

Consistent with the family-based approach at the Healey Center for ALS, the ALS PACT Program aims to support parents and their co-parents. A child psychologist or psychiatrist meets privately with parents to understand their children's (infants through young adults) unique strengths and needs, and to provide developmental guidance and support.



We recognize that parents are experts on their own children and families. We work collaboratively with parents and the ALS care team to help parents anticipate what to expect in terms of their children's ongoing adjustment, how to plan communication around a parent's medical condition, when to feel comfortable with a child's coping, and when to consider additional resources or interventions.

This service is available at no charge to patients receiving care at the Healey Center for ALS. We work with patients through in-person, phone, or virtual appointments.

For more information about our program, please visit

<http://www.massgeneral.org/als/>

or contact us at

mghALSpact@partners.org

or (617) 724-3914

The ALS PACT Program has been made possible through support from the EGL Charitable Foundation.

To make a donation to help sustain the program, please visit:

<https://giving.massgeneral.org/donate/healey-center/> and designate your gift for the ALS PACT Program, or, ask us about how you can help.

Thank you!

ALS Parenting at a Challenging Time (PACT) Program

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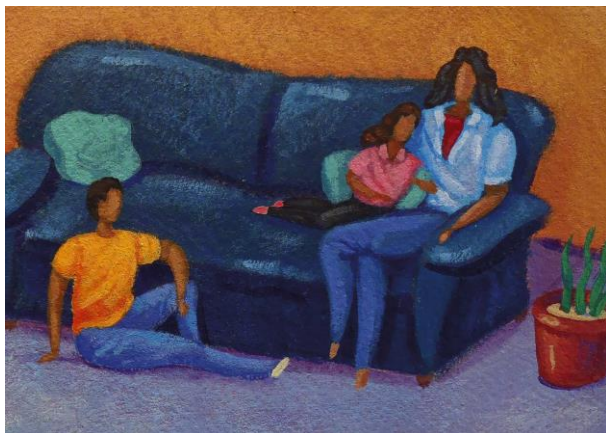


MASSACHUSETTS
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Guiding Principles

Start by naming your medical condition.

Call your illness by its name, ALS, or describe it— a problem with motor neurons. Share that it is not contagious to reduce your child's fear of "catching" ALS.



The worst way for a child to learn about troubling 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 at times, and in places where your child is more likely to talk with you, for example, being together 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 initial question.

from the ALS

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.

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."

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.

Keep the channels of communication open with 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- who they will talk to if they have a hard time at school.

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.

PACT Program

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.

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 about *your* illness 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.