

Late Stage and End-of-Life Care

Caregiving in the Final Stages of Life



As a family caregiver, the final stages of a terminal illness can be a highly challenging, emotional time. Care priorities tend to shift. Instead of continuing curative measures, the focus may change to palliative care for the relief of your loved one's pain, symptoms, and emotional distress. But ensuring their final months, weeks, or days are as good as they can be requires more than just a series of care choices. By preparing for the specific demands of end-of-life caregiving, you can help ease the journey for both of you, and make the transition from nursing and grief towards acceptance and healing.

What is late-stage care?

In the final stages of a terminal illness, it can become evident that in spite of the best care, attention, and treatment, your loved one is approaching the end of their life. At this point, the focus usually changes to making them as comfortable as possible in order to make the most of the time they have left. Depending on the nature of the illness and your loved one's circumstances, this final stage period may last from a matter of weeks or months to several years. During this time, palliative care measures can help to control pain and other symptoms, such as constipation, nausea, or shortness of breath. Hospice care can also offer emotional and spiritual support to both the patient and their family.

Even with years of experience, caregivers often find this final stage of the caregiving journey uniquely challenging. Simple acts of daily care are often combined with complex end-of-life decisions and painful feelings of grief and loss. You may experience a range of distressing and conflicting emotions, such as sorrow and anxiety, anger and denial, or even relief that your loved one's struggle is at an end, or guilt that you've somehow failed as their caregiver. Whatever you're experiencing, it's important to recognize that late stage caregiving requires plenty of support. That can range from practical support for end-of-life care and financial and legal arrangements, to emotional support to help you come to terms

with all the difficult feelings you're experiencing as you face up to the loss of your loved one.

Late-stage care is also a time for saying goodbye to your loved one, to resolve any differences, forgive any grudges, and to express your love. While late stage caregiving can be an extremely painful time, having this opportunity to say goodbye can also be a gift to help you come to terms with your loss and eventually find new meaning.

When is it time for late-stage and end-of-life care?

There isn't a single specific point in an illness when end-of-life care begins; it very much depends on the individual and the progression of their illness. In the case of Alzheimer's disease or another dementia, your loved one's doctor likely provided you with information on stages in the diagnosis. These stages can provide general guidelines for understanding the progression of Alzheimer's symptoms and planning appropriate care. For other life-limiting illnesses, the following are signs that you may want to talk to your loved one about hospice and palliative care, rather than curative care options:

- Your loved one has made multiple trips to the emergency room, their condition has been stabilized, but the illness continues to progress significantly, affecting their quality of life.
- They've been admitted to the hospital several times within the last year with the same or worsening symptoms.
- They wish to remain at home, rather than spend time in the hospital.
- They have decided to stop receiving treatments for their disease.

Patient and caregiver needs in late-stage care

As your loved one enters late-stage or end-of-life care, their needs can change, impacting the demands you'll now face as their caregiver. This can include the following areas:

Practical care and assistance. Perhaps your loved one can no longer talk, sit, walk, eat, or make sense of the world. Routine activities, including bathing, feeding, dressing, and turning may require total support and increased physical strength on your part as their caregiver. You can find support for these tasks from personal care assistants, a hospice team, or physician-ordered nursing services.

Comfort and dignity. Even if your patient's cognitive and memory functions are depleted, their capacity to feel frightened or at peace, loved or lonely, and sad or secure remains. Regardless of where they're being cared for—at home, in a hospital, or at a hospice facility—the most helpful interventions are those which ease pain and discomfort and provide the chance for them to experience meaningful connections to family and loved ones.

Respite Care. [Respite care](#) can give you and your family a break from the intensity of end-of-life caregiving. It may be simply a case of having a hospice volunteer sit with the patient for a few hours so you can meet friends for coffee or watch a movie, or it could involve the patient having a brief inpatient stay in a hospice facility.

Grief support. Anticipating your loved one's death can produce reactions from relief to sadness to feeling numb. Consulting bereavement specialists or spiritual advisors before your loved one's death can help you and your family prepare for the coming loss.

End-of-life planning

When caregivers, family members, and loved ones are clear about the patient's preferences for treatment in the final stages of life, you're all free to devote your energy to care and compassion. To ensure that everyone in your family understands the patient's wishes, it's important for anyone diagnosed with a life-limiting illness to discuss their feelings with loved ones before a medical crisis strikes.

Prepare early. The end-of-life journey is eased considerably when conversations regarding placement, treatment, and end-of-life wishes are held as early as possible. Consider [hospice and palliative care services](#), spiritual practices, and memorial traditions before they are needed.

Seek financial and legal advice while your loved one can participate. Legal documents such as a [living will, power of attorney, or advance directive](#) can set forth a patient's wishes for future health care so family members are all clear about their preferences.

Focus on values. If your loved one did not prepare a living will or advance directive while competent to do so, act on what you *know* or *feel* their wishes are. Make a list of conversations and events that illustrate their views. To the extent possible, consider treatment, placement, and decisions about dying from the patient's vantage point.

Address family conflicts. Stress and grief resulting from your loved one's deterioration can often create conflict between family members. If you are unable to agree on living arrangements, medical treatment, or end-of-life directives, ask a trained doctor, social worker, or hospice specialist for mediation assistance.

Communicate with family members. Choose a primary decision maker who will manage information and coordinate family involvement and support. Even when families know their loved one's wishes, implementing decisions for or against sustaining or life-prolonging treatments requires clear communication.

If children are involved, make efforts to include them. Children need honest, age-

appropriate information about your loved one's condition and any changes they perceive in you. They can be deeply affected by situations they don't understand, and may benefit from drawing pictures or using puppets to simulate feelings, or hearing stories that explain events in terms they can grasp.

Care and placement options

Your loved one's deteriorating medical condition and the 24-hour demands of final-stage care can mean that you'll need additional in-home help, or the patient will need to be placed in a hospice or other care facility. While every patient and each family's needs are different, most patients prefer to remain at home in the final stages of life, in comfortable surroundings with family and loved ones nearby. Often, multiple changes can be difficult for a terminally ill patient, especially one with advanced Alzheimer's disease or other dementia. It's easier for a patient to adjust to a new home or care facility before they're at the end stage of their illness. In these situations, planning ahead is important.

Hospice and palliative care

Hospice is typically an option for patients whose life expectancy is six months or less, and involves palliative care (pain and symptom relief) to enable your loved one to live their final days with the highest quality of life possible. [Hospice care](#) can be provided onsite at some hospitals, nursing homes, and other health care facilities, although in most cases hospice is provided in the patient's own home. With the support of hospice staff, family and loved ones are able to focus more fully on enjoying the time remaining with the patient.

When hospice care is provided at home, a family member acts as the primary caregiver, supervised by the patient's doctor and hospice medical staff. The hospice team makes regular visits to assess your loved one and provide additional care and services, such as speech and physical therapy or to help with bathing and other personal care needs.

As well as having staff on-call 24 hours a day, seven days a week, a hospice team provides emotional and spiritual support according to the wishes and beliefs of the patient. They also offer emotional support to the patient's family, caregivers, and loved ones, including [grief counseling](#).

Deciding to care for a terminally ill family member at home

Some questions to ask yourself when deciding to undertake end-of-life care of a loved one at home:

- Has your loved one set forth their preferences for end-of-life care that include remaining at home?

- Is qualified, dependable support available to ensure 24-hour care?
- Will your home accommodate a hospital bed, wheelchair, and bedside commode?
- Are transportation services available to meet daily needs and emergencies?
- Is professional medical help accessible for routine and emergency care?
- Are you able to lift, turn, and move your loved one?
- Can you meet your other family and work responsibilities as well as your loved one's needs?
- Are you emotionally prepared to care for your bed-ridden loved one?

Source: *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease*, by Donna Cohen, PhD, and Carl Eisdorfer, PhD.

Caregiving in the final stages of life

While the symptoms in the final stages of life vary from patient to patient and according to the type of life-limiting illness, there are some common symptoms experienced near the end of life. It's important to remember, though, that experiencing any of them does not necessarily indicate that your loved one's condition is deteriorating or that death is close.

Common Symptoms in End-of-Life Care

Symptom	How to provide comfort
Drowsiness	Plan visits and activities for times when the patient is most alert.
Becoming unresponsive	Many patients are still able to hear after they are no longer able to speak, so talk as if your loved one can hear.
Confusion about time, place, identity of loved ones	Speak calmly to help re-orient your loved one. Gently remind them of the time, date, and people who are with them.
Loss of appetite, decreased need for food and fluids	Let the patient choose if and when to eat or drink. Ice chips, water, or juice may be refreshing if the patient can swallow. Keep your loved one's mouth and lips moist with products such as glycerin swabs and lip balm.
Loss of bladder or bowel control	Keep your loved one as clean, dry, and comfortable as possible. Place disposable pads on the bed beneath them and remove when they become soiled.
Skin becoming cool to the touch	Warm the patient with blankets but avoid electric blankets or heating pads, which can cause burns.
Labored, irregular, shallow, or noisy breathing	Breathing may be easier if the patient's body is turned to the side and pillows are placed beneath their head and behind their back. A cool mist humidifier may also help.

Source: National Cancer Institute

Providing emotional comfort

As with physical symptoms, a patient's emotional needs in the final stages of life also vary. However, some emotions are common to many patients during end-of-life care. Many worry about loss of control and loss of dignity as their physical abilities decline. It's also common for patients to fear being a burden to their loved ones yet at the same time also fear being abandoned.

As a late-stage caregiver, you can offer emotional comfort to your loved one in several different ways:

Keep them company. Talk to your loved one, read to them, watch movies together, or simply sit and hold their hand.

Refrain from burdening the patient with your feelings of fear, sadness and loss. Instead, talk to someone else about your feelings.

Allow your loved one to express their fears of death. It can be difficult to hear someone you love talk about leaving family and friends behind, but communicating their fears can help them come to terms with what's happening. Try to listen without interrupting or arguing.

Allow them to reminisce. Talking about their life and the past is another way some patients gain perspective on their life and the process of dying.

Avoid withholding difficult information. If they're still able to comprehend, most patients prefer to be included in discussions about issues that concern them.

Honor their wishes. Reassure the patient that you will honor their wishes, such as advance directives and living wills, even if you don't agree with them.

Respect the patient's need for privacy. End-of-life care for many people is often a battle to preserve their dignity and end their life as comfortably as possible.

At the end-of-life

The *end-of-life period*—when body systems shut down and death is imminent—typically lasts from a matter of days to a couple of weeks. Some patients die gently and tranquilly, while others seem to fight the inevitable. Reassuring your loved one it is okay to die can help both of you through this process. Decisions about hydration, breathing support, and other interventions should be consistent with your loved one's wishes.

Saying Goodbye

Although this is a painful time in so many ways, entering end-of-life care does offer you the opportunity to say goodbye to your loved one, an opportunity that many people who lose someone suddenly regret not having.

If you wonder what to say to your loved one, palliative care physician Ira Byock in his book, *The Four Things That Matter Most*, identifies the things dying people most want to hear from family and friends: “Please forgive me.” “I forgive you.” “Thank you.” “I love you.”

Don’t wait until the last minute to say goodbye. No one can predict when that last minute will come so waiting for it puts a huge burden on you.

Just talk, even if your loved one appears unresponsive. Hearing is the last sense to shut down, so even when your loved one appears comatose and unresponsive, there is a strong likelihood they can still hear what you are saying. Identify yourself and speak from the heart.

You don’t have to speak to say goodbye. Touch can be an important part of the last days and hours, too. Holding your loved one’s hand or giving them a kiss can bring comfort and closeness between you.

You can say goodbye many different times and in many different ways. You don’t have to formally issue a goodbye and say everything all at once. You can do it over days. Don’t worry about repeating yourself; this is about connecting with your loved one and saying what you feel so you are less likely to have regrets later about things left unsaid.

Source: Hospicare.org

After your loved one has passed away, some family members and caregivers draw comfort from taking some time to say their last goodbyes, talk, or pray before proceeding with final arrangements. Give yourself that time if you need it.

Caring for yourself

As impossible as it may seem, taking care of yourself during your loved one’s final stages is critically important to [avoid burnout](#). Research suggests that spousal caregivers are most likely to experience despair rather than any kind of fulfillment in their caregiving role. But whatever your circumstances, it’s important to seek the support you need to adjust, gain acceptance, and eventually move on.

Caregiving in the final stages of Alzheimer's disease

Late stage [caregiving for patients with Alzheimer's disease](#) or other dementia can create unique challenges. In most cases, you've likely been grieving your loved one's physical, cognitive, and behavioral regression for years. Many caregivers struggle to make difficult treatment, placement, and intervention choices through the pain of these continuous losses. But as your loved one's serious decline becomes more evident, try to draw on the skills and understanding you've developed during your caregiving journey to help you through this final stage.

At this point in the progression of Alzheimer's, your loved one can no longer communicate directly, is totally dependent for all personal care, and is generally confined to bed. Unable to recognize once-cherished people and objects, or to verbally express basic requirements, your family member with Alzheimer's now completely depends on you to advocate, connect, and attend to their needs.

Managing pain

Even in the last stages, patients with Alzheimer's disease can communicate discomfort and pain. While pain and suffering cannot be totally eliminated, you can help to make them tolerable.

Managing pain and discomfort requires daily monitoring and reassessment of your loved one's subtle nonverbal signals. Slight behavioral changes can indicate their needs aren't being met. Communicating such changes to your loved one's medical team will provide valuable clues about their level of pain. You can also help to ease your loved one's discomfort through touch, massage, music, fragrance, and the sound of your soothing voice. Experiment with different approaches and observe your loved one's reactions.

Connecting and loving

Even when your loved one cannot speak or smile, their need for companionship remains. They can no longer recognize you but may still draw comfort from your touch or the sound of your voice.

- Staying calm and attentive will create a soothing atmosphere, and communicating through sensory experiences such as touch or singing can be reassuring to your loved one.
- Contact with pets or trained therapy animals can bring pleasure and ease transitions for even the most frail patient.
- Surrounding a loved one with pictures and mementos, reading aloud from treasured books, playing music, giving long, gentle strokes, reminiscing, and recalling life stories

promote dignity and comfort all the way through life's final moments.

Coping with grief and loss as a late-stage caregiver

While the death of a loved one is always painful, the extended journey of a disease such as Alzheimer's or some cancers can give you and your family the gift of preparing for, and finding meaning in, your loved one's end of life. When death is slow and gradual, many caregivers are able to prepare for its intangible aspects, and to support their loved one through the unknown. While it won't limit your [grief or sense of loss](#), many find it less traumatizing than being unprepared for the imminent death of a loved one.

Talking with family and friends, consulting hospice services, bereavement experts, and spiritual advisors can help you work through these feelings and focus on your loved one. Hospice and palliative care specialists and trained volunteers can assist not only the dying person, but also caregivers and family members, too.

Moving on after final-stage care

From the moment a loved one is diagnosed with a terminal illness, a caregiver's life is never the same. It can, however, be happy, fulfilling, and healthy again. Take time to reflect on your loved one's life and remember the quality time that you were able to share together.

Reconnect

Join a caregivers' bereavement support group. Being with others who know your situation can help you better understand and come to terms with your feelings.

Volunteer, enroll in an adult education or fitness class, or join a book club. Acquiring new skills and staying physically active can ease stress and promote healing.

Use your loss

Create lasting tributes to your loved one. Consider memorial sites, scholarships, plaques, scrapbooks, or charitable contributions to honor their memory.

Write a story, create a poem, or make a recording. Share your loved one's unique story with family members and other caregivers.

Use your knowledge to help another. Contact your local hospice provider and ask them to pair you with a first-time caregiver.

Gain perspective

Keep a journal. Writing down thoughts and feelings can provide a release for your emotions.

Talk to a therapist or grief counselor. Giving yourself permission to find new meaning and relationships can be difficult, but you have earned health and happiness.

Your acts of care and connection sustained your loved one through the most difficult and perhaps a very long passage. Sharing what you have learned, cultivating happiness, and finding new meaning can provide a fitting finale to your caregiving journey.

Recommended reading

[Alzheimer's Disease: Anticipating End-of-Life Needs](#) - End-of-life needs of people with Alzheimer's disease. (Mayo Clinic)

[End of Life Care](#) - What patients and caregivers can expect in the last few months of life. (American Cancer Society)

[End-Of-Life Support and Resources](#) - Caregiver resources and support before, during and after the dying process. (Hospice Foundation of America)

[Late-Stage Caregiving](#) - Specifically late stage Alzheimer's caregiving. (Alzheimer's Association)

[Live Life on Your Terms](#) - Resources for end-of-life planning such as living wills and advanced directives. (Compassion & Choices)

[Being with a Dying Person](#) - Includes how to say goodbye to a loved one who's dying. (Hospicare and Palliative Care Services)

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