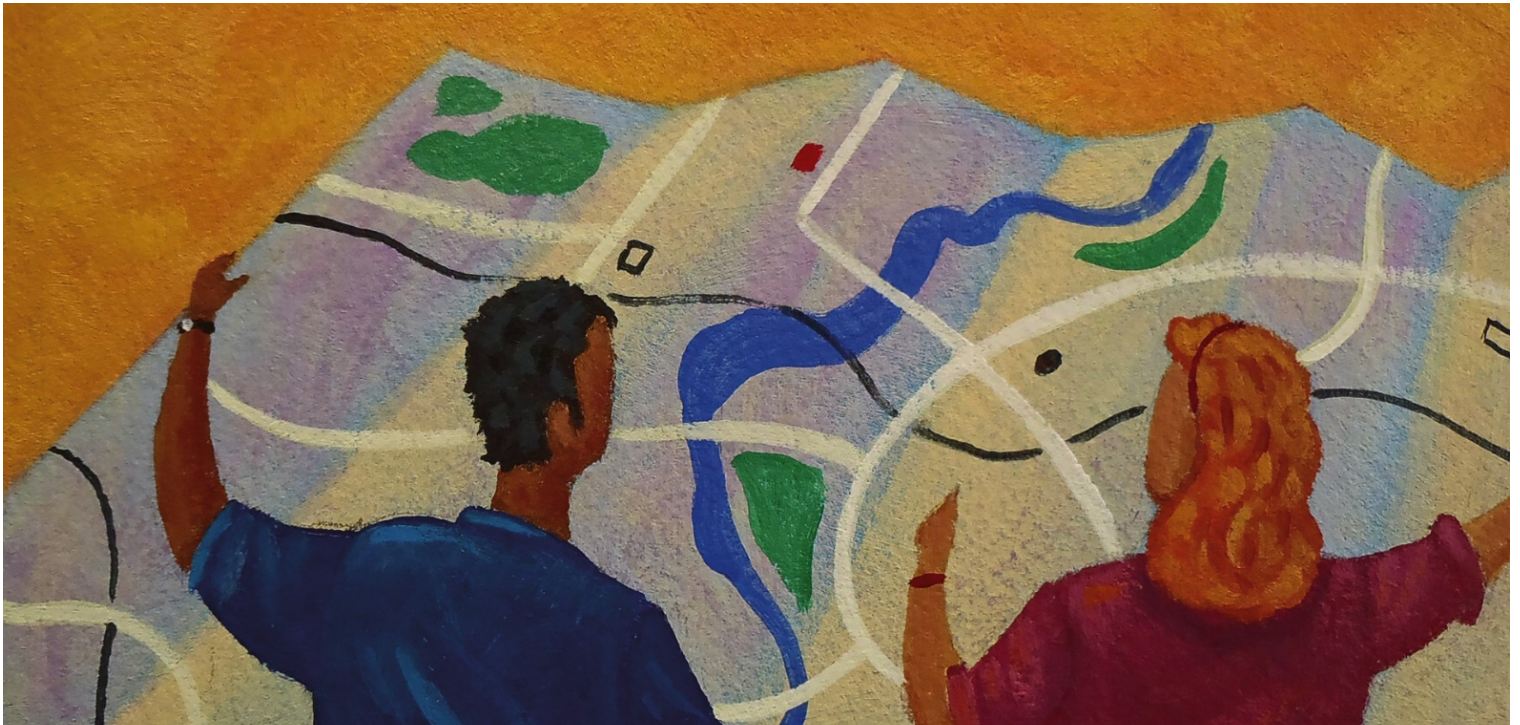


# GENETIC SUBTYPE OF ALS

*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>

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# Genetic Subtype of ALS

This handout focuses on common concerns about supporting children for parents with a genetic subtype of ALS. Parents of children of all ages worry about the potential implications for their children, wonder about how to answer children's questions about the causes of the disease, and want to help children plan for the future.

This handout is in no way meant to substitute the personalized guidance a genetic counselor can provide. It is instead intended to help prepare a parent for a consult by providing a brief overview of the genetic counselor role and an outline of possible topics for parents to raise with their multi-disciplinary team.

## **The genetic subtype of ALS handout discusses:**

- The importance of parents making their own emotional adjustment to ALS a priority
- How to talk with children about the genetic subtype of ALS, in coordination with guidance from a genetic counselor
- How to help children integrate the experiences of other ALS-affected family members with expectations for their parent's illness course

## Introduction

Parents of children of all ages have questions about how best to support their children when faced with a genetic form of ALS. For instance, parents may wonder about the range of potential implications for their children, how to talk about these, and how to answer children's questions about the causes of ALS.

Whether, when, and how much to discuss regarding the genetic basis of ALS with children is ultimately a unique and personal choice for each parent and family. This choice will depend on children's ages, emotional readiness, the degree of ALS progression, and each family's own communication style. Working with the genetic counselor on your care team can provide foundational information to inform your conversations with your children and family.

While acknowledging that there are no "correct" choices, this handout offers some considerations and strategies informed by developmental and clinical psychology, the available research with patients with ALS, and from ALS PACT consultations with parents and grandparents (hereafter referred to collectively as parents) in collaboration with multidisciplinary providers in the Massachusetts General Hospital ALS clinic (<https://www.massgeneral.org/neurology/als>). When appropriate, especially when there is a paucity of research data from patients with ALS, we also reference research with people with other terminal or serious medical conditions.

Although predictive genetic testing of minors is not offered by ALS multidisciplinary clinics, a non-comprehensive list of written resources about discussing genetic testing with children appears at the end of this section.

## The experience of genetic screening as a parent or grandparent

For a subset of people with ALS, the disease is caused by a genetic mutation that can be passed on to children, conferring a high risk of developing ALS (see "Basics of ALS for Mental Health Clinicians", which can be accessed <https://www.massgeneral.org/als-pact>). Parents with the genetic subtype of ALS are also often adjusting to a range of changes in their own physical functioning, day-to-day routines, and family experiences. Additionally, the process of being diagnosed with ALS and genetic screening often involves many meetings with different medical teams and specialists who present a great deal of new information. It can be overwhelming.

## Coping with your feelings and worries as a parent/ co-parent

Parents experience a range of emotions (e.g., uncertainty, shock, sadness) as they cope with all of this. In PACT consults and discussions with our Neurology colleagues, many parents with the genetic subtype of ALS describe feeling uniquely responsible or guilty. They worry about how their own ALS may affect children, and also, their children's potential risk of being diagnosed with ALS later. So, in addition to planning for their own treatment and providing emotional support to children in the moment, parents are also often gathering information about future genetic testing for their children.

Parents are familiar with hearing that they should, "put on your own oxygen mask before helping your children with theirs." Here are a few ideas for what that might look like as you cope with a diagnosis of a genetic form of ALS:

**Prioritize your own emotional adjustment to the diagnosis.** Parents' own emotional functioning and coping is foundational to supporting children. Take the time to understand the emotional impact of diagnosis for yourself. For example, while feeling some guilt for having an illness that will affect your family is not uncommon (but it can be unfair to yourself), some people can become “stuck” with guilt in a way that affects their ability to live with ALS and also to support their children. Think about your own needs and plan for your support. Ultimately, this will allow you to be more emotionally available and supportive of your children.

**Consider working with a mental health professional** (e.g., psychologist, psychiatrist, licensed clinical social worker) trained in assessing and treating mental health concerns. Given that ALS is a rare illness, most mental health care professionals may not have experience working with families coping with ALS. But finding a mental health professional with experience working with people coping with serious or terminal hereditary medical conditions can be helpful.

In addition to your medical care team, family, and friends, including a mental health professional either for your own individual care and/ or as a family therapist could be valuable in supporting your children (e.g., thinking through different decisions, planning for difficult discussions as a family, understanding if or when either you or your children need more intensive support).

**Plan your communications with your children.** This section builds on the handout, “Communication with children about a parent’s ALS diagnosis” available at <https://www.massgeneral.org/als-pact>.

But talking with children in the context of a known genetic risk for ALS may require additional information gathering from various sources. For instance, you will talk to your neurology team, you may meet with a genetic counselor, and you may want to talk to a mental health professional. While genetic testing is only recommended for adults (not minors who do not have symptoms of ALS), you may wish to learn about specific screening or other guidelines related to reproductive/ family planning for your children.

Some parents also choose to contact research programs (see “[Basics of ALS for Mental Health Clinicians](#)” at <https://www.massgeneral.org/als-pact>) or patient communities for support, or explore information about gene-specific research for pre-symptomatic gene carriers. We provide a brief outline for planning communication with your children, beginning with gathering information for yourself and your family at end of this section.

## Talking to your Children About a Genetic Basis for ALS

**Discussions with children about the genetic basis of ALS will vary across families.** There is no single correct approach to sharing information about your illness and any associated genetic risk with your children. The way you approach this will depend on many things such as your children's ages, emotional readiness, the ALS progression, and your family's own communication style. Even children of the same age can vary with respect to cognitive development, understanding, and emotional readiness. Older children, children seeing more advanced ALS progression, children who have experience with another family member with ALS, and sometimes children with older siblings may be more likely to ask questions about ALS.

**Available research suggests that communicating with children in a way that helps them feel supported, can promote acceptance, openness to preparing for their future, and better psychological adjustment** to the possible risks to their own health (Rowland & Metcalfe, 2019) Talking about a parent's ALS diagnosis can feel more difficult when a parent has a genetic subtype (Metcalfe et al., 2008).

In addition to having difficulty managing their own feelings and worries, some parents note that they find it harder to reassure children. This can make parents avoid engaging in these discussions. **It is helpful to keep in mind that it is best for children to learn about this information from a person they love and trust**, rather than to learn such information accidentally. Knowing that such information was withheld can affect children's trust in you and even their overall sense of connectedness with you. This could affect children's willingness to seek support from you when they most need it.

**One conversation is almost never enough- so it doesn't have to be "perfect" the first time.** It is common for parents to share information over many conversations. Indeed, studies interviewing children with a parent with a genetically based illness (not specific to ALS), suggest that children may prefer to learn about genetic conditions gradually throughout childhood (Gallo et al., 2005; Metcalfe et al., 2011). Also, illness and treatment related information is often new, and can be confusing or feel emotional. Plan to repeat information as relevant or helpful. Consider having a supportive person like a friend or extended family member be present when you and your children talk. Ask your medical team for advice on how to accurately and simply describe any medical information that you are unsure about.

**Consider your child’s developmental stage and personality.** Each new developmental stage brings growth in children’s abilities to understand information and apply it to new situations. In general, young children will need basic information about health, illness, and the role of genes to start. Information about familial risk for ALS can be included in discussions as your child gets older. Young adult/adult children are likely to need information so they can consider genetic screening for a variety of reasons including reproductive and family planning and decision-making. Adolescents who are still too young to be eligible for genetic testing may also benefit from knowing about the genetic basis of your illness, so they have the opportunity to think about how and when to approach genetic testing as an adult, to explore and understand the emotional impact of this information for themselves and their sense of identity, or how this might shape their approach to partner relationships. Here are some specific topics that children at each developmental stage may be curious about:

- *Preschool (ages 3-5):* What are names of body parts and what do they do? What is an illness? Did I somehow make that happen? Perhaps, what is a gene?
- *Elementary school-age children (ages 6-10):* Could our whole family get ALS? What is a gene? Why did (family member) get ALS when they take such good care of themselves? Who will take care of me?

- *Pre-adolescents/ Adolescents (ages 11-18):* Could I have ALS someday? Could I have the gene? How will I know? Why me? How do I deal with being different? What does this mean for my own future?
- *Older adolescents/ Young adults (ages 19-25):* Should I have children? Could they get this too? Who should I talk to? Who can understand this? Why me? What can I hope for?

Remember that children in the same developmental stage won’t all understand the same information in the same way. Some 5-year-olds think more like a typical 8-year-old, and vice versa. So, your children may be curious about topics that are listed under a developmental stage that is earlier or later than the one they are in.

**Consider your child’s developing identity and your “family story.”** How a family understands their shared experiences is sometimes called a “family story,” and these stories contribute to a child’s sense of identity. Your family’s experience of ALS will become part of your “family story.” These stories can influence how someone understands and approaches different life experiences, for instance, dating and partner relationships and family planning or reproductive decisions. They can affect a broader worldview, like the child’s sense of the world being fair or unfair (“why did this happen to my family and not to someone else?”). Family stories also affect how children think about adapting and coping with difficult experiences or challenges. Talking about ALS together gives you the opportunity to help shape the family story, and your child’s story.

**Thoughtful planning can help children recognize and cope with the emotional impact of ALS.** Conversations with parents can help children to sort through their emotional reactions to upsetting information, which will change over time. They also provide the opportunity to discuss and model how your family copes with challenges. Some families prefer to have conversations facilitated by a mental health professional. As a parent in the ALS PACT program said, “It is so sad to go through this... that my children and family have to experience this... but here we are... and I would want my child to also see how we deal with difficulties...together.. as a family.”

**Consider children’s experience with other family members with ALS.** If another family member has previously been diagnosed with ALS, your child might learn about aspects of ALS even though you, the parent, are pre-symptomatic or early in the course of the illness. For instance, children may see you or someone else in the family assist a family member with ALS. They may overhear or they may have participated in conversations about ALS or treatment for it. Your child might be spending time with the family member themselves and may even be helping the family member. Adolescents and older children may access information online. Thus, consider the broader family context, your illness progression, and your child’s development to develop a plan for talking with your children.

### **Common Assumptions to Avoid:**

- **Children will ask for more information when they are ready.** It might be tempting to assume that children will ask questions, “when they are ready.” Limited available research suggests that waiting for children’s questions may lead children to be less likely to talk about things because they may want to avoid topics that are upsetting for their parents (Metcalf et al., 2011).
- **Children won’t have questions or confusion because they have known someone else with ALS.** If another family member had ALS, some parents assume that their child has ‘always known ALS’ i.e., it is a not a new experience they are adjusting to. But having a parent with ALS in the same household, is a different experience compared to knowing another relative with ALS. Young children who have known other family members with ALS in their pre-asymptomatic and symptomatic stages may assume that ALS symptoms are a part of typical aging. Talk to your children, as they get older, about their understanding of ALS to clarify misconceptions or assumptions. Building on this, you may also gradually share more detail about the genetic basis of the illness and its implications for the children as they reach later developmental stages.
- For older children with a symptomatic extended family member, questions or worries about the potential impact of the illness for their asymptomatic parent or even implications for their own health are likely to come up sooner. Thus, planning sooner for such conversations can help you feel more prepared in supporting your children.



# An Outline for Gathering Information for Yourself and your Family

You will likely be talking with many different professionals as you learn about the genetics of ALS. Here, to add to your own information gathering “tool kit,” we offer an outline of topic areas you might want to raise. There are certainly others that are not listed here, and some questions in our list may not apply to you or your family’s needs. We hope this might serve as a springboard for conversations, that you will elaborate upon and tailor for your own purposes.

*Talking with the Neurology team:* Your neurologist is likely to be one of the first people you talk with about ALS, and will likely be able to provide guidance on a range of topics such as:

- Differences in progression of the genetic vs non-genetic subtypes of ALS.
- Current genetic testing and monitoring procedures for adult children of patients with the genetic subtype.
- How to discuss genetic testing results with your children or other family members.
- Current research trials or areas of innovation for ALS that could be helpful for a patient or for family members, including children.
- Opportunities for peer support.
- Discussing genetic testing with children. While predictive genetic testing of minors for ALS is not offered by ALS multidisciplinary clinics, are there additional resources or guidelines to consider? What are typical next steps for adult children? Is the ALS care team available for questions from my children either now or in the future?
- Finding a therapist. ALS care teams may know local therapists who have worked with other families.
- Commercial genetic testing kits: these are not equipped to provide information about risk for ALS. Additionally, commercial kits typically do not come with genetic counseling support. Consider if you or your children may have additional questions about commercial genetic testing kits.
- You may find it helpful to have information about laws that protect against genetic discrimination (for example, having to pay more for health insurance because of a known genetic risk for an illness). For instance, federal Genetic Information Nondiscrimination Act of 2008 (GINA) laws provide some protection against discrimination for medical insurance and employment purposes. You may wish to understand the extent of the protection and the limitations of the laws as they apply to you and inquire about any additional state level considerations, or additional considerations related to disability insurance.

# An Outline for Gathering Information for Yourself and your Family

Talking with genetic counselors: Broadly speaking, a genetic counselor is a specialized healthcare professional who provides information about how certain illnesses might run in families. They review your health information and also your family health history to help you decide whether you or someone in your family would benefit from genetic testing. They can also help you understand test results and treatment options and provide information to connect patients with patient advocacy groups, psychological support, or other relevant healthcare resources. Below are some of the topics to consider for a conversation with a genetic counselor:

- Genetic testing may not be the best choice for everyone. Some people may not want to know their genetic status or may need more time to think through this decision. Even individuals in the same family may have different goals or preferred timelines for genetic testing. Consider what is best for your family and your adult children, in consultation with your medical team and a genetic counselor.
- Ask genetic counselors for recommendations or guidance for families where one adult child has a positive screen for the genetic subtype, but another adult child does not.
- Inquire about materials such as stories, books, or videos that may help your children to better understand this information.
- Consider asking for recommendations for mental health professionals. Genetic counselors can provide initial counseling support and may know of local mental health professionals with relevant experience.
- It can be helpful to have information about laws that protect against genetic discrimination (for example, having to pay more for health insurance because of a known genetic risk for an illness). For instance, federal Genetic Information Nondiscrimination Act of 2008 laws provide some protection against discrimination for medical insurance and employment purposes. You may wish to understand the extent of the protection and the limitations of the laws as they apply to you and inquire about any additional state level considerations, or additional considerations related to disability insurance.

# Possible Topics of Conversation with Children in Different Developmental Stages

- *Preschool (ages 3-5)*: Understanding body parts and typical body functions, different types of illness, what is a gene?
- *Young children (ages 6-10)*: what is a “gene”, “will our whole family get ALS”?
- *Pre-adolescents/ Adolescents*: Could I have ALS someday? Could I have the gene? What does this mean for my own future? Why me? How do I deal with being different
- *Older adolescents/ Young adults*: Should I have children? Could they get this too? Who should I talk to? Who can understand this? Why me? What can I hope for?

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## Resources linked in text

- Genetic Information Nondiscrimination Act of 2008 (GINA) Laws: <https://www.eeoc.gov/genetic-information-discrimination>

## Other resources

- ALS overview written by genetic professionals that discusses hereditary ALS: <https://www.ncbi.nlm.nih.gov/books/NBK1450/?report=printable>
- Genetic testing in ALS: <https://vimeo.com/200405715>