

COMMUNICATION ABOUT PSEUDO-BULBAR AFFECT AND FRONTOTEMPORAL DEMENTIA

*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>

**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.*

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Communication about Pseudo-Bulbar Affect and Frontotemporal Dementia

Communicating about pseudo bulbar affect (PBA).

PBA is a condition involving bouts of sudden, involuntary laughing or crying, that occurs in some people with ALS. These experiences are uncontrollable, may not match what a person is really feeling (e.g., crying when they are not sad) or the intensity may be out of proportion to the situation. This can be confusing, worrisome, or even embarrassing for children.

To explain what is happening, you might build on your initial description of ALS as an illness that affects nerve functioning and communication between the brain and different body parts. Describe how the brain also sends signals to parts of our face and mouth that help us smile, laugh, or cry, and help us show our feelings.

- Just like ALS keeps the brain from talking properly with other parts of the body like hands or legs, ALS also affects brain signals that help us show our feelings. So even when a person may not mean to laugh or cry, it might happen. Or they may laugh or cry too much for the situation.”

You could use an analogy.

- Sometimes our feelings are big and sometimes they are smaller. For example, when something is funny for us, we might smile. But if it is very funny, we might laugh or even laugh loudly. ALS makes it hard for the brain to control how someone shows their feelings. It's like changing the volume on the TV or radio. We can make the TV or radio louder or quieter depending on what we need. But with ALS it can be hard to control the volume of feelings.”

Children may have a range of feelings about a parent's pseudobulbar affect - confused, worried, sad, embarrassed. Also, children may not feel comfortable talking about it or may not want to embarrass or upset their parent. Have a co-parent or trusted adult talk with your children to explore and validate their emotional reactions to these experiences.

Communicating about Frontotemporal Dementia (FTD) in ALS.

People with FTD symptoms may show a range of cognitive and behavioral difficulties. See “Basics of ALS for Mental Health Clinicians” here (<https://www.massgeneral.org/als-pact>) for descriptive and epidemiologic information about FTD. Children of all ages are likely to need help understanding FTD symptoms in a parent, as well as emotional support.

FTD can cause obvious behavioral or emotional changes. These may include apathy (a lack of interest or enthusiasm), and in some cases, inappropriate behaviors such as aggression or hypersexuality. It can be difficult to shield children from witnessing a parent's personality changes. Children may have a range of feelings including loss, confusion, sadness, embarrassment, and worry.

Talking to children about FTD may include several elements.

- First, explain that ALS is causing the parent's behaviors, and that parent is not actively choosing to behave in that way.

“Dad did not behave this way before his illness and if he could really choose, would not be doing these things now.”

- Second, link how ALS affects the brain, as described in earlier sections above, and then link the illness and behaviors.

“Remember we talked about how ALS changes the way different parts of the brain talk to each other, and how the brain talks to different body parts? ALS is changing the way his brain works, how he shows his feelings and the way he behaves. Dad cannot control these behaviors.”

You might also add, “Sometimes it also seems like he is not listening to us or doesn’t care about us the same way he did before.”

- Next, explore the emotional impact of these experiences. Ask your children how they are feeling. Let them know that it is okay to have different feelings (e.g., confusion, worry, sadness, embarrassment).

“Dad does not feel like the same person.”, or “I miss the way we used to be and how we all spent time together.”, or “It is sad to see how ALS has changed him.”, or “Dad’s behaviors are confusing for me too”, or “Are there other things about how Dad is behaving that you worry about or want to talk about?”.

Less commonly, FTD symptoms may include speech related changes due to the way that ALS affects nerve cells in regions of the brain that control language. People with FTD might have difficulty finding the words that they want to use or in understanding what is said to them. This is different than the slurred speech due to weakness of the tongue and vocal cords caused by ALS. See section on Speech, swallow, salivation, and eating for more detailed guidance on speech related difficulties. This handout can be accessed here <https://www.massgeneral.org/als-pact>.

Unfortunately, people with FTD may experience a relatively rapid progression in symptoms. It is important to help children prepared for continuing changes by not delaying conversations about ALS.

Resources:

The Association for Fronto-Temporal Degeneration website resources for children:
<https://www.theaftd.org/living-with-ftd/kids-and-teens/>