

INCLUDING CHILDREN IN CARING FOR A PARENT

*From the Massachusetts General Hospital
ALS Parenting At a Challenging Time (ALS PACT Program)*



Parenting with ALS: Guidance for Supporting your Children

From the Massachusetts General Hospital ALS Parenting at a Challenging Time (PACT) Program

1. Supporting Children's emotional well-being: child development and resilience
2. Communication with children about a parent's ALS diagnosis
3. Communication about pseudo-bulbar affect (PBA) and frontotemporal dementia (FTD)
4. Genetic subtype of ALS
5. Changes in Motor Skills and Mobility
6. Bulbar symptoms: Speech, swallow, salivation, and eating
7. Breathing difficulties: Using a BiPAP machine
8. Breathing difficulties: Having a Tracheotomy
9. **Including children in caring for a parent**
10. Talking to children about an imminent loss
11. Supporting children through the end of someone's life
12. Legacy leaving
13. Bereavement
14. Seeking professional mental health support for your child

The entire series is available in both English and Spanish and can be downloaded at no cost from <https://www.massgeneral.org/als-pact>

**Parenting with ALS: Guidance for Supporting your Children" is intended for educational purposes. It is not medical treatment or advice. If you have questions about your or a loved one's medical condition, please contact a medical provider.*

**Resources noted in the "Parenting with ALS: Guidance for Supporting your Children" are intended solely for illustrative or informational purposes. It does not constitute an endorsement or recommendation of any products, services, websites, or organizations mentioned herein. Readers are encouraged to exercise their own judgment and discretion to evaluate the information.*

Including Children in Caring for a Parent

Home health aide and visiting nurse hours are increasingly difficult to obtain, and families often have to cobble together supports to manage ALS at home. The limited availability of outside help and time-intensive care needs that accompany ALS can push families to rely on both adult and dependent children for hands-on care. While understandable, this reliance on dependent children may have unintended negative effects on children, along with some positive ones (Kavanaugh et al., 2020)

This handout offers suggestions for parents as they consider the tasks for which they will request help from their children. It discusses:

- looking for a match between the job and the child's physical, emotional, and cognitive capabilities
- why certain kinds of tasks are usually better completed by an adult
- the need for children to receive education and supervised practice
- why it is important to talk to children about the difficult parts of helping with a parent's care

Caring for a family member with ALS requires a great deal of time and energy. Outside help from visiting nurses or home health aides may be limited and expensive. Many families end up relying on their children to help out in a variety of ways, including providing hands-on care for the parent (Kavanaugh et al., 2020).

Deciding what to ask of a child is of course a very personal decision that will depend on your family's need and values, and your child's age, maturity, temperament, and willingness to help. Even with all that in mind, it is not always easy to decide whether certain tasks are appropriate or not for a given child. We offer these ideas to help you think about which tasks may be a good match for your child, and which are not.

It is helpful to think about your child's physical capabilities—size, strength, fine motor coordination, energy level—and to look for tasks that do not demand more than what your child is capable of doing. For example, a young child may be too small to carry a hamper of laundry to the washing machine, but could still help fold or put away bath towels. Using a power mower may be asking too much of an elementary school child (based on their strength and on safety concerns), but they could help rake leaves or pick up branches.

It's also helpful to look for a good match between your child's emotional and cognitive strengths, and the skills/qualities that are needed to do the task. For example, is your child:

- Organized?
- Persistent?
- Overly perfectionistic?
- Willing to ask for help when they are confused?
- Able to follow multi-step directions
- Sensitive about smells, bodily functions, touching people?
- Are there any tasks your child enjoys more than others, like cooking, or outdoor work, or something that can be done while listening to music?

And does the task require:

- Remembering to do something at a certain time of day, or to do something repeatedly (like, every week)?
- Multiple steps to complete?
- The ability to learn a new skill that requires practice or being open to feedback?

Some children find it more difficult than others to remember and complete a weekly or even daily chore (like taking out the trash) without frequent reminders. A better fit might be asking that they give 15 minutes a day of help with whatever's needed in that time—then when the timer goes off, they're done for the day

Even when a child is clearly physically and cognitively capable of a task, it may still be wise to avoid asking for certain kinds of help whenever possible:

- If the child could make a mistake doing the task that could lead to a bad outcome for the parent with ALS, for example, administering medications, it is better to have an adult handle that task. It is all too easy to feel guilty and ashamed when our actions result in a bad outcome for someone else, even when we have the best possible intentions. It is also easy to worry that we have done something wrong when there is an outcome we don't want, even when everyone we know is saying that we did everything right. Both of those situations have the potential to cause lasting distress for children and adolescents, who are less well emotionally equipped to process them
- Some children are squeamish about bodily functions, bodily fluids, medical equipment, or medical care in general. Unless they are very motivated to provide hands-on care and can learn the required skills very gradually, it's better to ask them to help out in other ways. It is important to be clear that everyone feels differently about this kind of work and that no one thinks the child loves the parent any less or is disappointed in a child who is uncomfortable with this kind of care.
- Sometimes when outside help is limited, adolescents and young adults may be asked to help with daily hygiene or other care during which the parent is not fully clothed. Families and individuals have different levels of comfort with adult nudity, and this will affect how a child reacts to caring for a parent who is partly undressed.

Whether or not the child and parent are the same gender may also affect comfort levels. Adolescents and young adults should have a choice about participating in this kind of care, following a conversation about what might be involved. Whether a parent's dignity is preserved in front of the child is an overlapping, but distinct, goal to consider when deciding whether a task is appropriate or not for the adolescent.

All children are likely to need multiple demonstrations of new skills and repetition of information, hands-on practice with support and feedback, and lots of patience as they take on new responsibilities. This is even more true if the task is one that might bring up strong feelings in the child, like providing any physical care for a parent. Let children know that mistakes are part of learning- you expect some, and want the child to let an adult know about them quickly so the situation can be improved.

Creating new routines can be a slow process. Some families use written charts to serve as reminders of what needs to be done, and who will do it. Some hold a weekly meeting to protect time to identify any challenges and to highlight and appreciate all the things going well.

Children are likely to need multiple demonstrations of new skills, repetition of information, and hands-on practice with support and feedback.

Here is one way to think about the range of tasks involved in caring for a family, from those requiring the least maturity and smallest skill set to those involving the most maturity and highest skill level:

- Tasks that are routine and not care-related (e.g., picking up toys, feeding pets, folding laundry, washing laundry, yard work)
- Tasks that are routine and care-related (e.g., bringing something to a parent, cooking for a parent, carrying or picking things up, cutting food, driving the parent)
- Care that falls outside everyday activities (e.g., any help with dressing, feeding, hygiene, cleaning equipment)
- Medical care where there's some room for error (e.g, suctioning, cleaning a tracheostomy stoma, using a feeding tube)
- Care, medical or personal, where a child could feel responsible for serious problems(e.g., being alone with a ventilator dependent parent {especially in a power outage}, changing a tracheostomy tube, helping a parent up a flight of stairs where a fall is possible).

Providing care to a parent and helping at home can teach children new skills and allow them to feel included and valued. However, helping can also be stressful, boring, or time-consuming. As you talk with your children about how they can help at home, it is critical to frequently check in with them about the support and opportunities that *they* need- including emotional, social, academic, spiritual, and physical.

What are they missing that their peers are doing or learning? What do they wish they had more time to do? Talk about how your family might make room for each child to continue to develop as a whole person, not only as a caregiver. Having time to pursue friendships and personal interests like art, music, or athletics, is one key to building child's confidence and competence.

Resources

One resource for adolescents that might be helpful was written by Melinda Kavanaugh, PhD and Megan Howard, MA. It includes some discussion of the caregiving experience.

The ALS Experience-It's Different and Hard:

<https://www.als.org/sites/default/files/2020-04/youth-guide2.pdf>

References

Kavanaugh, M. S., Cho, C. C., Howard, M., Fee, D., & Barkhaus, P. E. (2020). US data on children and youth caregivers in amyotrophic lateral sclerosis. *Neurology*, 94(14), e1452–e1459. <https://doi.org/10.1212/WNL.00000000000009217>