



A Guide for Families and Caregivers:

Understanding the End-of-Life Journey

Prepared for those who give care with love, courage, and dedication.



A Note to You, the Caregiver

The role you are filling right now may be the most profound thing you ever do for another person. Caring for someone as they move through the final chapter of life is not easy — it is exhausting, disorienting, and deeply emotional. And yet, it can also be one of the most meaningful experiences of a lifetime.

Many caregivers say the same thing: they did not know what to expect, and that uncertainty was one of the hardest parts. This guide was created to help with that. Not to make death feel simple, but to help you feel less alone in the unknowing — and more prepared to be present.

The dying process is natural. It follows patterns that have been observed and documented over many generations of hospice care. While no two people experience it in exactly the same way, there are common changes — physical, emotional, and behavioral — that tend to appear as the body prepares to let go. Knowing what those changes look like, why they happen, and how to respond can make a real difference in the quality of care you provide and in your own sense of peace.

"You do not need to fix anything or have the right words. Your presence — steady, loving, and calm — is the most powerful gift you can offer."

This guide is organized to walk you through the most common aspects of the end-of-life journey. Read it at your own pace, return to specific sections when needed, and do not hesitate to reach out to your hospice team at any time. You are not doing this alone.

The Inner Work of Dying

Much of what happens near the end of life is invisible — it takes place inside the person, not on the surface of their body. Understanding this inner dimension can help you respond with greater compassion and calm.

Turning Inward

As the body slows down, so does the person's engagement with the outside world. They may grow quieter, sleep more, and seem less interested in news, visitors, or the daily routines that once mattered to them. This is not sadness or resignation — it is a natural inward turning that allows a person to focus their remaining energy on the deeper work of dying.

This withdrawal can be painful for those who love them. When someone stops asking about the grandchildren or turns away from a favorite television program, it can feel like loss — because it is a kind of loss. Give yourself permission to grieve these small goodbyes even as you continue to show up.

Finding Completion

Many people near the end of life experience a quiet but powerful need to feel that things are finished — that relationships are at peace, that love has been expressed, that wrongs have been forgiven. Whether or not a person can voice this, you may sense it in the way they reach for a hand, hold a gaze a moment longer than usual, or become calm in the presence of a particular person.

This is meaningful work. If there are conversations left to have, forgiveness left to offer or receive, or simple words of gratitude or love still unspoken, the time around end of life often creates the space — and the urgency — to say them.

Letting Go

Dying requires a person to release everything they have known: their body, their relationships, their identity, their future. This is no small thing. Some people move through it with surprising grace; others struggle and resist. Both responses are human.

What caregivers can offer in this space is not answers, but presence. Sitting quietly beside someone. Holding their hand. Speaking softly. These things matter more than any words, and they communicate something that words cannot: you are not alone, and you are loved.

"Being there — truly, fully there — is the whole of it. You are already doing something extraordinary."

Changes in Communication and Social Connection

What Happens

In the weeks and days leading up to death, most people gradually become less communicative. Conversations grow shorter. A person who once loved to talk may now be content with silence. They may stop initiating contact, show less interest in visitors, and spend increasing amounts of time sleeping. Toward the end, they may become largely unresponsive, even when awake.

Why It Happens

As the body's systems begin to slow, the brain receives less oxygen and the person's energy is redirected toward internal processes. Social interaction, which requires significant cognitive energy, becomes less possible and less necessary. This withdrawal is the body's way of conserving what remains.

It Is Normal

This is one of the most consistent and well-documented patterns in the dying process. It is not a sign of depression, rejection, or that the person has given up on those they love. It is simply the body preparing itself.

HOW YOU CAN HELP

- Schedule visits and meaningful activities during the times of day when your loved one seems most alert — often mid-morning for some, or early afternoon.
- Hearing is believed to be one of the last senses to diminish. Continue to speak naturally and warmly, even if there is no visible response.
- Identify yourself by name each time you speak. Let the person know what you are about to do before you do it: "Mom, it's Sarah. I'm going to help you turn over now."

- Be mindful of what you say in the room, even when the person appears asleep. Assume they can hear you.
- Silence is not empty — it can be deeply comforting. Simply sitting together, holding a hand, or resting nearby is enough.

Changes in Appetite and Thirst

What Happens

As death approaches, a person's interest in food and drink typically diminishes significantly, and eventually disappears. They may reject meals they once loved, take only a few sips of liquid, or simply turn their head away when food is offered. In the final days, they may stop eating and drinking entirely.

Why It Happens

The body is shutting down its systems in an orderly way. The digestive tract slows dramatically, and the body can no longer process nutrition the way it once did. Forcing food at this stage does not restore strength — it can actually cause discomfort, as the body is no longer equipped to handle it. This loss of appetite is not starvation; it is a sign that the body no longer needs external nourishment.

It Is Normal

This is one of the most difficult things for families to accept, because feeding someone is how we show love and care. Watching a loved one stop eating can feel like abandonment. But the hospice perspective is clear: not eating near the end of life does not cause suffering. In fact, the natural fasting that accompanies dying may release compounds in the body that contribute to comfort and even a gentle sense of euphoria.

HOW YOU CAN HELP

- Follow the person's lead. Do not push food or fluids. Offer small amounts gently, and accept a refusal without distress.
- If they can still swallow safely, small ice chips, sips of water, or a damp sponge swab on the lips can provide comfort.
- The smell or taste of a favorite food in small quantities may still bring pleasure, even if nothing is swallowed.

- Perform frequent mouth care — gently moistening the lips and mouth with a damp swab prevents dryness and discomfort.
- Resist the instinct to interpret reduced eating as suffering. Ask your hospice nurse if you are uncertain about any signs of discomfort.

Changes in Urination and Bowel Function

What Happens

As the body's circulation diminishes and fluid intake decreases, urine production typically declines. The urine that is produced may become very dark, concentrated, or have a strong odor. Incontinence — loss of bladder or bowel control — may also occur as the muscles in the lower body relax.

Why It Happens

The kidneys receive less blood flow as circulation is redirected to the body's core. This causes them to produce less urine and to filter less effectively. Muscle tone throughout the body, including the sphincters that control elimination, gradually decreases as part of the natural dying process.

It Is Normal

These changes are expected and not a sign of infection or crisis in most cases. They reflect the body's normal winding-down. Dark or decreased urine is a reliable indicator that death may be days or hours away. Incontinence, while uncomfortable to manage, does not indicate that the person is in pain.

HOW YOU CAN HELP

- Use disposable absorbent briefs and waterproof bed pads to manage incontinence comfortably. Your hospice aide can demonstrate how to change these for a person who is bedbound.
- Check and change the person frequently to prevent skin breakdown. Keep the skin clean and dry.
- Apply skin barrier creams or ointments as recommended by your nurse to protect sensitive skin.
- A urinary catheter may be recommended by the nurse to reduce skin exposure to urine. This is a simple, minimally uncomfortable procedure when done properly.

- Protect the person's dignity during all personal care — provide privacy, work quietly and gently, and avoid drawing attention to changes in elimination.

Changes in Breathing

What Happens

Breathing patterns often change significantly in the final days and hours of life. You may notice breathing that is slower than usual, or alternating periods of rapid breathing followed by pauses that can last anywhere from a few seconds to a full minute. As death draws very near, breathing may become shallow, irregular, and audible — sometimes with a low rattling or gurgling sound caused by relaxed throat muscles and accumulated saliva.

Why It Happens

The body's respiratory center in the brain becomes less active as oxygen levels shift and circulation decreases. The alternating pattern of breathing and pausing — sometimes called Cheyne-Stokes respiration — is a neurological response to reduced blood flow to the brain's breathing centers. The "death rattle" sound, while distressing to hear, occurs because the person is no longer able to swallow or cough effectively, and secretions pool in the back of the throat.

It Is Normal

These breathing changes, including the sounds they produce, are not signs of suffering or air hunger. They are signs that the body is nearing completion. The person is typically unaware of these changes. Suctioning is not recommended and often causes more distress than relief.

HOW YOU CAN HELP

- Gently repositioning the person onto their side can help secretions drain by gravity and may reduce the rattling sound.
- Elevating the head of the bed slightly (15 to 30 degrees) can also ease breathing and reduce congestion sounds.
- If the person appears to be struggling or laboring to breathe, contact your hospice nurse. Medication can be prescribed to ease breathing discomfort significantly.

- Continue mouth care to keep the mouth from becoming dry, as the person is often breathing with their mouth open at this stage.
- Stay calm. The sounds of changing breath can be alarming, but your calm presence is reassuring to the dying person even when they cannot respond.

Skin Color and Body Temperature Changes

What Happens

As circulation diminishes, the skin's color and temperature change noticeably. The hands and feet may feel cool or cold to the touch, while the person's face or torso may remain warm. Skin may take on a pale, gray, or yellowish tone. You may notice a bluish or purplish discoloration in the knees, ankles, wrists, and around the lips and fingernails — a condition called mottling. Some people also develop a fever in the final days, while others feel cold.

Why It Happens

The heart becomes less effective at circulating blood through the body, and the body instinctively draws blood away from the extremities to protect the vital organs. This causes coolness and color changes in the hands, feet, knees, and other peripheral areas. The mottled, blotchy pattern of color reflects this uneven circulation. Fever may occur because the brain's temperature regulation center is no longer functioning normally.

It Is Normal

Mottling and cool extremities are reliable signs that death is likely within hours to days. These changes do not cause discomfort. Fever is more variable — it may or may not cause distress and your hospice nurse will guide you on whether treatment is appropriate.

HOW YOU CAN HELP

- Use lightweight, breathable blankets for warmth. Do not use electric blankets, which can cause burns when circulation is poor.
- If the person feels warm and seems uncomfortable, remove blankets, apply a cool damp cloth to the forehead, or increase air circulation with a fan.

- Do not assume the person is cold because the room feels cool to you — their perception of temperature may be very different from yours.
- Gentle hand or foot massage may be soothing if the person is comfortable with touch. Check with your nurse first, as some individuals have fragile skin.
- Notify your hospice nurse when you first observe mottling, especially if it appears above the knees — this is an important sign for your care team.

Confusion, Visions, and Symbolic Communication

What Happens

Many people nearing death experience a form of altered consciousness that can look like confusion, delirium, or hallucination. They may not know what day it is, where they are, or who is in the room. They may speak to people who are not visibly present — often deceased relatives or beloved figures from their past. They may use unusual language that seems to reference a journey, a destination, or leaving: "I need to get ready," "I have to go," "Help me find my coat," or "The boat is here."

Why It Happens

Reduced oxygen and altered brain chemistry in the dying process shift the way the brain perceives and processes experience. Some researchers and hospice clinicians believe that what looks like confusion may actually be a form of expanded awareness — a transition experience that is meaningful to the person having it, even if it cannot be fully understood from the outside.

It Is Normal

These experiences are reported so consistently across cultures, settings, and medical conditions that they are now considered a recognized part of the dying process. Whatever their ultimate nature, they appear to bring comfort more often than distress. Do not dismiss or argue with what the person reports experiencing.

HOW YOU CAN HELP

- Listen without judgment. If a person says they can see their mother standing at the foot of the bed, do not contradict them. Respond gently: "That sounds peaceful. Is she saying anything?"

- Speak slowly, simply, and soothingly. Reorient gently as needed: "You're at home, in your bedroom. I'm right here with you."
- Minimize stimulation in the room — lower the lights, turn off televisions, reduce the number of visitors. A quieter environment often reduces agitation.
- Pay attention to symbolic language. Statements about needing to travel, get packed, or find their keys may be the person's way of telling you they are getting ready to go. Receive this with openness.
- If the person seems frightened or agitated by their experiences, contact your hospice nurse. Medication can help ease distress significantly.
- Consider writing down what the person says during these moments. Many families find these accounts meaningful and comforting later.

Restlessness and Agitation

What Happens

Some individuals experience a period of significant restlessness in the final days of life — sometimes called terminal restlessness. They may pick at their bedding, make repetitive motions with their hands, attempt to get out of bed, call out, or seem unable to settle no matter what is done to comfort them. This can be one of the most distressing experiences for families to witness.

Why It Happens

Terminal restlessness can have multiple causes, including decreased oxygen to the brain, pain or physical discomfort that the person can no longer communicate clearly, the effects of medications being metabolized differently, a full bladder or constipation, or unresolved emotional and spiritual distress. In many cases, it is a combination of physical and non-physical factors.

It Is Normal

This is a recognized pattern in hospice care and does not mean that something is catastrophically wrong or that you are failing. It does mean your hospice team needs to know about it promptly so the cause can be assessed and comfort measures — including medication — can be adjusted.

HOW YOU CAN HELP

- Contact your hospice nurse as soon as restlessness appears. They will assess for physical causes such as pain, a full bladder, or medication issues, and adjust the care plan accordingly.
- Speak in a quiet, calm, low voice. Avoid speaking loudly or over-explaining. Short, reassuring phrases work best: "You're safe. I'm right here."
- Try a gentle hand hold, a light touch on the arm, or simply sitting very close. Physical presence can be grounding.
- Minimize noise, bright lights, and multiple people speaking at once. Create as calm an environment as possible.
- Some people are soothed by soft music, nature sounds, or the sound of a familiar voice reading aloud.
- If there are unresolved personal matters — an apology unspoken, a relationship still in tension — consider whether a conversation, letter, or the presence of a specific person might bring relief.
- Bed rails can be used for safety, but restraints are strongly discouraged as they typically increase rather than reduce agitation.

Unexpected Clarity and Surges of Energy

What Happens

Occasionally — and sometimes remarkably — a person who has been largely unresponsive or very weak for days will suddenly become alert, communicative, and even energetic. They may ask for a specific food, recognize everyone in the room with unusual clarity, want to sit up or have a conversation, or speak lucidly for the first time in days.

Why It Happens

The exact mechanism is not fully understood, but this phenomenon — sometimes called terminal lucidity — is well-documented in hospice and palliative care literature. It may represent a final rallying of the body's neurological resources. It is typically brief, lasting anywhere from a few minutes to a few hours.

It Is Normal

This surge of clarity, while extraordinary to experience, is not a sign of recovery. It is usually followed by a deepening of the dying process, often within hours to days. However, it is a gift — and should be received as one.

HOW YOU CAN HELP

- Welcome this time without trying to analyze it or measure what it means. Simply be present.
- Use the opportunity to say what needs to be said. Express love, gratitude, and goodbye. Ask questions you've been holding.
- If other family members want to be present, contact them quickly — this window may be brief.
- Avoid interpreting this as a sign that the person is getting better. Prepare yourself and your family that it may be followed by a significant decline.

"Sometimes the most extraordinary moments come at the very end. Receive them as the gifts they are."

The Conversation of Goodbye

Giving Yourself Permission

Many caregivers wonder whether it is appropriate to say goodbye — whether it will somehow hasten death, or whether it will communicate something unintended. The answer, consistently offered by hospice professionals, is that expressing love and farewell does not hasten death. It offers comfort. And it is one of the most healing things a human being can do for another.

Saying goodbye is not about having the perfect words. There are no perfect words. It is about showing up — sitting close, holding a hand, letting the person know that they are loved, that they will be remembered, and that it is safe for them to go.

Practical Guidance

HOW YOU CAN HELP

- Use the person's alert periods to say what matters most. Do not wait for a "better time."

- Simple phrases carry enormous weight: "I love you," "Thank you," "I'm so glad you're my father," "You can rest now — we will be okay."
- Some people find it helpful to explicitly give their loved one "permission" to let go. Holding their hand and saying, "It's alright to go. You don't have to hold on for us," can bring profound peace to both the dying person and the caregiver.
- Unresolved conflicts, long-held grudges, or things left unsaid can be addressed — briefly, honestly, and with love. You do not need the other person to respond to have a healing conversation.
- Tears, laughter, and silence are all equally valid. Follow what is authentic to you.
- If you are not ready to say goodbye, that is also valid. Simply being there is enough.

"There is no wrong way to love someone at the end of their life."

A Timeline of Changes: What to Expect and When

Every person's dying process is unique. The following is a general framework drawn from extensive hospice experience. These changes may appear earlier or later, in different order, or some may not appear at all. Use this as a guide, not a prediction.

ONE TO THREE MONTHS BEFORE DEATH

- Increased time sleeping, sometimes 16 or more hours per day
- Decreased interest in activities, hobbies, and social engagement
- Reduced appetite with gradual weight loss
- Communicating less; conversations becoming shorter or less frequent
- A growing inward focus; desire to have fewer people around
- Emotional work of reflection, meaning-making, and spiritual preparation

ONE TO TWO WEEKS BEFORE DEATH

- Significant increase in sleep; difficulty staying awake even briefly
- Disorientation to time and place; may not recognize familiar faces consistently

- Appearance of visions or conversations with deceased loved ones
- Use of symbolic or metaphorical language about travel or leaving
- Cessation of eating; taking only sips of liquid
- Measurable physical changes: blood pressure decreasing, pulse changing in rhythm or rate
- Skin color beginning to change; pallor or subtle grayish tone
- Temperature regulation becoming erratic

DAYS TO HOURS BEFORE DEATH

- Sleeping almost continuously; very difficult to rouse
- Possible brief surge of alertness or energy before deepening decline
- Breathing becomes irregular — long pauses followed by rapid breaths
- Audible rattling or gurgling sounds with breathing
- Mottling (blotchy discoloration) appearing on knees, ankles, and feet
- Extremities becoming cold; skin color deepening toward blue or purple
- Jaw relaxing; mouth may stay slightly open
- Significant decrease in urine output or no urine
- Eyelids may no longer close fully
- Restlessness may appear and then diminish into stillness

THE FINAL MINUTES

- Breathing becomes very shallow with increasingly long pauses
- No response to voice or touch
- Skin becomes pale, cool, and still
- One final, long breath — and then stillness

The Moment of Death

What You May Observe

When death occurs, breathing will stop completely. There will be no heartbeat, no response to voice or touch, and no movement. The eyes may be partially open, with pupils that are fixed and do not react to light. The jaw will relax and the mouth will likely fall open. The body becomes still in a way that is unlike sleep — peaceful, complete, and unmistakable.

Sometimes there is a small release of air from the lungs, or brief muscle relaxation in the bowel or bladder. These are natural physiological responses and do not indicate any distress.

You Have Time

One of the most important things to know is this: there is no emergency. When your loved one has died in a hospice setting, you do not need to call 911. You do not need to rush. The body can remain undisturbed for as long as you need — many families take an hour or more to simply be present before calling anyone.

What to Do

HOW YOU CAN HELP

- Call your hospice nurse. They will come to confirm the death, remove any medical equipment, provide guidance on next steps, and offer support. This is exactly what hospice is for.
- Call the people who need to be present — family members, a spiritual advisor, a close friend. There is time.
- When you are ready, the hospice team will help you contact the funeral home. You do not need to have a funeral home selected in advance, but it is helpful.
- Honor your loved one in whatever way feels right to you and your family. Light a candle. Play meaningful music. Sit in silence. Pray. Tell stories. There is no correct way to mark this passage.
- Do not be alarmed if you feel calm, numb, relieved, or even strangely peaceful — alongside grief. All of these responses are normal after a death that has been anticipated and prepared for with love.

"Death is not the opposite of life. Life and death are two sides of the same sacred whole."

Taking Care of Yourself

Caregiving is one of the most demanding things a person can do. The physical demands are real: disrupted sleep, physical exertion, long hours, and little time for yourself. The emotional demands are equally real: anticipatory grief, the ongoing stress of uncertainty, the weight of love in a painful situation.

You cannot give from an empty vessel. Your wellbeing matters — not just for your own sake, but because your loved one deserves a caregiver who is, as much as possible, sustained and present.

Physical Self-Care

HOW YOU CAN HELP

- Sleep when you can, even in short stretches. Sleep deprivation significantly impairs judgment and emotional resilience.
- Eat real meals at regular intervals. Caregivers frequently skip meals — keep simple, nourishing foods on hand that require little preparation.
- Move your body. Even a ten-minute walk outside can restore perspective and reduce stress hormones.
- Drink water. Dehydration compounds fatigue and affects mood.
- Accept help with concrete tasks — meals, errands, laundry, yard work. People want to help; let them.

Emotional Self-Care

HOW YOU CAN HELP

- Give yourself permission to feel everything — grief, anger, exhaustion, love, even moments of humor or joy. None of these emotions are inappropriate.
- Find at least one person you can be honest with. A trusted friend, family member, chaplain, or counselor.
- Your hospice social worker and chaplain are available to you as well. You do not have to be in crisis to reach out.
- Journaling, prayer, walks in nature, music, and time in silence are all legitimate forms of emotional sustenance. Use whatever works for you.

- Set limits on how much time you spend explaining the situation to others.
You are not obligated to give updates on demand.

Permission to Grieve Now

Grief does not wait for death. Many caregivers experience what is called anticipatory grief — the mourning of losses that are coming, or that have already happened in incremental ways: the loss of conversation, of recognition, of shared futures. This is a legitimate and important form of grief. It deserves to be acknowledged, not suppressed.

Caring for someone as they die is a form of love that asks everything of you. It will change you. And in the days that follow, when the caregiving is over and the silence arrives, give yourself the same compassion you have given to your loved one. You did something extraordinary. Let that be enough.

"Grief is the price of love — and it is always worth paying."

We Are Here With You

Comfort Hospice is with you through every step of this journey — not just for your loved one, but for you. Please reach out to us at any time, day or night, with questions, concerns, or simply the need to speak with someone who understands what you are navigating.

This work you are doing — this act of witness, of love, of steadfast presence — is holy. We are honored to walk alongside you.



Comfort Hospice

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Your hospice care team is always just a phone call away.