

Finding Harmony, Peace & Support

A caregiver's guide to navigating serious illness, changing care needs, planning and loss

Alive

For more than 50 years, Alive has helped Middle Tennessee families navigate serious illness, end of life and grief as a nonprofit care provider.

When someone you love is seriously ill, it can be hard to know what comes next. You don't have to have all the answers or make every decision at once.

Understanding your options can help you feel more prepared, find the right support and make decisions that reflect what matters most to your loved one and your family.

How to use this guide:

Start wherever you are. You can read it from beginning to end or jump to the sections that are most helpful right now.

- Learn about the types of care and support available.
- Prepare for conversations with doctors and family members.
- Keep track of important information and questions.
- Find support for yourself as a caregiver.
- Explore what to do next as needs change.

Keep this guide handy and return to it whenever you need it.

1. Start With What Matters Most

Before thinking about services or next steps, consider what matters most to the person receiving care.

What matters most to you and your loved one right now?

- ☐ Being comfortable
- ☐ Staying at home, if possible
- ☐ Continuing treatment
- ☐ Spending meaningful time with family and friends
- ☐ Having fewer hospital or emergency visits
- ☐ Feelig better day to day
- ☐ Maintaining independence
- ☐ Understanding what to expect
- ☐ Having a say in care decisions
- ☐ Something else: _____

What matters most to you as their caregiver?

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These answers can help guide conversations with doctors, family members and care teams.

2. Understand Your Options

What does care beyond hospice mean?

Alive is known for hospice, but our care and support extend beyond it. Help can begin during serious illness, continue through end-of-life care and extend to families and loved ones experiencing grief.

You may want to explore additional support if:

- Symptoms like pain, nausea, fatigue or shortness of breath are affecting everyday life.
- You're spending more time managing appointments, medications or care.
- You're unsure whether current treatment is meeting your loved one's goals.
- You're wondering about hospice but aren't sure what it means.
- You want to understand your options before making a decision.

One important thing to know:
Getting additional support doesn't mean giving up.

Different types of care can help at different points in the journey:

- **Complex care** can help manage symptoms and improve quality of life while someone continues other medical treatment.
- **Hospice care** focuses on comfort, symptom relief and quality of life for people with a terminal illness, while supporting their families.
- **Grief support** helps individuals and families navigate loss, both before and after a death.

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3. Explore the Types of Care and Support

You don't need to know which service is right before asking questions. Start with what's happening and what kind of help you need.

Complex Care

This may be worth exploring if:

- ☐ Your loved one has a serious or chronic illness.
- ☐ They're receiving treatment but struggling with pain, symptoms or stress.
- ☐ Medical decisions are becoming harder to navigate.
- ☐ You or your family could use another layer of support.

What it can provide: *Help managing pain and symptoms, care planning and improving quality of life alongside other medical treatment.*

Hospice Care

This may be worth exploring if:

- ☐ Your loved one has a terminal illness.
- ☐ The focus of care is shifting toward comfort and quality of life.
- ☐ Symptoms or care needs are increasing.
- ☐ You're concerned about keeping your loved one comfortable.
- ☐ Your family needs more support caring for them.

What it can provide: *A specialized care team focused on comfort, symptom management, needed equipment and support for both the patient and family. Alive has earned a CMS 5-Star Rating for patient and family experiences.*

Grief & Loss Support

This may be worth exploring if:

- ☐ Someone you love has died.
- ☐ You're grieving a loss from months or even years ago.
- ☐ A child or teenager in your family is grieving.
- ☐ You're experiencing grief before an expected death.
- ☐ You're supporting someone through grief and aren't sure how to help.
- ☐ You want to connect with others who understand what you're going through.

What it can provide: *Counseling, support groups, resources, youth programs and opportunities for remembrance. Support is available regardless of when the loss happened or whether the person who died received care from Alive.*

Community Education & Remembrance

Support doesn't always have to begin with medical care.

Alive also offers education, planning resources and opportunities to remember and honor loved ones. More than 350 local volunteers help make this community support possible.

4. Prepare for Your Next Conversation

Whether you're meeting with a doctor, talking with family or contacting a care team, having a few questions ready can help you feel more prepared.

Six questions to ask the care team:

- ☐ What should we expect over the next several weeks or months?
- ☐ What symptoms or changes should we watch for?
- ☐ How can we keep our loved one comfortable and maintain their quality of life?
- ☐ Are there other types of care or support we should consider?
- ☐ Who should we contact if their condition or needs change?
- ☐ Would hospice or palliative care help us now?

Make a note of what you learn:

What we know now:

What we still need to understand:

Who we should contact next:

5. Have a Conversation Together

You don’t have to figure everything out in one conversation. Starting with questions can help everyone understand what matters most before making decisions.

Try asking:

- “What matters most to you right now?”
- “What would make your days feel better or easier?”
- “What are you most worried about?”
- “What kinds of treatment or care feel worthwhile to you?”
- “If things change, where would you prefer to receive care?”
- “Who would you like involved in decisions?”

If the conversation feels too big, start small.

You might say:

“We don’t have to make any decisions today. I just want to understand what you would want if things change.”

If you don't agree, look for common ground.

You may not see every decision the same way, and that's okay. Try to find something you can agree on, even if it's simply wanting the person you love to feel comfortable, supported, and heard. Start there and keep the conversation going.

6. Get Organized Together

Caregiving can become complicated when several people are involved. Having important information in one place can make it easier to coordinate care and share responsibilities.

Keep track of key contacts

Primary medical contact

Name: _____ Phone: _____

Who should receive updates?

_____

Who should be contacted first if something changes?

_____

Divide up responsibilities

- ☐ Who can help with transportation?
- ☐ Who can help with meals, errands or household tasks?
- ☐ Who manages medications?
- ☐ Who has permission to speak with the medical team?

Know where to find important information

- ☐ Insurance cards
- ☐ Medical records and medication lists
- ☐ Advance directives and other important documents
- ☐ Contact information for doctors and care providers

Location of important documents:

_____

_____

_____

7. Take Care of Each Other, Too

Caring for someone often means adjusting routines, sharing responsibilities, and figuring things out as you go. Along the way, it's important to make sure everyone's needs are being considered, including yours.

Take a moment to check in with yourself.

Try asking:

- □ Am I getting enough sleep?
- □ Am I able to leave the house or take breaks?
- □ Am I missing work or other responsibilities because of caregiving?
- □ Am I regularly feeling overwhelmed, angry, numb or frightened?
- □ Do I feel like everything depends on me?
- □ Am I unsure how much longer I can manage the current level of care?

If you checked several of these, it doesn't mean you're failing as a caregiver. It may mean you need more support, too.

One thing someone else could help me with this week:

One person I can ask for help:

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8. Decide What to Do Next

You don't have to do everything at once. Choose the path that best describes where you are today.

I'm still learning about my options.

- ☐ Learn about complex care.
- ☐ Learn about hospice care.
- ☐ Explore planning resources.
- ☐ Write down questions for my next medical appointment.
- ☐ Save this guide and return to it as needs change.

My loved one's care needs are changing.

- ☐ Write down the changes I'm noticing.
- ☐ Ask their medical team whether additional support could help.
- ☐ Review what matters most to the person receiving care.
- ☐ Contact Alive to discuss available care options.

We're ready to explore hospice or other care.

- ☐ Contact Alive's care team.
- ☐ Gather basic medical and insurance information.
- ☐ Write down questions before calling.
- ☐ Identify the family member who should be the primary contact.

We're navigating grief or loss.

- ☐ Explore grief counseling or support groups.
- ☐ Find support specifically for children or teenagers, if needed.
- ☐ Explore remembrance opportunities.
- ☐ Share grief resources with family members who may need them.

9. Know When to Reach Out

You don't have to wait until the final days of life to ask questions about hospice, complex care or other support.

Consider contacting Alive when:

- Symptoms are becoming harder to manage.
- Care needs are increasing.
- Hospital or emergency visits are becoming more frequent.
- Your family is unsure what comes next.
- Comfort and quality of life are becoming bigger priorities.
- Caregiving is becoming difficult to manage.
- You simply need help understanding your options.

Asking questions doesn't commit you to receiving care. You can reach out to learn what's available and whether additional support may be helpful now or in the future.

10. Find Support Through Grief

Grief can begin before a death and continue long afterward. There's no single timeline or right way to experience it.

You may want additional support if:

- ☐ You want a safe place to talk about someone who is dying or has died.
- ☐ You feel isolated in your grief.
- ☐ You're supporting a child or teenager after a loss.
- ☐ The loss was sudden or especially difficult.
- ☐ You want to connect with others who have experienced something similar.
- ☐ You'd like a meaningful way to remember or honor someone you love.

Alive offers grief support for adults, children and families experiencing different kinds of loss.

We're Here to Help

You don't have to navigate serious illness, changing care needs or grief alone. Alive can help you understand your options and find the support that's right for you and your family.

Contact Alive

615-346-8704
The call center to connect you to the care you need.

Alive