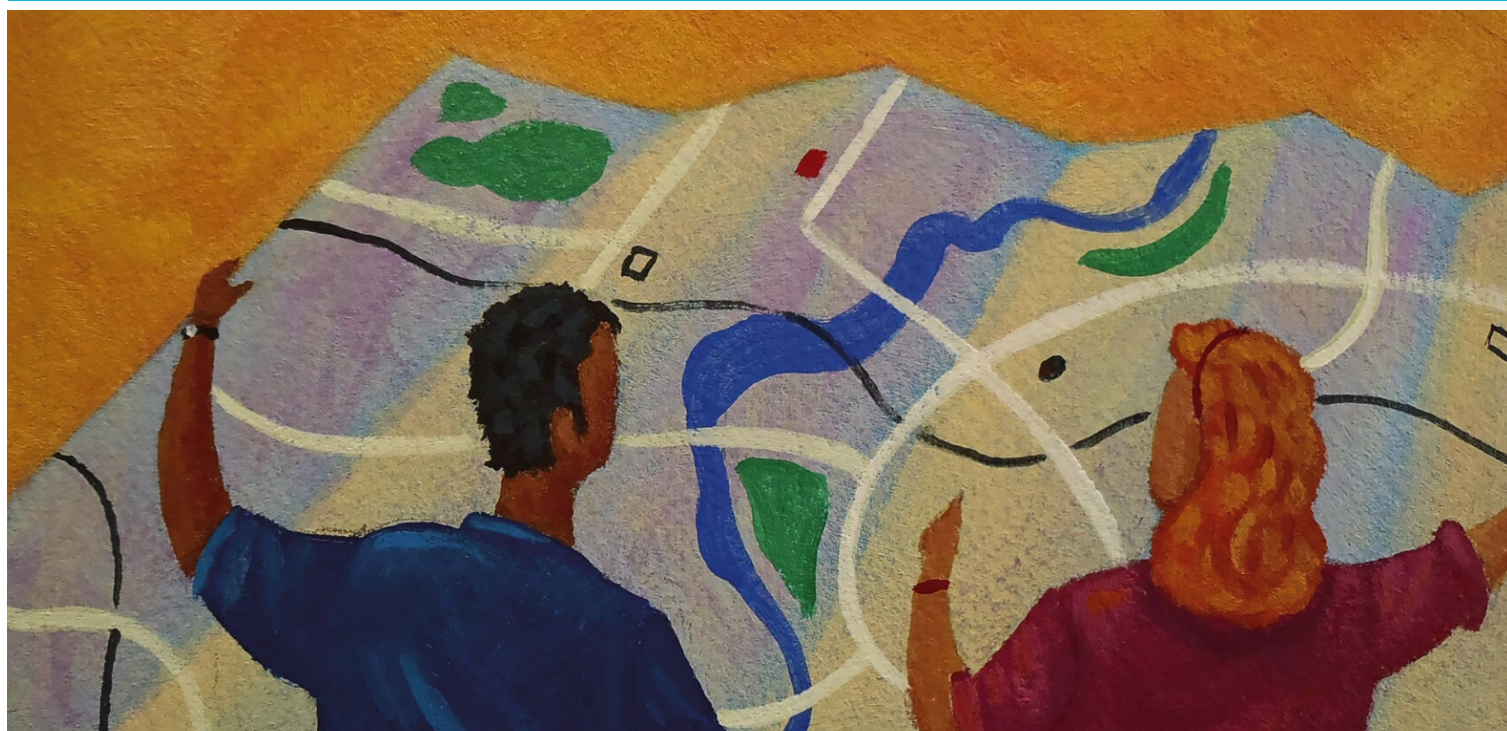


# COMMUNICATION WITH CHILDREN ABOUT A PARENT'S ALS DIAGNOSIS

*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://massgeneral.org/als-pact>

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# Communication with Children About a Parent's ALS Diagnosis

A common concern expressed by patients who are parents is uncertainty about how to talk about ALS with their children. Recently published guidelines (Dalton et al., 2019) affirm clinical experience- that being open and honest with children about a parent's medical illness supports, rather than worsens, children's adjustment to that illness. It is possible even for parents who can't imagine using the term "ALS" with children to find truthful ways to talk about changes in their functioning. Children benefit when family challenges are "talk-about-able" in age-appropriate ways.

## The Communication Handout Provides:

- a rationale for talking about ALS
- concrete ideas for preparing for a first conversation
- ideas for explaining ALS to children at different developmental stages
- suggestions about communicating with children's schools
- suggestions about communicating with the family's broader support network

There is no one "best" or "correct" approach to sharing information about your illness with your children or to supporting children's adjustment and coping. Drawing from ALS PACT consultations with parents and grandparents (hereafter referred to collectively as parents) and our collaborations with multidisciplinary providers in the MGH ALS clinic (<https://www.massgeneral.org/neurology/als>), this section offers guidance and strategies informed by developmental and clinical psychology and available research with patients with ALS. When there is limited research data from patients with ALS, we also reference research with people with other terminal or serious medical conditions.

## Introduction

### Parenting while coping with ALS poses challenges

The process of being diagnosed itself often involves multiple medical teams and specialists. You are likely to be adjusting to changes in functioning, daily life, or family experiences. You may be experiencing ongoing uncertainty, shock, and sadness. Managing all of this on top of continuing to care for your children can be enormously challenging.

### Should I tell my children about my diagnosis?

Most parents wonder how and when, or even if, they should share information about their illness with their children. The desire to protect children from distressing news is understandable. However, avoiding discussion about your illness also keeps children from understanding what they are likely already seeing or experiencing (e.g., changes in speech, movement, or changes to your family's schedule). Additionally, children of all ages can sense when a parent is worried or upset.

Talking to your children helps you to know what your child is noticing, any concerns or confusion they may have, and how they are adjusting to changes. It is important that your children know that you don't want them to worry alone and that they can come to you with questions or worries. Being included in discussions lets children learn about how you are doing, and that you are the best source of information for your health. In sum, communication is a two-way process and connection – parents can help children to understand changes to a parent's health or family routines, and by listening to their children, parents can learn about their children's adjustment.

## Preparing for Initial Conversations

### Plan for what is right for your family

There is no one right way to talk to children about a parent's illness. What is most important is that you find some way to make changes that children see “talk-about-able” and that you be truthful. Being honest will mean different things depending on your child's age and personality, family communication style, the pace of illness progression, and your own emotional adjustment to the diagnosis of ALS.

### Take time for yourself and co-parent

Caring for your own mental health and emotional well-being will help you support your children. Before talking to your children, take the time to reflect on your own adjustment to your or your co-parent's diagnosis. Consider how are you feeling, and what are ways in which you can support your own mental health now and in the long term.

### Plan together

Parents and co-parents may have different communication styles, comfort levels, or different ideas about how to talk to their children. Discuss how you want to share news of your diagnosis with your children. Think about when you want to talk to your children. For example, look at your family calendar together and choose a weekend when you have more time together as a family.

Talk about the specific language you want to use and how much detail you want to share in the beginning. There are examples of this below. Consider each of your children— their ages, temperaments, personalities, and their unique circumstances. Talking all together as a family with all children can often be beneficial, particularly when children are close in age. If you have children in very different developmental stages, you might start by talking separately with each child. Speaking to a 7-year-old will be different than a 17-year-old. Even when you have separate conversations with children, let each child know that you have also talked to their siblings. It helps children to know that everyone has the same important information.

### **Prepare for your own emotional response**

If you think you might feel too upset or overwhelmed to be able to talk about ALS with your child, consider asking a trusted friend or family member to join you. This person could even do the talking while you are present, if needed.

### **The worst way for a child to learn about difficult news is to overhear it**

Though painful, it is much better that your child learns sensitive information directly from you. This way you can plan for how much detail to share initially, and to anticipate the types of questions that your children might have. It is a very different experience for a child to hear such information accidentally- and this can so easily happen. Children can overhear conversations between parents or other adults while they are playing nearby, or quiet in bed, or may listen to one side of a phone conversation and figure out that something is wrong. Even when other adults who were informed have been sworn to secrecy, their children may also overhear information and share it with your child. News learned by accident can be confusing, even inaccurate, and leave children feeling overwhelmed, confused, or shocked.

Communicating directly with your children allows you to control how your children learn about your illness – the words and the level of detail. Importantly, it lets children know that they can trust you to tell them what is happening, what to expect, and that you can be present for them for these emotionally difficult conversations. After talking with children, parents often share how their children “already had an idea” that a parent was unwell, sometimes wondering about the frequency of doctors’ visits.

## ***Planning for Specific Conversation(s)***

### **Take it step-by-step**

Communicating about the initial diagnosis and any changes along the course of the illness often involves a series of conversations. It can take several different discussions over time to explain ALS to a child. It is not possible to anticipate every question or scenario in communicating with your children. You can have an initial plan, begin conversations with the information you have, and then take it step-by-step responding to your children’s needs or questions, along the way.

### **Start with what your children already know:**

Often, parents and children have already been talking about some bodily or functional changes for a parent (e.g., changes to how they walk). Sometimes children know that there have been many appointments with doctors. If children don’t have any context, you can start by asking what your children have noticed. For example, have they noticed that you have difficulty walking, lost your balance, or changes to your speech or another physical change? Have they noticed that you are receiving extra help from friends or family? You might ask if your child has their own ideas of why they think this change has occurred.

This helps you know if your child knows more than you thought or if they are confused about something. Acknowledge the changes they may have observed, by letting them know that they are correct and let your child know that you want to explain more about these changes.

## **Explaining ALS**

### **Name your illness – ALS**

Most children are not familiar with ALS. Naming the condition helps your child to talk about their experience of your illness and to have their questions answered appropriately. If you are not ready to use the term ALS, you could say that you have a neuron disease. Describe it. For example, “It is a problem with motor neurons, which allow the brain to talk to different parts of the body. Some of my motor neurons are not passing the messages from my brain to different parts of my body.” The table at the end offers sample scripts and language to consider.

### **Use concrete examples or analogies**

You might explain that neurons or nerves are like electrical wires that send information from the brain to the muscles. Just like flipping a switch in a house sends signals through electrical wires to a light, messages from the brain travel through the nerves to different body parts and makes them work (or move). ALS is a problem that affects the neurons and prevents signals from travelling through the nerves and making the muscles do their jobs.

### **Check in about children’s feelings while sharing information**

Much of the information you share is likely to be new to children. As you talk, pause to check in with your children about whether they have any questions, and about how they are feeling about what you shared. This will help you to pace the discussion in a way that is appropriate for your child.

### **Provide realistic reassurance**

Remind your child that you still enjoy hearing about their school, playtime or other activities. You can remind your children that the illness does not affect how much you love your child, but it does affect some of the things that you are able to do with them. Share that you miss not being able to do those fun things together (e.g., playing a sport together). Think of other fun things you can still do together (e.g., watch your child’s soccer practice, or watch a game together on TV).

### **Welcome your child’s questions**

Ask your child what confuses them about your explanations and about any questions or worries. Let them know that they can ask you questions at a later time too. If your child asks a question that you do not know how to answer, let them know that you think it is a good question and that you want to ask the right person about it (doctor, nurse, minister, priest, teacher, family member) and get back to them

### **Figure out what is the “real” question your child is trying to ask**

Many times, there is a specific concern that a child has that can be easily answered. For example, a child who has questions about whether a parent will need a wheelchair soon, might be wondering about how a parent’s mobility might impact family travel plans rather than feeling anxious about the speed of disease progression. You might say, “I’m glad you asked me. What got you wondering about that?”

### **Respect a child’s wish to not talk**

Talking to children about information related to your illness, as well as your child’s ongoing emotional adjustment are both important. But it is okay, and common for children of all ages, to not want to have lengthy discussions about it, or to be more open to talking sometimes but not at other times. A lot of this depends on your child’s personality or temperament – some children consistently prefer more limited information.

Try to be available when your child is more likely to talk with you, such as when you are together in the car, while you cook, or at bedtime. Check in about how they are doing, if they are hearing too much, or too little about your health or whether they have any questions.

### Identify trusted adults

Let children know who among your family and friends know about the illness. Identify other caring adults among your friends or family, whom you trust can talk to your children about your illness or about how your children are feeling. Children of all ages feel protective of their parents and may not want to worry or upset them. Naming other adults they can speak with assures them that you are comfortable with their seeking information and emotional support from other people and that this is not disloyal. It reminds your child of all the people, in addition to you, in your lives who care about them. Especially with younger children, you might request that these adults let you know if your child does talk to them so that you can monitor your child's distress.

### Involve the school

Decide with children, even college students, whom they will talk to or where they will go if they have a hard time at school. Children usually appreciate knowing who else is aware of important information about them or your family, so let your children know about conversations you've had with teachers, counselors, nurse, the principal, or other school staff. Let the school know about your ALS so the teacher (or school psychologist or guidance counselor) can provide extra support and understanding. Ask teachers to let you know if they have concerns about how your child is coping or any changes that may suggest the need for additional support (e.g., changes in behaviors, changes in motivation and engagement in school).

Some children welcome more involvement from a school, such as by organizing events to raise awareness about ALS or even fundraising. Some may be open to speaking individually with a school counselor for support. Other children prefer if school feels like an "island of normalcy." Talk to your child about their preferences. For children of all ages, it helps to communicate your child's preferences about whether it's ok to bring up something or whether to wait for the child to do so. It also helps to let your child know what to expect from school staff.

### Talk about what will change and what will stay the same

Change and uncertainty are constant aspects of the experience of ALS. As much as possible, it can help to anticipate what changes are likely to occur in the near future. Talk together and help children understand any changes to the family routine or to your home (e.g., increased appointments, home modifications, introduction of new medicines or medical equipment). Also talk about changes that affect your child more directly (e.g., changes to who will take them to soccer or dance practice or changes to any upcoming family holiday plans). At the same time, remind your children about the things that will stay the same such as any planned trips, or longer-term support such as the presence of loving family and other caring adults. Encourage normal activities. Familiarity and predictability are helpful and comforting.

### Questions about the end of life

Some parents worry about being asked if they will die from ALS. This worry can keep parents from talking with their child altogether. Young children are unlikely to understand or ask about the progressive and terminal nature of ALS, but adolescents or young adults may understand and learn about life expectancy with ALS independently.

It is best to acknowledge that people die from this illness but that you hope this will be a long time in the future. You can share that your doctors are not worrying about you dying very soon. You can let your child know that your treatment is designed to slow the progression of symptoms and to provide comfort. The handout on “Talking to children about an imminent loss” offers more detailed guidance, and can be accessed <https://massgeneral.org/als-pact>.

### **Designate a “Captain of Helpers”**

If you have people offering different types of support to you or your family, you might consider appointing one or more people to organize these well-wishers. You may provide a list of things that you need assistance with, and your captain of helpers can help designate specific tasks (e.g., household errands such as grocery shopping, cooking meals, driving you or your children) to volunteers.

### **Build a shared understanding of ALS with your medical team and family**

It can be helpful for your ALS care team and your family to have a common understanding of your health and treatment (e.g., medications, assistive devices). Over time you may consider sharing specific language or examples that you learn from your medical team with your children, based on illness progression and your child’s age. This is especially important with older adolescents or young adults, and children who are actively involved in your care or who attend medical appointments. With co-parents and with your ALS care team, plan how and when to introduce children to specific issues, so your children can understand and anticipate the changes that come with ALS over time and feel comfortable asking questions about your care.



# Age-Specific Guidance for Parents

## Child's Experience and Reactions

## Guidance for Parents

### Infants and toddlers (0–2 years)

- Particularly affected by disruptions in their routine and caregivers' distress

- Consistency in caregivers or day care attendance, mealtimes, and sleep routines help to provide stability and predictability

### Pre-schoolers (3–5 years)

- Aware of physical and emotional changes in a parent
- Typical explanations for illness may be incorrectly self-centred or self-blaming ('I got mad at mom, and made mom sick')
- Concrete thinking (relies on what they see and experience rather than abstract abilities) and egocentric thinking (based on child's own experience rather than alternate perspectives) are characteristic of this stage. So, questions may sound like 'When can you play with me again?', 'When people get older they stop walking?'
- Unlikely to understand death as permanent and irreversible. See additional guidance in the handout on Bereavement here <https://massgeneral.org/als-pact>.

Explore child's understanding of ALS

- Correct misconceptions
- Reassure them that nothing they did could have caused the parent to be ill (i.e., ALS is not contagious like a cold). This can also reduce your child's fear of "catching" ALS (or help them not worry that the co-parent will also get sick with ALS)
- If a parent is sad or worried, clarify that nothing the child did caused the adult's distress.
- Provide concrete descriptions of ALS symptoms (e.g., 'her leg is becoming weaker, her brain does not work like it used to')
- Use concrete analogies to clarify. See above for analogy of electricity in a house.
- Children need repetition to understand what ALS is, and how it has led to changes or symptoms for their parent

### School-age children (6–12 years)

- Simple cause and effect logic promotes curiosity about causes of illness and death, but may have significant gaps in understanding, e.g., may believe that ALS is infectious or that ALS is caused by stress. May be extremely concerned about 'stressing out' the parent with less-than-perfect behavior, poor school performance, or even talking about worries
- Worry about the health of other important adults
- Understand that death is final and irreversible, but do not fully appreciate that it is universal
- May experience guilt about things they did or did not do with their parent with ALS

- Provide a simple explanation of ALS and treatment plans. ("There aren't any medicines that can make ALS go away completely. But doctors are helping mom to feel as strong as possible right now")
- Dispel inaccuracies about the causes of illness, or possibility of infection-like contagion for the child or a co-parent i.e., possible worries of catching ALS like a cold
- Maintain predictable routines and expectations
- Maintain school as an island of normality
- Somatic complaints like belly aches are common; ask for updates from school about frequency of visits to the nurse

# Age-Specific Guidance for Parents

## Child's Experience and Reactions

## Guidance for Parents

### Adolescents and young adults (13 years and older)

- Growing capacity for abstract reasoning promotes adult-like worries (e.g., about family finances, the well-being of siblings) as well as questions about fairness or justice, and the meaning of life and suffering
- Egocentrism and emotional immaturity may still cause them to focus on the effects of illness for themselves that may appear selfish (e.g., worrying about plans with friends)
- Children at this stage understand that death is final, irreversible, and may feel anxious about their own mortality, e.g., susceptibility to a heritable illness
- Sensitive to how a loss sets them apart from peers, particularly in school or other peer settings
- Conflictual relationships with either parent may produce resentment, guilt, or regrets, that complicate adaptation to the illness and grief

- Provide information about the illness, and clear, accurate information about available treatments of ALS. Be prepared to discuss the terminal nature of ALS early on, especially with older adolescents and young adults.
- Likely to seek information from the internet. Encourage them to check the accuracy of this information with parents.
- Respect adolescent's wish for privacy and control over dissemination of information about an illness or loss, as much as seems reasonable. For example, discuss the decision to talk to your child's school with your child first
- Encourage conversations and relationships with appropriate non-parental adults whom you trust
- Recognize that adolescents are likely to be inconsistent in keeping up with their responsibilities/ chores
- Watch for significant consistent changes in mood, or risk-taking behaviors or substance use, or significant loss of motivation and engagement in activities that your child previously enjoyed

### 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)