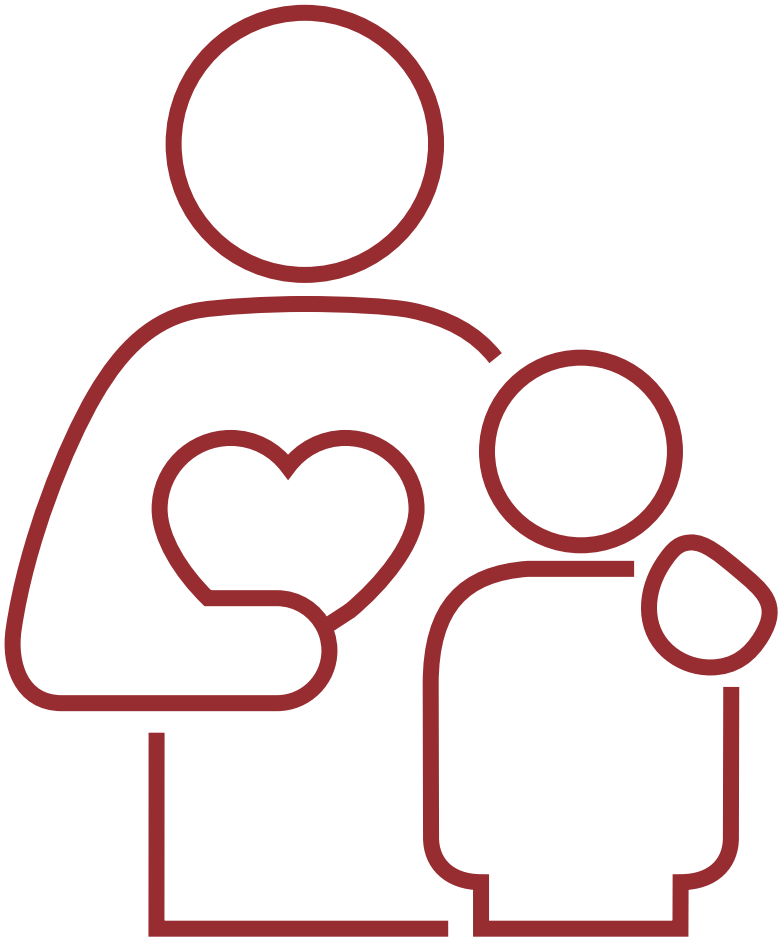

ALS & CHILDREN/ YOUTH

Talking to Children About ALS: A Les Turner ALS Foundation Guide for Families

LES TURNER ALS FOUNDATION®

Talking to Children About ALS

Learn how to talk to children about an ALS diagnosis, support young caregivers, and help children cope. Explore practical advice, family resources, and support programs.

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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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ALS & Children/Youth

An ALS diagnosis affects the entire family, including children and teenagers. Parents and caregivers may struggle with how much to share, when to start the conversation, and how to help their children navigate the changes happening at home. Talking openly about ALS can help children understand what's happening, ask questions, and feel included rather than left in the dark.

Whether you're a parent living with ALS, a caregiver, or another family member supporting a child, this guide offers practical strategies for talking about ALS, recognizing the needs of youngcaregivers, and helping children feel supported. Our intention is to provide you with information that you need today and tomorrow.

Conversations with children about ALS

When a family is dealing with an ALS diagnosis, children/youth are often more aware than parents may realize. Thus, beginning a conversation with them about an ALS diagnosis can be very challenging. Although you may feel you do not know how to approach the conversation, it is important to be honest and direct with your children/youth. They can sense when you are stressed and may believe that they are to blame. Moreover, they have access to the Internet, which may give them either more detailed information or incorrect information. Therefore, having an open conversation can prevent them from either thinking they have done something wrong, or learning incorrect information.

> **"I would have liked an explanation of the disease in a way I could have understood.**

> **"I wish someone would have told me to snuggle with him more.**

> **"I wish I would have been treated more like a big kid since what was happening was so big.**

The following information is part of a partnership with Dr. Melinda S. Kavanaugh and Global Neuro YCare, a global foundation dedicated to providing education and resources for children, youth and families living with ALS/MND - across language and culture. All materials listed below, and others, are freely available at (**www.globalneuroycare.org**).

How to speak with your children about ALS

The guide, *Families and ALS: A guide for talking with and Supporting Children and Youths*, provides detailed suggestions for conversations by age and developmental stage.



Start the conversation sooner rather than later

You may never feel "ready" to begin the conversation about ALS with your children. Although you should begin the conversation when you feel it is appropriate, psychologists recommend having the conversation sooner rather than later. Pick a time when you are doing something normal and calm, like relaxing at home, to put less pressure on both you and your children. If they don't want to talk, that is fine. Let them know they can come to you at any time when they are ready. The key is to open the door for them.



Be honest

Being honest with your children about ALS can be difficult, but ageappropriate honesty is necessary to maintain trust. This may include sharing honestly your own fears and concerns.



Use age-appropriate language

Using age-appropriate language will help your children better understand what is happening and what to expect in the future.



Allow them to ask questions and be prepared to answer them

Your children will likely have questions for you. It is important that you are prepared to answer them to the best of your ability. ALS is a complex disease, and some questions will be hard for you to answer because you may not know the answer yourself. If you do not know the answer to a question, let your children know, and don't hesitate to seek out support to help you get the answers you deserve.



Keep the conversation open

Check in with your children often. As the disease progresses, children may not always feel comfortable asking questions. Make sure they know that they can talk to you about what is going on at home.



Acknowledge their feelings

Children experience complex feelings just like adults but often have a more difficult time regulating emotions. They may not react to the news in a way that you expect. Create a safe space for them to discuss their emotions by meeting them where they are and acknowledging their feelings.

Resources for talking with your children

Talking with your children about ALS with Melinda Kavanaugh, PhD, MSW, LCSW
This ALS Learning Series webinar features features Dr. Kavanaugh's clinical expertise and many years of research with children in families with neurological disorders, as it guides families in engaging with children and youth about ALS. Additionally, Dr. Kavanaugh discusses the several books she has written, using the children's own words to help guide these conversations. To learn more, visit: alslearningseries.org



The following guides and webinars were developed by Dr. Kavanaugh to support parents and school professionals who have a child impacted by ALS. **uwm.edu/ycare/resources**

Guides

Real Kids Talk About ALS: Feeling Normal, Sad, and Different: graphic novel for youth, ages 7-12

The ALS experience: It's Different and Hard: A guide for middle school youth, ages 13-18

Families and ALS: A guide for talking with and Supporting Children and Youths

School, Friends, Work, and ALS: A Young Adult Guide to Balancing Life with ALS

At School: A guide to supporting Students who have been affected by ALS

Webinars

Talking with Children about ALS: **lesturnerals.org/support-services/als-learning-seriestalking-with-children-about-als/**

Grief & Loss in Children & Youth: **lesturnerals.org/support-services/als-learning-series-grief-loss-in-children-youth/**

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Young caregivers

Care for ALS often requires multiple caregivers, including children and youth. Yet, parents sometimes feel guilty when their children assist with caregiving. The reality is that family caregivers provide most home care.

Children/youth are often involved in many areas of caregiving with ALS. They typically assist with tasks such as transferring, dressing, assisting with feeding and showering/toileting. Yet, children/youth generally receive inconsistent training, which impacts their confidence to provide care and the quality of life for the care recipient. With training and support, caregiving can be a source of pride for the children.

Having your children help with caregiving is not inherently bad, but it is important for them to feel supported to prevent burnout, distrust and resentfulness.

How to increase your child's confidence in providing care:



Attend family trainings
Allow your children to attend YCare and family trainings with healthcare professionals when appropriate. Your ALS care team can assist with family trainings.



Explain how to help
Take the time to explain how to complete tasks and why you need their help. Always use ageappropriate language and engage trained healthcare professionals



Work together as a team
Caregiving is a team effort, and your children are part of your team! Working together as a team will help reduce stress for everyone.

Child/youth Caregiving Training and Support

Developed and informed by clinical practice and research with families in ALS/MND, the YCare program provides hands-on training and support for children and youth caregivers.

Led by ALS/MND health professionals, trained in the YCare model, the day-long activity-based YCare program provides children and youth the opportunity to: 1) meet health professionals, 2) ask questions about care, 3) learn and adapt care skills, and 4) meet and interact with "like" peers, who are also in families with ALS/MND.

YCare is available across the U.S. and globally. For more information, contact Global Neuro YCare (**www.globalneuroycare.org**).

Supporting your children

Many children report that being a caregiver makes them feel good about themselves and the care they provide. At the same time, many young caregivers experience anxiety and depression, and may have difficulty in school. Being proactive about the implications of caregiving can reduce stress for your child and help build support around them.

How to support your children



Support groups & camps

Children have a desire to connect with other individuals that are their age. Support groups can help your child connect with other children who are going through something similar and help them feel less isolated. Hope Loves Company is dedicated to providing emotional and educational support to children and young adults who have or had a loved one living with ALS. To learn more about their programs, visit: hopelovescompany.org.



Counseling

Children are at a higher risk for psychosocial distress during this time. Counselors are trained professionals who can help your child talk through their feelings and manage emotional distress.



Lead by example

Model healthy coping behaviors such as making time or sel-care. Leading by example does not mean you have to be perfect, but children are likely to mirror your responses to challenging situations.



Engage in enjoyable activities

It is important for your children to take time for themselves and have fun. Encourage them to continue to participate in activities they enjoy such as participating in sports, playing video games or hanging out with friends.



Collaborate with your child's school

Children may be afraid to talk with their teachers and peers about how ALS is impacting their life. It is important for families, teachers, and school counselors to communicate and ensure that children feel safe and supported at school. The guide, "At School: A guide for supporting Students who have been affected by ALS," is an excellent tool to share with school staff, so they are prepared to support your child.

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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 about some 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. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, 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, their caregivers and family 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.



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