



ALS & CHILDREN

A Les Turner ALS Foundation Guide for Families

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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

Children are impacted by ALS in many ways. In this guide, you will find information on how to talk with your children about ALS, how young people experience caregiving, and how to support your children during this time. 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 are often more aware than parents may realize. Beginning a conversation with your children 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. Children can sense when you are stressed and may believe that they are to blame. Having an open conversation can prevent them from thinking they have done something wrong.

“ 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.

How to speak with your children about ALS



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.



Be honest

Being honest with your children about ALS can be difficult, but age-appropriate honesty is necessary to maintain trust.



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.



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 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. alslearningseries.org



Guides

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

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

**To learn more, visit:
alslearningseries.org**

Young caregivers

Parents sometimes feel guilty when their children assist with caregiving. The reality is that family caregivers provide most home care.

Children 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. Children generally receive inconsistent training, which impacts their confidence to provide care. 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 resentment.

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



Attend family trainings

Allow your children to attend 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 age-appropriate language.



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.

Supporting your children

Many children report that being a caregiver makes them feel good. However, young caregivers are at a greater risk for anxiety and depression. Being proactive about the implications of caregiving can reduce stress for your child.

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 for self-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.

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.

