



EMBRACING WHOLE-PERSON CARE WITH A TERMINAL ILLNESS

A Brief Guide Rooted In Being
Organically Human

FOR YOU & YOUR SUPPORTERS



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THE DIAGNOSIS CONVERSATION:

“YOU/THEY HAVE A TERMINAL ILLNESS WITH LIMITED TIME”

GUIDE INTRODUCTION

You or someone you love has been diagnosed with a terminal illness. This means the illness is progressive, unresponsive to treatment, no medical interventions can cure it, and time is limited. In this moment, it might feel like the ground beneath is now completely distorted - leaving you all standing in a space you never imagined you'd be. So, what now?

Some of the hardest questions to ask is: **“Do I/you want to continue treatment that will not cure but may prolong life with difficult symptoms? Do I/you want to refrain from treatment & refocus on quality of life and pain management in the time that remains? Do I/you want to continue treatment for a certain duration of time?”** These are not easy questions, but it opens the door to choices and exploration.

Understanding the difference between Palliative Care and Hospice Care can help make informed decisions and feel confident that all options have been explored. We will discuss this more in section 3.

As humans, we are conditioned to act—to fight, to fix, to hold on. The idea of shifting to different types of medical treatment or refraining from it can feel like surrendering something too precious to lose. But what if this time wasn't about fighting? What if it was about living—truly living—in a new, unexpected yet meaningful way?

This guide isn't here to give you a roadmap or tell you what to do or how to feel. It is something you can come back and reference again and again as the journey develops, no matter what type of care you choose. It's here to walk alongside you as a gentle companion. It offers comfort, validation, and practical insights to help you navigate this difficult journey. Most of all, it's a reminder that love, connection, and presence can soften even the sharpest edges of grief and uncertainty.

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PROCESSING & FEELING:

Making Enough Space

When you or someone you are supporting is now faced with a terminal illness: grief, shock, and overwhelm can snowball and may feel like a complete loss of control. Processing and feeling aren't something that is completed—they're part of the journey, constantly showing up in every moment, again and again.

Give Yourself Permission to Feel

Sadness, anger, fear, confusion—even moments of relief or gratitude—are all valid, raw, and real. Let yourself cry, scream, sit in silence, write, or create. Let yourself be human. There's no right way to grieve, no timeline, and no "finish line." For supporters, creating space for your loved one's emotions is as important as honoring your own. Sit in silence with them, listen without trying to fix and giving advice, or simply be present.

Finding Balance

Denial can keep you stuck in resistance, while depression can make it hard to engage with the time you have left. Let yourself visit these places, but don't live there. Processing emotions doesn't mean getting rid of the pain—it means letting it move through you so it doesn't weigh you down as heavily.

Emotions Are Nonlinear

Grief isn't a straight line. It's messy and will come in unexpected and new ways, sometimes bringing back emotions you thought you'd already processed. This is normal. Let go of judgment—whether for yourself or others—and focus on allowing the feelings to surface as they need to.

The Importance of Allowing

By allowing space for emotions, you create room for connection, clarity, and even healing. Processing doesn't erase pain, but it can soften its grip, helping you remain present in the unknown.

REFRAMING & REWORKING GOALS:

Shifting Focus to the Moment

It's deeply ingrained in us to fight for life, to do everything possible to survive. When faced with a terminal illness, survival often becomes the driving force. When survival is no longer the only goal and we may need to be expansive on how we care for ourselves, it can be difficult to imagine what's next. The truth is, there are still opportunities to create rich, meaningful, and purposeful moments. It's about redefining what's important during this time, managing care, being supported by others, and finding peace amidst the uncertainty, unfamiliar, and unexpected.

Reframing Survival

Rather than focusing on what's no longer possible, shift the perspective to: "I/they are alive now—what moments can we create that bring joy, connection, or lasting reminders of this life?" This reframing allows a shift of energy - away from resisting the inevitable and toward embracing the time that is here now.

Redefining Goals

When survival is no longer the primary focus, new goals emerge—prioritizing connection, joy, legacy, and well-being. These goals may seem simple, but they're deeply meaningful. Managing pain and anxiety is just as crucial, helping you stay present and in control of the moments that matter.

- **Connection:** Spend quality time with loved ones, share stories, attend special events, or express unspoken feelings to strengthen bonds.
- **Joy:** Enjoy simple pleasures like watching a favorite movie, listening to music, feeling the warmth of the sun, or savoring a favorite meal.
- **Legacy:** Create keepsakes, record memories, or write letters—these tangible pieces of your life offer lasting comfort and connection.
- **Well-being:** Actively manage pain and anxiety through treatments or relaxation techniques. Focus on rest and moments of peace to improve emotional and physical comfort.

The Gift of Presence

By reframing and reworking goals, you give yourself or your loved one permission to focus on more than the illness. The gift of presence—noticing and savoring the small, meaningful moments that arise—can bring profound peace and purpose in a time that feels otherwise overwhelming. Embracing these moments, as fleeting as they may seem, can offer profound peace.

UNDERSTANDING PALLIATIVE CARE & HOSPICE CARE:

A Gift, Not Giving Up

Understanding the difference between Palliative Care and Hospice Care is essential for making well-informed decisions that make you feel you still have control and can formulate what you/they deem as quality of life.

- **Palliative Care:** If you decide to continue treatment, Palliative Care is available to help manage symptoms and improve quality of life alongside your treatment plan. It focuses on relieving pain, managing symptoms, and supporting emotional and spiritual well-being. Importantly, Palliative Care is not Hospice Care—it can be provided at any stage of illness and is often used to complement curative treatments. Sometimes you have to be the one to bring this model of care up. Speak with your doctor to request a referral.
- **Hospice Care:** If you decide to discontinue treatment, a referral to Hospice sooner rather than later can provide the best support for comfort and quality of life. Hospice is for when curative treatments are no longer effective, and your doctor has deemed life expectancy is six months or less. However, life expectancy can go beyond this projection and the assessment is done to receive the Medicare benefit while the exact length of time is never truly known.

Reframing Hospice: The Truth About Its Purpose

There's a lot of misunderstanding about Hospice Care. You might have heard things like, "Hospice just gave them drugs and made them die faster." Here's the truth: hospice doesn't cause death—it supports the natural process. When someone is already dying, hospice ensures that their final months, weeks, or days are filled with as much comfort and dignity as possible. If you or someone chooses to enroll in Hospice early, it isn't "giving up hope"—it's choosing to lean into care that focused on comfort and well-being. Hospice isn't about prolonging or hastening death; it's about making the time that remains as peaceful and meaningful as possible.

UNDERSTANDING PALLIATIVE CARE & HOSPICE CARE:

A Gift, Not Giving Up

What Hospice Provides

Hospice offers a team of compassionate professionals to support both the dying person and their caregiver and support system:

- **A Team:** Doctors, nurses, social workers, chaplains, and volunteers to address physical, emotional, and spiritual needs
- **Pain Management:** Ensuring the body is comfortable and relaxed, allowing for a more peaceful transition
- **Emotional and Spiritual Support:** For both the individual and their circle of support, providing comfort and guidance through this sacred time
- **Location:** Hospice is not a place you go. It is a service that comes to where you/they consider home. Sometimes this can be a house, assisting living home, hospital, etc. There is Hospice Care Centers in most cities when symptoms are not able to be controlled “at home” and is also an option for respite for the caregiver.

Adding an End-of-Life Doula

Hospice Care, when paired with an End-of-Life Doula, creates a more holistic web of support. Doulas focus on the emotional, non-medical aspects of the journey. They provide:

- Presence, companionship, advocacy
- Help with creating meaningful moments and honoring legacy
- A calm, grounding presence for the dying and their supporters
- Logistical End-of-Life Planning + Documentation + Education

Doulas complement Hospice Care by filling in the gaps with time and death & dying training - focusing on what makes this time uniquely meaningful for the person and their supporters. Together, Hospice and Doulas ensure that this sacred transition is met with compassion, dignity, and love.

CREATING MEANING:

Love, Forgiveness, Ceremony, Legacy

Creating Meaning

Just as birth is a sacred beginning, death is a sacred transition. While the physical body may fade, the love, memories, and impact someone has made continue to live on in those they leave behind. Creating meaning is not just something to focus on at the end of life; it's an essential part of every stage, especially in the face of a terminal illness. This time offers a unique opportunity to reflect on, honor, and enrich the legacy you've created. The remaining days, no matter how few, can still be filled with purpose, connection, and moments that matter.

How Do I/They Want to Spend This Time?

Creating meaning doesn't require grand gestures—it's about presence. Sitting together, holding hands, and making space for connection are often the most profound acts of love.

For some, this might mean:

- Life reviews, art, creativity, making space for grief & difficult conversations
- Planning unique rituals, ceremonies, or gatherings that honor personal values
- Connecting with spirituality or faith practices
- Meditation, yoga, visualization
- Documenting journey with openness & honesty

For others, it may mean making amends, offering forgiveness, or finding peace in unfinished conversations.

Ideas for Meaning-Making

- Recording memories: Letters, videos, or messages for loved ones. Have someone transcribe while you/they are talking, documenting recipes
- Living Farewell gatherings: A small meal, celebration, or ritual. There is no limit to having multiple gatherings centered around various themes based on where you/they are at in their processing journey
- Simple joys: Engaging the senses that are accessible, lighting candles, tasting a special drink, creating a special altar of favorite items/memories

These moments don't need to be elaborate—what matters is that they reflect your/their unique life and relationships.

A Time of Connection

While this time is difficult, it can also bring profound closeness. By focusing on love and connection, you create a space to honor the fullness of life and the bonds that will always transcend death.

ADVANCE CARE DIRECTIVES & END OF LIFE PLANNING

Last Gift of Clarity

Talking about end-of-life plans can feel overwhelming, but it is one of the most loving and compassionate gifts you can give—to yourself and those left behind. These conversations provide clarity, reduce uncertainty, and ensure that your wishes, or those of your loved one, are honored without guilt or guesswork. Everyone should have an Advance Care Directive in place. It is not just for those with a terminal illness.

Advance Directives: Clarifying Your Wishes

Advance Directives are essential tools that guide medical decisions when someone is no longer able to communicate their preferences. They typically include:

- **Living Will:** A document that outlines what quality of life means to you (or your loved one) and the types of medical interventions you would or would not want.
- **Medical Power of Attorney (POA):** A trusted person appointed to make healthcare decisions on your behalf if you cannot.

When selecting a POA, it's important to choose someone who can carry out these wishes with love and clarity, even in emotionally difficult moments.

End-of-Life Planning: Easing the Burden

End-of-life planning goes beyond medical decisions. It helps organize practical and logistical details, allowing the focus to remain on love, connection, and peace. Some key aspects include:

- **Organizing important information:** Compile passwords, financial details, and legal documents in one accessible place. Avoidance of probate is helpful for those left behind. Speaking with an estate attorney will assist in your own unique situation re: trusts, assets, last will & testament, naming beneficiaries & executor of will
- **Funeral or celebration of life planning:** Outline your preferences for how you would like to be honored, from ceremonies to personal touches, planning & sitting vigil (who is there/who is not there) after-death care / body disposition
- **Other logistical + emotional concerns:** Wrap up unfinished tasks—whether it's handling finances, canceling subscriptions, or preparing letters or specific items that need to go to loved ones.

These preparations not only reduce stress for those left behind but also ensure that your life is celebrated in the way you envision.

Why It Matters

End-of-life planning isn't about control—it's about care. It removes unnecessary stress and leaves fewer questions for loved ones during a deeply emotional time. By addressing these decisions now, you give the gift of clarity, allowing everyone to focus on what truly matters: love, connection, and joy.

This time is about creating peace for everyone involved. The conversations may feel heavy at first, but they offer a profound opportunity to honor the values, wishes, and legacy.

DEATH & DYING EDUCATION

Knowledge is Empowerment

Death can feel unfamiliar and terrifying as it is not a topic our society is truly comfortable with educating on or incorporating into our lives. Just as the body knows how to live, it knows how to die. No matter what stage of living we are in, having knowledge of the natural process could help ease fear, foster acceptance, and create peace for everyone involved while still companioning anxiety and fear. Even if death feels distant, learning about the dying process now can help us feel empowered. It also helps create awareness and understanding, so when changes do come, you'll feel more prepared and less overwhelmed by what you are experiencing or witnessing.

Some Examples of What to Expect: The physical process of dying is normal, though it may look unfamiliar. Hospice and End-of-Life Doula's can assist in educating on the below and the timing of what these signs mean.

- Breathing changes: Cheyne-Stokes breathing (irregular or paused breathing) is common as the body slows, labored breathing, "fish out of water" breathing
- The Rally: A burst of energy or clarity before decline, often misunderstood as improvement.
- Terminal secretions: The "death rattle," a sound caused by throat secretions, can often be eased by repositioning - it is not harmful for the person.
- Mottling: Visible discoloration on the skin that appears in a purple/pinkish color. It results from poor blood circulation as the body begins to shut down.
- Visioning: Seeing deceased loved ones or describing peaceful visions, a common and sacred part of dying. Be open and ask questions; refrain from diminishing what they are seeing.
- Withdrawal: Reduced responsiveness, which reflects an inward focus on the dying process - they are teetering in and out of the physical body. Progressing to non-verbal and not able to respond to environment
- Unique Death & Dying: Everyone's dying process is unique and not everyone experiences all of these signs but it is important to be aware of what is normal. Dying is not painful, the disease they are dying from is what makes it painful.

Understanding the Body's Needs

As the body declines, its needs change. Food and drink, once symbols of life and care, are often no longer required in the same way. For many, this can be difficult to accept. We associate eating with love, nourishment, and strength. Reframe this change: the body is conserving its energy and naturally letting go of what it no longer needs. The phrase from Hospice Nurse & Educator Barbara Karnes "always offer, never force" is key. Offering food and drink shows care and gives options on having autonomy, but forcing them can create discomfort. Let the body guide you—it knows what it needs to feel comfort and peace.

Sitting Vigil: Hearing is the Last Sense to Go

Even when unresponsive, a dying person can often hear. Talk as you always talked to them, play calming music, or sit in silence. Their environment matters—keep it soothing, supportive, and filled with warmth. Having conversations about what you/someone wants the setting to look like and represent your/their life while communicating who should be present and should not be.

Surrendering to the Process

Dying is a natural part of life, like birth. Read that again. **Dying is natural.** Tension and unmanaged pain can make it harder for the body to let go, so comfort care—relaxation, pain relief, and emotional support—is key. Hospice and End-of-Life Doula's can help create a peaceful transition. In addition, sometimes the body may linger due to how you/they lived their life, unresolved trauma, waiting on visitors, wanting to transition alone, or fear.

How This Helps

Understanding the signs of dying shifts the experience from something looking completely obscure to normal and expected. No matter what it will be difficult to process and introducing more education around it can provide support in the processing of what is happening.

COMPASSION & HUMOR

Lifelines for the Journey

When life feels consumed by the weight of a terminal diagnosis, compassion and humor can be lifelines, reminding us we are still human and it's okay to care for ourselves in different ways and LAUGH!

Compassion for Yourself

Whether you're the one dying or supporting a someone, this journey demands energy—emotional, physical, and spiritual. Self-compassion means giving yourself permission to rest, feel, and step away when needed. For supporters, this might look like taking a quiet moment for tea, setting boundaries, or asking for help. For those dying, it's about letting others care for you without guilt, finding small joys, and practicing self-forgiveness. Compassion isn't about perfection—it's about showing up as best you can and allowing space for grace.

Compassion for Others

When emotions run high, small irritations can feel magnified. Compassion reminds us that everyone is doing the best they can with the uncontrollable circumstances. Choose understanding over criticism, and forgive yourself or others when stress or frustration arises.

Humor: A Balm for the Soul

Laughter might feel unnatural or unexpected, but it can remind us we are human with the ability to experience more than one emotion at once. A shared joke or funny story isn't a betrayal of grief—it's a celebration of being alive. Humor helps us feel connected and gracious. Laugh at the small things: Grandpa's pants, a funny family memory, or even an awkward moment. Humor doesn't erase pain, but it can bring happy feelings to a strange yet sacred time.

Why It Matters

Taking care of yourself—whether you're the one dying or supporting— isn't selfish; it's essential. Compassion and humor create space for rest and joy, making the journey more bearable and meaningful. We cannot receive or give if we are not refilling ourselves. If you're dying, be vocal...be loud...about what you need and what you don't need.

A FINAL NOTE

From Organically Human

Whatever you're feeling right now is completely valid—this situation is devastating, whether it's you or someone close to you experiencing the grief of losing time, plans, and the future.

You are not alone. You are loved. You are enough.

The path ahead will have many layers, and it will be as individualized as each person walking it. We are all complicated, diverse, and beautiful beings. This guide is designed to be a living resource—something you can come back to as you move through different stages of the journey. It may offer insight at times you didn't expect, and speak to you in new ways as you process.

If you need more resources, conversations, or support, it's always there for you.

If you have any questions or need more end-of-life support, please don't hesitate to reach out:

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or visit:

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Sending you love + light xo