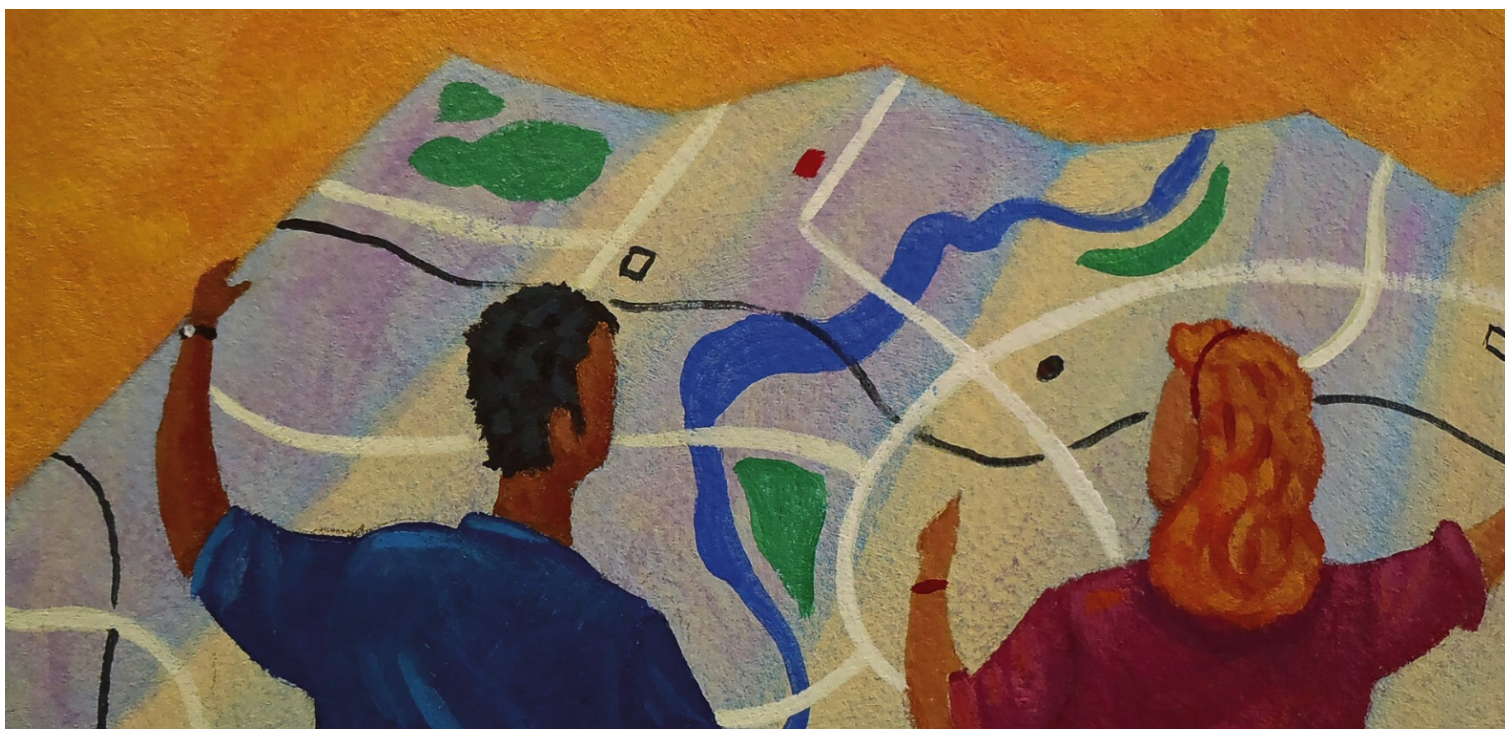


# TALKING TO CHILDREN ABOUT AN IMMINENT LOSS

*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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# Talking to Children About an Imminent Loss

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. This handout, and another one titled “Supporting children through the end of someone’s life,” address complementary issues facing parents trying to prepare children for a loss.

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

- why and how you might start conversations with children about a loss that you expect could occur quite soon.

**“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

## Introduction

As your family copes with ALS, each person will find their own blend of hoping for the best, while preparing for the worst. That blend will change over time for each family member. At some point you may wonder whether there are ways to help your children prepare for “the worst” - for a parent’s death. At the same time, you may not want to give anyone the impression that you have given up hope, or take away their hope.

From our experience working with patients near end of life and from the limited literature available on the subject (Dalton, et al., 2019), we believe that talking in advance about an imminent death is most helpful for children.

These are some of the most difficult conversations an adult could have with a child. It takes a great deal of courage to be honest with children about a loss that we know will hurt them deeply. There is no way to talk about this that will prevent painful feelings. Some children might not even be aware that a parent may not live much longer. So why consider talking about anticipated loss?

### Why is it helpful to talk about such a difficult topic?

Children often have worries that they do not share with parents. It is common for children to worry that a parent could die, but not bring it up. Talking honestly with children often leads them to share their unvoiced worries, so that they are **not worrying alone**. Talking honestly with children about your belief that someone they love could die soon has a number of benefits:

- Children may feel better prepared for what is coming and reassured that they will have support.
  - Practical preparations, like planning how your children would be notified if they weren’t at home when a death occurred, can take away uncertainty and give children a little more sense of control.
  - Being “emotionally prepared” might not make a loss less painful when it happens, but can make it feel less shocking or unpredictable. Children can also adjust more gradually to what will be a huge change, with parents’ support. Delaying a conversation until it is truly unavoidable might postpone a distress, but the delay could also add to the child’s anxiety or distress after the death.
- Adults can reassure children that even with big changes, some things will stay the same:
  - The child will be loved and cared for no matter what.
  - Many relationships, routines, activities, and plans will continue, as the child is ready to return to them.
- Adults can remind children about other difficult things they have faced together and what has worked to get through.
- Children can better understand what they are observing, and how their own explanations for what they have noticed might be off the mark. It is easier to cope with something when you know what you are facing and are not confused.

- Children can participate in decisions about how best to utilize the time that is left with a parent
- Talking about difficult topics builds children’s trust that they can come to you with questions and concerns, and feel heard and supported
- Children feel included rather than excluded from what is going on

### How can I prepare for a conversation?

When talking with your children about a parent’s limited remaining time:

- If possible, calm yourself before talking to your child; take some slow, deep breaths. Children take their cues from adults’ emotional reactions. You don’t have to make yourself look “normal” to your child, or even be able to talk without any crying, but calming yourself down enough that you are able to pay attention to your children’s reactions will be helpful to them.
- Take some time to think about what you will say. Some parents even write notes for themselves.
- If your conversation should happen soon, but does not need to happen immediately, consider whether a certain time of day might be better than another. It will likely never feel like a good time to share bad news, but perhaps there are times when there are fewer distractions when you can spend as much time with your children as they might need, and when they are not hungry or tired.

### What can I say? Finding the words

Just as every family is different, the “right” words for your situation may not be the same as what would work best in another family. Suggestions here are offered to help get you started thinking about these conversations and are not meant to imply that there is one correct way to talk with children.

Unless you’re responding to a child’s direct question about whether you or your partner might die, it can be difficult to know how to start this kind of conversation. One way is to ask your children if they’ve noticed any changes in you or your partner, and why they think these are happening or what they mean. If they’ve already mentioned or questioned a change, follow up and find out if they’ve noticed other things too.

- “What else have you been noticing/have you seen and heard?”
- “What else have you learned about this?”
- “What are you wondering or worrying about?”
- “What do you think this means?”
- “What is scary or confusing about this?”

You might summarize their observations. Then, describe any other recent changes, and try to provide a simple explanation about what is causing the changes.

- “You’ve noticed that Dad is using his BiPAP during the day and not just at night. I’ve seen that he is also getting out of breath even when he hasn’t moved around very much. That’s because ALS is making it harder and harder for his chest muscles to move, which makes it harder to breathe in and out. The BiPAP was helping get oxygen to his lungs but is not enough at this point.”

Prepare them—describe what you think might happen soon (in the next day for young children, to several days to weeks, for older children). If death is likely, be honest about this, as painful as it is.

- “No one thinks I’ll die this week or this month, but I am very sick. I am trying to prepare. Mom or I will let you know if it seems like I could die soon.”
- “ALS is affecting Dad’s breathing so much that I am not sure he will live much longer. It’s possible/likely he could even die in the next few weeks/days/as soon as today or tomorrow. It’s important that we try to make the most of the time we have with him.”

Children have a wide range of reactions to these conversations, depending on their ages and personalities. Some cry, some ask a lot of questions, and some want time with adults to snuggle or just sit together.

Others do not say much or ask questions, ask to go back to playing or retreat to their own rooms, or may not even seem to fully take in the news. If your child seems unable to stay engaged in the conversation at this point, you might ask if there is anything they want to be sure to say or do with the parent.

You know your own child best- trust your instincts in deciding how best to comfort them right away and in coming days. Let children know that adults and children may express a range of emotions in different ways and that they might also feel a mix of emotions.

Let children know you will continue to check in with them frequently, and that you want them to come to you with feelings, questions, or worries. Choose follow-up times when children are more likely to share feelings (bedtime, car rides, and doing side-by-side activities are often good times for talking).

- “If you overhear more, or learn more about this on your own, or have questions, will you let me know?”
- “Please don’t ever worry alone.”

At some point, a conversation about what children might see and hear, from the parent nearing end of life and from anything else nearby (for example, visitors, or patients in nearby hospital rooms) could be helpful. See the handout, “Supporting children through the end of someone’s life” for more information on what to expect.

## References

Dalton L, Rapa E, Ziebland S, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *The Lancet*. 2019;393(10176):1164-1176. doi:[10.1016/S0140-6736\(18\)33202-1](https://doi.org/10.1016/S0140-6736(18)33202-1)