

RECOGNIZING CHILDREN AS CAREGIVERS



When a parent or family member is living with ALS, children and youths are often involved in care, whether or not anyone formally names it that way. They may help with daily tasks, provide emotional support, assist with communication, or take on added responsibilities in the household. Recognizing children as caregivers is not about labeling them or placing adult expectations on them; it is about seeing their role clearly and responding with support, honesty, and care.

COMMON CARE TASKS CHILDREN & YOUTH TAKE ON

Keeping a person company

Feeding the person

Cleaning the home

Helping with dressing & hygiene

Cooking meals

Using communication devices

Grocery shopping

Talking to doctors

See a need, fill a need

Many children step into caregiving naturally. They notice what needs to be done and want to help. At the same time, they are still children, developing emotionally, cognitively, and socially. Without recognition and guidance, caregiving responsibilities can become confusing, overwhelming, or isolating. Children may not have the language to describe what they are doing or how it makes them feel, especially if the family does not openly talk about ALS.

How can you support them?

Children who are not acknowledged as caregivers may internalize stress or believe their role is simply “what’s expected.” They may feel pressure to be strong, hide their emotions, or take responsibility for things beyond their control. Some may feel guilt when they want time away, or resentment when caregiving interferes with school, friendships, or typical childhood activities.

On average,
young carers of a
person with ALS
engage in **5 hours** of
care tasks each day



These feelings are common—and they are important to address.



Start by talking

Recognizing a child as a caregiver starts with conversation. Naming what the child is doing helps validate their experience. Simple statements like,

- I notice how much you help, or
- What you're doing matters, and it's okay to have feelings about it

These can make a meaningful difference. This recognition helps children understand that their role is seen and appreciated, not invisible or assumed.

Recognition also means maintaining balance

Children benefit when adults clearly communicate what is and is not their responsibility. Reassure them that helping does not mean they are in charge of the illness or outcomes. It is especially important to remind children that ALS and hard days are not their fault and that they are not responsible for fixing it.

Noticing Care Tasks and Supporting Safety

Children often help in ways that feel natural to them. They may be helping with transfers, bringing equipment, interpreting speech, managing schedules, or assisting during moments of frustration or fatigue. Even well-intentioned help can carry risks if a child has not been shown how to do a task safely. Once you notice these tasks, create opportunities to teach and guide. Explain why certain steps matter, demonstrate proper techniques, and invite questions. Keep instructions simple and age-appropriate, and be clear about which tasks are safe for them to help with and which require an adult.

Keep communication going

Keeping communication open allows children to share when caregiving feels too heavy. Regular check-ins—without pressure—help children feel safe to speak honestly. Some children may prefer to talk with another trusted adult, such as a teacher, coach, counselor, or healthcare professional. Supporting these connections is a strength, not a failure.

Giving them space to be kids

Finally, recognizing children as caregivers includes maintaining space for them to be children. When possible, routines, friendships, and activities help preserve a sense of normalcy and identity beyond the illness. Caregiving may be part of their experience—but it should never define who they are.

By recognizing, naming, and supporting the caregiving role children may take on, families can reduce isolation, prevent misunderstandings, and create an environment where children feel valued, supported, and emotionally safe while living with ALS.



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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