

CHANGES IN MOTOR SKILLS AND MOBILITY

*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

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

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Changes in Motor Skills and Mobility

Changes in gross and fine motor control affect day to day functioning in ways that necessitate new equipment and home modifications. The changes may also lead to disruptions in family routines or requests for children to assist a parent in new ways. Even parents who would prefer to avoid any mention of ALS to children can find that they are forced to come up with some explanation for such obvious changes.

The Changes in Motor Skills and Mobility handout describes:

- ways that mobility changes may impact children and family life
- the value of clear descriptions to children of the purpose of new equipment
- ideas for talking about changes with children of different ages
- examples of typical age-specific concerns related to mobility impairments in a parent and potential ways for a parent to respond
- challenges that limitations in mobility pose to family closeness and connection, and suggestions for parents to remain engaged with children
- ways to check in with a child who has witnessed a parent's fall

Introduction

Changes in fine and gross motor skills are among the most obvious signs of ALS. ALS can cause declines in gross motor skills such as walking (with obvious weakness or falls), climbing stairs and self-care (getting dressed, bathing, brushing teeth). Changes in fine motor functioning include skills such as writing with a pen or pencil, keyboarding or texting and cutting food. Children will likely notice, and be curious or worried about all of these kinds of changes.

Equipment and interventions

A wide variety of equipment is available to help manage motor skill and mobility changes. For walking and climbing stairs, orthotics for ankle support, a cane, a walker, and at some point, a wheelchair may become necessary. Items like a shower stool or a reach extender can support independent self-care. Hand splints and neck collars can support weak muscles. If movement becomes more difficult, a hospital bed or a Hoyer lift may be helpful. Some families make changes to their living space to improve accessibility. Eye gaze technology allows typing even when fine motor coordination is compromised. See Handout on Speech and Swallow Changes for more details about this, which can be found <https://massgeneral.org/als-pact>.

Children will easily notice new equipment in the home but may not necessarily understand how it helps unless an adult takes the time to explain this. Parents understandably often focus first on adjusting to the changes that make the equipment necessary and then on learning how to use the equipment. It can be easy to forget that children, particularly younger children, may be confused about what these things are for, or simply anxious about changes they see.

Older teens and young adults are also likely to need explanations whether or not they are involved in assisting a parent (Kavanaugh, et al., 2015), and also support in exploring the emotional impact of these changes.

The experience of children and families

Physical limitations due to ALS can affect everyone in the family, in obvious and some less obvious ways. It's easy to see what changes on the surface, but also helpful to be curious about why those changes really matter to children and to family life- because this makes it possible to be creative about finding other ways to meet children's needs. For example, family members may take on or give up different roles and responsibilities, familiar ways of feeling connected and having fun together may no longer be available, new worries can come up, and ideas about what makes a family special and unique might have to change.

Strategies and age-specific guidance for parents

Thinking about how your children experience the mobility and motor skill challenges you face can be painful- it is very easy to feel you are letting your children down, to feel guilty or inadequate, or angry about what is no longer possible. Even though it's not easy, it is usually helpful to talk as a family about what has changed and why, how each family member is affected, and whether there are ways to cope differently with the new, and ever- changing situation.

Keep talking: explain and prepare for changes

- Make any changes in functioning “talk-about-able”- rather than pretending they aren’t happening, assuming that children already know what has caused mobility changes, or conveying that it isn’t ok to discuss.
- It is helpful to try to prepare children for new equipment before it arrives or soon after. You can do this by naming the items, allowing your child to see things up close and to handle them (when doing so won’t put the child or the equipment at any risk), and demonstrating how using the equipment helps you manage a challenge so you can keep doing as much as possible as you live with ALS.
- If you can, try to frame things for your children in a positive, yet realistic, way. It feels different to hear, “I can’t walk anymore and I’m going to be stuck in this wheelchair, this is going to make it impossible to go where I want,” vs, “My legs are weak because of ALS so I can’t walk far, but this wheelchair is going to help me get around. I know it will take some time to get used to this being in our house, but I want to be as active as I can and this will help.”
- Ask children directly about the impact of mobility/functional changes, new equipment, or changes in the environment (such as home remodeling).

Actively invite their reactions and let them know you recognize that these changes might affect their relationships with both parents, or how it feels to be part of your family. Check in about, and normalize, a blend of emotions.

Toddlers/early preschoolers (2-4):

“You know that I’ve been sick [whatever words you are using to talk about ALS] and my legs are weak. Weak legs make it very hard to carry you around. You are crying and I know you really want me to carry you. It looks like you’re feeling mad and sad right now? I understand, you like being carried and it’s really hard when I tell you “no.” We still need to get to your bedroom, so would you like to hold my hand, or hop like a bunny, or stomp like a dinosaur to get there?”

Preschoolers/early school age (4-6):

“You know that I’ve been sick [whatever words you are using to talk about ALS] and because of this, my arms are weak. Weak arms make it really hard to push you on the swings/throw you the ball/carry your school backpack even though I wish I could. You are looking upset and I know you don’t like this. It looks like you’re feeling mad and sad right now? I understand, you’re tired and wish I could do this for you. Would you like to stay on the swing and pump your legs or go to the slide instead? (Or, ...to kick a ball to each other or find something to do indoors instead?)”

Keep talking: explain and prepare for changes

School aged children (6-12): “You know that I’ve been sick [whatever words you are using to talk about ALS] and this is making my hands and arms weak. It makes dinnertime feel a lot different to me- I get frustrated trying to cook/eat without dropping things. Is there anything you’re wondering about? What feels different to you about dinner? What’s better and worse about having family meals? I can understand how you’re feeling. I wonder if we could come up with some ways to make dinner feel more fun and relaxed? I think the time we spend together at the table hearing about everyone’s day is really important.”

Teens and young adults (13+): “It’s been a few weeks since I stopped driving because ALS has made my arms so weak. I have mixed feelings- I know I used to complain about all the driving I had to do, but I’m finding that I miss spending time with you and your friends in the car. We’ve started to figure out how to make sure you get where you need to go on time but I wanted to check in about how this is going for you. What has this change been like for you? What are the downsides? Any upsides? Anything we should be trying to improve?”

Talk to children about changes: explain what is happening now and prepare them for upcoming changes.

Talk to children about feelings: help them recognize, name, and share their feelings.

Keep talking: naming and processing emotions

Some children find it easy to tell parents about how they feel about a lot of situations. Others have more difficulty recognizing, naming or sharing emotions, or prefer to process emotions by themselves, in their own time.

Children might find it easier to agree that they have a particular concern, than to describe their concerns in a more open-ended way. You might check in with children with something like, “I could imagine that in your shoes, I might be wondering about...Is that something you ever think about?” or, “I’ve heard that some other kids who have a parent with ALS sometimes worry about... what about you?”

Examples of specific kinds of concerns include:

- *Toddlers, preschoolers, school-age children and adolescents:* Uncertainty about whether they have done something wrong, if they notice you looking upset or that you are not interacting in the same ways as before. Try to ensure that your children understand that you are not engaging in usual or hoped-for activities due to physical changes related to ALS, so there is no chance they worry that you love them less, are angry at them, or not interested in them. (This sounds obvious, but not all children will recognize this).
- Affirm how much you wish you could engage in the activity with your child- “I really wish I could do that...because of ALS making my hands weak I can’t...let’s figure out how to make sure you get what you need (time with parent, some other need met)”

- *School-age children and early adolescents:* Use of assistive devices in public- different children in a family can have very different reactions to being out in public, especially when peers are nearby, with a parent using equipment that stands out in any way. Some children worry about increased focus on them; others about not knowing how to respond to questions or insensitive comments from peers. Adolescents are especially known for being critical of and easily embarrassed by parents in public about very small things. Some children may also recognize that adults may feel hurt or annoyed by their discomfort. They may be ashamed to talk about how they feel, or simply try to avoid these situations all together.
- You could ask directly if this is a concern, or wonder out loud if this is ever uncomfortable for your child. If you can, ask what makes the situation awkward for them, and why that is uncomfortable (“Ok, so you feel like everyone is looking at us...what feels uncomfortable about that? What do you think those people are thinking?”), then see if you can come up with some ideas together that would work for both of you (maybe reassuring your child that people are curious about wheelchairs but will find other more interesting things to look at soon, or, helping your child come up with responses to questions from peers in advance).
- *Adolescents:* Financial challenges- you may reduce work hours or stop working all together due to mobility changes. Some children (often adolescents) will worry about family finances but not ask directly about plans. This can prompt other worries that may or may not be realistic- will we have to move? Will I change schools? Is there money for college? Should I get a job or add hours to my job?
- Try to be reassuring if you can, without saying anything that is not true. For example, you could let a teenager know that you are very aware of finances and actively looking for outside support where it’s available; that right now you are not concerned about, food or basic necessities but that the family will need to cut back on some extras; that you will talk about any changes in household spending that will affect your teenager with them, before they happen if possible.

Look for New Ways to Stay Connected

Recognizing the types of losses that come with mobility and motor changes allows you to look for substitute family and 1:1 activities that can continue to meet your children's needs.

Here are some examples:

- Family outdoor activities (walks, bike rides, skiing, beach, sports) become more challenging or no longer possible- so the family loses important ways to have fun together, to burn off excess energy, and to enjoy time that might be more about doing than talking (which some family members might prefer).

Can outdoor physical activities be adapted or made easier, perhaps with new assistive equipment? Can a parent be at the site of the activity (eg, the beach, the back yard), and observe but not participate? What other non-verbal activities are possible?

- One-on-one activities with you and your child (hobbies, sports, dining out)- this time is also important for a feeling of closeness and connection, for you to teach your child skills and values, and sometimes for managing sibling rivalry. For these reasons, it's valuable to look for new activities that are still possible, despite physical changes.

Is there something new you can do with each child that is fun for them? For a preschooler, could pretending games (doctor-patient, teacher-student) replace some kinds of physical play? While it may not be possible to build with blocks or kick a ball around, you can still watch, and your loving attention to what your child is doing is very powerful. Narrating, ("Looks like the animals are at a picnic together"), working together to meet challenges in their play, ("Oh, that is a tricky puzzle piece, what if you turn it around?"), and recognizing their accomplishments, ("Wow that is such a tall tower!") are all ways to connect to a child during play and to build their language and emotional vocabulary.

For school age children and adolescents, could a new, related activity replace another (reading about dinosaurs online rather than going to a science museum, choosing a new recipe to cook at home rather than going out to eat)? Watching and discussing movies, shows or sports, and any shared interests (e.g., books, art, computer games) can all continue to be opportunities for staying connected.

- Coaching a child’s athletic team- along with the benefits of family and 1:1 activities noted above, children might feel proud about how teammates value their parent’s coaching, or feel valued in the same way as older siblings were when the parent coached them. Coaching also offers an opportunity to talk about values such as teamwork, fair play and perseverance, among others.

If you can’t coach, can you still watch games? Practice skills with your child at home in any way? Check in about how practices are going? Ask a friend to video record a game and watch highlights with your child? Watch professional sports together?

- Driving may no longer be possible, and given the amount of driving that many parents do for children, this can have a big impact on daily routines and leave people feeling extra stressed while a new system gets established. Co-parents or adolescents with a driver license will likely have new responsibilities for getting family members to activities or appointments. Some children are more talkative while in the car than at other times so you may feel you hear less about their lives.

Could you still be a passenger some of the time? Attend events even if you’re not driving to them yourself? Try to enlist friends or family to help with a carpool, to help build a new routine?

- Family meals may feel more stressful if a parent with ALS has difficulty using utensils, cutting food, or helping prepare the meal. While people are adjusting to changes, or if they continue to feel uncomfortable, other topics of conversation may not get discussed and the family loses important bonding time.

Can you talk with other family members about the challenges you face at meals and problem-solve together about whether there are things that others can do to help (eg, having food cut in advance, using special utensils). Can you acknowledge the changes, let children know that the time together is important to you, and encourage everyone to focus on the talking rather than on your eating?

- Your ability to provide physical care for your children may change. This might affect children’s after-school, bedtime, bath-time or mealtime routines, even the ways you are able to be physically affectionate with your child. Some children resist having another adult take over those roles (“but I want Daddy to do it!”); some may miss the sense of security that comes with lap time or hugs.

Would a young child like to sit on your lap in a wheelchair for a story or a ride? Could you cuddle on a couch after school? Are there ways to give children choices about how those routines will now happen? Are there opportunities to encourage children to do a little bit more for themselves, with you being right there to coach and cheerlead?

Checking in About Frightening Experiences

Your children may witness falls that result from tripping or weakness. They may feel frightened or even guilty that they couldn't prevent the fall or do more to help afterwards.

- Preschoolers: Provide simple language to help young children understand what happened, and reassurance that even though it hurt to fall down, your body isn't hurting from the fall anymore (or, is hurting less)- "You saw me trip and fall and call Mommy for help. I did have some scrapes, but Mommy put some band-aids on and they are feeling better. I'm going to use this cane now to help me keep my balance." You may notice preschoolers bringing falls into their pretend play- this is one way young children process upsetting events.
- School aged children: These children may be curious about why a fall occurred and what different people did. Check in about what they saw and how they felt, and make the connection between ALS and the fall explicit. "What do you remember about my fall- what happened first? Then what? What was that like for you? Do you still think about it much? I think what happened is that my foot was dragging because of ALS and got caught and I tripped and fell. It hurt, but I was lucky that I didn't get badly hurt."

- Adolescents: With increasing ability to think about future "what-ifs," teens may wonder about what they should do if you had another fall. Discussing a plan in advance might help reduce any anxiety. It is a good idea to write down phone numbers or emergency instructions and post them where children can see them easily.

Acknowledge Difficult Emotions

Try to talk about your emotional outlook- for example, if you are feeling very frustrated with poor coordination and snap at your child, try to help your child understand that you aren't angry at them, but are very frustrated with how your body is working, and that you wish you hadn't been grouchy and yelled at them. Similarly, it is okay to share your mixed feelings or sense of loss. You might share that you miss participating as a coach the way you used to, or that you feel sad not to be able to teach them to drive as you had planned to, and that you are happy to see them play soccer or proud of them as they learn to drive. Even if it is not an elaborate discussion, such acknowledgements can help children know that it is okay to talk about a range of feelings, and can them develop an understanding of their own feelings.

References

Kavanaugh, M. S., Stamaopoulos, V., Cohen, D., & Zhang, L. (2015). Unacknowledged caregivers: A scoping review of research on caregiving youth in the United States. *Adolescent Research Review*, 1(1), 29-49. doi:10.1007/s40894-015-0015-7