

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

ALS Parenting at a Challenging Time (PACT) Program

Archana Basu, PhD

Cindy Moore, PhD

Paula Rauch, MD

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!



Healey Center
Sean M. Healey & AMG Center
for ALS at Mass General



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.



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.

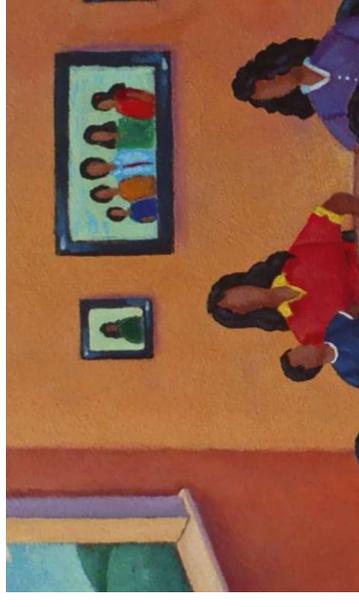
PACT Program

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.

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.

For more information about the House Call Program please call Mayra at 617-643-7290 or visit our website

<https://www.massgeneral.org/als/ourservices/house-call-program.aspx>



Who is eligible for the House Call Program?

Currently all MGH ALS Multidisciplinary clinic patients who live east of route 495 are eligible for a house call.

What if I do not live east of route 495?

We hope to be able to expand our scope in the future.

When are visits scheduled?

Visits are typically scheduled every 3 months between scheduled clinic visits. House call visits are available from 9:00am to 3:00pm and at other times by appointment if necessary.

How do I pay for the House Call Program?

The House Call Program is paid for through a combination of private funds and insurance. Patients may be responsible for a standard co-payment charge.

Will I still see my doctor?

Yes, we will work closely in collaboration with your ALS neurologist as an extension of your clinical team to adjust your plan of care as needed. You may continue to see your physician and clinic team as often as needed.

“The house call was amazing. It was so great to have them come to us to see what we are dealing with at home... The team was positive, helpful and knowledgeable.”

- ALS House Call patient

“I feel like the providers have a much better understanding of me as an individual, my house, and caregiver’s situation, and what needs may arise in the future”

- ALS House Call patient

“Thank you very much for the home visit. It was invaluable, and I greatly appreciate your generosity and kindness.”

-ALS House Call patient

MGH/CCALS House Call Program

Offering House Call visits to current Massachusetts General Hospital ALS Clinic patients in collaboration with Compassionate Care ALS.



Healey Center

Sean M. Healey & AMG Center
for ALS at Mass General

CCALS

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<https://ccals.org>

(508)-444-6775

If I am already seen by CCALS, am I eligible for the program?

Yes, this program will supplement the care you are already receiving. CCALS continues to make regularly scheduled visits and communications as often as necessary

Can I continue receiving care from my visiting nurse?

Yes, our program is designed for patients to receive additional help and a stronger connection with the ALS Clinic. The House Call Program is not designed to replace any other program, but enhance the effectiveness of them.

Who will be coming to my house?

Debra Skoniecki NP and Kristen Kingsley RN comprise the nursing team from MGH. A representative from CCALS may also join for the visit.

How often will the team visit me?

The MGH team routinely see patients every 3 months in their home. If a more urgent visit is needed, please let us know and we will be happy to coordinate the best plan of action. The CCALS team continue to make regularly scheduled visits and communications as often as necessary.

Members of the MGH team:



Debra Skoniecki, NP



Kristen Kingsley, MSN, RN



Mayra Alvarado, Program Coordinator

Members of the CCALS team:



Ron Hoffman, Founder of CCALS



Erin MacDonald Lajeunesse, MSW, LICSW



Shannon Carey, Family Care Liaison



Kristine Copley, Communication Director