

BEREAVEMENT

*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.*

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 suggestions for helping a child cope with the recent death of a loved one, including:

- Psycho-education about grief, and words to use to talk to children about grief
- 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

Why Talk About Grief?

No matter how many losses we experience, grief can feel different and unfamiliar every time. Children may have heard the word “grief” but still not have a clear understanding of what the word even means, let alone how to cope with it. Sharing information about grief with children can help them understand that their reactions are normal- an expectable part of being human and connected to other people.

Providing *psycho-education*, or information, about grief to children is a little like giving them a guidebook about a country they’ve just been dropped into- not quite as detailed as a map, but useful information about the terrain. Use words that match your own child’s ability to understand- then check in with them about whether what you’re talking about makes sense.

Finding the Words to Talk About Grief

You know your children best- how they have reacted to other losses or difficult times and how they may react now to this loss. This knowledge of your children will help you figure out how to talk about grief.

Some parents like to see examples of words to use or change to better fit their family's needs, so we provide ideas here:

After losing someone we love, people usually have very, very strong feelings (emotions), stronger than how we usually feel and maybe even the strongest feelings we ever remember having.

Most people feel sad and many also feel anxious or afraid, angry, shocked, like they can’t believe this happened, lonely and like no one else can understand what they are feeling. Sometimes people feel relief and even gratitude, especially if the person had been suffering for a while. Other feelings can come up too. And sometimes, people just feel numb-like they aren’t feeling much at all, or like they don’t know how they are feeling.

- *What feelings have you been having?*

Each of us feels grief in different ways.

Some people notice feelings most in their bodies- a tight chest, a pit in the stomach, balled-up fists. Some people notice feelings in the way they think about things- “I don’t care about anything anymore,” “I can’t stop worrying about what our family will do now,” or “I can’t believe this happened.” And for many, grief can leave us feeling truly broken-hearted, like our hearts hurt.

- *Where do you notice your feelings?*
- *What feelings do you notice in your body? Your mind? Your heart?*

Some people feel mostly one way, like just sad or angry, while others notice a mix of feelings. Sometimes the mix can be confusing because the feelings don’t fit together very easily, like when you feel sad one minute but a little relieved the next, or feel angry and guilty at the same time.

- *Have you had mostly one feeling or lots of different ones?*
- *What are some of the feelings you’ve been able to notice happening at the same time?*

Grief can feel like a big jumble of feelings, like a big knot with lots of different colors all twisted up together. Sometimes noticing and naming the feelings is a way to untangle that knot, to turn it into something more like a basket with each yarn color in its own ball. Some feelings are hard to ignore, but others stay a little more hidden or in the background- those ones are important to notice and name too.

- *What is one feeling in the knot of feelings?*
- *Are there others that might be part of that knot?*
- *Which ones take longer to notice?*

A lot of people notice that grief seems to come in waves. At first, the waves are huge and can feel really hard to get through. The waves usually get further apart over time and smaller over time, but certain reminders at particular times of the year can stir up stronger feelings for a while. It will help if we all try to let other people know when we have a wave of grief and to learn together about what makes us each feel better when those waves get bigger. We can figure out how to plan for those times.

Strong feelings might make you really uncomfortable. You might want to try to ignore them or push them away. Believe it or not, it helps to slow down and pay attention to these feelings, to let the wave pass by or through you, rather than fighting it.

- *Which feelings do you sometimes try to push away?*

As waves of grief come, try to help your child tolerate and accept their emotions, rather than too quickly trying to push them away. You might talk about how it usually works better to try to allow the wave of grief to come and go... like being in the ocean and letting really big waves carry you in the water, rather than fighting the wave the way you might try to do when you're standing on the shore and trying to balance as it comes crashing in. Children can be reminded that even the strongest feelings eventually pass.

The way we feel when we're grieving changes- sometimes very quickly, sometimes more slowly. Sometimes we move from one feeling to another, then another. Sometimes we have the same feeling for a while, and what changes is how strong the feeling is.

- *Have you noticed your own feelings changing today? This week?*

Grief can be confusing because different people who are all dealing with the same loss, probably have different feelings at different times. It can seem a little easier when everyone feels the same thing together. When they don't, it can be hard to know what to expect from the people around you, and hard to know how to act around those people.

It's ok for us all to have our own reactions at different times. There's no one right way to feel. Even people who all love someone who died very, very much might feel, and show their feelings, in different ways. That's ok. Everyone lost the same person, but that person meant different things to all of us.

- *What have you noticed other family members feeling, and how can you tell?*
- *Are there some reactions that are hard for you to understand?*
- *Are there some reactions that are hard for you to see and hear?*

Talking with someone who loves you about your feelings can help you to feel better.

Why? Because:

- Talking helps you to recognize what you're feeling and why.
- Talking about feelings can make even very strong feelings easier to bear- like having someone to encourage you when you're carrying a heavy load- the weight isn't less but it feels different.
- Talking can make the feelings less strong- like having someone help you carry something heavy.
- Talking can untangle a big knot of feelings and when feelings are sorted out, they are a little easier to manage.
- Talking with someone you trust helps you think more clearly about the situation- when we are upset, some of our thoughts can make those feelings even worse.
- Talking to someone else might help you see that there are different ways to understand some parts of what is happening, or give you information that helps you feel better.

Talking about emotions with other people can be hard for children *and* adults, even when they want to share their feelings. Keep trying- this is a skill like learning to read or draw or play a sport that gets better with practice. Think about trying these things:

- Figure out who can be most patient with your learning how to do this better and try to talk with them: Is it a parent, grandparent, other family member, teacher, coach, mentor, religious leader, friend, or friend's parent?
- Let those people know what helps you to talk about emotions: Is it easier to answer their questions? To write things down in back-and-forth notes? To rate how strongly you feel different emotions on a 1-10 scale? To draw how you're feeling and then talk about the drawing?

Age-Specific Strategies

Children younger than about age 7 are still learning about the whole concept of "death." It takes a combination of experience and brain growth for children to develop a mature understanding of death. This means that younger children may not fully understand that death is universal (it happens to all living things and cannot be avoided) and also irreversible (something that has died cannot become physically alive again). They may not understand that the body of someone who has died no longer functions at all (the person or animal does not breathe, see, hear, feel, etc).

.

As children begin to understand that our bodies are made of specific systems and parts (like, the circulatory system that includes the heart, arteries, veins, and blood), they can also begin to grasp some causes of death (the heart not beating any more, breathing no longer being possible).

Once children are able to understand the physical meaning of a death, they may become more curious about the idea of how or whether a person's spirit continues on although their body does not.

Here are a few ideas for supporting children of different ages/developmental stages.

Infants and toddlers (0–2 years)

These children will be aware of a parent's absence, but not understand the reason for it. They will be sensitive to disruptions in their routine and to caregivers' distress.

- Try to provide consistent caregivers, routines, and settings

Preschoolers (3–5 years)

Preschoolers will also be very aware of the absence of a loved person but it may take some time for them to understand what it means that the person has died. They may understand death as a long separation with the deceased physically alive somewhere else, and may not understand that death is irreversible. They may offer "solutions" to death (like trying a new medicine). Because they are still learning about death as a concept, euphemisms (i.e., indirect or vague ways of talking about difficult topics) like "Mummy is in Heaven now" are likely to be confusing.

- Provide concrete descriptions of death (his body does not work anymore: he can't see, hear, or feel anything; his heart stopped pumping and he stopped breathing)
- Be patient in repeating that the deceased will not come back
- Explanations for illness and death may be self-centered or self-blaming ("I got mad at Daddy, and made Daddy sick"). Therefore, try to explore your child's understanding of what happened and reassure the child that nothing they did caused the illness or death.
- Egocentric questions are common ("When can you play with me again?") If adult caregivers are withdrawn, explain that the person is sad or worried, and why, and that the child did not cause the adult's distress.
- Maintain consistent caregivers, preschool attendance, play dates, meal times, and bedtime rituals, as much as possible.

School-age children (6–12 years)

This age group will likely understand that death is final and irreversible, but may be less clear that it is also universal and unavoidable. As this understanding develops, they may start to worry more about the health of other adults. Their ability to apply simple cause and effect logic to understanding why things happen in the world might promote curiosity about causes of illness and death, but there will likely be significant gaps in their understanding (for example, may believe that a fall caused a parent's leg weakness rather than the other way around). And while they are starting to better understand the physical aspects of death, they may struggle to know how to talk about the spiritual aspects.

- Be clear that someone has died and provide clear, accurate information about the cause of death if you can (“ALS was making it more and more difficult for Grandma to breathe. We need to breathe to stay alive.”)
- Children may experience guilt about things they did or did not do with or for the deceased. Help put guilt and other concerns in perspective by thinking together about the entire relationship rather than only the recent past.
- As much as possible, maintain predictable routines and expectations. Many children prefer to maintain school as an “island of normality” and don’t want to talk about their loss at school. Others appreciate check-ins from school staff, and having a plan for taking a break if they become upset during the day.
- Somatic complaints (headaches, stomachaches) are common; ask for updates from the school about visits to the nurse.

Adolescents and young adults (13+)

Teens understand that death is final, irreversible, and universal. They are increasingly able to use abstract reasoning (e.g., to think about hypothetical situations) and this may lead them to have more adult-like worries (e.g., about family finances, the well-being of siblings) as well as questions about justice, and the meaning of life and suffering. However, their age-typical egocentrism and emotional immaturity may still cause them to focus on the personal effects of illness or loss in ways that can feel selfish to adults.

Adolescents may also feel more anxious about their own mortality, and sensitive about how a loss sets them apart from their peers. A conflictual relationship with either parent can contribute to resentment, guilt, or regrets that can complicate mourning.

- Provide clear, accurate information about the causes of death
- Respect an adolescent’s wish for privacy and control over dissemination of information about loss, as much as seems reasonable. Adolescents may use social media in different ways to process a loss. It may be helpful to talk together about what is private for the family and what can be posted. It is important to be sensitive to timing of posts to avoid having close family members and friends learn of a death that would be better shared with personal outreach.
- Do not expect adolescents to assume adult responsibilities without time and teaching, and a balance of age-typical activities and time with peers.
- Watch for evidence of risk-taking behavior or substance abuse in response to a loss and be prepared to seek professional support.

Resources:

Finding professional support: 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 they would share with the parent about the child’s treatment. See the handout, “Seeking professional mental health support” in this series for more information, available at www.massgeneral.org/als-pact.

Support groups:

Grief support groups are sometimes offered through hospices and local non-profits. You might not need to have been cared for by that hospice to qualify to join the group.

Websites:

- The Dougy Center for Grieving Children <http://www.dougy.org/>
- National Alliance for Grieving Children <https://childrengrieve.org/> (Has a workbook on grief for children)