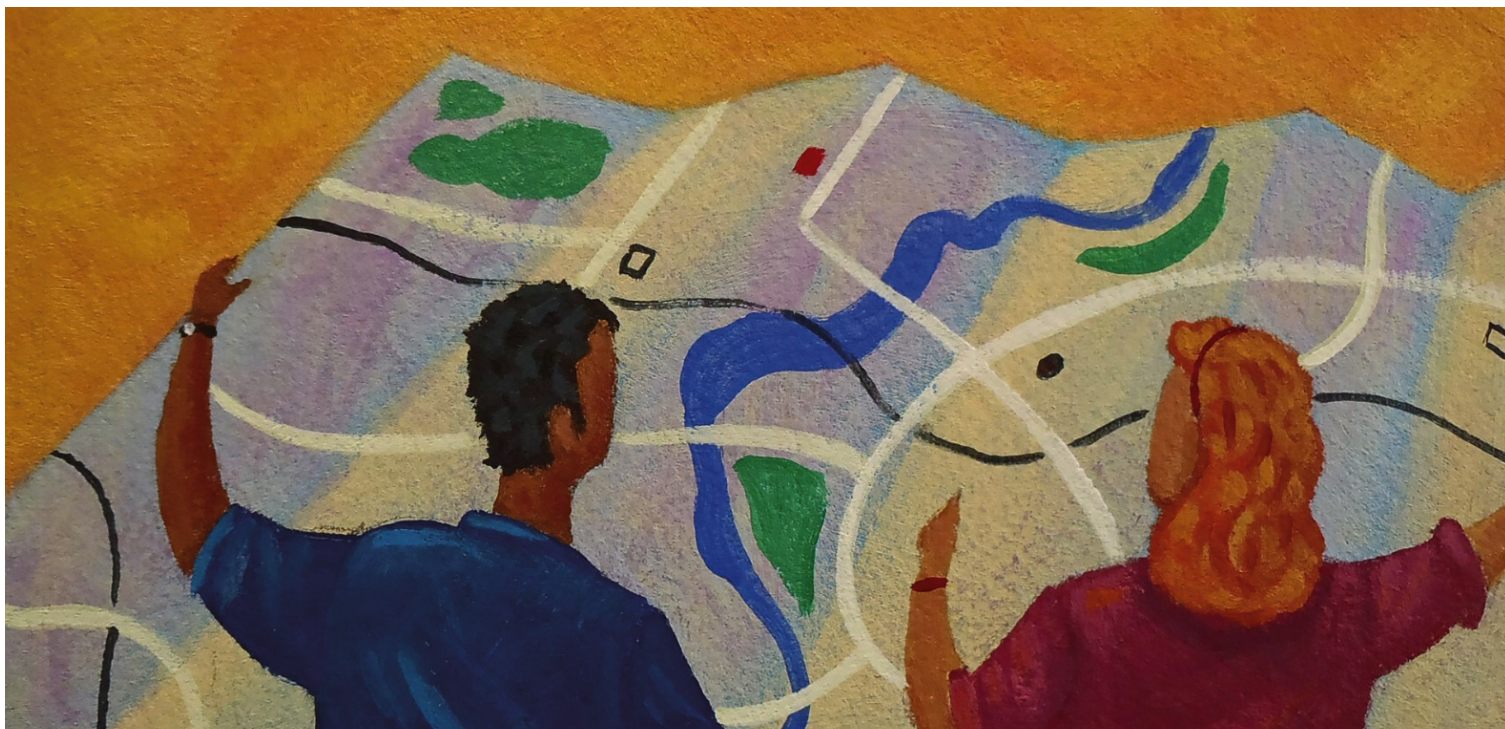


SUPPORTING CHILDREN THROUGH THE END OF SOMEONE'S LIFE

*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
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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 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 and 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, grieve, and sometimes, to talk or spend time with a parent in uniquely meaningful ways. This handout and another address complementary issues facing parents trying to prepare children for a loss.

“Supporting children through the end of someone’s life” might help you decide *when* to talk with children about a potential loss, and also:

- describes physical changes that may signal that someone is nearing end of life
- describes services or interventions (eg, 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

“Talking to children about an imminent loss” focuses more specifically on communication and discusses:

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

Introduction

No matter how someone's body is functioning, it is impossible to know for sure how long that person will live. Even with a progressive, life-limiting illness like ALS, a death can happen suddenly and feel surprising, or someone with very limited functioning can survive longer than expected. This uncertainty can leave parents wondering *when* to prepare children for a loss that could come soon.

Despite the difficulties in predicting someone's lifespan, there are some common experiences that signal that time could be short. These are often helpful starting points for talking with children and preparing them for an expected loss. Your ALS multi-disciplinary care team is the best source of guidance around these kinds of milestones in your care. Letting them know that you are thinking about how to talk with your children will help them understand what kind of information you might need.

Physical changes and changes in daily functioning

Breathing changes

ALS causes breathing difficulties that become gradually worse over time. There are different ways to manage this, and the two handouts about "Breathing difficulties," (available at www.massgeneral.org/als-pact) offer an overview. A person's becoming more and more dependent on a non-invasive ventilator (like a BiPAP machine), struggling to breathe even with this support, or needing to use a ventilator, are all milestones that should be addressed with children.

Stopping food and drink

Some people with ALS choose not to use a feeding tube (sometimes called a "G tube") even though their nutritional needs are not being fully met by eating (see handout entitled, "Bulbar changes: Speech, swallow, salivation and eating" for more information about feeding tubes at www.massgeneral.org/als-pact).

Other people decide at some point to stop using a feeding tube, often when other ALS symptoms become more and more challenging. If able, they may still want to eat or drink for pleasure or comfort. Children will notice this and might have questions, especially if they have been helping with tube feeds. Whether they ask questions or not, this is an important opportunity to talk about the likelihood that the person's remaining time is probably limited.

Interventions

Hospitalizations

ALS can cause other medical complications (for example, pneumonia) that may need to be treated in a hospital. Sometimes symptoms are so serious that a person requires care in the Intensive Care Unit (ICU). Inpatient care and ICU teams are used to talking about prognosis and can help parents anticipate what to expect. Hospitalizations, and particularly ICU stays, create opportunities to talk with children about disease progression and prognosis.

Hospice Care

At some point in the course of ALS, hospice care may be offered. This care can occur at home, in a location specifically designed for caring for people who are nearing end of life (a hospice house), or sometimes in the hospital.

Home Hospice: A person with ALS may receive a hospital bed at home. Because of its size, the bed may need to be placed in a common area of the home. This has upsides and downsides- it allows the person with ALS to continue to feel a part of things, but can also make home feel less comfortable and familiar to children, and more difficult for them to take breaks from witnessing changes that might be upsetting.

- When a hospital bed is in the middle of a home, or when your home is filled with visitors, it can feel hard to escape constant reminders of what is happening. If possible, make sure that children have a place they can retreat to if they need some privacy or downtime.

Staff from the hospice agency will visit to provide some hands-on care and ongoing guidance. But they are not present around the clock. A lot of hands-on care will be needed to support someone staying home through end of life. This is physically and emotionally exhausting. Balancing children's needs at the same time as the needs of the parent with ALS may require having more adults available to help.

- Look for at least one adult to check in regularly with your child when you cannot. Your child may not say much through this time but is noticing, absorbing and feeling a great deal. It may be impossible for a parent who is caring for the person with ALS at this stage to talk with children very often about any of this. Ask an adult you trust, who knows your child, to check in- this could be an extended family member, teacher, coach, or the parent of your child's friend.

When your home is filled with visitors, it can be hard to escape constant reminders of what is happening... make sure that children have a place where they can retreat, for privacy or downtime.

Inpatient hospice: Visiting an inpatient hospice setting may be easier for some people than a hospital. They are often quieter and smaller, with rooms and common spaces designed to feel more like home. There may be a kitchen area with snacks and drinks. It may be easier and more comfortable for family members to stay overnight. Family can be as involved as they want in making the person with ALS comfortable, but the staff manages medications and care that is more physically demanding. Some people describe feeling they are free to be a spouse or partner at this time, rather than a care provider.

Children may appreciate having home feel more normal and at the same time, having the opportunity to spend as much time as they'd like with their parent. However, sometimes traveling back and forth between home and the hospice setting is difficult and can limit opportunities for visits.

Medications

If breathing becomes so difficult that a non-invasive ventilator (like a BiPAP machine) cannot prevent discomfort from shortness of breath, medications may be offered to help the person with ALS feel more comfortable. These include morphine and Ativan. If the person with ALS is cared for in a hospice home or at the hospital, the staff will administer these medications. If the person is cared for at home, often a family member will administer these medications, based on recommendations from a nurse or doctor.

People can have mixed feelings about this experience- on one hand, it can feel good to be able to do something to make a loved one more comfortable. But on the other, giving pain medication to someone nearing end of life can leave the caregiver with a concern that they somehow caused or hastened the death, even though this is not the case. Because of the complicated feelings people can have, children should not be involved in this kind of caregiving.

The experience of children and families when a parent nears end of life

For most children and adults, spending time with someone who is believed to be very near the end of their life is a completely new experience. The time together may be profound and meaningful. It can feel like a privilege to accompany someone through the end of their life. Families may spend time together talking about shared memories, singing, praying, or looking at pictures. All of this helps people through a very difficult time.

Different children in one family may need a different blend of time with the parent and family, and time spent doing their usual activities (school, time with friends, enjoyable activities). Some children may need reassurance that taking time for “normal life” is valuable and necessary.

Others are uncertain about spending time with a dying parent for a variety of reasons. Some children feel uncomfortable witnessing strong emotions in adults around them, or uncomfortable with the strong feelings they are experiencing. Some worry they will show emotion in ways that will feel embarrassing- like crying in front of other people. Some feel upset at seeing physical changes in a parent, particularly signs of discomfort- it is very difficult for most people to witness any signs of suffering in someone they love.

If adults take the time to try to understand and respond with care to a child’s concerns, the child may feel comfortable with spending time with the parent. But, it is important to avoid insisting on a visit if a child is not comfortable or saying things to make a child feel guilty. Adults can instead help children in different ways to feel connected to their parent, such as sending a short video or message, having another adult pass along a hug or words of love, helping the child send a token of their love, or giving the child something of the parent’s to keep with them.

Strategies for parents to support children

Providing very clear descriptions of what children may see, hear, and experience, reminding children that they may leave the parent's room at any time (with a designated adult, if the parent is not at home), and normalizing a variety of emotional responses can all help prepare children for spending time with a parent nearing end of life.

Here are some ideas for helping your children through parts of the process that may be confusing, frightening, or distressing:

When a person is at end of life, their breathing may sound different. There may be gurgling sounds, even when caregivers continue to suction secretions. The pattern of breathing can also change.

- *Explain that this sound is common as people are dying and that the person is not uncomfortable. Let children know that it is ok for them to leave the room if it's upsetting them*

Children who are old enough to understand that our bodies need nutrition to survive may react with confusion or worry if tube feeds are discontinued.

- *It might help to explain that this is not a choice to "give up" but rather the parent's recognition that their body is shutting down in many ways, that food is not enough to help them survive a lot longer because the other systems in the body are not working well, (or that food is no longer helping their body, and that tube feeds are creating discomfort) and that the parent is choosing to focus instead on comfort and time with family that is as close to normal as possible.*

- *You might let children know that you are talking with the medical team about how to provide the best possible care, and to make whatever time is remaining as comfortable as it can be.*

A person nearing end of life may become confused or agitated, and these changes can be stressful for children. They may be worried about how the parent is feeling (are they suffering? uncomfortable?) It can be confusing and sad if the parent doesn't recognize family members.

- *Consider not having younger children (or sensitive older children) in the room if a parent is agitated; wait until the parent is more sleepy or calm for visits. Let children know that as someone's body shuts down, their brains also work differently and so they may not think, talk, or remember things the way they used to.*

Children will observe strong emotions in the adults around them, and will also feel their own strong emotions. These might include sadness, fear, anger, and loneliness along with love, pride, compassion, and concern for caregivers. Some children may feel worried that they will cry in front of other people and then feel embarrassed.

- *Tell children that it is normal to feel lots of different feelings at the same time and that they will keep changing. Let them know you and others are there for them and want to know what they are feeling. Allow your child to have some time with the parent with just another close adult in the room, or no one else if the child seems old enough and wants that.*

- *With children who seem to be holding in all their feelings, talk about where they can go to feel safe to express feelings: “Where would you feel most comfortable being, if you ever did want to cry?”*

You may have more people, and new people, coming to your home during this time period. Some children love the attention they may receive from having extra adults around. Others may feel uncomfortable, feel they can't express emotions in the ways they might like, feel that too many people are telling them what to do, or feel that these visitors are taking away time and attention from them. The longer this period goes on, the more challenging it can feel.

- *If you can, encourage children to talk about what this period is like for them—are there any good parts? Any parts they really don't like? Is there anything you could consider changing that might make any of this easier for them? Normalize mixed feelings and problem-solve around specific concerns. They may feel small to adults given the bigger picture, but feel big to children.*
- *Ask your children if they feel they are getting enough time with the parent nearing end of life—by themselves, or in a smaller family group.*

As people near the end of life, they sometimes become more withdrawn and less interested in the lives of the people they love. They may emotionally disengage, in a gradual way. This can leave children wondering if the parent doesn't love them as much anymore, and why.

- *If you notice that this is happening, you might describe how there are a lot of changes happening in the parent's body and mind that we can't see but that pull very hard on the person's attention. They are facing a huge transition and this might be part of getting ready. It's hard for them to show love right now but you are positive that their love has not, and will never, disappear.*

Other Ways to Support Children

- Offer choices when you can to help your child feel some sense of control even when life feels very uncontrollable. Choices that matter to children might include whether to go to school or not on a certain day, how and when the child wants to be notified if something changes while they are at school, and whether the child would like to have some time alone with the parent with ALS to share any thoughts.
- Notify your child's school about what is happening or help your child to do so. Ask the guidance counselor to notify other teachers and to reassure your child that they will find a way together to figure out how to make up missed work. With your child, decide whether sharing an update with classmates at some point would be helpful, and then with people at school, decide who would be the best person to do so.

Finally, you might be hearing that taking care of yourself is critical for getting through this time. And you might be thinking that there is really no time at all for “self-care.” There is likely some truth in that. Still, eating some nutritious food, drinking water, sleeping as you can, and saying yes to offers of help that might make a difference are the most basic forms of self-care. Sustaining yourself in these ways is necessary for you to continue to support and sustain your children.

Resource:

<https://www.nia.nih.gov/health/providing-comfort-end-life>