

INTRODUCTION TO
“PARENTING WITH ALS:
GUIDANCE FOR SUPPORTING YOUR CHILDREN”
FOR ALS MULTIDISCIPLINARY CLINIC TEAM MEMBERS

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



Patients with ALS often highly value their roles as parents or grandparents of young, adolescent or early adult-aged children or grandchildren. Raising and caring for children may foster a sense of purpose and meaning even as a patient’s physical functioning becomes more limited. However, raising children while coping with ALS may also create a range of emotions, questions and challenges that can be difficult for providers to respond to in the course of a patient’s visits with a multi-disciplinary ALS care team.

Thanks to support from a “We Care” grant from the ALS Finding a Cure Foundation, the ALS Parenting At a Challenging Time (ALS PACT) Program from Massachusetts General Hospital has developed a series of written parent guidance materials that we hope may be useful to patients you treat who are parents or grandparents of children ages birth – 25 years. This series of 14 handouts aims to support adults with ALS, and their co-parents, to improve their children’s coping and resilience in response to a variety of ALS-related challenges at different stages.

These evidence-informed and developmentally sensitive materials, developed by two child psychologists in collaboration with multi-disciplinary clinicians in the Healey Center for ALS, address the concerns that most frequently arise during our conversations with parents. They are freely available for download in English and Spanish, online:

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

This document was written for multi-disciplinary groups of ALS providers (including physicians, nurses, physical therapists, speech and language pathologists, psychologists, social workers, chaplains, and palliative care providers), rather than for your patients. While every practice is different, we offer here a brief summary of the 14 parent guidance handouts, and a few ideas for how providers might consider asking about, and addressing, the kinds of parenting concerns that frequently arise. We hope that these materials will support you in caring for your patients and by extension, for families affected by ALS. We welcome your feedback and questions and can be contacted at mghalspact@mgh.harvard.edu

Parenting with ALS: Guidance for Supporting your Children

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

List of parent guidance handouts:

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-pac>

**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.*

1. Supporting children’s emotional well-being: child development and resilience

This first handout establishes the theoretical basis for the parent guidance provided by the ALS PACT Program and described in these materials. It is meant to orient parents to a range of factors that can influence children’s development, beyond parental medical illness. It includes:

- A brief description of ALS PACT Program
- A rationale for focus on communication
- A summary of individual, family and community-level factors that promote resilience in children

2. Communication with children about a parent’s ALS diagnosis

A common concern expressed by patients who are parents is uncertainty about how they will talk about ALS with their children. Recently published guidelines (Dalton et al., 2019) affirm clinical experience- that being open and honest with children about a parent’s medical illness supports, rather than worsens, children’s adjustment to that illness. It is possible even for parents who can’t imagine using the term “ALS” with children to find truthful ways to talk about changes in their functioning. Children benefit when family challenges are “talk-about-able” in age-appropriate ways.

The Communication handout provides:

- a rationale for talking about ALS
- concrete ideas for preparing for a first conversation
- ideas for explaining ALS to children at different developmental stages
- suggestions about communicating with children’s schools
- suggestions about communicating with the family’s broader support network

ALS Multidisciplinary Care Team considerations

- This handout may be well suited for parents who are questioning whether or how to tell children about an ALS diagnosis, whether or not the diagnosis was made recently.
- As you are getting to know patients, take the time to inquire about children and grandchildren in their lives. If possible, document names, ages, and any specific information shared by a parent that might influence the child’s reaction to the parent’s ALS (e.g., prior mental health history, developmental delay).
- Ask what they believe their children understand about their condition, what they expect to happen next, and if the parent feels prepared to provide important updates based upon your visit.

- Often, parents need time to adjust to a new diagnosis themselves, before being ready to reveal it to children. Your team can encourage a parent's taking this time and building up their own support system, while keeping in mind that their children could well be noticing, and worrying about, physical changes as well as sensing a different emotional climate at home.

3. Communication about pseudo-bulbar affect (PBA) and frontotemporal dementia (FTD)

ALS can present with comorbid conditions that will also affect a child's experience of their affected parent. In particular, pseudo-bulbar affect and frontotemporal dementia may be quite obvious to children as well as disruptive to family life. The Communication about PBA and FTD handout provides:

- a brief summary of symptoms of PBA and FTD
- suggestions for explaining both of these conditions to children
- suggestions for exploring the emotional impact on children of living with a parent with either of these conditions

ALS Multidisciplinary Care Team considerations

- Pseudobulbar affect in a parent can be very confusing and embarrassing for children, who themselves are learning to identify feelings and regulate emotional experience and expression.
- You might suggest to parents that they describe and talk about PBA with children, rather than ignoring it, and when possible, to identify an emotional response as being the result of PBA and not the parent's true feelings.
- Frontotemporal dementia in a parent with ALS can be even more disruptive for adult co-parents and children. Your team's ability to describe and, within limits, predict the course of FTD symptoms might allow you to work with a coparent so that adequate supports are in place to ensure the safety of children and adults.
- Help co-parents plan for how they would address hypersexualized behavior or other kinds of impulsive behavior, and how they would explain this to children.

4. Genetic subtype of ALS

This section focuses on common concerns for parents with a genetic subtype of ALS related to supporting their children. Parents of children of all ages worry about the potential implications for their children, wonder about how to answer children's questions about the causes of the disease, and want to help children plan for the future.

This handout is in no way meant to substitute for the personalized guidance a genetic counselor can provide. It is instead intended to help to prepare a parent for a consult by providing a brief overview of the genetic counselor role and an outline of possible topics for parents to raise with their multi-disciplinary team. In addition, the Genetic subtype of ALS handout discusses:

- the importance of parents making their own emotional adjustment to ALS a priority
- how to talk with children about the genetic subtype of ALS, in coordination with guidance from a genetic counselor
- how to help children integrate the experiences of other ALS-affected family members with expectations for their parent's illness course

ALS Multidisciplinary Care Team considerations

- Although parents may be upset by the idea that a child could inherit a genetic risk for ALS, having information about what an adult child can do proactively, once they know about a genetic risk for ALS, can restore some sense of control.
- Making decisions about when children will be told about a genetic form of ALS in a first-degree relative can be very complicated when the span of children's ages is broad. Similarly, when genetic testing results in adult children are shared among siblings and other relatives, complicated and conflicting reactions can arise (e.g., about a sibling's perceived role in the family as being always unlucky, or the least deserving of this outcome, or the best able to handle it).

Let patients know clearly what you are able to do, or not, for their children. If possible, provide patients with ideas about best sites for their children to seek guidance depending on their geographic location.

If possible, develop a list of a few clinicians (genetic counselors, psychologists, other mental health providers) who could provide therapeutic support or a family consultation around some of these decisions.

Listen for any guilt expressed by patients and be clear that they and their children are all unlucky recipients of the gene- try to avoid language that might heighten a sense of responsibility (e.g., you gave the ALS gene to your child, you passed down the gene- vs. your child inherited the gene).

5. Changes in Motor Skills and Mobility

Changes in gross and fine motor control affect day to day functioning in ways that necessitate new equipment and home modifications. The changes may also lead to disruptions in family routines or requests for children to assist a parent in new ways. Even parents who would prefer to avoid any mention of ALS to children can find that they are forced to come up with some explanation for such obvious changes (the Communication handout may be appropriate for these parents).

The Changes in Motor Skills and Mobility handout describes:

- ways that mobility changes may impact children and family life
- the value of clear descriptions to children of the purpose of new equipment
- ideas for talking about changes with children of different ages
- examples of typical age-specific concerns related to mobility impairments in a parent and potential ways for the parent to respond
- challenges that limitations in mobility pose to family closeness and connection, and suggestions for parents to remain engaged with children
- ways to check in with a child who has witnessed a parent's fall

ALS Multidisciplinary Care Team considerations

- This handout may be well suited to patients who have declines in ALSFRS-R scores on items 4-9, or who are open to thinking proactively about future changes.
- Ask about how children are doing- what do they notice and comment on, and how is the parent talking about changes with them?
- As you preview or demonstrate potential assistive devices with patients, let them know that it may be helpful for them to do the same with their children, ideally somewhat in advance of their use.
- If a patient's fall was witnessed by a child, ask whether the child has shown any signs of ongoing distress in the ensuing weeks. If so, suggest they consider checking in with the child's pediatrician or a school counselor. Also discuss how the parent should instruct the child to respond should another fall occur, and encourage they post a written list of emergency numbers.
- Acknowledge the ways that declines in mobility may change usual family routines, while remaining positive about the family's ability to find new ways of staying connected that are still meaningful.
- Ask whether parents anticipate asking for their children's help with any new care needs. Provide enough details about what will be required to allow a parent to be realistic about a child's capacity to do so.

6. Bulbar symptoms: speech, swallow, salivation, and eating

Bulbar symptoms, whether present at the onset of ALS or later in its course, create their own unique challenges for the parent-child relationship. Spoken language is a tool parents use to communicate support, expectations, information, and crucially, emotion. Verbal communication supports the emotional attachment between people, and its loss may cause parents to notice a shift in their feeling of connection with their children. Similarly, changes to a parent's participation in mealtimes may affect connection and family cohesion (Brown et al., 2019; Franko et al., 2008). Children may feel anxious in response to choking episodes, and curious or confused about a g-tube, but parents are not always comfortable talking about these changes.

This handout offers:

- explanations for how ALS creates bulbar symptoms for children of different ages
- descriptions for children of augmentative communication devices, and ideas for preparing children for their use
- descriptions of common concerns for children in using this technology and potential solutions
- a summary of some effects on family meals of swallow and salivation changes
- ideas for talking about episodes of choking
- explanations for g-tube placement and use for children of different ages

ALS Multidisciplinary Care Team considerations

- This handout may be well suited to patients who have declines in ALSFRS-R scores on items 1-3, or who are open to thinking proactively about future changes.
- Encourage voice banking and early adoption of augmentative communication devices to facilitate continued verbal communication between parent and child.
- As you preview or demonstrate any of these options (augmentative communication, g-tube) with patients, let them know that it may be helpful for them to do the same with their children, ideally somewhat in advance of their use.
- If a patient's choking episode was witnessed by a child, ask whether the child has shown any signs of ongoing distress in the ensuing weeks. If so, suggest they consider checking in with the child's pediatrician or a school counselor. Also discuss how the parent should instruct the child to respond, should another episode of choking occur.
- Ask whether parents anticipate asking for their children's help with any new care needs. Provide enough details about what will be required to allow a parent to be realistic about a child's capacity to do so.

7. Breathing difficulties: Using a BiPAP machine

ALS-related breathing difficulties, including shortness of breath doing activities while upright, shortness of breath while lying down, difficulty with airway protection, and respiratory insufficiency, are both obvious and a common source of concern to children.

This handout:

- provides a brief overview of types of breathing difficulties a person with ALS may encounter
- describes ways that children may notice or experience a parent's breathing difficulties
- makes suggestions for how parents can explain the BiPAP machine to children across the developmental spectrum
- considers how parents can support children as they navigate conversations with peers about the parent's assistive equipment

ALS Multidisciplinary Care Team considerations

- This handout may be well suited to patients who have declines in ALSFRS-R scores on items 10-12, or who are open to thinking proactively about future changes.
- The ALS care team can offer support to parents by inviting conversations about how they plan to talk with children about breathing changes and new equipment, and the care that children will observe at home. For example:
 - How might your children react to the new equipment? Would you like to think together about how to prepare them for what they will see (or, a handout that might help you prepare them?)
 - Do you feel equipped to talk about possible breathing challenges and interventions with your children? Can we help?
 - Ask whether parents anticipate asking for their children's help with any new care needs. Provide enough details about what will be required to allow a parent to be realistic about a child's capacity to do so.
 - Who is (or, will be) involved in providing support around BiPAP use? If children are (or will be) involved, what are their roles and how have they been prepared?

8. Breathing difficulties: Having a tracheotomy

Many patients never opt for a tracheotomy procedure, but when a BiPAP machine no longer adequately manages respiratory insufficiency, the choice to move to mechanical ventilation may be offered. The tracheostomy is discussed in its own handout to allow a patient who is ready to read more about breathing difficulties to better control their exposure to content that may be more distressing.

The handout offers:

- an overview of types of breathing difficulties (repeated from the prior handout)
- a brief description of an endotracheal tube and tracheostomy and how they work
- a description of tracheostomy care, given that children may be asked to help with this
- guidance for talking about a tracheotomy with children of different ages

ALS Multidisciplinary Care Team considerations

- This handout may be well suited to patients who have declines in ALSFRS-R scores on items 10-12, or who are open to thinking proactively about future changes.
- The ALS care team can offer support to parents by inviting conversations about how they plan to talk with children about breathing changes and new equipment, and the care that children will observe at home. For example:
- How might your children react to a tracheotomy and ventilator? Would you like to think together about how to prepare them for what they will see (or, a handout that might help you prepare them?)
- Do you feel equipped to talk about potential breathing challenges and interventions with your children? Can we help?
- Ask whether parents anticipate asking for their children's help with any new care needs. Provide enough details about what will be required to allow a parent to be realistic about a child's capacity to do so.
- Who is (or, will be) involved in providing tracheotomy care? If children are (or will be) involved, what are their roles and how have they been prepared?

9. Including children in caring for a parent

Home health aide and visiting nurse hours are increasingly difficult to procure and families often have to cobble together supports to manage ALS at home. The limited availability of outside help and time-intensive care needs that accompany ALS can push families to rely on both adult and dependent children for hands-on care. While understandable, this reliance on dependent children may have unintended negative effects on children, along with some positive ones (Kavanaugh et al., 2020; see handout for full reference).

This handout offers suggestions for parents as they consider the tasks for which they will request help from their children. It discusses:

- looking for a match between the job and the child’s physical, emotional and cognitive capabilities
- why certain kinds of tasks are usually better completed by an adult
- the need for children to receive education and supervised practice
- the value of conversations that acknowledge the challenges for children of helping with a parent’s care

ALS Multidisciplinary Care Team considerations

- Parents may experience a mix of pride in the child’s capabilities coupled with shame about needing the support, and as a result, children’s care of a parent may be very evident to the team, or somewhat camouflaged. If the team routinely expresses curiosity about dependent children at home, then inquiring about the ways that children contribute to care may be less likely to be perceived as anything other than caring and supportive.
- Ethically challenging situations can arise both around a child’s care for a parent, and the parent’s ability to care independently for a child. (For example, questions could arise in the context of worsening driving abilities in a parent who typically transports children, or limited mobility or communication possibly preventing a parent from assisting a child who gets accidentally hurt while in their care.)
- It is important to be aware of your state’s mandated reporting laws for cases of child neglect or endangerment.
- If possible, identify someone in your organization who could advise you on the need to file, should there be a question of child safety.
- Children’s accepted roles and responsibilities in the family, and their experience of those roles, are shaped by a family’s cultural and ethnic identities. Even so, clinicians can respectfully encourage parents to be attuned to how individual children in the family are responding to these expectations. When talking with parents about the impact on children of providing care, try to express openness to the positives along with any concerns, for instance,
 - “Many parents I speak with are quite proud of the ways their children have learned to help them, while others are concerned about the kinds of help they need to ask of their children. How is that going in your family? What are the tasks related to your care that your children routinely do?”
 - “Are any of your children struggling to do what you ask them/need them to do?”
 - Or, “Are any of your children frustrated that you won’t allow them to do more?”
 - “I certainly understand how difficult it is to find at-home help, and your quality of life is one of my major concerns. At the same time, I am worried that having your (X) year old responsible for (X) may have downsides for both of you. I wonder if we could think together about how to minimize those?”

- One resource that might be helpful was written by Melinda Kavanaugh for adolescents: The ALS Experience- It's Different and Hard: <https://www.als.org/sites/default/files/2020-04/youth-guide2.pdf>

10. Talking to children about an imminent loss, and,

11. Supporting children through the end of someone's life

An anticipated death creates both challenges and opportunities, and parents may experience deep uncertainty about how to best respond to these. Parents often express concern about talking about an anticipated death too soon, thereby unduly burdening their children. However, by avoiding the subject for too long, parents can miss important opportunities to help children understand the events around them, process a variety of emotions, begin to grieve, and sometimes, to talk or spend time with a parent in uniquely meaningful ways. These two handouts address complementary issues facing parents trying to prepare children for a loss.

“Talking to children about an imminent loss” focuses on communication and offers:

- a rationale for talking with children about what is expected to happen
- concrete suggestions for starting a conversation about an anticipated death

“Supporting children through the end of someone's life”:

- describes physical changes that may signal that someone is nearing end of life
- describes services or interventions (e.g., hospice care, hospitalization, medications) that may be offered at this stage
- helps parents consider when to talk about these changes
- offers a variety of strategies in addition to open communication that can help parents to support their children

ALS Multidisciplinary Care Team considerations

The work of talking about a patient's own prognostic awareness and hopes and fears for their final weeks may be shared by several team members, or perhaps largely undertaken by a particular professional role such as a Palliative Care clinician. Acknowledging that the parent (or their co-parent) faces some version of this conversation with their children may invite a parent to describe a new set of concerns. These can be very difficult to talk about, yet excluding them from discussion does not make them go away- a point that is made in the materials for parents as well (Dalton et al., 2019).

If your practice does not already include a professional who feels comfortable talking with parents about the ways they might prepare children for a death, perhaps it would be possible to find a consultant to meet with the multi-disciplinary team to help develop a team approach, or with whom patients could speak. Child psychologists and psychiatrists, child life specialists, grief counselors and chaplains may all have something to offer.

12. Legacy leaving

One opportunity afforded by being forced to focus on one's own mortality is that of intentionally creating a legacy to share with loved ones, often children and grandchildren. These take a variety of creative forms, and can serve to help children feel closer to a loved one, assured of being loved and encouraged during difficult times, and also to provide information about a parent that may be of interest as the child reaches more advanced developmental stages.

The Legacy leaving handout:

- Describes what is meant by legacy and why they can be valuable
- Offers examples of several types of legacies (e.g., writing, photos, important belongings)
- Notes some ways that particular types of legacies may cause unintended distress

Some parents may choose to make this a project over many weeks, others may spend a few hours to write a meaningful letter, and still others may never choose to engage in this kind of project. It is important that a parent not be made to feel guilty for not engaging in this kind of reflection.

ALS Multidisciplinary Care Team considerations

Introducing the idea of legacy leaving requires the ability to strike a delicate balance between aligning with a parent in hoping for the best (whatever that means to the person) while preparing for the worst. A parent's mentioning interest in "making memories" as a family might offer an opening. Along with supporting a parent in making new family memories, the team might find ways to encourage a parent to capture memories already made, so that the parent's perspective on these experiences will always be readily available to children.

Speech and language pathologists may have an opening to discuss legacy as well, during discussions of voice banking. A parent might be motivated to record favorite stories for younger children, or words of encouragement or congratulations for children for a future challenge or milestone.

13. Bereavement

Despite losses being inevitable for all of us, many adults struggle to find a way to talk about the experience of grieving and feel quite anxious about supporting a grieving child. Because awareness of the potential for loss is an unavoidable aspect of living with ALS, some parents find that learning about children's ways of grieving well before a loss offers some sense of control, as well as a framework to understand children's anticipatory grief reactions.

The Bereavement handout offers:

- Psycho-education about grief and words that may help convey this to children
- A rationale for children about why talking about grief can be helpful
- Age-specific strategies for supporting grieving children
- A list of resources that provide further information about children's grief

ALS Multidisciplinary Care Team Considerations

Parents may ask for your help finding a grief therapist for their children. There is no "grief therapist" credential, but some mental health clinicians are more experienced with a range of losses and grief-related responses than others. Even if it's not possible to find a therapist for every child, there are several things that clinics can offer that parents may appreciate:

- Share a list of grief-related resources (e.g., local grief resources, groups and clinicians; this Bereavement handout; websites for well-respected national organizations such as those shared in the Resources section of the handout)
- Parents may have success finding support using the Psychology Today "Find a Therapist" search engine, using an interest in grief as one of the filters. Some questions to ask a prospective therapist include what kind of training they have received in working with the bereaved, how do they think therapy might help a child, how they would include the parent (or not) in the work, and what kind of information would they share with the parent about the child's treatment.
- Grief support groups are sometimes offered through hospices and local non-profits. A list of any in your area would likely be appreciated by parents.

Children's coping in the aftermath of a loss is closely linked to the surviving caregiver's functioning. Encouraging the co-parent to prioritize their own health and emotional well-being is another way to facilitate children's positive adjustment to loss.

Sometimes parents deeply appreciate thoughtful, respectful reassurance that children's lives aren't forever ruined by a loss. While losing a parent inarguably has an enormous impact on children of all ages, it is also true that the majority will not develop serious mental health problems and will go on to have lives in which they find relationships and work that sustain them. Without minimizing the pain experienced by a family, it may be possible to offer the perspective that with time and support as needed, grief will begin to move further to the background of the rest of life.

14. Seeking professional mental health support for your child

Parents often request advice on how to recognize that their child may need professional mental health services and how to locate appropriate mental health clinicians, particularly those who are experienced with ALS and accepting new patients. Unfortunately, this group is a very limited resource. The Seeking Professional Mental Health Support for your Child handout offers:

- factors that can contribute to a child's adjustment
- how to know if a child could benefit from mental health assessment and support
- suggested steps and resources to access a mental health specialist
- brief information of the different types of mental health therapists
- suggestions about what to look for in a prospective therapist
- questions to ask a prospective therapist

Parents will likely be deeply grateful for any suggestions you can provide about mental health resources for adults and for children, in your local area.

References:

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