

TALKING TO KIDS & YOUTH ABOUT ALS



A guide to developmentally appropriate conversations

When you're living with ALS, talking to your child about the illness can feel overwhelming. You may worry about upsetting them or saying the wrong thing, and it can be tempting to put the conversation off. But children and teens want to understand what's happening, and hearing the truth from you helps reduce fear, confusion, and uncertainty.

You don't need to share every detail at once. Your goal in the first conversation is simply to open the door—help your child feel informed, supported, and comfortable asking questions. Talking early also gives you the chance to correct anything they may have heard online or from others.

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- Start the conversation early and in a calm, everyday moment.
- Ask what your child already knows and gently correct any misunderstandings.
- Share simple, honest information, appropriate to their age.
- Admit when you don't know an answer.
- Let your child set the pace—stay open, available, and pressure-free.
- Keep checking in over time as things change, listening and supporting their feelings.

Children handle a parent's illness in different ways. It helps to think about how your child usually responds to stress, and also how their age and stage of development might shape their reactions

The sections below offer simple starting points for talking with children of different ages. There is no "right" way to have these conversations and no "ideal" reaction. But understanding what children typically need at each stage can make these discussions easier and more supportive for your family.

Infants & Toddlers

Babies and toddlers need routine, need to feel safety, and can pick up anxiety and fear in the parent.

- Keep the normal routine as much as possible.
- Allow the child to ride on the wheelchair or sit with the person with ALS. Create a "new" normal environment (meal times, feedings, sleep, etc.).

Young Children – Ages 3 – 7

Children at this age are concrete and literal thinkers who don't need complex explanations, but they are naturally curious and may ask many direct questions. They often engage in “magical thinking,” which can lead them to believe that their thoughts or behavior caused the illness. Because they focus on what they can see and are not yet future-oriented, abstract or long-term concepts may be hard for them to understand.

- Be honest and simple in your explanations, focusing on what your child can see (like changes in walking or using a wheelchair) and avoiding complex or abstract terms or timeframes.
- Reassure your child that they did nothing wrong and are not responsible for the illness, since young children may blame themselves.
- Talk in the present moment, using clear, concrete language, and help your child understand that the illness—not anything they did—is causing the changes they notice.

Middle Childhood – Ages 8 – 12

Children at this age are exploring their identity and may wonder what it means to be “the kid with a parent in a wheelchair.” They are beginning to use logic and problem-solving skills to make sense of what they see. Clear, honest information helps them understand the illness without defining themselves by it.

- You can share more detail about ALS at this age, while continuing to reassure your child that the illness is not their fault and that having a parent with ALS does not define them in a negative way.
- Help “normalize” the experience within your family by talking openly about changes and outcomes, and by connecting what they see with clear explanations.
- Support them in naming their thoughts and feelings—letting them know it's OK to be sad or unsure—and encourage them to talk as much or as little as they need.

Adolescents – Ages 13 – 18

Adolescents often experience strong emotions and may focus on feelings even while struggling to manage them, influenced by hormonal changes and their developing sense of identity and belonging. At this stage, they have more advanced thinking skills and can understand abstract ideas, including imagining what life may be like with ALS. They respond best when they feel heard, respected, and that their perspective is valued, even if they seem distant or conflicted.

- Check in with your adolescent about how they feel and allow them to express emotions without judgment, even when discussing difficult hypotheticals about ALS.
- Consider involving a professional who can help your adolescent process emotions and provide a confidential space for them to explore their feelings.
- Keep communication open and supportive, acknowledging their growing independence, and let them know you are available whenever they are ready to talk.



Our Mission: To unite and empower the ALS community through a collaborative approach of providing comprehensive care and support to individuals and families affected by ALS, advancing national and state advocacy, and fostering bold research initiatives.



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