

# BULBAR SYMPTOMS: SPEECH, SWALLOW, SALIVATION, AND EATING

*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*

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

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# 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 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

## Introduction

Parenting while coping with ALS poses a number of challenges and considerations. The process of being diagnosed itself often involves multiple medical teams and specialists. Parents are likely to be grappling with different aspects of their diagnosis, such as adjusting to ongoing changes in their own functioning, the impact on their daily life, employment, or family experiences, while also coping with ongoing uncertainty, shock, and sadness. Thus, parents are often in various stages of coping and thinking through how to best support their children. This section focuses on initial communications with children about a parent's diagnosis of ALS.

There is no certainty as to the “best” or “correct” approach to sharing information about your illness with your children or to supporting children's adjustment and coping. We draw from our ALS PACT consultations with parents and grandparents (hereafter referred to collectively as parents) and our collaborations with multidisciplinary providers in the Massachusetts General Hospital ALS clinic <https://www.massgeneral.org/neurology/als> to offer guidance and strategies informed by developmental and clinical psychology and available research with patients with ALS. When appropriate, especially when there is a paucity of research data from patients with ALS, we also reference research with people with other terminal or serious medical conditions.

## Physical Changes and Changes In Daily Functioning Related to Bulbar Symptoms

Depending on the age of a child, you can explain that ALS also affects neurons that transport messages from the lower parts of the brain (bulbar region) to the muscles in the face and mouth i.e., the muscles that help to move the tongue, jaw, lips, vocal cords. As these muscles become weaker, a person's speech, swallowing, eating etc. change. It takes more energy or effort to talk and eat i.e., chew and swallow changes. This is also what makes it harder to swallow the saliva that is naturally produced in our mouth. So, people drool more and need help with wiping their lips or mouth to keep it dry.

Parents can explain bulbar symptoms to children building on concepts and explanations used to introduce ALS (see examples in the handout hyperlink: “Communication with children about a parent's ALS diagnosis” in the Table: Developmental considerations at different ages).

Toddlers and younger preschoolers are unlikely to understand a lot of information about the connections between the brain and body parts. They are developing their vocabulary, and naming and learning about different parts of the body. Brief descriptions that acknowledge the changes for a parent can be a starting point (e.g., “Daddy needs help with eating” or “Daddy need the applesauce. He can't bite that apple” or “Daddy talks through his phone sometimes and not his mouth”). You may build on this over time to explain how a brain and different body parts ‘talk to each other’ or send signals. Drawing a body or looking at age-appropriate pictures of a body together can be the building blocks to developing an understanding in later stages of how the motor neuron signaling processes deteriorate in ALS.



For children ages 6 and older, begin by reviewing information you may have shared before. E.g., “Remember we talked about how the brain and different parts of the body talk to each other? The brain can tell the hand to pick up a cup on a table, and the hand can also tell the brain, ‘hey that cup is hot!’ We talked about how these special wires can help the brain and body parts talk to each other. Consider analogies like a computer keyboard connected by wire to the computer or a light switch connected to a light bulb through electric wires to explain a motor neuron. See examples in the handout titled “Communication with children about a parent’s ALS diagnosis” available at <https://www.massgeneral.org/als-pact>.

“In mamma’s body, ALS is changing how these wires or neurons work and how the brain and body parts talk to each other.” If appropriate, link to an observable problem that the child may already have seen (e.g., “that’s why her legs are not working like they used to”). Building on this, “Now the signals between the brain to parts of her mouth (e.g., lips, tongue) are not working as well. So, it takes more energy or effort for mamma to chew and eat food”...“It takes a lot of energy for her to make words and talk”...“As mamma gets more tired through the day eating and talking get harder and take more time and energy. So, these are times when we need to be more patient or help her more. We will do this together.”

While older adolescents and young adults are likely to understand the descriptions noted above, and are likely to independently review information online, it can still be helpful to review concepts using simple analogies, and to ask what questions they have or if anything is confusing. Adolescents and young adults maybe more likely to be a part of their parent’s visits with their ALS care team.

It is helpful to acknowledge that participating in visits can bring up a range of feelings. While questions may be clarified, and interventions can bring a sense of relief, it can also feel sad or worrying. If possible, talk to your care team in advance to let them know that you wish to bring your child to the appointment, so that you, your co-parent, and the care team can plan for how the visit might be structured and what might be discussed. This can help you prepare your children, including sharing specific language or examples that you learn from your medical care team with your family. Particularly if your children are involved in caring for you, these appointments can serve as an opportunity to clarify their understanding of specific procedures or interventions, and to ask any questions they may have.

### **Physical Changes and Changes In Daily Functioning in Speech**

Speech changes occur gradually from being normal to having some speech disturbances (e.g., slurring, strained/ hoarse voice or dysarthria), to communicating using speech combined with non-vocal communication (e.g., writing, gesturing or typing/ texting), and ultimately to loss of speech. For parents with bulbar onset subtype of ALS, changes in vocal communication are evident sooner than for those without bulbar onset. With these details in mind, parents can consider how and when to prepare for discussions with their children and families for such changes, as well as related interventions, such as the use of augmentative and assistive speech devices to facilitate communication.

## Equipment and Interventions: Speech and Vocal Communication Devices and Interventions

A range of technological tools and assistive devices help to augment or replace vocal communication. See resource section at the end of this section for sources that provide detailed descriptions of various speech and vocal communication devices.

Commonly used devices such as cell phones and computers, that are not exclusively used for communication purposes, are familiar to nearly all children. Most children also understand these devices are used for texting and typing, in addition to making phone calls. However, it is likely still helpful for children, especially for younger children, to explain how and why a parent is using their phone or computer to communicate (e.g., it is easier than talking, it takes less effort or time than to vocalize).

With respect to dedicated communication devices that are exclusively for speech generation, (e.g., eye gaze technology-based devices), children of all ages are likely to benefit from an explanation of how these devices help their parent communicate more efficiently. Also, individuals may choose to use voice banking, which uses recorded samples of someone's natural speech to produce a "voice" from their speech-generating device that sounds more similar to their natural voice. This enables people with ALS to communicate with others and still sound similar to themselves.

In consultation with your team's recommendations, you may consider using text to speech applications to practice use of the technology before a parent is more dependent on it.

For example, the parents and children (if they use phones) may all download text-to-speech apps on the phone and everyone communicates using the app for a specific activity such as movie they saw together. This can help the whole family acclimate to the pacing and patience required for both the speakers and communication partners. This can increase understanding and decrease frustrations for everyone involved in later stages.

Toddlers and younger preschoolers are likely to need simple explanations of. E.g., "I use this special machine/ computer (or 'box') to talk." Preschoolers may also be able to understand, "I tell the machine the words and it says the word aloud for me". Children at this stage will likely need clarifications such as, "These are my words (or what I want to say) ideas, and the machine is saying the words for me in its voice".

For children ages 6 and older, "My doctors and I are thinking about ways to make it easier for me to continue talking. It takes a lot of time and energy for me to say what I want". Or in later stages, "My mouth muscles are not able to make sounds and words the way they used to", or "I have been using the phone. But it is getting harder to use my fingers to type the words. We are thinking of getting a special machine that helps people to say what they want to, without using their voice or typing with fingers. I can tell the machine what I want to say by 'typing words' with my eyes or using a mouse controlled by my head, and then the machine says the words for me."

Older adolescents and young adults are likely to understand the same information as their parents but may benefit from simple explanations of assistive and augmentative devices, as these are likely to be novel interventions, and they may still need clarifications.

## Experience of Children and Families

Exploring the impact of changes in a parent's speech and the associated interventions are instrumental to emotionally supporting children of all ages. Given the centrality of vocal communication in human interactions and daily functioning, speech declines change how children experience their interactions with their parent in meaningful ways. It is also emotionally difficult for parents in many ways to experience change in their voice, and to feel that they can't express themselves as quickly and naturally, especially to their children.

Most children are likely to have a range of feelings or thoughts about changes to a parent's vocal communication. This may take the form of feelings or thoughts of loss, such as missing a parent's voice, feeling like they have lost a part of their parent or aspects of their relationship with their parent. Children may also worry about illness progression. Exploring these losses with a loving parent or another trusted adult can help children understand their experiences and feelings, and to feel supported.

It can also feel awkward for a child to talk to a parent with bulbar symptoms or when a parent is using a speech-generating device due to the changes in the rhythm of the conversation. Children may worry about adding to a parent's burden of communication, seeing how effortful it can be or because the device-generated voice does not have the typical emotional tone of voice.

It is also common for children of all ages to feel impatient, and therefore they may feel less motivated to talk. On the other hand, parents may feel frustrated or hurt that there isn't enough opportunity to talk with their children. Parents can acknowledge these changes in communications, and when possible, plan around it. For instance, weekends maybe better suited to longer discussions than busy school days especially for discussions that are not time sensitive. Parents could also consider noting down some of their thoughts or ideas in advance to facilitate more detailed discussions. To address the lack of emotional tone from a speech-generating device, parents can be intentional in using words to emphasize something or to convey emotions (e.g., "I am SO SO SO proud of you", "This is important, and I need you to listen right now").

Children also worry about changes to aspects of interactions with family or other social situations (e.g., what will it be like when we go for baseball practice together). They may feel embarrassed or worried about how a parent's speech is perceived (e.g., what might others think about dad slurring when he talks). Especially initially, prior to social gatherings, talk to children about potential scenarios that might come up (e.g., "Not everyone at the get together knows that I am unwell. Let's talk about what to say if someone notices something about the way I am talking now".) You might choose to lead by sharing with others about the speech changes, without discussing your diagnosis of ALS, if that is what feels most comfortable for you.

## Physical Changes and Changes in Daily Functioning Related to Swallow and Salivation Difficulties

Early stages of swallow problems may be evident through prolonged mealtimes, changes in food preferences or occasional coughing or choking. Over time, changes in dietary consistency, such as consuming soft foods and thicker fluids, become necessary. Eventually, when eating orally is no longer feasible or too effortful, interventions such as the gastrostomy tube (commonly referred to as g-tube) feeding become necessary to provide nutrition. Persons with ALS with swallow difficulties also have excess saliva accumulation in the mouth. Starting with mild excess salivation this increases over time requiring frequent wiping of the mouth, use of medications to reduce secretions or ultimately mechanical support, such as suction.

A common concern with swallow difficulties, is the increased risk of choking. Speak to your ALS care team, about how to manage swallowing difficulties effectively and what to do in the event that a patient is choking. For instance, consider speaking to your ALS care team about whether to learn abdominal thrusts (formerly known as the Heimlich maneuver) from accredited training programs (e.g., American Red Cross).

*Help explain observable changes during meal times for a parent with ALS. For e.g., explain that the parent may need more time to eat or require softer foods.*

## Experience of Children and Families

Mealtimes, particularly dinners are often the most consistent times when families come together (see the MGH Family Dinner Project website for more information), especially during busy weekdays. Additionally, some foods and recipes are often a hallmark of special occasions, holidays, or celebrations, and may also represent shared family traditions. Daily meal routines or long-standing family rituals change when a parent struggles to eat and feed themselves. In practical terms, a parent with ALS may need more time to eat, may experience choking difficulties, require soft foods etc.

Parents can talk to children about what has changed about mealtimes, or celebrations and holidays, and what has stayed the same. You can acknowledge the changes and help children voice their feelings. Ask if they have questions about celebrating a particular holiday or occasion. You may plan and foreshadow how certain plans may change, but other traditions may stay the same. E.g., “we still plan to celebrate as an extended family, but daddy’s food will be different this year”. Talking about the continuity of rituals are helpful reminders of stability. Families can also create new traditions that do not revolve around food such as playing a game or decorating in a different way.

Seeing or hearing a parent choke can be worrisome for children. They may not always connect the dots that choking is related to a parent’s illness. Make the connection with bulbar symptoms (as described above) to help them understand why this is happening.



Check-in with children after a scary episode of choking to see how they are feeling, and explain what will be done about it e.g., “daddy will have softer foods, so it is easier for him to eat (or swallow) that”, so that things don’t feel so out of control or frightening. If your children witness their parent receiving abdominal thrusts (formerly known as the Heimlich maneuver), explain the procedure and that they were based on a care team’s recommendation. Ask children about any questions they may have.

If there is a planned g-tube placement, these instances can also be a time to foreshadow the procedure with your children. Consider sharing that there are other ways also to get nutrition and fluids besides eating through the mouth. Explain that a special feed can be given directly in the stomach through a tube called a g-tube (or gastrostomy tube).

### **Equipment and Interventions: Gastrostomy (also known as g-tube) Placement:**

Talk to children about why the g-tube is needed, what the tube placement procedure will entail, and helping them anticipate the changes that come with having a g-tube and help to alleviate children’s worries about a parent’s eating/ swallowing difficulties.

### **Age Specific Guidance**

For younger children, you might explain that “this is a way for daddy to get the food he needs, because he has been having trouble eating (e.g., “it has been taking longer to eat and it is harder to chew”). His doctor will put a special tube in his belly so he can get the food straight to his belly. This will help his body have the energy he needs.” Some young children may need to draw this or point to parts on a doll, to understand it better.

Additionally, young children may also need the clarification that g-tube is not intended for common use. For example, you might clarify that most people don’t need such a tube i.e., one would not need a g-tube if someone had a stomach upset or just because someone did not get hungry on a given day. But some people need special food or formula (show the bag if one is used). They decide to use this with their doctor.

Older children are more likely to understand that their parent’s difficulties in eating that they have already been seeing, has necessitated a g-tube placement. Parents can note “when it gets harder for people with ALS to chew and swallow, they can get a g-tube placed in the stomach to provide the nutrition and hydration they need. This way daddy gets the calories and fluids he needs, in his stomach, without having to eat/ swallow in his mouth.”, or also add “This is discrete and will allow daddy to continue to participate in our favorite activities as you can use the tube for nutrition/ hydration, put it away and carry on with the day.”

### **Other key points to consider discussing or clarifying:**

- Explain that the parent with ALS will be in the hospital to have the tube placed by doctors. Most children will not know that this is a typical procedure and may worry about the hospital stay. “The g-tube is put in the belly by a doctor. Daddy will go to the hospital to get the tube”. Sometimes patients may stay overnight in the hospital but often it maybe a day procedure. Based on guidance from the medical team, you might explain how long a parent is expected to be there, leaving some room for change and flexibility.

If you expect to have home care nurses, you can foreshadow that a team of helpers or nurses will come to the home for the next few days to help us learn how to use the tube for feeding (or for older children “to help us with eternal feeding use).”

- Child(ren) might wonder whether their parent will feel pain during the procedure. Consider sharing that before putting the tube in someone’s body doctors give medicine (or anesthesia) so the person does not feel pain when the tube is placed in the stomach or belly. They will experience some discomfort for approximately two weeks following the procedure; until they get used to/ comfortable with the tube being there.
- You can also clarify that even after a g-tube is placed, a parent might continue eating for taste and nutrition but having a g-tube also helps support how difficult it is to get enough to safely eat and drink by mouth, and may reduce risk for choking, and/or reduce fatigue related to eating.
- Family members, especially older children, may need to learn how to care for the tube and the skin around it, to keep it hygienic and clean. Help children foreshadow the fact that they may also need to learn how feeds are given through the tube, or any other instructions related to daily activities (e.g., bathing) or what to do if the tube falls out or if any other problems occur (e.g., infection). Alongside, it is key to acknowledge that this can feel like a lot of new information at the beginning, and everyone needs time to figure this out (“we will do this together, and with practice, it will get easier”). Remind children that they should say something or ask if anything feels uncomfortable or is unclear.

Children may be involved in helping their parent with ALS in various ways depending on the child’s age and a parent or family’s needs and preferences. For instance, children may help with some smaller needs (e.g., wiping excess drool), or helping to prepare soft foods, to more complex tasks for older children such as older teens or young adults assisting with aspects of g-tube feeds or g-tube maintenance. Often family members, including children, also help a parent with speech difficulties to communicate with others, typically before they may have started using an augmentative or assistive device, or because they know their parent’s preferences or likely response. Children assuming responsibilities as helpers or roles as part-time caretakers represents a shift in the parent-child relationship that can be emotionally complex (Sommers-Spijkerman et al., 2022). Parents may wonder or worry about the impact of these additional responsibilities on their children or feel sad or guilty. Children are likely to recognize the differences in their experiences relative to their peers. However, parents and children may also experience a sense of self-efficacy and closeness that comes from caring for a loved one. As a parent, understanding your own feelings about these shifting roles is helpful. Parents may be reluctant to request help from their children or it might be easier to ask for help for some tasks but not others. Children may feel similarly. Ask children how they feel about helping their parent, whether they think they are doing too much or if it feels okay or if there are some tasks that they are more comfortable assisting with than others. Not wanting to worry their parent with ALS, children may not always feel comfortable sharing their experiences and feelings. They may prefer to speak to a co-parent, or parents can also identify trusted extended family members or grownups with whom children can talk further.

## Resources

Augmentative and alternative communication devices:

<https://www.als.org/navigating-als/living-with-als/therapies-care/augmentative-alternative-communication>

Family Dinner Project: <https://thefamilydinnerproject.org/resources/faq/>

ALS Association's Youth Education and Support: <https://www.als.org/navigating-als/resources/Youth-Education>

Boston Children's Hospital, Jay S. Fishman ALS Augmentative Communication Program: <https://www.childrenshospital.org/programs/als-augmentative-communication-program>

## References

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