



ALS & HOSPICE

A Les Turner ALS Foundation Guide for People living with ALS

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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What is hospice?

Hospice is a specialized type of health care for people with life-limiting serious illnesses like ALS. Health care for people with ALS often focuses on slowing disease progression: helping people live longer and preventing their ALS symptoms from getting worse. Hospice is different because it shifts the focus from slowing disease progression to making every day as good as it can be.

The goal of hospice is to help you experience the best possible quality of life. It's about choosing to live as fully and comfortably as possible in the time you have.

Hospice provides:



Help with managing ALS symptoms like pain, breathing and swallowing difficulties, fatigue, and anxiety



Support for mental health concerns, emotional challenges, and spiritual or existential questions related to ALS or the end of life



24/7 phone line to connect with your hospice team



Some medical equipment and supplies



Decision-making and advance care planning support to help you make choices guided by your goals and values



Support for family and caregivers

Some hospice programs provide additional support, including therapies like physical, speech, or music therapy and other services to support you and your family.

Who can receive hospice?

In the United States, people typically need to meet certain guidelines to qualify for hospice. The Centers for Medicare & Medicaid Services (CMS) sets the guidelines for everyone who has health insurance through Medicare or Medicaid, and most private health insurance companies set their own rules based on the CMS guidelines. You will need a health care provider to determine if you qualify for hospice. If you qualify, your provider will write an order for you to receive hospice services.

Your ALS care team can help you learn about hospice options in your area, advocate for your needs, and make a plan for starting hospice. It's a good idea to meet with recommended hospice programs and ask each program about its acceptance requirements.

For suggested questions to ask when considering a hospice program, see page 13.

If you don't qualify for hospice, palliative care may be helpful for you and your family. Palliative care can help you proactively manage your symptoms and enjoy the best possible quality of life at any stage of ALS.

To learn more about palliative care and what sets it apart from hospice, check out our companion guide, **ALS & Palliative Care**:
www.lesturnerals.org/als-palliative-care-guide





How long does hospice last?

Hospice can be hard to talk about because many people associate it with death and dying. It's true that hospice offers support near the end of life, but each person's experience is different.



Where can I receive hospice?

Hospice care is a service provided wherever a person calls home, including private residences, nursing homes, assisted living facilities, hospitals or designated inpatient hospice centers.



Is hospice covered by health insurance?

Medicare, Medicaid, and most private insurance plans cover hospice services. To learn more, talk to your ALS care team.

When is it time to start hospice?

There is no single "right time" to start hospice. But starting hospice earlier — rather than waiting until a crisis happens — can give you and your family more time to benefit from the support that hospice provides.

It may be a good time to ask your ALS care team about hospice if:



Your ALS symptoms are getting worse or happening more often



You want to focus on making every day the best it can be



You have had more emergency room (ER) visits or hospital stays recently



Your caregiver is feeling burned out or needs more support



You have experienced loss of strength or function

Some people choose not to pursue treatments that help slow the progression of ALS, like breathing and nutrition support. If you choose not to pursue these treatments, hospice can help you experience the best possible quality of life in the time you have.

If you think hospice might be right for you, talk to your primary care team or ALS care team. A health care provider can assess whether you qualify for hospice and write an order for you to receive hospice services.

Keep in mind that if you choose to start hospice, you are not stuck with your decision. You can decide to leave hospice if your goals change.

“Kate knew she was not going to get a feeding tube or a trach, so we both understood there was no downside to starting hospice when we did. My recommendation for anyone with ALS: have the hospice conversation earlier rather than later.”

-Sean M., former caregiver and partner

How can hospice support me and my family?

Hospice provides additional support to help you live as fully and comfortably as possible in the time you have. If you choose to enter hospice, you and your family will have access to a team of specialists with expertise in different areas. Your hospice team can work together with your ALS care team to support you and your family in all aspects of life – physical, emotional, social, and spiritual.

Health care and symptom management

In the United States, every hospice program is required by federal guidelines to provide a hospice physician and hospice nurse. Your physician can work together with your ALS care team to oversee your health care. Your nurse will visit you regularly to provide pain and symptom management, monitor your health, and coordinate your care with other team members.

“ [Hospice professionals] are angels. The knowledge and care that they bring is truly motivational and inspiring.

-Ashley C., person living with ALS



Your hospice team will become your primary health care team and can work in collaboration with your ALS care team if you wish.

Mental health, emotional, and spiritual support

U.S. hospice programs are required to provide a social worker and a chaplain. These professionals can help you and your family/caregivers through the transitions, emotions, and spiritual matters that often come up during hospice. They can also connect you with resources in your community.

Some hospice programs provide access to additional specialists and services, including:



Hospice aides or Certified Nursing Assistants (CNAs) to help with personal care tasks like bathing



Speech therapy, physical therapy, and other therapies like music, massage, art, or pet therapy



Volunteers to provide additional support and companionship



Child life specialists to help children and their families cope with the stress of serious illness

If you are looking into a specific hospice program, it's a good idea to ask what services they offer, so you'll know what to expect.

“ I get physical support from the nurse, along with necessary equipment and supplies, as well as medications. I get bathing visits from the CNA. I get social and emotional support from the social worker. I get spiritual support from the chaplain. I get massage therapy for maximizing comfort and reducing pain. I get respiratory therapy for supporting my breathing and new equipment. I also get comfort cards in the mail from a volunteer!

-Ashley C., person living with ALS



Medical equipment and supplies

Hospice programs typically provide some types of basic medical equipment, like hospital beds and Hoyer lifts. They may also provide personal care items, wound care supplies, and incontinence supplies like absorbent pads or protective underwear.



24/7 support

Most hospice programs have a 24-hour phone line, so you and your family can always reach your hospice team, even at night or on the weekend.

Decision-making and advance care planning support

Hospice professionals can help you navigate the choices that come with ALS on your own terms, guided by your goals and values. Hospice teams are trained to help you and your family:



Clarify what matters most to you and put it into words



Prepare for conversations with loved ones and your ALS care team



Document your wishes by completing advance directives and Physician/Provider Order for Life-sustaining Treatment (POLST) forms or the equivalent forms in your state



Make decisions at your own pace, without pressure

No matter what you choose, your hospice team will support you in your decisions.



Specialized support for families and caregivers

Caring for someone with ALS is one of the most demanding and meaningful things a person can do. Hospice isn't just for people living with ALS — it's also designed to support families and caregivers.

“

The entire hospice team was amazing from the moment we started until Kate passed away. No BS, these folks were like family, with lots of love, tears, education, and care.

-Sean M., former caregiver and partner



Education and hands-on training

Hospice programs often provide guidance and training on topics like managing symptoms. They also offer education to help caregivers and loved ones understand what to expect in the months ahead. Having this knowledge can help everyone feel more prepared during a difficult time.



Emotional, spiritual, and grief support

Hospice social workers and chaplains provide mental health, emotional, and spiritual support for the whole family. Many hospice programs also offer grief support for loved ones and caregivers for up to 13 months after the patient's passing.



Help with advance care planning and difficult conversations

Hospice teams support the whole family through the process of advance care planning. They can also offer guidance on navigating difficult conversations about the future.



Respite care

Caregiver burnout is real. To give caregivers time to rest, recharge, and tend to their own needs, many hospice programs offer respite care. With respite care, a person living with ALS can receive 24/7 care in the community, typically at an assisted living or nursing facility, for a short time (often up to 5 consecutive days).



Understanding what hospice can and cannot provide

Hospice provides support for people living with ALS and their families in many areas of life. Hospice nurses can help to coordinate your care, and in some hospice programs, aides or CNAs are available to help with bathing and other personal care tasks. However, it's important to understand that hospice is not meant to replace a full-time caregiver or meet your daily care needs. You will still need caregiver support while on hospice.

A note to caregivers

It's important to remember that taking breaks is not selfish. When looking back on their experience with hospice, many caregivers say they wish they had used respite care more. If your hospice team offers respite care, don't hesitate to use it.

Taking care of yourself is an important part of taking care of your loved one — in fact, it can help you provide better care.

For more on taking care of your own needs and well-being as a caregiver, see our ALS & Caregiver Self-Care Guide: lesturnerals.org/als-caregiver-self-care-guide



How can I start the conversation about hospice with my family and ALS care team?

Talking about hospice can feel overwhelming, but there are benefits to starting the conversation sooner rather than later. Discussing your care options and preferences before a medical crisis arrives can give you more time to make plans and more control over choosing your next steps. It can also save you and your loved ones a lot of stress. Most people living with ALS find that talking about hospice openly can bring clarity and relief — in fact, it can even bring families closer together.

You don't have to have all the answers going into the conversation. Talking with your family and ALS care team can help you learn about your options, reflect on what you want, and address any questions you may have. Here are a few tips to consider.



Share this guide with your loved ones so that they can learn about hospice alongside you. You can also bring it to doctors' appointments to support conversations with your ALS care team.



Let your ALS care team or Support Service Coordinator know that you're ready to learn more about hospice options. Ask, "What would hospice look like for someone in my situation?"



Talk to your family and ALS care team about your goals and values. For example, what matters most to you? What does a good quality of life mean to you?



Don't hesitate to ask questions.



Keep in mind that hospice is about adding support, not losing support or care. You can continue to work with your ALS care team while in hospice.



Remember that you don't have to make a decision right away. You can continue to explore your options for as long as you need.

“

I discussed [starting hospice] with my ALS clinic beforehand, and my neurologist said it would be a good idea. . . It was difficult because I [knew I wasn't] getting better . . . but it was done at the right time.

-Ashley C., person living with ALS

When considering hospice, what questions should I ask?

When you're considering hospice, it's helpful to meet with multiple hospice programs and learn about the services they offer. As you explore your options, remember that you're in the driver's seat. It's okay to advocate for your needs and ask plenty of questions so you can find the program that's right for you.

Here are some questions that can help you learn more about a hospice program. For a checklist to use to get ready for your first hospice meeting or revisit it anytime to learn more about your options, see page 13.

Hospice services

Asking these questions can help you understand what services a hospice program provides.



What services are included in hospice?



What services are covered by my health insurance?



How often will a nurse visit? What services will they provide?



How often will a hospice aide or CNA visit? What services will they provide?



Do you offer special therapies such as massage or music therapy?



Who can I call after hours or on weekends?



How will you collaborate with my ALS care team?

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Planning for your future care needs

These questions can help you learn more about what to expect and how the hospice program will support your care needs.



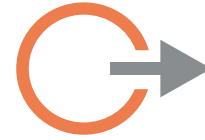
How will you manage my breathing as ALS progresses?

Do you have a respiratory therapist on staff?



What does the end of life typically look like with ALS?

What should we expect?



What happens if my care needs change?

Can I leave hospice if it's not meeting my needs?

Coordinating care

These questions can help you understand how the hospice program will work together with your existing ALS care team or treatments.



How will you work together with my neurologist or ALS clinic?



What medicines can I continue to take while on hospice?



Can I continue to use non-invasive ventilation (NIV) while on hospice?



Can I continue to use a feeding tube while on hospice?

What is your coverage for tube feeding supplies?



Can I continue to participate in a clinical trial while on hospice?



Will I be able to use my current respiratory equipment provider?

Family and caregiver support

These questions can help you learn what resources the hospice program offers to families and caregivers.



How can you support my family and caregiver(s)?



What is respite care? How and where can I use it?



What grief support is available?

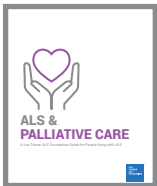


Do you have services or support that you can provide to the children in my family?



Starting hospice is not the end. For many people and families, hospice is the beginning of a new chapter filled with more support, more comfort, and more time to focus on what matters most.

Additional resources



ALS & Palliative Care Guide

To learn more about palliative care and what sets it apart from hospice, check out our companion guide, ALS & Palliative Care: www.lesturnerals.org/als-palliative-care-guide



Hospice video

Watch this video from our ALS Learning Series to learn more about hospice: <https://lesturnerals.org/support-services/als-learning-series-hospice-care-and-als/>.



Hospice directories

Use these tools to search for hospice providers in your area:

National Alliance for Care at Home: allianceforcareathome.org/find-a-provider

National Hospice Locator: nationalhospicelocator.com

Medicare's Hospice Compare Tool: medicare.gov/care-compare/?providerType=Hospice

What to ask when considering hospice

You can use this checklist to get ready for your first hospice meeting or revisit it anytime to learn more about your options.

Hospice services

- ☐ What services are included in hospice?
- ☐ What services are covered by my health insurance?
- ☐ How often will a nurse visit? What services will they provide?
- ☐ How often will a hospice aide or CNA visit? What services will they provide?
- ☐ Do you offer special therapies such as massage or music therapy?
- ☐ Who can I call after hours or on weekends?
- ☐ How will you collaborate with my ALS care team?

Coordinating care

- ☐ How will you work together with my neurologist or ALS clinic?
- ☐ What medicines can I continue to take while on hospice?
- ☐ Can I continue to use non-invasive ventilation (NIV) while on hospice?
- ☐ Can I continue to use a feeding tube while on hospice? What is your coverage for tube feeding supplies?
- ☐ Can I continue to participate in a clinical trial while on hospice?
- ☐ Will I be able to use my current respiratory equipment provider?

Planning for your future care needs

- ☐ How will you manage my breathing as ALS progresses? Do you have a respiratory therapist on staff?
- ☐ What does the end of life typically look like with ALS? What should we expect?
- ☐ What happens if my care needs change? Can I leave hospice if it's not meeting my needs?

Family and caregiver support

- ☐ How can you support my family and caregiver(s)?
- ☐ What is respite care? How and where can I use it?
- ☐ What grief support is available?
- ☐ Do you have services or support that you can provide to the children in my family?

Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, lesturnerals.org/resources.

My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn more about common ALS treatments, answer a few questions to help you think through what is most important to you, and get ready to talk with your ALS care team about your options. To learn more, visit: alsdecisions.org.

**MY ALS
DECISION
TOOL**

ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Monthly educational webinars and interactive Q&As cover a diverse array of topics, from nutrition to respiratory care. Presenters include members of the Foundation's Supportive Services team, our Lois Insolia ALS Clinic at Northwestern Medicine, and other national ALS experts. To learn more, visit: alslearningseries.org.

**ALS
LEARNING
SERIES**

My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: lesturnerals.org/passport.

**MY ALS
COMMUNICATION
PASSPORT
TO QUALITY CARE**

Support Groups

We facilitate support groups to provide people living with ALS and their caregivers and families the opportunity to share their experiences, give encouragement, and help each other navigate their journey with ALS. To find out more, visit: lesturnerals.org/support-groups.



Explore More Educational Resources from the Les Turner ALS Foundation

We offer a variety of educational resources for people living with ALS and their families and caregivers. Our decision tools, guides, and webinars cover many aspects of living with ALS, from symptoms to communication, caregiving and relationships, financial decisions, and much more. To explore these resources, visit: <https://lesturnerals.org/als-decision-tools-guides-and-webinars/>.