

End-of-Life Care: Comfort, Wishes & Dignity

A compassionate guide for patients, families, and caregivers

When someone is living with a serious illness or advanced dementia, care can focus on comfort, connection, and what matters most to that person. Families do not have to navigate these decisions alone.

Palliative Care and Hospice: What Is the Difference?

	Palliative care	Hospice care
Main goal	Relieve symptoms and stress while supporting quality of life.	Prioritize comfort and quality of life when an illness is approaching the end of life.
When available	At any stage of a serious illness, including alongside treatment intended to prolong life.	Generally when a clinician certifies a prognosis of about six months or less if illness follows its expected course (Medicare criteria).
Treatments	May be provided with chemotherapy, dialysis, hospital treatment, or other disease-directed care.	Care generally shifts away from treatments intended to cure the terminal illness; treatments for comfort can continue.
Where provided	Home, clinics, hospitals, nursing facilities, and other settings.	Often at home, assisted living, or nursing facilities; inpatient hospice when needed.
Support	Symptom care, decision-making, emotional and spiritual support.	Nursing, medications/equipment related to terminal illness, social work, chaplaincy, aide services, and bereavement support per plan/benefit.

Hospice does not mean “giving up.” It means choosing a plan centered on comfort and goals that matter to the patient. Hospice eligibility and insurance coverage vary; ask the care team to explain the options.

Honoring the Person’s Wishes

- Ask what matters most: being at home, time with family, spiritual practices, relief of pain, alertness, privacy, or other priorities.
- Review advance directives, a healthcare power of attorney, and any portable medical orders (such as a DNR/POLST where applicable). A DNR addresses CPR; it does not mean “do not treat.”
- Include the patient in decisions to the greatest extent possible. When the patient cannot decide, the authorized decision-maker should follow known wishes and values.
- Discuss hospital transfers, CPR, feeding tubes, antibiotics, artificial hydration, and other interventions in the context of expected benefit and burden.
- Preserve dignity: explain care before touching, offer choices, respect cultural traditions, and protect privacy.

What Families May Notice Near the End of Life

The timing varies greatly. Some changes happen over weeks; others occur in the final days or hours. Not everyone experiences every sign. A hospice or palliative team can help distinguish expected changes from treatable distress.

Possible change	What it may mean / how to help
Sleeping more; less conversation	Energy and awareness often decrease. Speak gently, introduce yourself, and allow quiet rest. Hearing may remain meaningful even when there is no response.
Eating and drinking less	Appetite and thirst often diminish naturally. Offer small sips or favorite tastes only when safe and wanted; never force food or fluids. Provide frequent mouth and lip care.
Trouble swallowing	Ask the care team about safer ways to offer comfort, adjust medication routes, and reduce choking risk.
Breathing changes	Breathing may become irregular, with pauses or noisy secretions. Repositioning and medications when appropriate can help; noisy breathing does not always mean suffering.
Cool or mottled hands and feet	Circulation may slow. Use light blankets and gentle touch; avoid heating pads that may burn fragile skin.
Restlessness, confusion, or agitation	May reflect pain, urinary retention, constipation, medication effects, delirium, or other distress. Tell the care team promptly.
Less urine; increasing weakness	Body functions slow. Focus on comfort and ask the team what changes are expected.

Comfort Measures That Often Help

- Pain or breathlessness: tell the nurse promptly; medicines and positioning can relieve distress. Opioids may be used carefully for pain or air hunger when clinically appropriate.
- Dry mouth: gently clean and moisten the mouth, use lip balm, and offer ice chips or sips only if swallowing is safe.
- Anxiety or restlessness: a calm room, familiar voices, gentle touch (if welcomed), music, and medication when needed may help.
- Skin comfort: reposition according to comfort and skin needs, use pillows, keep linens dry, and avoid unnecessary painful procedures.
- Reduce burdens: consider fewer alarms, interruptions, tests, and transfers when they no longer support the patient's goals.

Important: Never change, crush, stop, or administer medicines differently without instructions from the treating team. Call the care team for uncontrolled pain, severe breathlessness, persistent agitation, seizures, or other concerning symptoms.

Comfort for Family Members, Too

- Be present in your own way. Sitting quietly, holding a hand, reading aloud, sharing photographs, or playing meaningful music can be enough.
- Say what matters: “I love you,” “Thank you,” “I’m sorry,” “I forgive you,” or “We will take care of one another,” when these words feel appropriate.
- Give permission for rest. Family members do not need to maintain a constant bedside vigil to demonstrate love.
- Ask for help with overnight coverage, meals, child care, transportation, and updates to relatives.
- Expect many emotions—sadness, relief, guilt, anger, numbness, and even laughter. There is no single correct way to grieve.
- Invite spiritual care, cultural rituals, social work, or bereavement counseling if these are meaningful to the patient or family.

Questions to Ask the Care Team

- What changes are likely in the coming days or weeks? What signs should prompt a call?
- How will pain, shortness of breath, anxiety, nausea, and agitation be treated? Who is available after hours?
- Can care be provided at home? What equipment, supplies, nursing visits, and caregiver support are available?
- What happens if the person cannot swallow medications?
- Which treatments may still improve comfort, and which might cause more burden than benefit?
- Who should we call at the time of death, and what happens afterward?
- What support is available for children, relatives, and caregivers before and after death?

Planning Checklist

- ☐ Identify the healthcare decision-maker and share advance directives with the care team.
- ☐ Record the patient’s preferences for location of care, visitors, spiritual needs, and hospital transfers.
- ☐ Save the hospice/palliative care phone number where everyone can find it.
- ☐ Review the comfort medication plan and who to call if symptoms change.
- ☐ Ask about caregiver respite, equipment, and bereavement services.

Trusted Resources

- National Institute on Aging — End-of-Life Care: nia.nih.gov/health/end-life
- Medicare — Hospice Care Coverage: medicare.gov/coverage/hospice-care
- National Hospice and Palliative Care Organization (NHPCO): nhpco.org
- CaringInfo — Advance care planning and hospice information: caringinfo.org
- New Hampshire ADRC / ServiceLink — aging and caregiver services: dhhs.nh.gov (search “ADRC”)
- 988 Suicide & Crisis Lifeline — emotional crisis support: call or text 988

This handout is general education, not an individualized prognosis or treatment plan. Ask the treating clinicians about the patient’s specific illness, care goals, and local hospice options.