

EXPLAINING ALS GENETICS

TO CHILDREN & YOUTH



Talking about genetics can feel intimidating, especially when ALS is already hard to explain. You may worry about causing fear, confusion, or unnecessary worry about the future. This guide is meant to help you explain genetics in a way that is clear, calm, and appropriate for children and youth—without overwhelming them or yourself.

Start with the basics

You don't need to begin with genes or DNA. Start with the idea that bodies have instructions that help them work. You might say:

"Everyone's body has instructions that help it grow and work, kind of like a recipe or an instruction book."

From there, you can explain that sometimes a change in those instructions can affect how a body works. Keep the explanation simple and grounded in what the child already understands.

Explain that ALS is usually not inherited

One of the most important messages for children to hear is that most ALS is not genetic. Many children worry that they caused the illness or that they will "catch" it. You can say:

"Most people who have ALS did not get it from their family, and it is not something you can catch."

If genetics are part of your family's ALS story, it's still important to emphasize that genetics does not mean certainty or blame.

Be clear about what genetics does—and does not—mean

If ALS in your family is genetic, explain that genetics means a possibility, not a guarantee. You might say:

"In some families, ALS can be passed down, but even then, it does not mean someone will definitely get it."

Avoid discussing percentages, timelines, or adult medical decisions unless the child specifically asks and is developmentally ready.

Reassure children about responsibility and fault

Children often internalize information in personal ways. Make it clear—more than once—that nothing they did, thought, or felt caused ALS. Reinforce messages like:

- This is not your fault
- You did not cause this

You are not responsible for fixing it



Let questions guide the conversation

Children and youth will vary in how much they want to know. Some will ask many questions; others may not ask any at all. Both responses are normal. Let them know:

“You can ask questions now, later, or not at all—and that’s okay.”

If you don’t know an answer, it’s appropriate to say so and to model calm uncertainty. Nothing about this conversation is easy for anyone. It has the potential to bring up fear, anger, anxiety, depression, and overall feelings of helplessness. Therefore, it is vital to be extremely aware of how your child typically responds to major issues. Pay attention to any change in behaviors after initial discussions.

You know your children best. Pay attention to their body language, and how open or closed they seem to continue the conversation. Don’t push, especially when discussing potential genetic implications. Give them the basics, make sure they know they can and should come to you for questions, but let them process in whatever way they need.

Keep the conversation open over time

Explaining genetics is not a one-time conversation. As children grow and their understanding changes, they may return to the topic with new questions. Revisit the conversation gently and as needed, especially if circumstances change.

Your role is not to be a genetics expert—it is to be a steady, honest, and reassuring presence. By keeping explanations simple, correcting misconceptions, and staying open to questions, you help children feel informed without feeling burdened by information they are not ready to carry.



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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