

PACT Program Offers Parenting Support for Families Facing ALS

Learning to navigate life with ALS can be overwhelming for a person with the diagnosis, even more so if that person is also the parent of young children. That's where the Daniella Lipper ALS Parenting At a Challenging Time (PACT) Program provides support.

The ALS PACT Program offers guidance to parents and grandparents with ALS on how to talk to children about the illness and support their healthy coping with it. The service offers one-on-one education sessions with clinical psychologists for patients of the Healey & AMG Center. These services are free of charge thanks to a generous gift from the [EGL Charitable Foundation](#).

PACT Program director, Dr. Cindy Moore, along with Dr. Christine Wu and Dr. Allison White, work with families to help children and young adults, up to age 25, cope with an ALS diagnosis in a parent or grandparent.

Dr. Moore explains, "Our role is as thought partners with adults with ALS and their co-parents, around the concerns they have about how children are coping with the changes that come with the disease. We are available from the time of the initial diagnosis throughout the person's care at Mass General."

Dr. Moore and the team help families manage strong feelings that children have in response to the parent's illness and changes in functioning. This can include issues with mobility and speech, as well as preparing children for a parent or grandparent's end-of-life.

Interacting with families at such a vulnerable and frightening point in their lives is very rewarding, according to Dr. Moore. "The conversations can be challenging and hard and painful, but also very meaningful. And I think they can create hope for parents that their children can develop in healthy ways and have good lives, despite the parents' illness."

In addition to parent support services, the PACT Program has a wealth of valuable resources, in English and Spanish, available to download from [the website](#). Healey & AMG Center patients with questions about the program can reach the PACT team via email at: mghALSpact@mgh.harvard.edu.