

# THE IMPACT OF PROTECTING CHILDREN FROM ALS



When a parent or family member is living with ALS, many adults feel a strong urge to protect children from the reality of the disease. This protection often comes from love and fear—fear of saying the wrong thing, fear of upsetting a child, or fear of facing painful truths themselves. While these feelings are understandable, avoiding conversations about ALS can unintentionally cause more harm than comfort.

## Children are observant

They notice physical changes, emotional shifts, and disruptions to family routines, even when no one explains what is happening. When developmentally appropriate information isn't shared, children are left to make sense of these changes on their own. This can lead to confusion, fear, and self-blame. Many children engage in “magical thinking,” believing their thoughts or behavior somehow caused the illness. Silence can also create emotional distance, making children feel excluded from their own family's experience.

## “I just want things to feel normal”

Many parents share this sentiment with us. Secrecy often sends a different message: that the topic is too scary, shameful, or overwhelming to discuss. Over time, this can limit trust and make it harder for children to ask questions or express emotions. Research and clinical experience consistently show that **children and youths want honest, age-appropriate information—and they want to hear it from the adults they trust most.**

## Coping with your own discomfort

You may still be processing the diagnosis, grief, or uncertainty. You may worry about becoming emotional, not having answers, or being asked questions they fear themselves. Working through this discomfort is an essential part of not only supporting the children in your family but also supporting your own mental health.

## How to get started

**Start with self-reflection.** Ask yourself the scariest questions you can imagine:

- What if my child asks if I'm going to die?
- What if they ask how bad it will get?
- What if I don't have an answer?

Naming and being prepared for these fears helps prevent them from stopping the conversation altogether and gives you time to process on your own.



**Prepare instead of avoiding.** Remind yourself that you do not need to have all the answers. Here are some examples of what to say when you are unsure or the words are too hard in the moment.

- That’s a really good question. I don’t know the answer right now, but we can learn more about it together.
- I’m not sure yet, and it’s okay to not have all the answers. What I do know is that we will face this as a family.”
- I need a little time to think about the best way to answer that, but I’m really glad you asked, and we can talk more about it soon.

**Coach your support network.** Talk with the adults children in your family trust. This could be

- Spouse or partners,
- Extended family members,
- Friends,
- Faith leaders
- Counselors,
- Community support professionals

Unite as a community around the answers to questions children might ask and how to respond calmly and consistently. Practicing answers ahead of time can ease anxiety for everyone.

**Start small and stay present.** Keep conversations short and focused on what your child can see and understand right now. You don’t need to explain everything at once. For more guidance on what is developmentally appropriate, check out our guide, *‘Talking to kids & youth about ALS’*


**Let their questions guide the conversation.** Follow the children’s lead and respond as they ask, building trust through simple, honest exchanges over time.

**Protecting your child does not mean hiding the truth. It means walking alongside them with openness, reassurance, and care—helping them feel included, supported, and safe as your family lives with ALS.**


## Looking for more resources?



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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