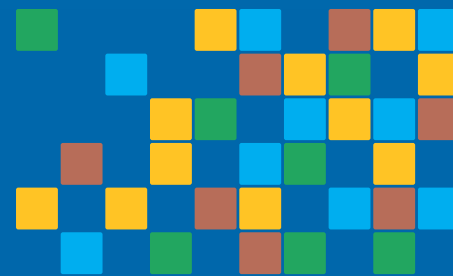


Things to Know: Caring for Someone at the End of Life



Caring for someone who is at the end of life is a difficult experience. It can be both rewarding and stressful. Many people provide this care to relatives, friends, neighbors, and people they choose to call family. You're not expected to be an expert and it is okay to feel overwhelmed.

This overview offers some things to know about end-of-life caregiving. Keep in mind that every caregiver's experience is personal and this is a starting place. Decide what works for you and the person you are caring for.

There is no "right way" to be a caregiver.

What does a caregiver do?

Below are things that may be a part of your role. Remember that care may change over time and is based on the needs of the person you care for as well as your own.

- Help with understanding medical information and options
- Assist with medications and symptoms
- Help create legal documents like a living will, advance directive, and power of attorney
- Assist with paying bills and organizing health insurance information
- Communicate with friends, family, and providers

- Help with provider and location transitions
- Schedule appointments and give rides
- Cook, clean, shop, and make sure the home is safe
- Help with eating, dressing, and hygiene
- Take part in spiritual activities

A caregiver who provides support in many of these areas may need support from others. Talk with the person you're caring for and others involved in caregiving, so everyone is clear on the plan.

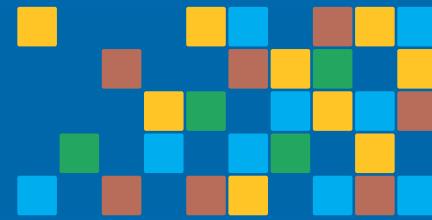
What can you expect?

Each caregiving experience is different. Here are a few things experienced caregivers wish they'd known sooner:

- Taking breaks from caregiving is important
- The time caregiving can take
- How to manage legal and financial matters
- The impact of caregiving on mental health

Being aware of these things and planning now can reduce stress and surprise later. It may also lead to a better quality of life for you and the person you care for.

Planning can decrease stress and improve quality of life.



What kind of support can help?

Taking care of someone else requires taking care of yourself. People with strong support systems tend to cope better and provide better care.

Always include self-care in your caregiving plan.

Support comes in many forms. Here are some ways to practice self-care while caregiving:

- Schedule respite—time when someone else can be with the person you care for
- Take breaks to do something you enjoy, outside the caregiving space
- Ask for or hire help with non-personal tasks like cleaning
- Join a support group, talk to a friend, or reach out to a health provider

Home- and facility-based health services can provide additional support. Learn and ask questions about:

- Palliative care—treatment of the discomfort, symptoms, and stress of serious illness
- Hospice care—supports that focus on the quality of a person’s final months of life

Support can also come in the form of professional advice about financial and legal matters.

How can conversations help?

Talking about death is uncomfortable for most people. It’s natural to avoid conversations about it, but honest and early discussions are important. They help the person you’re caring for express their needs—and help you meet them.

Conversations may include the person you’re caring for, family members, friends, and health providers, as well as other professionals like financial advisors and attorneys.

Here are some tips that may help with conversations:

- Involve the person you care for in all caregiving conversations, if possible
- Offer emotional support by letting others know it’s okay to talk about tough topics
- Write down your thoughts in advance to speak more comfortably and clearly

Place the needs of the person you care for at the center of conversations.

What next?

It’s okay to feel overwhelmed or not know where to start. Find resources that can help at nir.nih.gov/end-of-life.



Caregiving isn’t easy.
Ask questions. Talk about it. Take care of yourself, too.