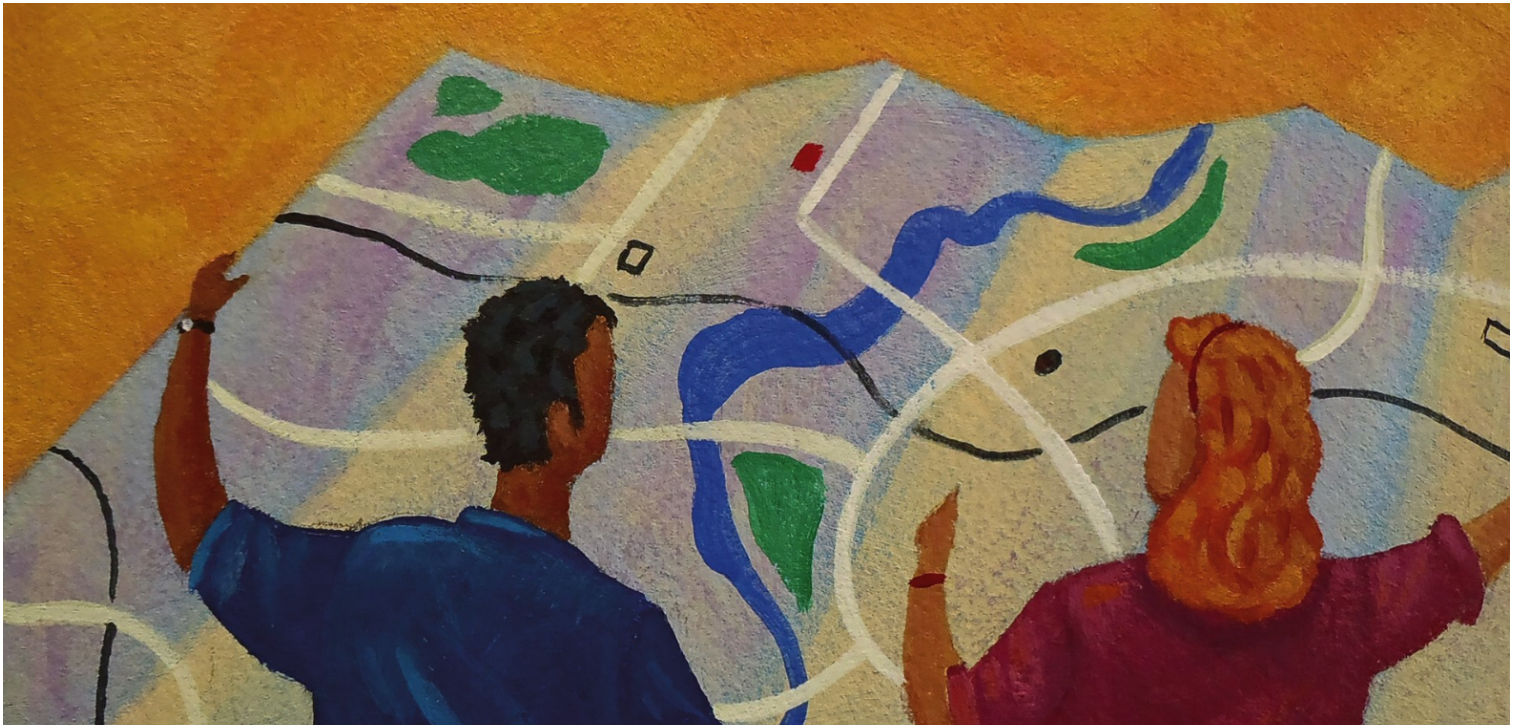


SEEKING PROFESSIONAL MENTAL HEALTH SUPPORT FOR YOUR CHILD

*From the Massachusetts General Hospital
ALS Parenting At a Challenging Time (ALS PACT Program)*



Parenting with ALS: Guidance for Supporting your Children

From the Massachusetts General Hospital ALS Parenting at a Challenging Time (PACT) Program

1. Supporting Children's emotional well-being: child development and resilience
2. Communication with children about a parent's ALS diagnosis
3. Communication about pseudo-bulbar affect (PBA) and frontotemporal dementia (FTD)
4. Genetic subtype of ALS
5. Changes in Motor Skills and Mobility
6. Bulbar symptoms: Speech, swallow, salivation, and eating
7. Breathing difficulties: Using a BiPAP machine
8. Breathing difficulties: Having a Tracheotomy
9. Including children in caring for a parent
10. Talking to children about an imminent loss
11. Supporting children through the end of someone's life
12. Legacy leaving
13. Bereavement
14. **Seeking professional mental health support for your child**

The entire series is available in both English and Spanish and can be downloaded at no cost from <https://www.massgeneral.org/als-pact>

**Parenting with ALS: Guidance for Supporting your Children" is intended for educational purposes. It is not medical treatment or advice. If you have questions about your or a loved one's medical condition, please contact a medical provider.*

**Resources noted in the "Parenting with ALS: Guidance for Supporting your Children" are intended solely for illustrative or informational purposes. It does not constitute an endorsement or recommendation of any products, services, websites, or organizations mentioned herein. Readers are encouraged to exercise their own judgment and discretion to evaluate the information.*

Seeking Professional Mental Health Support for your Child

Parents may wish to consider professional mental health support for their children and family. As children adjust to news of a parent's diagnosis of ALS, and experience changes in their parent functioning or family's routines, they are likely to have understandable reactions such as worry or anxiety, sadness, physical symptoms (e.g., changes in appetite or sleep), behavioral changes (e.g., withdrawal from social interactions, acting out), among other responses. But it is important to note that most children with a parent with a serious or terminal illness do not develop serious mental health problems (Calvo et al., 2015; Haine et al., 2008; Kavanaugh et al., 2020).

Monitor changes and seek help early

Parents know their children well. If your child's behaviors or adjustment worry you, or if changes to their mood or behaviors persist for several days, or if these changes affect your child's day-to-day functioning (e.g., your child's ability to play or spend time with friends, study or engage in school), consider professional support. You may start by contacting your child's primary care doctor. Your pediatrician can help with an initial screening of the range and severity of issues. Your child's school psychologist or social worker may also be able to complete an initial screening and provide guidance and support in school.

If you notice changes such as thoughts of suicide or any other behaviors that affect your child's imminent safety, seek urgent professional health services immediately, including contacting 911 or the nearest emergency room.

Consider factors that can negatively contribute to your child's current adjustment

Monitor your child's adjustment closely, and seek professional mental health support sooner, if there are additional prior stressors or risks for your child or in your family's history.

- Does your child have a prior history of any mental health concerns (e.g., depression, anxiety, ADHD) or developmental concerns (e.g., autism spectrum concerns, cognitive difficulties)?
- Does your child have low self-esteem, or difficulty coping with stressors (e.g., easily overwhelmed)? Can your child understand their feelings?
- Are they likely to come to you or another trusted adult to share their experiences or concerns?
- How is your and your co-parent's mental health? While children can tolerate parents' negative feelings (e.g., sadness, worry, distress), sustained parental mental health problems, especially if untreated, can impact the parent-child relationship, parents' ability to be emotionally attuned and to support their child effectively.
- Is there consistent high level of co-parenting stress? Is there a tense 'emotional climate' in your family?
- Has your family experienced a number of negative life events such as traumatic experiences (e.g., household or community violence), significant life stressors (e.g., difficulties with peers, bullying) or instability (food, housing, or employment instability)?

Next steps to access a mental health specialist

- If you plan to use your health insurance plan for mental health services, learn about your behavioral and mental health plan benefits, and review therapists covered by your insurance plan.
- Your child's pediatrician can help provide initial screening and guidance regarding your child's adjustment. They may also be able to suggest referrals for local mental health professionals. If needed, some pediatricians may also be able to assess and prescribe medications to address emerging mental health concerns based on the severity and impact of symptoms for your child.
- There are also a number of online searchable directories to identify a therapist according to location, specialty, age group, insurance, or other considerations (gender, training or specialty, language).
- PsychologyToday.com: <http://www.psychologytoday.com/>
- Onlinetherapy.com: <https://www.onlinetherapy.com/>
- Goodtherapy.org: <http://www.goodtherapy.org/>
- Social Work Therapy Referral Service: <http://www.therapymatcher.org/>

What type of mental health professional would be best?

Each child and family's unique profile of needs determine the range of mental health services (e.g., therapy, psychiatrist, school-based mental health services) your child or family might need. Additional factors such as access to mental health services in school, local hospitals or clinics, and mental health services in the community, are also key considerations.

“**Therapist**” or “**counselor**” are umbrella terms, often used to represent a range of professionals with varying educational and training backgrounds. To learn more about the general training and background of different mental health professionals you can refer to these websites:

- **Clinical psychologist:** <https://www.apa.org/ed/graduate/specialize/clinical>
- **Counseling psychologist:** <https://www.apa.org/ed/graduate/specialize/counseling>
- **Psychiatrist:** <https://www.psychiatry.org/patients-families/what-is-psychiatry>
- **School psychologist:** <https://www.nasponline.org/about-school-psychology/who-are-school-psychologists>
- **Licensed Clinical Social Worker:** <https://www.socialworkers.org/Practice/Clinical-Social-Work>
- **Related informational resources:** <https://www.nami.org/About-Mental-Illness/Treatments/Types-of-Mental-Health-Professionals>

What to look for in a prospective therapist?

- Training and experience in working with children and families. Working with children and adolescents requires a unique set of developmentally tailored trainings. Additional training specializing in working with children of specific age groups can be particularly helpful.
- Training and experience in working with families coping with serious and terminal medical conditions. Since ALS is a rare illness, it is uncommon for mental health professionals to have direct experience working with families coping with ALS. However, experience with other serious or terminal illness can provide an important foundation that a therapist can build upon.
- Training and experience with bereavement, particularly for children and families. For some children bereavement can be particularly traumatic, look for therapists with specialized evidence-based interventions (e.g., Trauma-focused Cognitive Behavior Therapy, Trauma and Grief Component Therapy for Adolescents).

Questions to ask a potential therapist

- What is their background in working with children of the same age as your child?
- How do they think therapy can help a child?
- How would they include the parent (or not) in the work? Will the sessions include just your child, or you and your child, or some combination?
- What kind of information would they share with the parent about the child's treatment?
- How do they collaborate with other professionals who may be involved in supporting your child (e.g., psychiatrist, school-based counselor)
- Consider logistics such as remote (video or phone) or in-person therapy. Ask about what they offer and recommend, and why?

Start early on identifying possible mental health services

The demand for mental health services often exceeds available services. Thus, identifying possible mental health professionals or services early, and registering for waitlists, if needed, can be helpful. It may take some time to identify a therapist that is a good fit for your family or your child, to build a collaborative working relationship with a therapist, and develop a sense of trust that can facilitate sharing deeply personal and often painful experiences.

Group-based services

Mental health support groups are sometimes offered through non-profit organizations, hospice facilities, and local hospital or mental health practices. These groups are often available to people even if they have not received services directly from that clinic or hospital, or hospice.

Peer groups

Peer groups for children and parents who share the experience of coping with a loved one's ALS or parental loss and grief, can be a valuable source of emotional and practical support.

<https://hopelovescompany.org/virtual-programs>

References

Calvo V, Bianco F, Benelli E, Sambin M, Monsurrò MR, Femiano C, Querin G, Sorarù G, Palmieri A. Impact on children of a parent with ALS: a case-control study. *Front Psychol*. 2015 Mar 17;6:288. doi: 10.3389/fpsyg.2015.00288. PMID: 25852606; PMCID: PMC4362044.

Haine RA, Ayers TS, Sandler IN, Wolchik SA. Evidence-Based Practices for Parentally Bereaved Children and Their Families. *Prof Psychol Res Pr*. 2008 Apr;39(2):113-121. doi: 10.1037/0735-7028.39.2.113. PMID: 20585468; PMCID: PMC2888143.

Kavanaugh MS, Cho CC, Howard M, Fee D, Barkhaus PE. US data on children and youth caregivers in amyotrophic lateral sclerosis. *Neurology*. 2020 Apr 7;94(14):e1452-e1459. doi: 10.1212/WNL.0000000000009217. Epub 2020 Mar 18. PMID: 32188763.

Resources

1. <https://istss.org/public-resources/friday-fast-facts/grief-and-bereavement>
2. <http://www.dougy.org/>
3. <https://childrengrieve.org/>
4. <https://www.cdc.gov/violenceprevention/aces/fastfact.html>
5. <https://www.als.org/navigating-als/resources/Families-and-ALS-Resource-Guide>
6. <https://mghcme.org/courses/when-a-patient-with-cancer-is-a-parent-practical-parent-guidance-to-address-parenting-concerns-and-enhance-parenting-skills-to-support-child-coping/>
7. <https://www.psychologytoday.com/us/basics/therapy>
8. <https://www.apa.org/monitor/2022/10/evidence-based-practices-grief#:~:text=There%20are%20several%20effective%20evidence,developed%20by%20psychiatrist%20Judith%20A.>