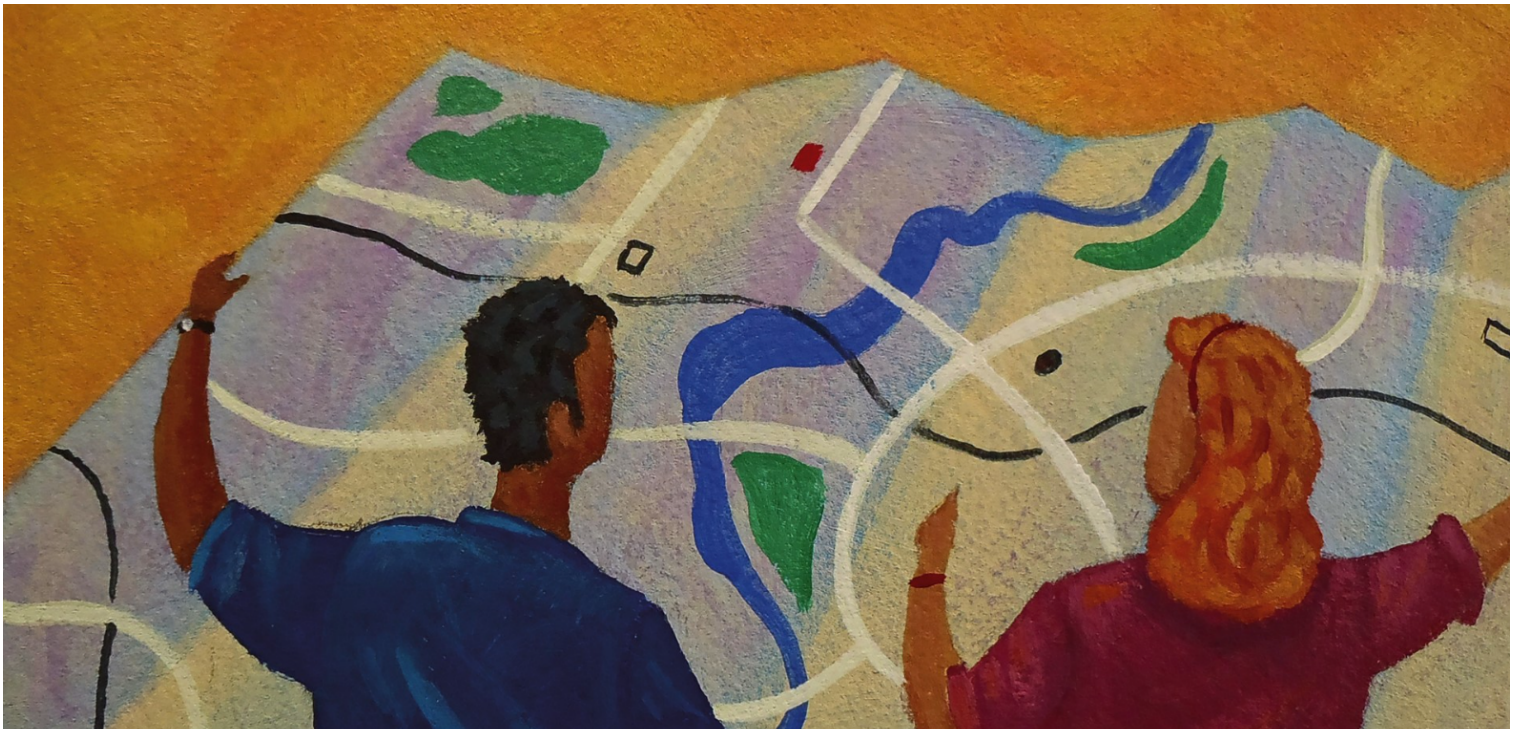


SUPPORTING CHILDREN'S EMOTIONAL WELL-BEING: CHILD DEVELOPMENT AND RESILIENCE

*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.*

Supporting Children's emotional well-being: Child development and resilience

This handout provides a brief overview of the ALS Parenting At a Challenging Time (ALS PACT) Program in the Massachusetts General Hospital (MGH) Healey Center for ALS, and our model of parent guidance consults. We describe a range of factors that shape children's development and adaptation that may be engaged as resources to support children's emotional well-being and coping across all stages of a loved one's illness.

It is written for people with ALS and their co-parents, as well as for mental health clinicians and for ALS multidisciplinary team members (e.g., nurses, physicians, occupational therapists, speech and language pathologists, psychologists, social workers, chaplains, and palliative care providers) who support parents and grandparents, or other adults (hereafter referred to as "parents") who are consistently involved in caring for children who are coping with a loved one's ALS illness.

Drawing on the ALS PACT Program's model of psycho-educational guidance in the multidisciplinary ALS clinic, we developed evidence-informed written psycho-educational resources to help parents recognize and address concerns about children's adjustment to a loved one's illness. These guidance materials are developmentally tailored and discuss how to support children from birth – 25 years. We recognize that parent guidance cannot provide the level of personalized support as an individual consultation, but we hope to address many of the common questions concerns that parents have shared with the ALS PACT team during consults with parents, who are patients at MGH.

We are grateful for the "We Care" grant from the **ALS Finding a Cure Foundation** (<https://www.alsfindingacure.org>) which enabled us to create this open access online library of written parent guidance materials designed for parents and clinicians (including ALS multidisciplinary teams and mental health clinicians). The parent guidance materials include a series of 14 handouts developed by clinical psychologists in collaboration with multi-disciplinary clinicians (e.g., speech and language therapists, occupational therapists, genetic counselors, neurologists, nurses) in the Healey Center for ALS at MGH. All of these handouts are available for download at no cost in English and Spanish, online here: <https://www.massgeneral.org/als-pact>.

ALS Parenting At a Challenging Time Program

The ALS PACT Program was formally launched in the MGH Healey & AMG Center for ALS in 2019, building on prior collaborations with the MGH Cancer Center PACT Program (www.mghpact.org). The team combines expertise in child development, clinical psychology, family systems, pediatric behavioral medicine research on serious and terminal medical conditions, trauma and resilience, and grief and bereavement.

We collaborate with parents to support children's coping and ability to thrive throughout the course of a parent's ALS illness. The loving, attuned support of a parent is a powerful predictor of children's adaptation through life's challenges, including the life-altering experience of grieving a parent (Haine et al., 2008; Weir, K., 2017). We believe that parents know their children well and are powerful advocates in engaging supports for their children.

Our program recognizes that each child has a unique profile of strengths and needs, stemming from hereditary factors, a child's temperament or personality style, life experiences within their family and social contexts (e.g., school, neighborhood), and a range of cultural considerations (Bronfenbrenner, U., & Morris, P.A. (2006).

Listening carefully to parents' stories of their children to understand how and where their children live, play, learn, and grow, the child's developmental history, and combining that with a parent's ALS-related functioning, we provide parenting guidance tailored to the needs of each child.

Finally, a key focus of the ALS PACT program and these guidance materials is on communicating about ALS related changes within the family, and particularly with children. Beginning with when and how to talk to children about the news of a parent's ALS diagnosis, to helping children understand ALS symptoms in their parent, and supporting children through everyday changes such as changes in rituals and routines, uncertainty, loss, and anticipatory grief – are all facilitated through emotionally attuned and age-appropriate conversations with children.

Communication is also central to planning and coordination efforts within and outside the family, including a range of medical and health care specialists, employers, schools, patient support groups, extended family, and friends.

Individual factors that affect children's adjustment

Child developmental stage

Knowing the developmental stage of a child is central to informing how parents can help their children understand a parent's diagnosis of ALS, what changes to anticipate, the timing and level of details in the information that is shared with children, and also in planning for supports for children. Accordingly, discussions within the same family across siblings may be different. Also, children of the same age can vary with respect to cognitive development, understanding and comprehension, and emotional functioning.

Thus, throughout these guidance materials, we provide age-specific information on each topic. In some sections, we also provide tabular information highlighting what to expect in each developmental stage and guidance specific to coping with a parent's illness.

All guidance materials can be found at:
<https://massgeneral.org/als-pact>

Developmental and mental health history

Each child's developmental history, their prior history of mental and emotional health will influence how they adjust to the stressors associated with their parent's illness. For instance, children with prior mental health concerns, may experience worsening symptoms or they may develop new symptoms. For some children this expected period of adjustment will involve short-term changes, often following changes in a parent's functioning, followed by a return to typical functioning. Other children may benefit from close monitoring and additional professional support.

Similarly, a family's prior history of experiencing adversities and how they coped with them, affects parents' own coping, their capacity to emotionally support their children, and in turn children's adaptation (Narayan, Lieberman, & Masten, 2021).

Children as caregivers to a parent with ALS

Children, youth, and young adults are often involved in caring for their parent with ALS and may be active participants in medical appointments (Kavanaugh et al., 2020). Consistent with parents' narratives about their complicated feelings regarding this care, children also often report a range of feelings about changing roles, expectations, and routines as they assume the responsibilities of caring for a parent. For instance, a prior study found that parents may feel guilty or worried about their children assuming caretaking responsibilities but may also feel grateful for their children's assistance (Kavanaugh et al., 2020).

Children may find their roles within their families differ from those of their peers, while also feeling positively about their ability to care for a parent. For more information on involving children in caring for a parent, the handout can be accessed at <https://massgeneral.org/als-pact>

Family level factors that affect children's adjustment

Parenting

Both parenting while coping with ALS, and co-parenting with a parent with ALS, are unique experiences. The demands and changes for each parent can affect a parent's own mental health. Recognizing and supporting both parents' mental health needs can often get lost in the flurry of responsibilities, busy daily routines, and planning and adjusting to ongoing changes. However, prioritizing parental mental health is key for individual health, to long-term coping with ALS, and importantly, to supporting children. Parents' own mental health and coping and parent-child interactions are associated with children's overall coping and adjustment (Haine et al., 2008; Krattenmacher et al., 2020; Weir, K., 2017). While younger children need different types of supports than adolescent or young adults, all children, including adolescents and young adults, benefit from parental support.

Co-parenting while caregiving

Co-parenting while caring for a partner with ALS is a complex experience that changes over the course of ALS progression. When co-parents collaborate on addressing changing roles and expectations, the emotional impact on the family, and plan together for ways to cope with the increased caregiving needs (e.g., caring for the children and the parent with ALS) it can reduce the individual burden for each person.

Thus, communication, planning, shared decision making, and access to additional supports are associated with more effective adaptation to changes, greater marital satisfaction, and less stress (Kolak et al, 2007).

Community Factors

School

A sense of connectedness in school and belongingness with peers is one of the key protective factors for school-age children and youth (Centers for Disease Control and Prevention, 2019). Being with friends and in school can provide a sense of normalcy when so much is changing at home. Thus, some children may prefer not to have very public discussions about their home life with people in school, especially in the initial stages of the illness.

At the same time, depending on factors such as a parent's progression or a child's overall adjustment, parents may want to inform someone in their children's school of a parent's diagnosis of ALS so that a trusted school counselor, teacher or principal can keep an eye on how their children are coping and functioning in school. Talking to children to decide whom to inform in school and when, helps children feel included, trusted, and respected.

Additionally, for many children, school might be the primary place where they work consistently with a mental health professional, hence involving the school can be supportive for children in a variety of ways (Ali et al., 2019).

Finally, for some children and families, schools may be more closely involved in a variety of ways. For instance, through school-based efforts to raise awareness of ALS or fund-raising events may occur in collaboration with families coping with ALS.

Extended family and social support

Family, friends, and colleagues may be supports for parents and children, and parents may want to inform and update them about your illness. There may be times, especially initially, when you communicate directly with them, and they may wish to express their support directly to you. But over time, parents might consider having assistance with managing ongoing communication, particularly if they have a larger network of family or friends. They might identify one or more persons, among the close family members or trusted friends to be “minister(s) of information” or a designated “Press secretary”. This person can help relay important updates and spread the word among your relatives, or a designated colleague may provide updates to coworkers.

Similarly, when parents receive offers to help them or their family, consider appointing one or more “Captain(s) of kindnesses” who can organize these well-wishers. While a parent might list activities or things with which they need assistance, the captain(s) of kindnesses can designate specific tasks (e.g., household errands such as grocery shopping, cooking meals, driving you or your children) among volunteers. See the resource section at the end of this handout, for sample websites and tools to help coordinate such volunteer efforts.

Involvement with patient advocacy and ALS communities

For many people with ALS and their families, patient communities and ALS advocacy groups provide a much-needed sense of connection, as coping with a rare illness can feel isolating.

Patient communities can provide support, a sense of belonging, feel empowering or inspiring, and provide a range of resources, information, and first-hand knowledge.

Anecdotally, patients or their partners and families describe a range of feelings when participating in patient communities. Patients are in varied stages of progression with different family contexts and needs. Understandably, especially initially, people report feeling nervous or worried as they may hear or see more than what they feel emotionally ready for, or they might feel guilty about their own circumstances. Thus, considering each family member’s own readiness, including your own, and what goals they might have, or whether and how each person might participate can be helpful. (Fayn et al., 2021; Guillamón et al., 2010).

Role of cultural factors

Cultural factors, including spirituality and religion, inform our beliefs, values, parenting approach, and coping strategies towards, illness, end of life care, and death. For instance, some cultures may emphasize individual autonomy in health-related decision making and coping while others may emphasize family involvement. Families find support, comfort and meaning in religious practices and communities, which can positively influence their quality of life (van Groenestijn et al., 2016).

Resources

Sample websites/ organizational tools to coordinate volunteer efforts:

<https://www.caringbridge.org/>

<https://lotsahelpinghands.com/>

<https://www.carecalendar.org/>

<https://www.mealtrain.com/>

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