

We know that Amyotrophic Lateral Sclerosis (ALS) affects more than just the person who has been diagnosed with the disease; it affects the entire family, including children and teens. We often call ALS a “family disease.” Parents and grandparents may wonder about how to talk with their children/teens about ALS — how much to discuss, when would be the best time to have these discussions, and how to support their children and teens who may be struggling with their loved one’s diagnosis.

The purpose of this pamphlet is to list **potential resources and suggestions** to help children and teens who are impacted by ALS. The suggestions listed are based on our collective experience working with people who have had ALS and their families. **Please reach out to your Social Worker or Mental Health clinician** if you have any questions or specific concerns about your children or grandchildren. We at ALS United Mid-Atlantic **want to support you and your family!** We hope you find this pamphlet helpful.

Having the Conversation

Research suggests it’s best to (eventually) have a conversation about ALS with children/teens, using age-appropriate language. They most likely know that something is wrong even if they cannot verbalize what they are thinking and feeling.

How to start the conversation:

- Recognize first the discomfort you are feeling as a parent or grandparent. Take a few days to explore what it is that you are feeling and use that emotion as fuel for having an honest conversation with your children/grandchildren. It’s okay for them to see you sad. It gives them permission to be sad too.
- Be honest. Begin with basic information and let them drive the conversation with more narrowing questions. You do not need to project too far in the future or provide every detail, but the more you include them in the process, the greater chance that they will feel informed and secure.
- It is okay to say, “I don’t know.” It is okay to be tearful and show emotion.
- Let them know that you have a team of clinicians involved in helping you cope with your illness.
- You know your children/grandchildren. They may at any point in the conversation either “check out” mentally or ask to stop. That’s okay — do not force the conversation or take it personally. This is most likely the way your children/teens are channeling their fears and uncertainty. Make sure they know that you will be there for them when they are ready to talk or if they have any questions.



Age-Specific Hints:

Ages 0-3

- Routine equals security for toddlers. Try to keep your child’s schedule predictable — minimize change, maximize security.
- When explaining the disease, use simple language, e.g., “Mommy gets more tired” or “Grandpop’s leg is not strong and won’t get stronger.”

Ages 4-10

- Tell them over and over, “Nothing you did made _____ get ALS.”
- And, “ALS is not a contagious disease, like a cold. You can’t get ALS from being around someone else.”
- Tell them how the family will adjust — who will be doing usual tasks that the parent or grandparent performs.
- Explain that most of the time when people get sick, they get better. Explain that their parent or grandparent is sick in a different way and will not get better.
- Concepts of time and finalities, such as death, are not as well-understood in this age group.
- Prepare to give the same answers on previous questions more than once.

Ages 10-18

- While teenagers and preteens may be in a phase where their world is their social sphere, it is important to remember that they can google and look anything up online. Online information may not be accurate. It is key to be honest with this age group about information and where to find accurate information about ALS.

- Finding out what your child/teen knows about ALS is a good place to start the conversation. Do they know a lot? A little? Maybe nothing?
- They may just want to be “normal” and “fit in” with their peers. If they do not want to talk about ALS, do not force the conversation. Let them know you will be there if, and when, they want to talk about the illness.

Further Suggestions

- You may wish to notify your child’s school counselors and/or teachers about the person in your family who has ALS, that your child may be struggling with their loved one’s illness, and therefore, may impact their work at school.
- It may be helpful to seek supportive counseling for your child/teen. Some psychotherapists accept some health insurance, others do not. Start the search by checking with your child’s pediatrician and/or school counselor to find a psychotherapist who specializes in children/teens. You can also call your child’s health insurance company to get a list of in-network counselors who deal with both children/teens and chronic illnesses. Other potential further resources: Check with your ALS Social Worker or Mental Health clinician or check with online referral sources, such as Psychology Today.
- Be wary of using vague language — it tends to confuse children more: “Mom is feeling foggy today” is better as: “Mom’s leg muscles are sore and tight today.”

- Practical Matters: Children may want to know if the practical matters will be taken care of (e.g., food shopping, making lunches, bedtime). Reassure them that all routine chores and care will be the same, although other adults may need to assist.
- Some families have created a “worry jar.” A worry jar provides the space for children/teens to write down questions they may be too afraid to ask. This also allows parents/grandparents to respond to questions when they feel comfortable to do so.

Resources

1. ALS Information: www.alsphiladelphia.org
2. Specific information for families including children and teens: www.alspafamily.org
3. The National ALS Association provides free hard copies of the books that are listed on the Chapter website (can download the books or order hard copies). www.als.org
4. Dr. Melinda Kavanaugh (University of Wisconsin-Milwaukee): Dr. Kavanaugh is a specialist in helping children/teens who are impacted by people with neurological disorders. Watch her YouTube presentation, Talking with Children and Youth about ALS: www.youtu.be/HpSaZtkcJUk
5. Hope Loves Company (HLC) offers free, monthly Zoom “hangouts” for children between the ages of 10 through young adult. There are two available, ages 10 to 12 and 13 to young adult. Group is led by a counselor. Registration is required. Once you register your child/teen, they will receive a care package from HCL. www.hopelovescompany.org/virtual-programs
6. Hope Loves Company Camps — offered at no charge for children/teens throughout the country. www.hopelovescompany.org/camp-hlc
7. ALS Society of Canada offers other information about talking to children/teens: www.als.ca/what-is-als/resources/for-youth
8. Getting children/teens involved in Advocacy and/or Chapter events. Some families have told us that these types of activities have been helpful for their children (to be part of supporting research, care, and advocating for issues that support people with ALS). In addition, the Chapter offers families a few fun events throughout the year (e.g., Holiday Parties, Knoebels Day, Phillies events, Longwood Gardens). If interested in Advocacy, reach out to Tony Heyl: Tony@alsphiladelphia.org. If interested in Chapter events, contact your Social Worker.
9. There are also resources available for children/teens who have a loved one with both ALS and the cognitive impairment that is sometimes associated with ALS. This would include Frontotemporal Degeneration or FTD. The Association for Frontotemporal Degeneration (AFTD) provides written literature and support for children/teens: www.theaftd.org/living-with-ftd/kids-and-teens
10. This website, www.aftdkidsandteens.org, provides a place where children and teens can ask questions, find answers, and share experiences with peers who are on the FTD journey. There are two separate sections of this site, aimed at both children (ages 4-12) and teens (ages 13 & up).

Scholarship: If you or someone you know has been touched by Lou Gehrig's disease (ALS) and has a dependent child or grandchild who is pursuing higher

education (two-year, undergraduate, graduate), Live Like Lou is pleased to invite them to submit an interest application for an Iron Horse Scholarship. This renewable, four-year scholarship provides up to \$2,130 per semester for up to eight semesters for students pursuing a degree.

www.livelikelou.org/news/iron-horse-scholarship-application-open-for-2023

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About ALS United Mid-Atlantic

Since 1977, ALS United Mid-Atlantic has worked to improve the quality of life for people with ALS by supporting critical ALS research, providing care and services to patients and their families, and promoting legislation that fosters ways to better manage, and eventually end, this devastating disease.

Potential Resources for Children and Teens Impacted by ALS



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