14, 2003
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	(3) to whom those restrictions to apply.
Get a list of those with whom we've disclosed information	• You and/or your legal representative can ask for a list (accounting) of the times we've disclosed your health information for up to six (6) years prior to the date you ask, who we disclosed it to, and why. To make this type of request, please submit your request in writing to the HIPAA Privacy Officer. • We will include all the disclosures except for those relating to treatment, payment, and health care operations, and certain other disclosures (such as any you asked us to make). Empath Health will provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a cost-based fee.
Get a copy of this Privacy Notice	• You and/or your legal representative can ask for a paper copy of this Notice at any time, even if you have agreed to receive the Notice electronically. We will provide you with a paper copy promptly. You may also obtain a copy of the current version of Empath Health's Notice of Privacy Practices at our website, www.empathhealth.org
Choose someone to act for you	• If you have given someone medical power of attorney, if someone is your health care surrogate or your legal guardian, that person can exercise your HIPAA rights and make choices about your health information. • We will verify the person has this authority and can act for you before we take any action.
File a complaint if you believe your rights are violated	• You and/or your legal representative have the right to express complaints to Empath Health and to the Secretary of US Department of Health and Human Services, Office of Civil Rights, if you believe that your privacy rights have been violated. • You and/or your legal representative can contact Empath Health using the HIPAA Privacy Officer contact information listed at the end of this Notice. Empath Health encourages you to express any concerns you may have regarding the privacy of your health information and offers its assurance that you will not be retaliated against in any way for filing a complaint. • You and/or your legal representative can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by: sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, or calling 1-877-696-6775, or visiting https://www.hhs.gov/hipaa/filing-a-complaint/index.html • We will not retaliate against you for filing a complaint.
Receive Notice of Breach of Protected Health Information	• In the event of any unauthorized acquisition, access, use or disclosure of Protected Health Information, Empath Health will fully comply with HIPAA's breach notification requirements, including any and all regulations that have been or may be promulgated, which will include notification to you of any impact that breach may have had on you.
Additional Florida Privacy Protections	• You and/or your legal representative have the right to any additional privacy protection granted through Florida law.

Original Effective Date: April 14, 2003
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YOUR CHOICES

For certain health information, you can tell us your choices about what we disclose. If you have a preference for how we disclose your information in the situations described below, talk to us. Tell us what you want us to do, and we will follow your instructions. You may revoke your authorization in writing at any time except to the extent that Empath Health has taken action in reliance upon the authorization.

In these cases, you have both the right and choice to tell us how you want to:	• Disclose information with your family, close friends, or others involved in your care. Empath Health may use or disclose health information to notify or assist in the notification of (including identifying or locating), your family member, your personal representative or another person responsible for your care, of your location, your general condition or your death. If you are present, then prior to use or disclosure of your health information, Empath Health will provide you with an opportunity to object to such uses or disclosures. In event of your incapacity or emergency circumstances, Empath Health will disclose health information based on a determination using its professional judgement disclosing only health information that is directly relevant to the person's involvement in your health care. • Include your information in a facility directory. If you are in an inpatient or residential facility, Empath Health may include in the directory your name, your general health status, your religious affiliation and your location while you are in the facility. Empath Health may disclose this information to people who ask for you by name. Please inform Empath Health if you do not want your information to be included in the directory. • Coordinate appointment Reminders. Empath Health may use and disclose your health information to contact you as a reminder that you have an appointment for an upcoming visit. • Educate you on treatment alternatives. Empath Health may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you. • Participate in Health Information Exchange programs. If Empath Health participates in HIE to allow timely and secure sharing of your information with other health care providers, health care companies, or their business associates as permitted by law, you will have a chance to opt-in to participate in the HIE. HIE programs can provide faster access, better coordination of care and assist providers and public health officials in making more informed decisions about your care.
In these cases we never disclose your information unless you give us written permission:	• Marketing purposes • Sale of your information • Sensitive information such as: HIV and AIDS, psychotherapy, and alcohol/drug notes.
In the case of fundraising	• Empath Health may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for Empath Health. Empath Health may also release this information to affiliated foundations. If you do not want Empath Health to contact you or your family, you should notify the HIPAA Privacy Officer. • If we have your substance use disorder patient records, subject to 42 CFR part 2, we will give you clear and obvious notice in advance and a choice about whether to receive fundraising communications that use your Part 2 information.

Original Effective Date: April 14, 2003
Effective Date of Last Revision: February 16, 2026

OUR USES AND DISCLOSURES

How do we typically use or disclose your health information? We typically use or disclose your health information in the following ways.

To Provide Treatment	• We may use your health information to coordinate treatment with others involved in your care, such as your physician, members of the care team and other health care professionals who assist in providing care. Empath Health also may disclose your health care information to individuals outside the organization who are involved in your care including family members, clergy who you have designated, pharmacists, suppliers of medical equipment, or other health care professionals. ○ *Example: physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications.*
To Conduct Health Care Operations	• Empath Health may use and disclose health information for our own operations in order to facilitate functions and, as necessary, to provide quality care to all. ○ *Example: Empath Health may use or disclose your health information to perform quality assessment activities or evaluate the performance of our staff and services.*
To Obtain Payment	• Empath Health may use and disclose your health information to obtain payment for services we provide to you, unless you request that we restrict such disclosures to your health plan when you have paid out-of-pocket and in full for services rendered. ○ *Example: We give information about you to your health insurance plan so it will pay for your services.*

How else can we use or disclose your health information? We are allowed or required to disclose your information in other ways, usually in ways that contribute to the good of the pubic. We have to abide by the law and meet certain conditions before we can disclose your information for these purposes. In all cases, including those listed below, if we have substance use disorder patient records about you, subject to 42 CFR part 2, we cannot use or share information in those records in civil, criminal, administrative, or legislative investigations or proceedings against you without (1) your consent or (2) a court order and a subpoena.

Help with public health and safety issues	• Empath Health may, consistent with applicable law and ethical standards of conduct, disclose your health information if Empath Health, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety, or to the health and safety of the public. We can disclose health information about you for certain situations such as: ○ *Reporting communicable diseases* ○ *Helping with product recalls* ○ *Reporting adverse reactions to medications* ○ *Reporting suspected abuse, neglect or domestic violence*
Research	• Empath Health may, under very select circumstances, use your health information for research. Before Empath Health discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.
Comply with the law	• Empath Health will disclose your health information when it is required to do so by any Federal, State or local law.
Respond to organ and tissue donation requests	• In the event you have chosen to be a donor, Empath Health may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

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Work with a medical examiner or funeral director	• Empath Health may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law. • Empath Health may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. Empath Health may disclose your health information to funeral directors prior to and in reasonable anticipation of your death, if deemed necessary to fulfill their duties.
Workers' compensation and other government requests	• Empath Health can use or disclose health information about you: o For workers' compensation or similar programs o With health oversight agencies for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. o For law enforcement purposes, as authorized by Federal, State or local law. o For special government functions such as to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.
Judicial and Administrative Proceedings	• Empath Health may disclose your health information in the course of any judicial or administrative proceeding, in response to court or administrative order or in response to a subpoena, discovery request or other lawful process, but only when Empath Health makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.
Law Enforcement	• As permitted or required by State Law, Empath Health may disclose your health information to a law enforcement official for certain law enforcement purposes such as: o Required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or similar process. o For the purpose of identifying or locating a suspect, fugitive, material witness or missing person. o Under certain limited circumstances, when you are or are suspected to be the victim of a crime. o To a law enforcement official if Empath Health has a suspicion that your death was the result of criminal conduct, including criminal conduct at Empath Health. o In an emergency in order to report a crime on the premises.
Business Associates	• Empath Health may disclose your health information with third-party "business associates" that perform various activities (e.g., billing, transcription services) for Empath Health. Whenever an arrangement between Empath Health and a business associate involves the use or disclosure of your health information, Empath Health will have a written contract that contains terms that will protect the privacy of your health information.

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OUR RESPONSIBILITIES

- Empath Health is required by law to maintain the privacy of your health information and to provide this Notice of its duties and privacy practices to you or your authorized representative.
- Empath Health will let you know promptly if a breach occurs that may have compromised the privacy or security of your health information.
- Empath Health is required to abide by the terms of this Notice and give you a copy of it.
- Empath Health will not use or disclose your information other than as described here, unless you tell us we can in writing. If you tell us we can, you may change your mind at any time. Let us know if you change your mind by contacting the Privacy Officer in writing.

CHANGES TO THE TERMS OF THIS NOTICE

Empath Health reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If Empath Health makes material changes to its Notice, Empath Health will make a copy of the revised Notice available to you or your authorized representative. The new Notice will be available upon request in our office and on our website.

ADDITIONAL NOTICE

A court order may be required pursuant to Florida Statute Section 400.611(3) before Empath Health will release your records after your death, unless during your life you (or your authorized representative) expressly state in writing that a specific person or entity is authorized, after your death, to request and receive your health information.

PRIVACY OFFICIAL CONTACT INFORMATION

Amanda Tippin, HIPAA Privacy Officer
5300 East Ave.
West Palm Beach, FL 33407
561-227-5123
atippin@empathhealth.org
www.empathhealth.org

Original Effective Date: April 14, 2003
Effective Date of Last Revision: February 16, 2026

Reporting Concerns/Complaints

Empath Health is fully committed to excellent customer service, both in principle and as a matter of policy. This policy is consistent with the mission, vision and values set forth by the Organization. Empath Health will, in a timely manner, address, review, and resolve all customer concerns and complaints. If you experience a service performance that fails to meet your expectations, Empath Health welcomes the opportunity to discuss the concern and achieve a resolution. We greatly appreciate your feedback, as it allows us to research, educate our staff, and ultimately improve our processes. Concerns or complaints may be reported to us via:

- Conversation with an Empath Health employee
- Posting to website: **EmpathFeedback.org** (contact us anytime)
- Telephone: Quality Line **(888) 391-0116**
- Letters: Empath Health, Quality Department, 6310 Capital Dr., Suite 200 Lakewood Ranch, FL 34202
- Comments submitted on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey
- If you do not feel that Empath Health has adequately addressed your concerns, you may also express your concerns to The Joint Commission, CHAP or the State of Florida.

Reporting Agencies

In the event you have already contacted Empath Health and we have not adequately addressed your concerns, you may also choose to contact the agencies listed.

The Joint Commission (Hospice of Marion County, Suncoast Hospice, Suncoast Hospice of Hillsborough & Trustbridge Hospice)

Empath Health hospice programs Hospice of Marion County, Suncoast Hospice and Suncoast Hospice of Hillsborough are accredited by The Joint Commission on Accreditation of Healthcare Organizations. Accreditation by this regulatory Agency means compliance with and adherence to the highest possible standards of quality care.

We encourage patients and families to share concerns with their hospice teams or any administrative personnel to ensure resolution of concerns and issues. The Organization provides a problem-solving procedure. We seek to resolve concerns fairly, equitably and within a reasonable time frame.

If you wish to make any comments to The Joint Commission on Accreditation of Healthcare Organizations, they may be contacted:

- Online: **JointCommission.org**
- Phone: **1-800-994-6610** (Mon - Thurs, 8 am - 5 pm Central time)
- Mail: Office of Quality and Patient Safety
  The Joint Commission
  One Renaissance Boulevard
  Oakbrook Terrace, IL 60181

The Joint Commission conducts periodic unannounced surveys during the course of the accreditation cycle. We desire to keep our patients and families informed of these important evaluations; however, we never know the exact date when the survey will occur.

CHAP (Empath Hospice & Tidewell Hospice)

Tidewell Hospice is accredited by CHAP. This accreditation shows compliance and adherence to a high quality of care for patients and families. We encourage Tidewell patients and families to share concerns with their hospice teams or Empath administrative personnel to resolve concerns or issues. We seek to resolve concerns fairly, equitably and within a reasonable timeframe.

If you wish to make comments to CHAP, they may be contacted:

- Online: **CHAPinc.org**
- Email: Through online form at **Complaints@chapin.org**
- Phone: **800-656-3656**
  Fax: **(202) 862-3417**
  (Mon.-Fri. 8:30 am-5:30 pm ET)
- Mail: CHAP
  Office of Quality and Patient Safety
  2300 Claredone Blvd., Suite 405
  Arlington, VA 22201

Florida Agency for Health Care Administration Hotline

We are licensed by the Agency for Health Care Administration. The Division of Health Quality Assurance protects Floridians through oversight of health care providers. Health Quality Assurance licenses and/or certifies and regulates 40 different types of healthcare providers, including hospitals, nursing homes, assisted living facilities, and home health agencies. To file a healthcare facility complaint:
Call Toll Free: **1-888-419-3456**
(Mon.-Fri., 8:00 am-6:00 pm)
or at **AHCA.MyFlorida.com.**

Medicaid Fraud and Reporting Abuse

Medicaid fraud means "an intentional deception or misrepresentation made with the knowledge that the deception could result in some unauthorized benefit to him/herself or another person." It includes any act that constitutes fraud under applicable federal or state law as is related to Medicaid. To report any suspected fraudulent behavior or suspected abuse with the Medicaid program:
Call Toll Free:
1-888-419-3456 (Mon.-Fri., 8:00 am-6:00 pm)
or **AHCA.MyFlorida.com.**

Abuse can come in many forms, such as: physical or verbal maltreatment, injury, sexual assault, violation, rape, unjust practices, wrongful practice or custom, offense, crime, or verbal aggression. To report any suspected abuse: Call Abuse Hotline: **1-800-962-2873** or **1-800-96-ABUSE** (24 hours/7 days).

Disposal of Medications

Talk to your care team before disposing of any medication. The proper disposal of medications is extremely important for health and safety reasons. Your care team will assist you to make sure medications are disposed of properly and safely.

If the medications you receive are no longer needed or you move from your private home to a facility, all Empath Health-provided prescription medications should be destroyed and recorded as disposed of with the assistance of your hospice nurse or other hospice team member. A family member may be asked to witness the disposal of certain medications. If you are a patient being cared for in an Empath Health inpatient center or other facility, any medications you no longer need will be disposed of according to that facility's policies. Nurses and other healthcare workers are not allowed to transport medication in their vehicles.

Empath hospice staff will assist you directly with the disposal of unneeded medications. In the event additional medication is discovered later, please dispose using the following options:

- **Preferred Option:** Bring all found medications to a drop-off location in your county or use a mail-back medication disposal bag purchased at your local pharmacy.
- Some facilities and businesses are registered with the U.S. DEA to collect your unused or expired medicines. Find an authorized drug collection site near you or call the DEA Diversion Control Division Registration Call Center at **1-800-882-9539** for more information about these collection sites.
- Scan QR code for year-round drop-off locations

Alternate Option: Dispose of your medications at home following the instructions below:

1. Separate out the medications listed below. These should be immediately flushed down the toilet when no longer needed and a take-back option is not readily available. These medicines may be especially harmful and, in some cases, fatal with just one dose.
2. Any medications not listed below should be poured from the original containers into a sealable plastic storage bag.
    - Remove or mark through any personal information on the now empty containers and throw away in the trash.
    - Add kitty litter, coffee grounds or flour to the bag with the medication.
    - Add a small amount of water to the bag
    - Throw away the bag into the trash. Do not place it in the recycle bin.

Active Ingredient	Found in Brand Name
Buprenorphine	Belbuca, Bunavail, Butrans, Cassipa, Suboxone, Subutex, Zubsolv
Fentanyl*	Abstral, Actiq, Duragesic (patch), Fentora, Onsolis
Diazepam	Diastat/Diastat AcuDial rectal gel
Hydrocodone	Anexsia, Hysingla ER, Lortab, Norco, Reprexain, Vicodin, Vicoprofen, Zohydro ER
Hydromorphone	Dilaudid, Exalgo
Methadone	Dolophine, Methadose
Methylphenidate	Daytrana transdermal patch system, Ritalin
Morphine	Arymo ER, Avinza, Embeda, Kadian, Morphabond ER, MS Contin, Roxanol
Oxycodone	OxyContin, Percocet, Percodan, Roxicet, Roxicodone, Targiniq ER, Xartemis XR, Xtampza ER, Roxybond
Oxymorphone	Opana, Opana ER
Tapentadol	Nucynta, Nucynta ER

* Fentanyl patches should be handled with gloves and never touched after opening with a bare hand. USED patches are the only exception to the safe medication disposal rule. They should be cut and then flushed down the toilet. Do NOT discard them in the trash.

Please call Empath Health with any questions.

Disaster Preparedness

Events during the past few years have highlighted the importance of being prepared for emergency situations. Because we live in Florida, most of our disaster planning efforts involve preparing for hurricanes. It is important to remember that hurricanes are not the only disasters that could strike our area. Power outages, tornadoes, localized flooding, acts of terrorism and fire are all examples of possible threats to normal living.

Having an evacuation strategy, an emergency kit in your home, written contact numbers and anticipating what loss of electricity would mean to your household will help you to be better prepared for any unexpected threat. Your care team will help you develop a disaster plan that fits your care needs and your living situation. Please contact your care team if you would like to discuss a change in your care needs or established plan. Plan may be updated to reflect changes in location/ condition.

- Make a family plan and be sure your hospice care team knows your plan. Inform our care team any time your plan changes.
- Develop a disaster supply kit. If not evacuating, include a 14-day supply of non-perishable food, one gallon of water per person, per day, and a 14-day supply of medications and supplies.
- Anticipate what loss of electricity might mean for you and your family.
- Make plans to protect your home before any storm.
- Purchase a battery-powered weather radio.
- Be sure to have a landline, non-electric phone.
- Inventory your possessions and store important papers such as insurance, title and ID in a safe, dry place. Send copies to a friend or relative outside the area.
- Review your insurance policies for your home and possessions.
- During hurricane season (June-November) work with your care team to be sure you have at least a two-week supply of medications on hand.

Advice for Evacuees to Special Needs Shelters

- Please note that special needs shelters are intended to be a place of last refuge and that the conditions in a shelter may be very stressful.
- It is recommended that a caregiver accompany an evacuee to the special needs shelter and remain with him or her. Other family and friends may be able to accompany an evacuee to a special needs shelter as well. Please note: if space is limited only one caregiver will be able to stay with the special needs registrant and the rest of the family and friends will be asked to stay in the general population area of the shelter.

Advice for Evacuees to Skilled Nursing Facilities or Hospitals

- Patients with special needs (oxygen greater than four liters flow per minute, ventilators, specialized IV medications and those that are bedbound) need evacuation plans to a non-evacuating skilled nursing facility or hospital.
- Your care team will help you register for transportation to the skilled nursing facility or hospital with the Emergency Management department of the county you live in if that should be needed.

Recommended List of Items to Take to a Special Needs Shelter, Skilled Nursing Facility or Hospital

- Personal identification showing current address
- Any personal important papers and contact information
- Your Patient & Family Guide notebook, including your: Plan of Care, medication, supply and equipment list (provided by hospice) advance directives, contact numbers
- 14-day supply of prescription and non-prescription medication
- Oxygen – take your concentrator
- Bedding, folding lawn chair, air mattress, linens and sleeping supplies
- Special diet items, non-perishable food for 72 hours and one gallon of water per person per day
- Glasses, hearing aids and batteries, prosthetics and any other assistive devices
- Personal hygiene items
- Extra clothing for 72 hours
- Flashlight and batteries
- Entertainment and comfort items – books, magazines, games

APPENDIX 2.
Planning Journal

Funeral Services and Memorial Services

Do you have strong feelings about how you would like to be remembered after your death? Do you as a family member or friend want to plan a memorial that honors your loved one? For some people, planning a funeral, memorial service or celebration of life is comforting and provides an opportunity to finish unfinished business. Others, quite understandably, would rather avoid the topic completely. If you are thinking about memorial planning, the following questions may help you decide what is important to you and share that information with friends or family members who will be involved in making decisions. Use the questions to start a conversation or as a worksheet to guide you in writing down your ideas. What are some of the things you would like your friends and family to remember about you?

Funeral Services and Memorial Services (continued)
Would you like an obituary in the newspaper, church bulletin, etc.? What would you like it to say or include such as place of residence, occupation, school attended, memberships in associations or clubs, religion, interests, survivors, contributions, or place of burial?
After your death, how would you like to be memorialized (funeral, memorial service, celebration of life, etc.)? Do you have specific wishes about how you would like it to be carried out?
Have you made (final, funeral, memorial service) arrangements? Have you made arrangements for your final resting place?
If yes, with which mortuary/funeral home did you make these arrangements? Where is the paperwork?
If not, where would you like your final resting place to be (cemetery, scatter ashes, urn and kept with family, memorial garden)? What about this place is important to you?

Funeral Services and Memorial Services (continued)
Do you prefer cremation or burial? Do you have a burial plot?
Are there any special clothes you would like to wear for burial/cremation?
If burial, is there anything you would like with you?
If burial, do you already have a headstone? Do you want a headstone, and if so, what would you like it to say?
Is there any special person(s) you want present at your funeral/memorial service?
Do you have a place of worship where you would like the funeral/memorial service to occur?
Do you have a preference for clergy?

Funeral Services and Memorial Services (continued)
Who would you want to read your eulogy?
What would you want to be said in your eulogy?
Do you have favorite songs, prayers, readings, rituals or sacraments that would honor your life and help people remember you?
Do you want flowers? Would you like donations to be given to a charity in your honor?
If flowers, what is your favorite?
If you choose donations, to which charity should the donations to be made?
Do you have any other final wishes? Any special wishes?

The chaplain on your care team can assist you with making these plans and arrangements and may also be able to officiate if you do not have someone to officiate at the service.

APPENDIX 3.

Hospice Care Training Resources for Patients and Families

In the following pages you will find educational resources to support caring for your loved one and for caregivers. If you need further instruction or have questions, please contact your care team 24/7.

For additional educational resources visit **EmpathHealth.org** or scan the QR code.

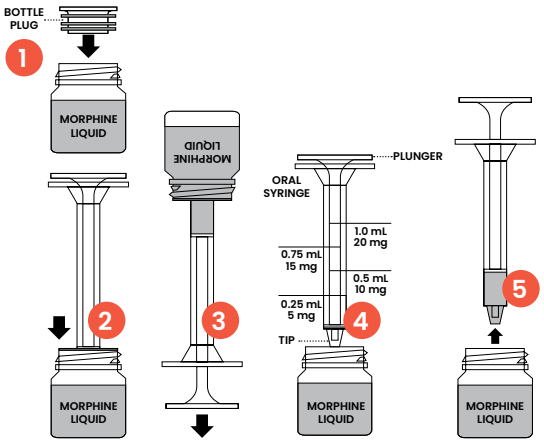
- Agitation and Restlessness
- Cardiac Program
- Compression Wrap
- COPD Support
- Decrease Itching
- Emergency Planning
- End-of-Life Care
- Fall Prevention
- Infection Control – Hand Hygiene
- Infection Control – MRSA
- Infection Control – VRE
- Low Salt Diet
- Medication Information Update
- Monitoring and Reporting Pain
- Oxygen Therapy
- Pain Management Log
- Pressure Ulcer Prevention
- Preventing Your Loved One from Falls
- Swallowing Problems
- Why Am I Being Discharged

Comfort Kit Information



General Directions

You will be receiving a Hospice Comfort Pak from the Empath Health Pharmacy. The Comfort Pak contains seven medications used to treat urgent symptoms. Store the pak on the top shelf of the refrigerator, safe from children and pets. Do not open the pak unless directed by a hospice nurse or physician. Remove only those medication(s) instructed by the hospice nurse or physician. The hospice nurse or physician will provide you the correct dose and other important information on the medication or symptoms at the time the pak is opened. Notify the hospice nurse immediately if you have questions regarding symptom(s) or medication(s).

MEDICATION	USES	HOW TO GIVE MEDICATION
Morphine Sulfate Oral Solution 100mg/5ml or 20mg/ml Quantity: 15ml	To treat pain and shortness of breath.	 *Patient may swallow medication or it may be placed under the tongue.* This medication may be mixed with a small amount of water, milk, juice, applesauce or pudding. Measure the correct dose of the medication carefully using the following five-step process. 1. Insert the plug in the neck of the bottle, ribbed-end first. 2. Insert tip of syringe into hole on the top of bottle plug until secure. 3. Turn bottle upside down and pull down on syringe to remove prescribed dose. The Morphine Oral Solution dosing chart is provided to help with removing the correct dose and volume. 4. Note that the manufacturer's morphine oral syringe is marked with fill lines indicating the dose in milligrams (mg) equal to volume of liquid in milliliters (ml) to withdraw. 5. Turn bottle right side up. Twist to remove syringe.

MORPHINE ORAL SOLUTION DOSING CHART (20MG/ML)

MG Dose	ML Volume
5mg	0.25ml
10mg	0.5ml
15mg	0.75ml
20mg	1ml

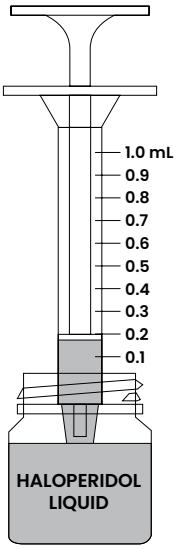
DO NOT USE THIS CHART FOR ANY OTHER MEDICATION OR STRENGTH

Comfort Kit Information (continued)



General Directions

You will be receiving a Hospice Comfort Pak from the Empath Health Pharmacy. The Comfort Pak contains seven medications used to treat urgent symptoms. Store the pak on the top shelf of the refrigerator, safe from children and pets. Do not open the pak unless directed by a hospice nurse or physician. Remove only those medication(s) instructed by the hospice nurse or physician. The hospice nurse or physician will provide you the correct dose and other important information on the medication or symptoms at the time the pak is opened. Notify the hospice nurse immediately if you have questions regarding symptom(s) or medication(s).

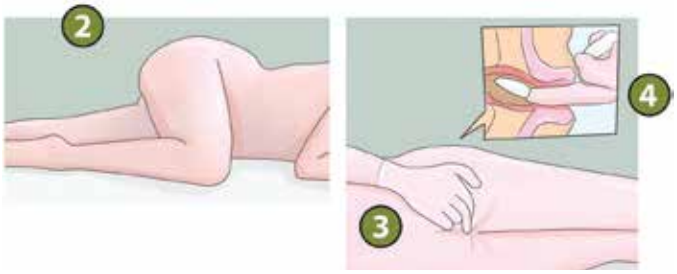
MEDICATION	USES	HOW TO GIVE MEDICATION
Haloperidol Oral (Haldol®) Solution 2mg/ml Quantity: 15ml	To treat agitation, nausea and vomiting. It may be used to treat other conditions as determined by the prescriber.	 *Patient may swallow medication or it may be placed under the tongue.* This medication also may be mixed with a small amount of water, milk, juice, applesauce or pudding. Measure the correct dose of the medication carefully using the following three-step process. 1. Insert the tip of the oral syringe into the liquid. 2. Pull back on the end of the syringe to remove the prescribed dose. Use the Haloperidol Oral Solution dosing chart below to help with removing the correct mg dose and ml volume. 3. Note that the 1ml syringe is marked with fill lines indicating volume of liquid in ml.
		HALOPERIDOL ORAL SOLUTION DOSING CHART (2MG/ML)
		MG Dose: 0.5mg; 1mg; 1.5mg; 2mg ML Volume: 0.25ml; 0.5ml; 0.75ml; 1ml
		DO NOT USE THIS CHART FOR ANY OTHER MEDICATION OR STRENGTH
Lorazepam (Ativan®) tablets 0.5mg Quantity: 10	To reduce anxiety, nausea, vomiting or difficulty falling asleep.	*Patient may swallow medicine or it may be placed under the tongue.*

Comfort Kit Information (continued)



General Directions

You will be receiving a Hospice Comfort Pak from the Empath Health Pharmacy. The Comfort Pak contains seven medications used to treat urgent symptoms. Store the pak on the top shelf of the refrigerator, safe from children and pets. Do not open the pak unless directed by a hospice nurse or physician. Remove only those medication(s) instructed by the hospice nurse or physician. The hospice nurse or physician will provide you the correct dose and other important information on the medication or symptoms at the time the pak is opened. Notify the hospice nurse immediately if you have questions regarding symptom(s) or medication(s).

MEDICATION	USES	HOW TO GIVE MEDICATION
Hyoscyamine (Levsin®) SL tablets 0.125mg Quantity: 12	To decrease secretions and saliva production. It may be used to treat other conditions as determined by the prescriber.	 *Medication should be placed under the tongue.* This medication may be swallowed if placing under the tongue is too difficult.
Prochlorperazine tablets (Compazine®) 10mg Quantity: 6	To treat nausea and vomiting.	*Patient may swallow medication.*
Acetaminophen suppositories (Tylenol®) 650 milligrams Quantity: 4	To treat mild to moderate pain and reduce fever.	*Medication is given rectally.* These medicines are rectal suppositories and should not be swallowed. Use this seven-step process to insert the suppository.  1. Wash your hands, remove wrapping and wet the suppository. 2. Patient should lie on his or her side facing you with lower leg straight and upper leg bent. 3. Lift the upper buttock to expose the rectal area. 4. Insert the suppository, pointed end first, into the rectum, about one inch for adults. 5. Hold buttocks together for a few seconds. 6. Patient should remain lying down for five minutes to keep suppository in place. 7. Wash your hands.
Bisacodyl suppositories 10mg (Dulcolax®) Quantity: 2	To treat constipation by stimulating bowel movements. Bowel movements are generally produced within 15 minutes to one hour of use.	

Morphine Myths



Morphine is an opiate used to relieve pain and manage difficulty breathing. A prescription is required to get morphine.

Myths About Morphine

Myth: Morphine causes drowsiness and mental clouding.

Fact: When morphine is first started, drowsiness and mental clouding are frequent side effects. They usually subside within 72 hours.

Myth: Morphine should only be given for severe pain.

Fact: Morphine is used effectively for the management of pain and difficulty breathing. As pain increases, the morphine dose can be adjusted upward to treat the increased pain. Morphine is considered the gold standard for three reasons: 1. It is effective and works quickly. 2. It can be administered by many routes. 3. It relieves pain and difficulty breathing.

Myth: Morphine is addictive.

Fact: Addiction is impaired control over drug use and can result in inappropriate medication use. Hospice patients taking morphine to control common symptoms such as pain or difficulty breathing is an example of appropriate medication use. This type of use is not considered addiction.

Myth: Morphine stops breathing.

Fact: Morphine is the drug of choice for managing difficulty breathing. Administering morphine allows the patient with difficulty breathing to rest more comfortably.

Myth: People who take morphine die sooner.

Fact: There is no evidence to support that morphine hastens death. Morphine is used to keep the patient comfortable. The timing of the patient death is dependent on the illness.

Morphine Allergy

You can be allergic to morphine just like any other medicine. Report signs of allergy immediately to your Empath nurse and discontinue the medication. Side effects can be mild or extremely bothersome but do not always require stopping the medication.

Signs of Allergy

- Swelling of the face and tongue
- Hives (itchy, red raised bumps on the skin)

Side Effects

- Drowsiness or mental clouding
- Constipation
- Nausea
- Vomiting
- Itching

Call your care team if you have questions or concerns about morphine.

Pain Medication Side Effects



Learning about the side effects of opioid pain medications is essential for helping you be confident and comfortable taking or giving these medications. The good news is that not everyone has side effects from pain medications. In fact, most side effects can be prevented and some mild side effects such as nausea, itching or drowsiness often go away after a few days as the body adjusts to the medicine.

The most common side effects of pain medications are drowsiness, constipation, nausea and vomiting.

Drowsiness

Pain medications may cause drowsiness when someone first starts taking them, but this usually goes away after a few days. If pain has kept the person from sleeping, he or she may sleep more for a few days after starting the new medication. Drowsiness also lessens as the body gets used to the medicine. The patient should take extra care and safety precautions when first taking pain medication and not do anything that requires them to be alert until the effects of the medicine are known. If the medication is not relieving the pain, the pain itself may be tiring the person out.

Constipation

Pain medications cause constipation in most people. They slow the movement of stool through the intestinal tract, which allows more time for water to be absorbed by the body and the stool to become hard. The body does not adjust to constipation from opioids, but it can often be prevented or controlled. It's best to start a laxative, stool softener or other treatment to keep the bowels moving at the same time as starting pain medication. The Empath Health nurse can provide information on stool softeners and laxatives, including how much and how to take.

Nausea and Vomiting

Nausea and vomiting caused by pain medications usually goes away after a few days. If someone has more nausea when up or walking around but not when lying down, it may be better for them to stay in bed for an hour or so after taking pain medicine. This type of nausea is like motion sickness. If the pain itself is causing the nausea, using medication to relieve the pain usually makes the nausea go away. Medicines that relieve nausea can be prescribed if needed. Constipation may also worsen nausea. Nausea and vomiting alone usually are not signs of an allergic reaction to pain medications.

When to Call Your Care Team:

- If side effects from pain medicine need to be managed
- If the patient is too sleepy for normal activities after taking the medication for a few days
- If taking other medications that could also cause drowsiness
- If the medication is not relieving pain
- If stool softeners or laxatives don't relieve constipation
- If there is no bowel movement for more than two days
- If the patient is unable to hold down food or liquids for a full day
- If nausea lasts more than a few days

Nutrition



There are many reasons a person's appetite and food intake can decrease. Although an encouraging, gentle approach may help, we must respect an individual's choice. Empath Health recommends not forcing someone to eat or constantly remind them of their decreased appetite.

You can encourage eating by serving meals in a relaxed, comfortable and bright atmosphere. When feasible, eat in the room with your loved one. Remove unpleasant odors and do not schedule unpleasant procedures around mealtime.

What to Do

- Offer mouth care before and after meals to freshen up the mouth and stimulate taste buds.
- Make the most of breakfast as appetite tends to decrease as the day goes on.
- Offer pain medications on a schedule that reduces discomfort before and during meals. For example, offer pain medication 30 minutes before mealtime.
- Keep the head of the bed elevated to promote digestion for 15-30 minutes after meals.
- Adjust the diet if your loved one can no longer wear dentures. Soft foods or small, bite-sized portions of food may be softened with sauces or gravy.
- Inform the Empath nurse if nausea is a problem. The nurse can ask the doctor about ordering a medication to reduce nausea.
- Offer small, frequent meals and leave a high-protein snack or drink at the bedside. Empath can provide information and recipes for high-protein supplements.
- Consider patient requests. For example, if the patient requests ice cream for breakfast, be open to this.
- If the patient is lying flat, elevate the head of the bed before beginning the meal.

Toothettes may be easier to use than a toothbrush. They may be obtained from the Empath team. Follow the same instructions as for a toothbrush.

Ask for special instructions for mouth care if your loved one is unconscious, unable to swallow or sit up.

When to Call Your Care Team:

- If the patient is unable to swallow
- If the patient reports pain when swallowing
- If the patient reports nausea or vomiting

Food and Fluids at End-of-Life



Food is nourishment for the body and soul. It is also one of the ways we show love and provide comfort to loved ones.

During times of distress, families often turn to familiar traditions for providing comfort and expressing love, and these traditions often involve food. At end-of-life, however, many people no longer desire food or drink. When your loved one stops eating and drinking, you may wonder how to show him or her you care. Refusing food and drink is one of the symptoms of the natural dying process and not its cause. Side effects of dehydration include thirst and dry mouth, both of which can be alleviated by providing frequent and thorough mouth care.

For the majority of people, food and fluids do not increase the quality or quantity of life. In fact, forcing someone to eat or drink at the end-of-life may cause discomfort, including shortness of breath, bloating, gas, nausea, vomiting or diarrhea. Additionally, the muscles used to chew and swallow become weak at the end-of-life, causing difficulty swallowing and possibly choking.

If you have any questions about your loved one's food and fluid intake, contact your care team. Here are some ways you can provide nutritional comfort to your loved one:

- Let your loved decide whether or not to eat or drink.
- Offer small meals or snacks.
- Eat with your loved one.
- Offer a balance of solid food and liquids.
- Offer soft food items to decrease the work of chewing and swallowing.
- Offer small chips of ice, frozen juice or popsicles; many people find these refreshing.
- Place your loved one in an upright position to eat or drink.
- Provide mouth care before and after each meal and snack.
- Avoid heavy and/or fried foods.
- Avoid foods with strong odors.

Discuss any questions or concerns you have about your loved one's change in eating or drinking habits with your care team.

Call your care team with any questions or if there is:

- Your loved one stops eating and drinking altogether for more than 24-48 hours.
- If you think your loved one has choked on food or liquid

Constipation



Constipation is a condition of the digestive system that occurs when stool becomes hard inside the bowel and/or is difficult to expel.

Some of the Causes May Be:

- Not drinking enough water
- Not enough fiber in the diet
- Certain medications
- Lack of activity
- Slowing down of the digestive system due to aging
- Certain illnesses such as Parkinson's disease and diabetes

It is important to have regular bowel movements even when eating only small amounts of food. Work with the Empath Health team to come up with a proactive plan to prevent constipation or to treat it effectively. Tell Empath Health about all over-the-counter medications being used as well as prescription medications.

Some Examples of Interventions that can Prevent or Treat Constipation:

- Prune juice
- Stool softeners
- Laxative tablets
- Laxative liquids
- Fiber powders added to drinks
- Suppositories
- Enemas

Early detection of constipation allows for less invasive interventions and avoids possible future discomfort. Talk to the Empath Health team about bowel habits.

Call your care team if the constipation is not relieved or getting worse.

Diarrhea



Diarrhea, or loose stools, may be accompanied by stomach cramping. If diarrhea is present keep a record of how often it occurs and notify the Empath Health nurse.

What to Do:

- Offer a bedpan or commode at least every two hours, or more often if needed.
- Increase fluid intake and encourage sipping slowly.
- Offer clear fruit juices (no pulp) as well as water. Avoid drinks with caffeine.
- Give frequent small meals such as oatmeal, strawberries, potatoes, apricots, pears, bananas, rice, applesauce or toast/crackers.
- Make sure all laxatives and stool softeners have been discontinued.
- After each loose stool, wash the rectal area with mild soap and water and apply skin protective cream.
- Make sure the commode or bedpan is readily available.
- If in bed, place in a sitting position for a bowel movement by raising the head of the bed.
- Do not remain on the bedpan/commode for long periods of time.
- Always wash hands after using the toilet, commode or bedpan.

Call your care team with any questions or if there is:

- Blood in the stool
- Nausea or vomiting
- Increased abdominal pain

Call your care team if the diarrhea is not relieved or getting worse.

Anxiety



Anxiety is a feeling of worry, nervousness or unease, typically about an imminent event or something with an uncertain outcome.

Signs and symptoms of anxiety can include feeling jittery, having a fast heart rate or breathing rate, sweating, excessive worrying, difficulty sleeping, difficulty concentrating, difficulty getting comfortable and trouble relaxing.

There can be many reasons a person feels anxious. Some common causes of anxiety include feelings of fear (of the unknown, of pain, of abandonment), loss of control or loss of independence. Also some medications and food products (for example, caffeine found in coffee and tea) can cause feelings of anxiety.

How to Help Yourself/Someone Feel Less Anxious

- Talk to someone about these feelings.
- Breathe slowly and deeply for a few minutes.
- Listen to calming music.
- Write down thoughts and feelings.
- Look at relaxing images (for example, relaxing photographs).
- When rest is needed, ask visitors to come at another time.
- Create a calm, quiet environment.
- Gently rub hands or feet.
- Reduce caffeine intake.

Breathing Assistance

If oxygen is needed, is the oxygen tank/concentrator being used correctly? Have you or someone else checked it to make sure it is functioning properly?

Take Prescribed Medications

- Anxiety medication
- Pain medication
- Medication for shortness of breath
- Other medication

Call your care team if anxiety is changing or getting worse.

Breathing, Shortness of Breath



Dyspnea is a medical term for difficult or troubled breathing. You may hear it referred to as shortness of breath, hard to breathe, heavy chest or not getting enough air.

This feeling of having difficulty breathing can be very scary and make someone feel anxious. There are things that can be done to help when this shortness-of-breath feeling occurs.

Environment

- Position properly by sitting upright and leaning forward slightly or standing and leaning forward slightly.
- Keep the room cool with circulating air (use of a fan).
- Make sure the area is calm and peaceful, allowing the person to relax.
- Stop any activity and rest.

Breathing Assistance

- If oxygen is being used, is it functioning properly?
- Pursed lip breathing (smell the roses, blow out the candle).

Medications

- Nebulizer treatment/inhaler
- Anxiety medication
- Pain medication

Call your care team if shortness of breath is not relieved.

Mouth Care



A clean mouth provides several benefits, including helping to prevent sores and possibly improving appetite. It also can help with the uncomfortable condition of dry mouth, which can be caused by mouth breathing, oxygen therapy, infrequent mouth care, a side effect of medications or a complication of radiation therapy. If your loved one cannot do mouth care, assist him or her to do so.

What to Do

- Raise the head of the bed and place a clean cloth under the chin.
- Remove any dentures and place them in a container of water.
- Allow a sip of water to moisten mouth.
- Apply toothpaste to the brush and gently brush teeth, gums and tongue.
- Allow sips of water and spitting alternately.
- Finish with cool water and/or alcohol-free mouthwash, as desired.
- If dentures were removed, brush them with toothpaste or clean them with denture cleanser before replacing them in a clean mouth.
- Leave poor-fitting dentures out of the mouth to prevent mouth sores.
- Pat lips with a clean cloth and apply non-petroleum lip balm to prevent dryness. Reapply lip balm frequently during the day.

Toothettes may be easier to use than a toothbrush. They may be obtained from the Empath team. Follow the same instructions as for a toothbrush.

Ask for special instructions for mouth care if your loved one is unconscious, unable to swallow or sit up.

Call Your Care Team if:

- Your loved one develops a sore throat or mouth sores.
- White patches are noted on the tongue, gum line or roof of mouth.

Wound Care



Keeping a clean and dry dressing on wounds promotes healing and keeps the patient comfortable. The goal of wound cleaning is to remove debris and contaminants that could damage healthy tissue.

If the patient's dressing falls off or becomes loose, it needs to be replaced. Please follow the steps below to change a dressing.

1. Prepare Workspace

- Wash hands.
- Clean work area and place a clean towel on it for supplies.
- Gather supplies:
  - Non-sterile gloves (bring 3 pairs)
  - Gauze sponges
  - Wound cleanser
  - New dressing
  - Plastic trash bag
  - Medical tape
  - Skin prep

2. Remove Wound Dressing

- Wash hands again.
- Put on gloves.
- Slowly lift edge of the dressing.
- Gently lift the dressing. Spray wound cleanser if dressing sticks to skin.

3. Clean the Wound

- Wash hands again and apply a new pair of gloves.
- Wet a gauze sponge with wound cleanser and dab the wound in circles, starting at the center and moving outward.
- Repeat cleansing with a new gauze sponge as described above.
- Pat wound dry with a new, dry gauze sponge.
- Assess for signs of infection – redness, pain, heat, odor, swelling, pus, drainage, fever, chills.

4. Apply New Dressing

- Wash hands again and apply a new pair of gloves.
- Open the dressing package, touching only the corners of the dressing.
- Open skin prep package and swab edges of the wound. Allow to dry.
- Carefully center the dressing over the wound and gently press down to secure in place.

5. Clean-up

- Place soiled dressing into plastic trash bag and place in garbage receptacle.
- Wash hands.

Contact your care team if you suspect any signs of infection or for any wound that requires packing or extensive wound care.

Safety



Special care should be used to prevent falls and injuries. If the patient needs help when walking, support them on the weakest side. Put one arm around the waist and the other forearm and hand in front of the shoulder. If a gait belt has been provided and your Empath Health nurse has provided education on its proper use, make sure it is on prior to the patient's transfer. Ask your nurse to demonstrate.

When the patient is getting out of bed, remind them to sit on the side of the bed for a few minutes. A change in position may cause dizziness or unsteadiness. If the patient becomes lightheaded, stay with them. When transferring, use care to transfer across the shortest possible distance. If in a hospital bed, adjust the level of the bed to reduce strain on your back. Ask your nurse to demonstrate.

Follow These Tips

- Lock wheels of beds and wheelchairs to prevent slipping.
- Remove throw rugs to avoid tripping and falling.
- Remove or relocate electrical cords running across the floor.
- Use bath mats or non-slip stickers in bathtub and shower.
- Place the bed near a bathroom, if possible, or place a commode near the bed.
- Do not use slippery shoes or slippers.
- Keep your back straight when lifting and bend and lift from your knees and hips. Stand as close as possible and keep feet spread for a firm base of support and good balance. Ask your nurse to demonstrate.
- Keep the electric bed in low position when patient is in the bed.
- When transferring the patient and they begin to fall, gently assist them to the floor. Do not attempt to stop or break the fall.
- Ask your nurse if fall pads are appropriate.

When to Call Your Care Team:

- If an accident or fall should occur
- If the patient complains of severe pain
- If any area (arm, leg, hip, etc.) is in an unusual position
- If fluid is draining from the patient's mouth, ears, nose, or if he or she is bleeding

Making an Occupied Bed



The best time to change the bed is just after the person has a bath, although you should periodically check for crumbs, creases or moisture as these can make the bed uncomfortable and contribute to skin breakdown.

When your loved one becomes too weak to get out of bed, follow this procedure to change an occupied bed. It is usually helpful to think of the bed as two halves: You can change one half of the bed while your loved one lies on the other, then move onto the clean half and make the other side. Ask your Empath Health team to demonstrate.



Place patient in side-lying position on far side of bed.

Fold soiled linens toward patient's back.



Place clean bottom sheet on bed with center fold close to patient's back. Patient in side-lying position on far side of bed.



Tuck in bottom sheets of bed. Patient lies on far side of bed on other half of clean sheet.

Following are Guidelines for Changing an Occupied Bed:

- Leave one pillow on the bed, placed under the head. Keep the body covered loosely with a sheet or light blanket.
- If changing in an electric bed, raise it to a height that is comfortable for you to work at the bedside.
- Help your loved one roll to one side of the bed. If in an electric bed, be sure the rail is up on the side the patient is rolling toward.
- Work from the side with the patient's back facing you. Loosen all bedding on that side and roll the bottom sheet to the middle of the bed.
- Place a fresh sheet on the bed with the middle of the sheet in the middle of the bed. If you are using a pull sheet or incontinence pad, place those in the same way.
- Tuck in the side, top and bottom of the sheet on the side you are working on, then roll the rest of the bedding to the middle of the bed, tucking the roll under the back and legs.
- Have the patient roll toward you over the folded linen and onto the clean side of the bed.
- If there's a side rail, pull it up before moving to the other side of the bed.
- Pull out the dirty linen.
- Unroll the clean bedding and tuck in side, top and bottom of sheet on the second side.
- Position the patient as the nurse has taught you, covering with a clean top sheet or blanket if desired. If your loved one prefers to be on his or her side, remember to use pillows between the knees. If the patient prefers to be on his or her back, consider placing a pillow under the lower calves to elevate the heels.

How to Say Goodbye



Saying goodbye to someone you love can be a challenging process. The goal of saying goodbye is to find peace for both people. Your Empath Health team can assist you in this process.

Suggestions for Saying Goodbye:

- Realize the dying person usually knows what is happening. Not talking about dying may create the additional stress of secrecy.
- Don't wait for the exact right moment; it may never come. Look for opportunities instead.
- Comments such as being tired of being sick, not being around for an upcoming event, or distress related to new symptoms might be a cue that your loved one is thinking about dying. Follow their lead.
- Show up. Be present. Be open to listening and sharing with your loved one. Review shared memories and accomplishments together. Circumstances and geographical distance often make this impossible to do in person. Phone calls, letters, video chat or other ways of communication can be helpful.
- Say "I am sorry, please forgive me" for any regrets you may have or issues that may have come between you.
- Offer forgiveness for any perceived wrongs or regrets, "I forgive you."
- Say "Thank you." Acknowledge the difference your loved one has made in your life and your gratitude for it. Be as specific as possible.
- Say "I love you." List the things you love and will remember about your loved one.
- Assure your loved one that you will be sad, but you will find your way and be "alright."
- Remember that hearing is the last sense to be lost. Continue to talk to your loved one even if there is no visible response. Hold a phone to their ear for people who wish to say goodbye but are not able to be physically present.
- Everyone says goodbye in their own way. Everyone experiences this journey on their own terms and there is no right or wrong way to do it.

Information inspired by "The Four Things That Matter Most" by Ira Byock, MD, and "It's Okay to Die" by Monica Williams, MD, and Kristian Murphy.

Sadness



Sadness is a normal emotion that everyone feels from time to time. It is often felt during a time of loss or anticipated loss. Someone experiencing sadness may feel a sense of disappointment, hopelessness, helplessness or despair.

Sadness can also affect someone's physical well-being. A person who is sad may feel lethargic, melancholy or lack a sense of purpose.

How to Manage Sadness

- Give yourself permission to be sad; it is a normal response to loss.
- Crying is therapeutic.
- Talk to someone about your feelings and experience.
- Focus on things you enjoy doing such as listening to music, going for a walk, drawing, painting, reading, being out in nature or writing in a journal.
- Get adequate rest. Sleep may be difficult, but try to maintain a routine schedule.
- Eat healthy foods and drink enough water.
- Find one thing in each day that brings you a moment of joy—a happy memory, a good meal, a shared laugh.
- Ask your Empath team about grief support services.

While sadness is a normal response to loss, thoughts of suicide, unexpected weight loss or an inability to perform daily activities may indicate a more serious issue. If you experience this, please seek the help of your family physician or healthcare professional.

Self-Care for Families



Caring for yourself is one of the most important things you can do as a caregiver. When your needs are met, the person you care for will benefit, too. The following are some effective tools Empath Health has identified for self-care.

Types of Self-Care

Emotional

- Watch a good movie
- Write the patient positive notes
- Verbalize and talk about feelings
- Draw self portraits
- Say "I love you"
- Spend time writing
- Have a sing-along
- Tell jokes
- Try a new craft

Spiritual

- Make a gratitude list
- Talk about forgiveness
- Write thank you letters or cards
- Volunteer
- Spend time outside or with nature
- Practice positive self-talk
- Plant a tree

Practical

- Clean up
- Declutter old toys
- Assign chores
- Make a grocery list together
- Learn about money
- Make a weekly budget check-in
- Make a weekly cleaning check-in
- Homework/study
- Have a morning and night routine

Physical

- Have a dance party
- Go for a walk
- Take a family bike ride
- Take a hike
- Play kickball
- Play tag
- Go roller skating
- Go to the pool
- Jump rope
- Practice yoga
- Play active video games

Mental

- Read together
- Draw or write stories
- Meditate
- Find shapes in clouds
- Practice belly breaths
- Go on a walk to find new things
- Make vision boards
- Try Headspace for kids
- Create mandalas
- Make mindfulness jars
- Play mind strength games

Social

- Play in the park
- Call or visit relatives
- Have a family dinner
- Play board games
- Host a sleepover
- Invite friends over
- Plan a BBQ
- Join a team
- Do a neighborhood food drive
- Have talks about friendship and how to be a friend

Remember your care team is here to support you. Contact them if additional support.

Your Questions/Concerns

Use the following pages to take notes of questions or concerns you want to share with your care team on their next visit. Remember, we are available to you 24/7 to address any questions or concerns that need to be addressed before then.

Your Questions/Concerns Continued

Use the following pages to take notes of questions or concerns you want to share with your care team on their next visit. Remember, we are available to you 24/7 to address any questions or concerns that need to be addressed before then.

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Empath Hospice
(855) 843-3935

Hospice of Marion County
(352) 873-7400

Suncoast Hospice
(727) 467-7423

Suncoast Hospice of Hillsborough
(813) 651-7300

Tidewell Hospice
(941) 552-5900

Trustbridge Hospice
(888) 441-4040

Emergency Line
(888) 855-2838

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HOS-24-0287
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