

TEACHING CAREGIVING SKILLS TO CHILDREN & YOUTH



"... sometimes I just feel kind of like always helping other people, and no one's there to help me, I guess. That would be the best thing is just kind of have someone go, hey, good job, whatever. You know, sometimes."

~15 year old

When children are involved in caregiving, they often step in instinctively—watching, copying, and helping where they can. Taking time to notice what your child is doing allows you to support them in learning caregiving skills safely and appropriately, for both themselves and the person living with ALS.

Notice the tasks they are already doing

Pay attention to the tasks they do like. Both those they are asked to help with and the ones they do in their own initiative. Children and youth have shared with us that they are:

- Setting up, managing, and supporting communication devices
- Talking to the doctor for the family member with ALS
- Assisting with preparing food and feeding the person with ALS
- Tracking and administering medication(s)
- Cleaning and managing respiratory equipment
- Engaging with range of motion exercises with the person with ALS
- Cleaning saliva and helping with oral hygiene
- Transferring and bathing

Taking the time to notice and acknowledge these efforts helps you understand where guidance may be needed.

Assess what is safe and appropriate for their age

Be thoughtful and intentional about how you explain caregiving roles to your child. Clearly share which tasks they can safely help with and which are best handled by an adult, while also talking through what to do if something unexpected or urgent happens. Framing these boundaries as support, not restriction, helps children feel confident, prepared, and safe, even in moments when normal rules may need to shift during an emergency.

Teach skills intentionally, not by assumption

Show your child how to do tasks correctly and explain why certain steps matter. Use simple, clear instructions and demonstrate whenever possible. Let them ask questions and practice with supervision.



Check in about how helping feels

Ask if any tasks make them nervous, confused, or uncomfortable. Children may continue helping even when unsure because they don't want to add stress. Reassure them that it's okay to speak up or step back. Let them know how you feel, that they are supported, and that they are not the only young caregivers in the world. They need to know their voices are heard in the care process. Many youths say they feel like they don't have a say in things, even though they are very involved in the care of someone. While it is not necessary to make young caregivers the decision makers, engaging them and hearing what they have to say will make them feel a part of the process.

Model asking for help

If a task feels too complex or risky, involve professionals such as care coordinators, therapists, or healthcare providers to teach safe techniques or suggest alternatives. This shows children that caregiving is shared and supported—not something they must carry alone.

Encouraging Questions with Healthcare Providers

Children are often in the room with healthcare providers, therapists, aides, and care coordinators. However, they usually aren't invited to ask their own questions or engage with providers. Encouraging them to ask questions helps build confidence, improves safety, and reinforces that they are not expected to know everything on their own. Start by letting your child know that healthcare providers are part of the support team—for everyone in the family. Explain that questions are welcome and that it is okay to ask for clarification, repetition, or help. This is especially important when children are learning new tasks or noticing changes they don't understand.

Listen when they tell you something

Children who are involved in care are often deeply intuitive. They spend time observing, listening, and responding in ways that allow them to notice small changes in mood, comfort, or routine—things adults may overlook when juggling responsibilities. Taking time to truly listen when a child shares an observation or concern communicates that their perspective matters. Even when their insights don't lead to immediate action, being heard helps children feel valued and included, and it reinforces that caregiving is a shared effort. Listening with openness also strengthens trust and can surface important information that supports both safety and well-being for the entire family.

Teaching caregiving skills is not about increasing responsibility. It is about providing clarity, safety, and reassurance. With guidance, boundaries, and ongoing support, children can help in ways that feel manageable—while knowing their well-being matters just as much as the care they give.



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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