

# End-of-Life Care

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Providing Care and Comfort

From the National Institute on Aging,  
National Institutes of Health





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Use the Table of Contents to help find things quickly. You will also find medical terms in bold, such as **cognitive function**. Find how to say these words and what they mean in the “Words To Know” section on page 32.



# What's Inside

There are many different decisions that need to be made at the end of life. You may feel more prepared for some of these than others. Read this booklet to learn about common situations people encounter at the end of life and how to approach them.

## This booklet will help you learn about:

- What to consider when making decisions for someone else
- Types of care
- Different care settings
- What to do after someone dies

# What Is End-of-Life Care?

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. A loved one may need care for days, weeks, or even months before breathing ceases and the heart stops beating. Other times, death comes suddenly.

How you help care for someone at the end of life will depend on their specific circumstances. Not all experiences are alike. Some people may lose physical functions, but their mind will stay clear. Others may remain physically strong while their **cognitive function** declines.

End-of-life care also depends on the person's preferences, needs, choices, and finances. While not everyone has the chance to decide where they will die, individuals and families can try to plan ahead and make choices that allow for the most comfort possible.





# Making Decisions for Someone at the End of Life

You are likely reading this because someone close to you or someone you know is dying. You may wonder how you can comfort the person, prevent or ease suffering, and provide the best quality of life possible in their remaining time. If the person can no longer communicate, you may be asked to make difficult decisions about their care and comfort. This can be overwhelming for family members, especially if they have not had a chance to discuss the person's wishes ahead of time — or if multiple family members are involved and do not agree.

Some people have advance directives in place that outline the care they want if they are unable to speak for themselves. Or they may have communicated their wishes to family members verbally. Even if your loved one has provided written or verbal guidance, some decisions may not be clear, and you may be called upon to make decisions on their behalf.

## Decision-Making Strategies

When making choices for someone else, you can consider different decision-making strategies to help determine the best approach for the person.

**Substituted judgment.** For this approach, you put yourself in the place of the person who is dying and try to choose as they would. Some experts believe that decisions should be based on substituted judgment whenever possible.

**Best interests.** For this, you determine what you, as their representative, think is best for the dying person. This is sometimes combined with substituted judgment.

If you are making decisions for someone at the end of life and are trying to use one of these approaches, it may be helpful to think about the following questions:

- Has the person ever talked about what they would want at the end of life?
- Has the person ever expressed an opinion about someone else's end-of-life treatment?
- What are their values and what gives meaning to their life?

## Questions To Ask the Health Care Team

To make a decision on someone's behalf, you will need as much information as possible from the health care team. The decisions you are faced with and the questions you may ask can vary depending on if the person is at home, in a hospital, or in a care facility.



Here are a few questions to consider asking:

- What might we expect to happen in the next few hours, days, or weeks if we continue our current course of treatment?
- Will treatment provide more quality time with family and friends?
- What if we don't want the treatment offered? What happens then?
- When should we begin hospice care? Can they receive this care at home or at the hospital? (See page 10 for more information on hospice care.)
- If we begin hospice, will the person be denied certain treatments?
- Which medicines will be given to help manage pain and other symptoms? What are the possible side effects?
- What will happen if our family member stops eating or drinking? Will a feeding tube be considered? What are the benefits and risks?
- If we try using a ventilator to help with breathing and decide to stop, how will that be done?

Understanding and making these decisions can be difficult. Consider having someone with you to take notes and help remember details. Don't be afraid to ask the doctor or nurse to repeat or rephrase what they said if you are unclear about something they told you. Keep asking questions until you have all the information you need to make a decision.

## Advance Care Planning: What Does Your Loved One Want?

Advance care planning involves sharing and discussing potential decisions about medical care if someone is unable to communicate their wishes. Having meaningful conversations with your loved ones about their preferences is the most important part of advance care planning. A loved one's requests can also be included in advance directives.

For example, a durable power of attorney for health care is an advance directive that identifies someone — called a health care proxy or health care agent — to make decisions for a person if they are unable to communicate their wishes themselves. The health care proxy can decide on care based on the person's values and what they believe the person would want.

Knowing about someone's wishes and having these documents in place can help alleviate the pressure family members and friends may feel if asked to make difficult medical decisions.

To learn more about advance directives and advance care planning, visit [www.nia.nih.gov/caregiving](http://www.nia.nih.gov/caregiving) or call the NIA Information Center at 800-222-4225.

# Types of Care: Palliative and Hospice Care

There are two common types of care that can take place at the end of life: **palliative care** and **hospice care**. Although the two have some similarities, they differ in several ways.

## Palliative Care

Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart failure. This type of care can be helpful at any stage of illness. However, it's best to start soon after a person receives their diagnosis.

A palliative care team is made up of many different professionals who work with the patient, family, and the patient's other doctors to provide medical, social, emotional, and practical support. A benefit of palliative care is that it can be provided in different locations, depending on preference and need. This includes hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home.

# Hospice Care

Hospice care also focuses on the care, comfort, and quality of life of a person with a serious illness. However, the main focus of hospice care is to relieve any symptoms that can come at the end of life, such as pain and discomfort. Hospice care does not attempt to treat the person's illness or condition.

Hospice care is meant for people who have a serious illness and a short time to live, often less than six months. Hospice care can be offered at home or in a facility such as a nursing home, hospital, or hospice center. Hospice care is not permanent, and a person can unenroll and reenroll as needed based on their own decisions and health status.



# Dolores' Story



When Dolores was 82, she chose to pursue hospice care after learning that her kidneys were failing. She had lived a long, good life and didn't want to go through dialysis or pursue any other treatment options. Two weeks after beginning hospice care, she found out that her granddaughter was pregnant. She decided for herself that she didn't want to use hospice care anymore. Dolores wanted to continue seeking treatment in hopes of seeing her future great-grandchild.

## Similarities and Differences Between Palliative Care and Hospice Care

Question	Palliative Care	Hospice
Who can be treated?	Anyone with a serious illness	Anyone with a serious illness who doctors think has only a short time to live, often less than six months
Will my symptoms be relieved?	Yes, as much as possible	Yes, as much as possible
Can I continue to receive treatments to cure my illness?	Yes, if you wish	No, only symptom relief will be provided
Will Medicare pay?	It depends on your benefits and treatment plan	Yes, it pays for some hospice charges
Does private insurance pay?	It depends on the plan	It depends on the plan

Question	Palliative Care	Hospice
<b>How long will I be cared for?</b>	This depends on what care you need and your insurance plan	As long as you meet the hospice's criteria of an illness with a life expectancy of months, not years
<b>Where will I receive this care?</b>	<ul style="list-style-type: none"> <li>• Home</li> <li>• Assisted living facility</li> <li>• Nursing home</li> <li>• Hospital</li> <li>• Palliative care clinic</li> </ul>	<ul style="list-style-type: none"> <li>• Home</li> <li>• Assisted living facility</li> <li>• Nursing home</li> <li>• Hospice facility</li> <li>• Hospital</li> </ul>

*Source:*

*[www.nhpco.org/palliativecare/explanation-of-palliative-care](http://www.nhpco.org/palliativecare/explanation-of-palliative-care).*

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# Different Care Settings at the End of Life

The three most common places people at the end of life die are at home, in a hospital, or in a care facility. When it's possible to choose where a person will die, several factors can go into this decision. These include knowing the type of care the person needs and wants, where they can receive this level of care, advance care directives, costs, and availability of family and friends to help.

## Home Care

Most people choose to receive end-of-life care at home. It's the most private setting and the person may feel comforted knowing they're in a familiar environment where friends and family can visit freely. Services such as visiting nurses, hospice and palliative care, and special equipment such as a hospital bed or bedside **commode**, can be arranged to be at the home.

## Ask for Help When You Need It

Caring for someone who is at the end of life at home can be physically, emotionally, and financially demanding for those providing the care. Extra support from paid caregivers or home service providers, also known as **respite care**, can help. Your local Area Agency on Aging may be able to recommend other sources of help. Visit <https://eldercare.acl.gov> or call 800-677-1116 to find services in your area.

## Hospital Care

If a person receives end-of-life care in a hospital, they will have direct access to medical professionals who understand the needs of a dying person. This can be reassuring to both the person and their family.

In addition to the regular care team, some hospitals have palliative and hospice care teams that can assist with managing uncomfortable symptoms at the end of life, such as digestive issues or pain. These teams can also help with making medical decisions for patients or families if plans are not already in place.

## Nursing Homes and Other Care Facilities

It's common for people who are already in **long-term care facilities** such as a nursing home to receive end-of-life care there. Many people choose this option because they already have a relationship with staff who work there, which can help make the care feel more personal than in a hospital. In other cases, someone may be discharged from a hospital to a long-term care facility to receive care.

In a nursing home, nursing staff are always present. Unlike a hospital, a doctor is not always in the facility but is available when needed. However, like in a hospital, palliative care and hospice care can both be accessed in long-term care facilities.

# Understanding Your Loved Ones' Needs

No matter where end-of-life care takes place, there may be steps you can take to increase the likelihood of a peaceful and respectful death for your loved one.

Generally speaking, people who are dying need support in four areas:

- Physical comfort
- Mental and emotional needs
- Spiritual needs
- Practical tasks



## Physical Comfort

There can be many sources of discomfort during the dying process. Depending on the cause of the discomfort, there may be things you or a health care provider can do to help make the dying person more comfortable.

**Breathing problems.** Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this **dyspnea**. To help ease breathing for your loved one, try raising the head of the bed, opening a window, using a humidifier, or running a fan to circulate air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

There may be times when a dying person has an abnormal breathing pattern, known as **Cheyne-Stokes respirations**. The person's breathing may alternate between deep, heavy breaths and shallow or even no breaths. Some people very near death might have noisy breathing. In most cases, this noisy breathing does not upset the dying person, though it may be alarming to family and friends. You may try turning the person on one side to rest or elevating their head. Prescription medicine may also help.

**Skin irritation.** Skin problems can be very uncomfortable for a person who is dying. Try to keep the person's skin clean and moisturized. Alcohol-free lotion, petroleum jelly, eye cream or gel, or a damp cloth can help to relieve itching and dryness, especially on parts of the face. If the inside of the mouth seems dry, try giving them ice chips (if the person is conscious) or wiping the inside of the person's mouth with a damp cloth, cotton ball, or specially treated swab.

If the person is sitting or lying in one position, it can put constant pressure on sensitive skin, which can lead to painful bedsores (sometimes called pressure ulcers). Watch carefully for bedsores, especially on the heels, hips, lower back, and back of the head.

Turning the person in bed every few hours may help prevent bedsores and stiffness. Try putting a foam pad under the person's heels or elbows to raise them off the bed and reduce pressure. Ask a member of the health care team if a special mattress or chair cushion might also help.

**Temperature sensitivity.** When a person is close to death, their hands, arms, feet, or legs may be cool to the touch. Some parts of the body may become darker or blueish. People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. For example, someone who is too warm might repeatedly try to remove a blanket and someone who is too cold may be shivering.

**Digestive problems.** Nausea, vomiting, swallowing, constipation, and loss of appetite are common at the end of life. The causes and treatments for these symptoms vary, so talk with a doctor or nurse about what you're seeing. Medicines can help control nausea or vomiting or relieve constipation, all of which are common side effects of strong pain medications.

If the person loses their appetite, try gently offering favorite foods in small amounts. Serve frequent, smaller meals rather than three larger ones. Help feed your loved one if they want to eat but are too tired or weak. But don't force a dying person to eat. Losing one's appetite is a common and normal part of dying. Going without food and/or water is generally not painful, and eating and drinking can add to a dying person's discomfort. A conscious decision to give up food can be part of a person's acceptance that death is near.

**Fatigue.** It is common for people nearing the end of life to feel tired and have little or no energy. Try to make things easier for them. For example, they can use a bedside commode instead of walking to the bathroom. Providing a stool so the person can sit in the shower, or sponge baths in bed, can also help.

**Pain.** Not everyone who is dying experiences pain. For those who do, experts believe that care should focus on relieving pain without worrying about possible long-term problems of drug dependence or substance use disorders.

Struggling with severe pain can be draining and can make the dying person understandably angry or short-tempered. This can make it even harder for families and other loved ones to communicate with the person in a meaningful way.

Caregivers and other family members can play significant roles in managing a dying person's pain. But knowing how much pain someone is in can be difficult. Watch for clues, such as trouble sleeping, showing increased agitation, or crying. Don't be afraid of giving as much pain medicine as is prescribed by the doctor. Pain is easier to prevent than to relieve, and severe pain is hard to manage. Try to make sure that the level of pain does not get ahead of pain-relieving medicines. Talk with the health care team if the pain is not controlled. Medicines can be increased or changed.





## What About Morphine and Other Painkillers?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling of shortness of breath. Successfully reducing pain and addressing concerns about breathing can provide needed comfort to someone who is close to dying. Side effects may include confusion, drowsiness, or hallucinations. Talk with the person's health care team if you have any questions about the side effects of morphine or other pain medications.

## Mental and Emotional Needs

When someone is nearing the end of life, they may feel depressed or anxious. Others may experience mental confusion and may have strange or unusual behavior, making it harder to connect with their loved ones. As a caregiver or family member, try to be present and listen to their concerns. If their emotional pain heightens, you may want to contact a counselor, possibly one familiar with end-of-life issues, to encourage conversations about their feelings. Medicine may help if the person's depression or anxiety is severe.

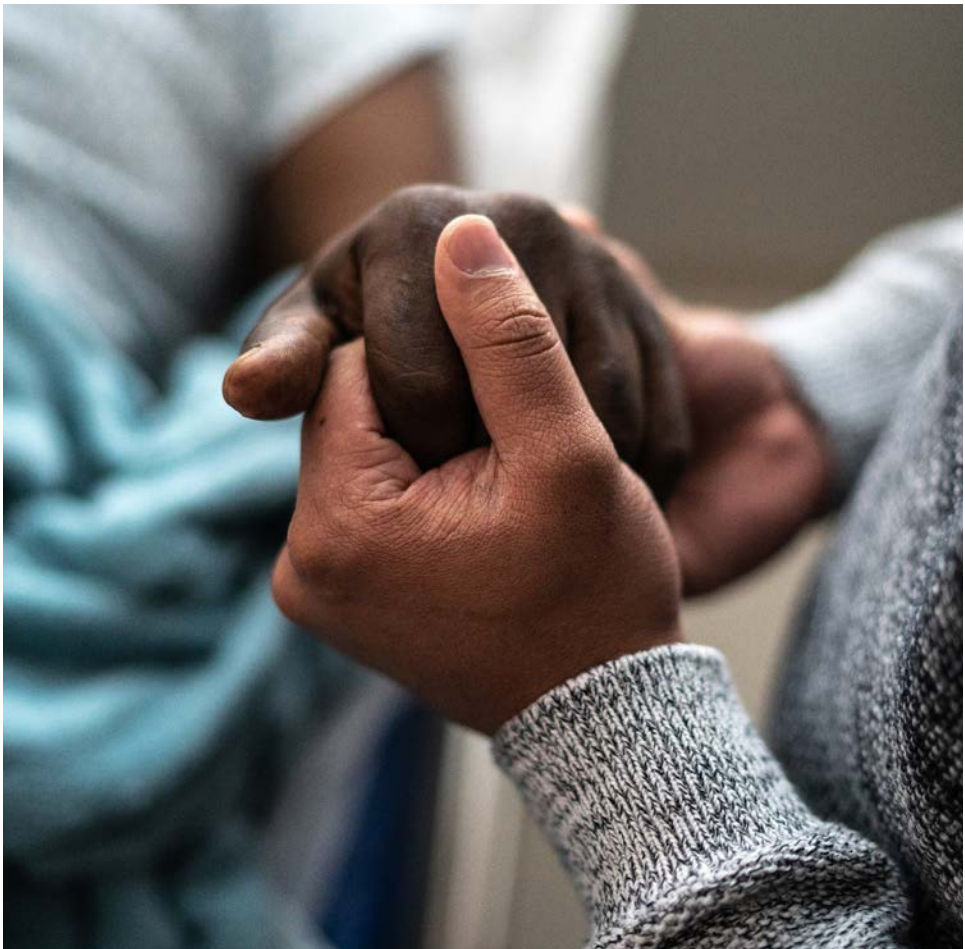
## Dementia and End-of-Life Care

Caregivers often experience special challenges surrounding the end of life for someone with Alzheimer's disease or a related dementia. People with dementia gradually lose their ability to think, remember, and communicate, which can make caregiving and related decisions more difficult. Below are some considerations for end-of-life care for people with dementia.

- **Considering quality of life.** Medications are available that may help with some symptoms, but caregivers may not want medicines or other treatments prescribed for people in the later stages of dementia if the side effects outweigh the benefits.
- **Connecting.** Caregivers may find it hard to provide emotional or spiritual comfort. Sensory connections involving hearing, touch, or sight may help bring comfort. For example, receiving a massage can be soothing or listening to music, white noise, or sounds from nature may help lessen agitation. Just being present can be calming to the person.
- **Coping.** People often live with dementia for years. It is not uncommon for caregivers to feel a sense of relief when death happens. Such feelings are normal. Hospice care experts can provide support to family caregivers of a person near the end of life as well as help with their grief.

## Spiritual Needs

At the end of life, some people may want to address their spiritual needs. These needs may include finding meaning in one's life, ending disagreements with others, or making peace with life circumstances. The person can also talk with someone from their religious community, such as a minister, priest, rabbi, or imam. Family members and loved ones can also help. Sharing memories can help bring comfort to both people.



## Practical Tasks

Everyday tasks, such as picking up the mail, answering the phone, or feeding a pet, can be a source of worry for someone who is dying and can overwhelm a caregiver. A family member or friend can provide the caregiver with a much-needed break by helping with small daily chores.

A person who is dying might also be worried about who will take care of things when they are gone. Talk with them about their concerns. Offer reassurance that everything will be taken care of, which may help provide a measure of peace. You may also remind the dying person that their personal affairs are in good hands.

### Helping Out the Caregiver

Caregivers can be overwhelmed when the person they are taking care of is near the end of life. If you're in a position to offer some relief to the main caregiver, here are a few questions to ask:

- How are you doing? Do you need someone to talk with?
- Do you want to take an hour for yourself?  
I can stay here while you're out.
- I'm headed to the store later. What can I pick up for you?
- I'm in the neighborhood, and I'm happy to stop by and take the dog out. Would that be helpful to you?

## Mark's Story



When Mark was caring for his wife in hospice, he felt overwhelmed by the chores he couldn't tend to. There were dishes in the sink, trash that needed to be taken out, and he wasn't able to respond to everyone who called about his wife's condition. He was so relieved when his brother came into town and offered to help take care of things around the house. Mark was able to focus his attention on his wife's care, while knowing that everyday things were being taken care of.

# What To Do After Someone Dies

What to do after someone dies depends on where the person died. If someone dies at home, there is no need to move the body right away. If the person was in hospice, a plan for what happens after death will likely already be in place. If the person wasn't in hospice, talk with the doctor, local medical examiner (coroner), local health department, or a funeral home representative about how to proceed.

Arrangements should be made to pick up the body as soon as the family is ready and according to local laws. This can be done by a funeral home or by the family themselves in most states. The hospital or nursing facility, if that is where the death took place, may help with these arrangements.

As soon as possible after death, it must be officially pronounced by someone in authority such as a doctor in a hospital or nursing facility, or a hospice nurse. The person who declares death also fills out forms certifying the cause, time, and place of death. These steps will make it possible for an official death certificate to be prepared. This legal form is necessary for many reasons, including life insurance and financial and property issues.

In the weeks following the person's death, you will want to notify places about your loved one's passing. This may include:

- The Social Security Administration
- Life insurance companies
- Credit card companies
- Banks and financial institutions

If your loved one had plans to be a brain donor, when death occurs, you will need to connect with the donation coordinator within two hours of death. If the person dies in a care facility or hospital and chose to be an organ donor, a local Organ Procurement Organization (OPO) will recover the organs for transplantation. In most cases, if the person is near death or dies in the hospital, the hospital is responsible for informing the local OPO.

## Getting Help With Grief

As a caregiver or family member, you may feel a mix of emotions when a loved one passes. These emotions may include sadness, relief, confusion, or numbness. It's important to know that all of these feelings are normal — there is no right way to grieve. While there are many steps and decisions to make after someone passes, it's important to remember to take time for yourself. Try to eat healthy foods regularly, exercise, and find time to socialize with friends and family. Joining a support group may also be helpful. Talk with your health care provider if your grief persists or if you are having trouble completing daily tasks.



# Points To Remember

- **Making decisions for someone at the end of life can be difficult.** If possible, start discussions early about the person's wishes and have advance directives in place.
- **There are different places where a person can receive end-of-life care.** If it's not stated in their advance care documents, make a decision about where the person will receive care based on their individual needs and preferences.
- **Care can come in many forms at the end of life.** Talk with the person's health care team to find the best ways to help manage their comfort.
- **After the person dies, you will need to make arrangements.** Hospice and hospital staff can help get a legal pronouncement of death. However, you may need to follow up with different institutions and agencies in the weeks following the person's death.
- **Grief comes in many different forms.** It's important to find time to take care of yourself. If your grief persists, talk with your health care provider.

# For More Information

## **Centers for Medicare & Medicaid Services**

800-633-4227

877-486-2048 (TTY)

[www.cms.gov](http://www.cms.gov)

[www.medicare.gov](http://www.medicare.gov)

## **Eldercare Locator**

800-677-1116

[eldercarelocator@n4a.org](mailto:eldercarelocator@n4a.org)

<https://eldercare.acl.gov>

## **MedlinePlus**

National Library of Medicine

[www.medlineplus.gov](http://www.medlineplus.gov)

## **Organdonor.gov**

Health Resources & Services Administration

[www.organdonor.gov](http://www.organdonor.gov)

## **American Geriatrics Society**

800-247-4779

[info.amger@americangeriatrics.org](mailto:info.amger@americangeriatrics.org)

[www.americangeriatrics.org](http://www.americangeriatrics.org)

## **Center to Advance Palliative Care**

212-201-2670

[capc@mssm.edu](mailto:capc@mssm.edu)

[www.getpalliativecare.org](http://www.getpalliativecare.org)

## **Family Caregiver Alliance**

800-445-8106

[info@caregiver.org](mailto:info@caregiver.org)

[www.caregiver.org](http://www.caregiver.org)

## **Hospice Foundation of America**

800-854-3402

[info@hospicefoundation.org](mailto:info@hospicefoundation.org)

[www.hospicefoundation.org](http://www.hospicefoundation.org)

## **National Hospice and Palliative Care Organization**

703-837-1500

[nhpco\\_info@nhpco.org](mailto:nhpco_info@nhpco.org)

[www.nhpco.org](http://www.nhpco.org)

# To Learn More About Health and Aging

## **National Institute on Aging Information Center**

800-222-2225

800-222-4225 (TTY)

**[niaic@nia.nih.gov](mailto:niaic@nia.nih.gov)**

**[www.nia.nih.gov](http://www.nia.nih.gov)**

Visit **[www.nia.nih.gov/health](http://www.nia.nih.gov/health)** to find more health and aging information from NIA and subscribe to email alerts.

Visit **<https://order.nia.nih.gov>** to order free print publications.

# Words To Know

## **Cheyne-Stokes respirations**

(chain-stowks reh-spr-ay-shunz)

A rare abnormal breathing pattern that can occur while awake but usually occurs during sleep.

## **Cognitive function**

(kog-ni-tiv FUNK-shuhn)

Refers to mental abilities, including learning, thinking, reasoning, remembering, problem-solving, decision-making, and attention.

## **Commode**

(kuh-mowd)

A portable toilet that can be placed at the bedside of someone who has limited mobile function.

## **Dyspnea**

(DISP-nee-uh)

Shortness of breath.

## **Hospice care**

(HOS-pis kayr)

An approach to care that focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.

## **Long-term care facility**

(long-turm kayr fuh-SIL-uh-tee)

Facilities that provide a variety of services, both medical and personal care, to people who are unable to live independently.

## **Palliative care**

(PA-lee-uh-tiv kayr)

A specialized medical care for people living with a serious illness. This care is meant to enhance a person's current care by focusing on quality of life for them and their family.

## **Respite care**

(REH-spit kayr)

A service that can provide short-term relief to caregivers.



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