

ALS & PALLIATIVE CARE

A Les Turner ALS Foundation Guide for People living with ALS

LES TURNER ALS FOUNDATION®

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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 palliative care?

Palliative care is a specialized type of health care for people living with serious illnesses like ALS. Palliative care focuses on relieving symptoms, reducing stress, and improving quality of life in the face of a serious illness. The goal is to help you feel better and function better, so that you can live as fully as possible at every stage of your ALS journey.

The goal of palliative care 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. Palliative care does not replace your ALS treatments or care team. Your palliative care team can work together with your ALS care team to support you and your family.

> **"Palliative care is about having the best quality of life for as long as possible."**
>
> -Amy H., former caregiver and partner

Palliative care provides:



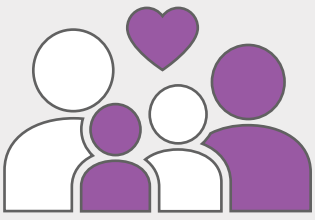
Help with managing ALS symptoms like pain, breathing and swallowing difficulties, fatigue, insomnia, and anxiety in collaboration with your ALS care team



Support for mental health concerns, emotional challenges, and spiritual or existential questions that may come with ALS



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



Family and caregiver support

What is the difference between palliative care and hospice?

Many people confuse palliative care with hospice. Palliative care and hospice share the same focus on comfort and quality of life, but they are not the same thing. Understanding the difference can help you get the support you need, when you need it.

 Palliative Care	 Hospice
Palliative care can begin at any stage of ALS, even right after diagnosis.	Hospice begins when you choose to focus on quality of life instead of slowing the progression of ALS, and a health care provider determines that you qualify for hospice.
Palliative care may continue for months or years.	Hospice may continue for weeks, months, or years — timing varies from person to person, but the goal is to provide support leading up to the end of life.
Your palliative care team will work alongside your existing ALS care team (including your neurologist and other doctors).	Hospice provides a primary care team focused on your comfort. You can also keep working with your ALS care team.
Palliative care helps you manage symptoms, relieve stress, and experience the best possible quality of life while you receive ALS treatment.	Hospice shifts the focus from slowing disease progression to helping you live as fully and comfortably as possible in the time you have.
You'll continue any therapies you are currently receiving, like physical, occupational, or speech therapy.	You may have the option to continue physical, occupational, or speech therapy, depending on the services available through your hospice program. Some hospice programs provide additional therapies, like music, massage, or pet therapy.
Palliative care is provided in some ALS clinics, at outpatient clinics, at home, and online via telehealth.	Hospice is provided at home and in assisted living or nursing facilities.
Palliative care is covered by most health insurance as part of your care plan, just like other types of specialty medical care.	Hospice is covered by Medicare, Medicaid, and most private insurance as a separate benefit.



If you would like to learn more about hospice, please see our companion guide, ALS & Hospice: www.lesturnerals.org/als-hospice-guide

When is it time to start palliative care?

Palliative care can begin whenever you are ready. Starting palliative care early has been linked to better outcomes for people living with ALS and their families.

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



You have just been diagnosed with ALS and want help thinking through your goals and priorities



You are struggling with physical or emotional symptoms that are affecting your quality of life



You want to talk through treatment options and important decisions before an emergency happens



You want to make sure that your wishes are clearly documented



Your caregiver would like more support

How can I advocate for palliative care with my ALS care team?

If you think palliative care may be a good fit for you, the next step is to ask your ALS care team or primary care team for a referral. Some people worry that asking about palliative care will send the wrong message or that their care team will think they have lost hope, but that's not the case. Palliative care is about striving to live as fully as possible at every stage of ALS. Asking about palliative care is an act of self-advocacy.

Learning more about the palliative care programs in your area can help you decide if palliative care is right for you. Some ALS clinics have palliative care professionals as part of a multidisciplinary team, so you can receive palliative care during your regular clinic visits. If this is not an option at your clinic, you can receive palliative care at an outpatient center, in your home, or online via telehealth.

Find a palliative care program near you

You can use these directories to find palliative care programs:

Find palliative care programs with expertise in ALS: als.org/navigating-als/living-with-als/therapies-care/palliative-care.

Explore additional palliative care programs in your area: getpalliativecare.org.

How can palliative care support me and my family?

Palliative care provides additional support to help you live as fully and comfortably as possible while you receive ALS treatment. Your palliative care 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.

Symptom management

Working side by side with your ALS care team, your palliative care team can help you manage ALS symptoms like:



Muscle cramps, spasticity, and pain



Fatigue



Excess saliva (spit) and secretions



Difficulty with swallowing (dysphagia)



Unintended weight loss



Breathing difficulty and shortness of breath



Sleep problems



Constipation

> **Just getting palliative care involved was an instant burden lifted. I was working during the day and coming home to care for my mom at night. It was so much to juggle.**
> -Nauzley A., former caregiver

> **I'm early in my palliative care journey, but just having another layer of support puts me at ease. My team is currently helping with some of my symptoms.**
> -Satrina B., person living with ALS

> **The palliative care team saw my mom once a month and could help with growing symptoms, compared to her ALS care team that saw her every 3 months. Because of that, the palliative care team were great advocates for us and worked well with my mom's ALS care team.**
> -Nauzley A., former caregiver

You do not have to accept these symptoms as simply "part of ALS." Many symptoms can be well managed with the right support. You can ask your palliative care and ALS care teams about any symptoms that are bothering you.

Emotional and mental health support

Living with ALS can bring grief, fear, anger, and depression. These feelings are completely understandable. Palliative care specialists can provide support to help you and your loved ones with:



Depression and anxiety



Adjusting to changes in your body and your roles



Relationships and intimacy



Grief, for losses you are already experiencing and those to come



Fear about the future, including the end of life

Spiritual and existential support

Living with ALS often brings up questions about meaning, purpose, mortality, and legacy. Your palliative care team can help you and your loved ones explore:



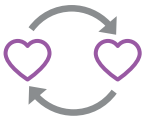
What matters most to you in the time you have



How you want to be remembered



Spiritual or religious concerns



Feelings of hope, peace, or unfinished business

> **"[Our palliative care team] would call and check in on me, and ask me, 'How are you doing?' Caregivers are not always checked in on. I felt the burden lifted."**
>
> -Nauzley A., former caregiver

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Decision-making and advance care planning support

Living with ALS means that you will need to make important decisions about your future health care. For example, as your disease progresses, your ALS care team may recommend treatments like breathing support or a feeding tube to help you stay as healthy and comfortable as possible. Even if you don't have trouble breathing or eating on your own right now, it's never too early to start planning ahead for your future care.

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



Understand your treatment and care options, including feeding tubes, breathing support, and hospice



Clarify what matters most to you and put it in words



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



Prepare for conversations with loved ones and your ALS care team



Make decisions at your own pace, without pressure

Whether you choose to pursue aggressive treatment, focus on comfort, or anything in between, your palliative care team will support you in your decision.

More resources to help you plan ahead and communicate your wishes

To learn more about POLST, visit: polst.org.

To learn more about advance directives, visit: fivewishes.org.

If you would like to learn more about ALS treatment options and think through what's important to you, visit My ALS Decision Tool™ at lesturnerals.org/my-als-decision-tool/.

To reflect on your values and future care needs, visit: unityhospice.com/als-values-assessment-guide-helps-patients-improve-quality-of-life.

For guidance on having difficult planning conversations with your loved ones, visit: lesturnerals.org/difficult-conversations-can-be-some-of-the-most-important/.

Specialized support for families and caregivers

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

Education and hands-on training

Palliative care programs often provide guidance on topics like managing symptoms. They also offer education to help caregivers and loved ones understand what to expect as ALS progresses. Having this knowledge can help everyone feel more prepared for the changes ahead.

Emotional, spiritual, and grief support

Palliative care programs offer mental health, emotional, and spiritual support, including counseling for family members and caregivers. Some palliative care teams may also provide grief support.

Help with advance care planning and difficult conversations

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

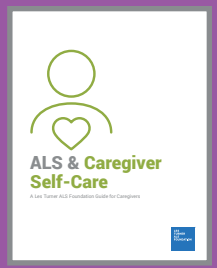
Additional resources to support the whole family

Palliative care professionals can help families connect with local resources like support groups and respite care. With respite care, a person living with ALS can receive 24/7 care for a short time (often up to 5 consecutive days) while their caregivers rest and recharge.

A note to caregivers

If you're caring for someone with ALS, remember that your feelings matter too. Grief, exhaustion, fear, and even resentment are normal parts of caregiving. You do not have to carry these alone. Ask your palliative care team what support is available for you.

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



> **I appreciated the offloading of the hard conversations, and for [our palliative care team] to take on the hard things, was great.**
>
> -Nauzley A., former caregiver

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Can I transition from palliative care to hospice?

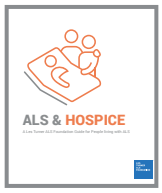


When the time comes, your palliative care team can help you and your family think about whether hospice is the right next step. Working together with your ALS care team, your palliative care team will guide you through the transition to hospice.

To learn more about hospice, visit our ALS & Hospice Guide at: www.lesturnerals.org/als-hospice-guide

Palliative care is about living as well as you can for as long as you can — with the right support team beside you.

Additional resources



ALS & Hospice Guide

To learn more about hospice when to consider hospice, and how it can support you and your family, check out our companion guide, ALS & Hospice: www.lesturnerals.org/als-hospice-guide

Palliative care resources

Explore palliative care resources designed for people living with ALS and their families and caregivers: alspalliativeresources.org.

Palliative care video

Watch this video from our ALS Learning Series to learn more about palliative care: lesturnerals.org/support-services/als-learning-series-living-fully-living-well-how-palliative-care-can-help/.

Palliative care directories

Use these directories to find palliative care programs near you:

Find palliative care programs with expertise in ALS: als.org/navigating-als/living-with-als/therapies-care/palliative-care.

Explore additional palliative care programs in your area: getpalliativecare.org.

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/.