

The Daniella Lipper ALS PACT Program

Parenting At a Challenging Time

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The Daniella Lipper ALS PACT Program offers parenting consults to adults cared for in the MGH multi-disciplinary ALS clinic and their co-parents, at no charge.

Our team offers guidance about helping children cope with ALS in a parent or grandparent, recognizing that you are the expert on your own children.



Common consult topics include:

- communication with children about ALS symptoms and interventions
 - how children may adjust to changes
- supporting children's resilience, given their unique strengths and needs
 - when to consider additional resources for a child

To schedule a consult, please contact us at mghALSpact@mgh.harvard.edu

For more information, <http://www.massgeneral.org/als-pact>

The Daniella Lipper ALS PACT Program has been made possible thanks to philanthropic support from the **EGL Charitable Foundation**.

To make a donation please visit: <https://giving.massgeneral.org/donate/als-pact-program>
or ask us about how you can help. **Thank you!**

Suggestions for supporting children affected by an adult's ALS

Start by acknowledging your medical condition.

Call your condition by its name, ALS, or describe it— a problem with motor neurons. For younger children, share that it is not contagious to reduce concern about others “catching” ALS.

The worst way for a child to learn about difficult news is to overhear it.

News learned by accident is often confusing and inaccurate. Let children know they can trust you by telling them directly what is happening and what to expect. Welcome all of your child's questions. Try to be available when and where your child is more likely to talk with you, for example, in the car, while you cook, or at bedtime.

Figure out the “real” question your child wants to ask.

Ask children to tell you what they are wondering about, and why. This may help you and your child uncover underlying worries. Many times, there is a specific concern that can be more easily answered than the first question. Not all questions need answers right away. It's all right to say, “That's a good question. I'll need to think about it or talk it over with my (doctor, nurse, family member) and get back to you.”

Don't let your child worry alone.

Encourage children to share their worries with you. Sometimes people say unhelpful things with kind intentions, so ask children what others say about ALS in general, and about you. Let children know that ALS is different for everyone, so someone else's experience won't be exactly like yours.

Respect a child's wish to not talk. All children need basic information about your illness, especially details that directly affect them. But it's okay if they don't want to have long discussions about it. Check in to find out if they are hearing too much, too little or the right amount about your illness and medical care.

Try to maintain your child's usual schedule.

Regular routines provide a sense of normalcy. It may help to assign tasks, post schedules, make lists or use calendars to help children and caregivers know what each day holds.

Keep the channels of communication open with other caregivers, such as teachers and grandparents, and let children know you've done so. Notify these people of changes in your condition or medical care so they can better support your children. Decide with children - even college students - whom they will talk to if they are having a hard day at school.

Protect family time. Maintain regular times when your children have your full attention, without phone calls or visitors. Ask to hear details about their days. Some families choose a “captain of kindnesses” who can organize other family and friends to find ways to be most helpful.

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<https://bit.ly/3SEmJCj>

Learn together about ALS. Teens and even younger children often use the internet to learn about new things. Remind them that you and your medical team have the best information, and talk together about anything they read. Help them understand that online statistics describe groups of people, and your experience may be different.

Take good care of yourself. This may include spending time with friends and family, doing favorite activities, or finding quiet time. It also includes seeking the information you need to feel confident about your medical care and getting support to address your emotional needs. Consider connecting with the larger ALS community, through family or fundraising events sponsored by advocacy groups.