

Understanding the Dying Process

A guide for families — what to expect and how to be present

This guide is provided by terminal2.org for hospice families. It is not a substitute for professional medical advice.

Introduction

Death from a progressive illness follows a recognizable process. While every person's experience is unique, the physical changes that occur are well-documented and broadly predictable. Understanding what is normal can reduce fear, help you feel prepared, and allow you to be fully present with your loved one during this important time.

This guide describes the physical and behavioral changes that typically occur in the months, weeks, days, and hours before death. Not every person will experience every sign, and the timeline can vary. Your hospice team is always available to answer questions specific to your loved one's situation.

You are not alone. Millions of families have walked this path before you. What you are doing — being present, learning, caring — is an act of profound love.

Months Before

In the final months of life, changes are often subtle. They may be easy to miss or attribute to a "bad day." Over time, however, a pattern emerges:

- Gradual increase in sleep and time spent resting
- Decreasing interest in activities that were once enjoyed
- Subtle changes in appetite — smaller portions, less interest in food
- Beginning to withdraw from social life and outside relationships
- Increased desire to stay home or in a familiar, comfortable space
- Possible periods of reflection, life review, or settling affairs

These changes are the body's natural way of beginning to slow down. They are not signs of giving up or depression — they are part of the dying process.

Weeks Before

As the body continues to prepare, the changes become more noticeable. In the final weeks, you may observe:

- Marked decrease in eating and drinking — the body no longer needs the same amount of fuel. This is normal and expected.
- Increased confusion about time, place, or the identity of people around them.
- Speaking to people who are not visibly present — they may talk to deceased relatives or friends. This is extremely common and not a sign of distress.
- Sleeping most of the day with brief periods of wakefulness.
- Skin color changes — pallor, yellowish or grayish tones.
- Restlessness — picking at sheets, repetitive motions, or agitation may occur. Your hospice nurse can help manage this.

Days Before

In the final days, the body is actively shutting down. These changes can be startling if you are not prepared for them, but they are a normal part of the process:

- Dramatic breathing changes — breathing may become irregular, with periods of rapid breathing followed by pauses.
- Mottling of the skin — purple or bluish patches appear on the knees, feet, and hands as circulation slows. This is a reliable sign that death is approaching.
- Body temperature fluctuations — the person may feel hot to the touch one moment and cool the next. A light blanket is appropriate.
- Very little to no food or fluid intake — the body is no longer able to process nutrition. Do not force food or water.
- Near-continuous sleep — the person may be unresponsive or respond only to voice or touch.
- May speak to deceased loved ones — conversations or reaching toward something unseen are common.

Hours Before

In the final hours, the following signs indicate that death is very near:

- Irregular breathing with long pauses (Cheyne-Stokes respiration) — breathing may stop for 10-45 seconds before resuming. This is not suffocation; the person is not in distress.
- "Death rattle" — a gurgling or rattling sound caused by secretions in the throat. This is NOT a sign of pain or choking. The person is not aware of it. Repositioning the head may help.
- Coolness and color changes in extremities — hands, feet, and legs may become cool, bluish, or mottled.
- Jaw relaxation — the mouth may fall slightly open.
- Eyes may be partially open — this is a relaxation of muscles, not an indication of awareness or discomfort.

Important

The "death rattle" sounds alarming but it is NOT pain. The person is not conscious of it. Suctioning is generally not recommended as it can cause more discomfort. Gently turning the head to the side or slightly elevating it may reduce the sound.

The Moment of Death

When death occurs, you will notice:

- No breathing and no heartbeat
- Jaw relaxed and mouth slightly open
- Eyes fixed and may be partially open
- A peaceful expression is common
- Bladder or bowel may release — this is a normal muscular relaxation

There is no rush. You do not need to call anyone immediately. You may sit with your loved one, hold their hand, say your goodbyes, pray, or simply be present. Take all the time you need. When you are ready, call your hospice team — they will guide you through the next steps.

What This Means For You

You are not helpless. Even when it feels like there is nothing you can do, your presence is the most powerful gift you can offer. Research consistently shows that the presence of loved ones provides comfort, even when the patient appears unresponsive.

Hearing is believed to be the last sense to fade. Speak words of love, comfort, and reassurance. Tell them it's okay. Tell them you love them. Tell them you'll be alright.

Ways to Be Present

- Hold their hand — gentle touch communicates love
- Speak softly — share memories, say what's in your heart
- Play their favorite music at a low volume
- Read to them — scripture, poetry, or a favorite book
- Simply sit beside them — your presence is enough
- Give permission to go — sometimes they need to hear it's okay

When to Call Your Hospice Team

- Uncontrolled pain or symptoms
- New symptoms you haven't seen before
- You are unsure if death has occurred
- You need emotional support — that's what they're there for
- After death has occurred — they will guide next steps

Sources

1. Barbara Karnes, RN — Gone From My Sight — <https://bkbooks.com/products/gone-from-my-sight>
2. Hospice Foundation of America — What to Expect — <https://hospicefoundation.org/End-of-Life-Support>
3. National Institute on Aging — Providing Comfort at the End of Life — <https://www.nia.nih.gov/health/providing-comfort-end-life>
4. Palliative Care Network of Wisconsin — Fast Fact #3 — <https://www.mypcnw.org/fast-fact/death-pronouncement/>

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Evidence-based resources for families navigating end of life

