



ALS & Genetic Counseling and Testing for Family Members

A Les Turner ALS Foundation Guide for Families

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your doctor before making any decisions about your health or treatment. Together, you and your doctor can find a treatment plan that works for you.

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ALS & genetics for family members

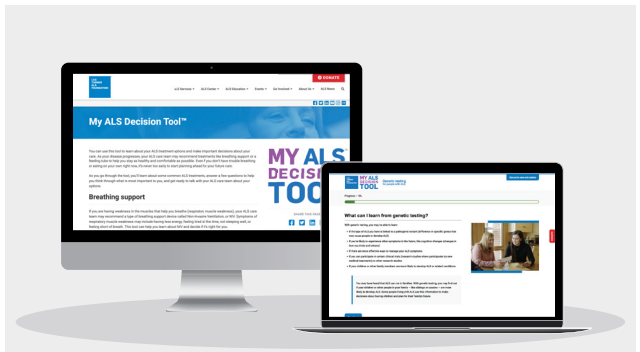
If you have a family history of ALS or a related neurologic condition — like FTD (frontotemporal degeneration), dementia, or Parkinson’s disease or a mental health condition like schizophrenia or bipolar disorder — you may have questions like:

- **Am I at higher risk of developing this condition because of my family history?**
- **Could my children/future children have a higher risk of developing this condition?**

Genetic counseling can help you find answers. After meeting with a genetic counselor, you can decide if you want genetic testing, also known as, **predictive genetic testing**. Through predictive genetic testing you can learn detailed information about your risk of developing ALS or related conditions in the future.

What is a genetic counselor?

A genetic counselor is a health care provider who specializes in medical genetics and how genes affect our health. Genetic counseling is an essential first step in the predictive genetic testing process, and meeting with a genetic counselor does NOT mean you need to undergo testing. A genetic counselor can help you understand how your genes and family medical history may affect your health in the future.



The **My ALS Decision Tool™**, a first-of-its-kind in the US, online, interactive guide, can walk you through genetic counseling, the predictive genetic testing process, the benefits and downsides of predictive genetic testing, and help you make an informed decision. It was developed in collaboration with people living with ALS, caregivers, advocates, researchers, and an international group of genetic counselors from Northwestern Medicine, The Ohio State University Wexner Medical Center, Penn Medicine, and Macquarie University in New South Wales, Australia.

lesturnerals.org/predictive/als-genetic-counseling-testing-family-members



You're most likely to get helpful information from genetic counseling and testing if 2 or more people in your family have ALS or a related neurologic or mental health condition.

A genetic counselor can:



Give you a personalized genetic risk assessment based on your family history



Help you understand/interpret your genetic testing results



Explain how genetic testing works and help you decide if it's right for you



Help you explore family planning options based on your genetic risk, if that's important to you



Help you decide when to get genetic testing, if you're interested



Offer guidance to help you cope with your emotions and have conversations with loved ones



To learn more about genetic counseling and predictive genetic testing for people at risk of developing ALS and other conditions, watch this webinar from our ALS Learning Series by Laynie Dratch, MsC, CGC, genetic counselor at the Penn ALS and FTD clinics.

alslearningseries.org



To schedule an appointment with an experienced ALS genetic counselor at Northwestern Medicine call 312.695.7950.



If you're looking to find a genetic counselor who specializes in ALS and other related conditions in your area, you can ask for a referral from an ALS Care Center, talk to your family's ALS Care Team, or contact The National Society of Genetic Counselors.

aboutgeneticcounselors.com

When using The National Society of Genetic Counselors search feature, first choose if you're interested in in-person counseling or telehealth. Then choose the state that you live in, click the specialization of "adult (including complex disease)" and "neurogenic," then hit search for a list of counselors.

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How can I prepare for meeting with a genetic counselor?

Before your first appointment with the genetic counselor, take time to gather some information about your health and family medical history:



Has anyone in your family been diagnosed with a neurologic condition like ALS, FTD (frontotemporal degeneration), or Parkinson's disease — or a mental health condition, like schizophrenia or bipolar disorder? If so, share this information with your counselor. If you can, it's helpful to gather details about each family member with a neurologic or mental health condition. For example, write down how old they were when their symptoms began and how old they were when they passed away (if applicable).



Has your family member with ALS or a related condition completed genetic testing? If so, it's helpful to try to get a copy of their genetic testing results to share with your counselor.



Have you talked to a doctor about your risk of developing ALS or a related condition? If so, bring your notes from the doctor's appointment or have your medical records sent to the genetic counselor's office.

You can also ask a support person (like a partner, family member, or close friend) to come with you for your genetic counseling appointment.



If you don't have all of this information regarding your family history, that's OK; a genetic counselor can still meet with you and offer support in collecting necessary information.

GINA

If you live in the United States, it's a good idea to learn about your rights under the **Genetic Information Nondiscrimination Act (GINA)** before you see a genetic counselor. GINA is a law that makes it illegal for health insurance companies and employers to request your genetic information, make decisions using your genetic information, or discriminate against you based on genetic information. This includes your genetic risk for ALS or related conditions. In general, that means:

- Health insurance companies **can't** refuse to give you insurance coverage or charge you more money based on your genetic information.
- Employers **can't** fire you, reject your job application, or pay you less based on your genetic information.

However, it's possible that you could experience genetic discrimination in other ways. Keep in mind:

- Life insurance, long-term care insurance, and disability insurance companies **can** deny your application for coverage based on genetic information in your medical records (including your genetic counselor's notes). If you're interested in applying for these types of insurance, you may want to do so before meeting with a genetic counselor.
- GINA doesn't apply to the Indian Health Service, the military, or companies with fewer than 15 employees, meaning you don't have legal protection from genetic discrimination under GINA if these situations apply to you. Depending on where you live, your state may offer additional legal protection.

To learn more about your legal rights under GINA, visit [GINAHelp.org](https://www.ginahelp.org).

What can I learn from genetic testing?



If your children may have a higher risk of developing ALS or related conditions



If there are reproductive methods that could reduce your chances of passing down genetic differences linked to ALS or related conditions



If you can participate in certain clinical research studies. Your genetic counselor can further explain inclusion and exclusion criteria.



Your genetic testing results may inform your health care choices in the future. For example, if your genetic testing results show that you're at higher risk for developing ALS or a related condition, your doctor might recommend that you consider getting evaluated periodically (like every year) and recommend possible treatment options.



To learn more about ALS and family planning view this webinar from our ALS Learning Series. Lisa Kinsley, MS, CGC, genetic counselor at Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, explains genetic testing and reviews family planning options for those who are interested in reducing the risk of passing on a genetic condition.

alslearningseries.org

In 2023, the FDA granted accelerated approval of Biogen's **Qalsody (qalsody.com)** for treatment of SOD1-ALS. Qalsody is the first FDA-approved treatment to target a genetic cause of ALS.



Emotions associated with genetic counseling and predictive genetic testing

Whether or not you decide to pursue predictive genetic testing, your genetic counselor can offer expert guidance and support. Learning about your genetic risk for ALS or related conditions can bring up strong emotions – and sometimes this can lead to conflict between family members. Your counselor can share advice to help you cope with these emotions and navigate hard conversations with loved ones. They may also recommend helpful resources like local support groups.

The genetic testing process may be overwhelming or confusing at times. You may feel anxious as you wait for your results. Learning about your results can bring up difficult emotions for you and your loved ones, too. For example,



You might feel shocked or relieved to get answers about your risk for developing ALS or related conditions.



If you find out that you have a higher risk of developing ALS in the future, you may feel sad, anxious, or depressed after hearing the news.



If you learn that you don't have a higher risk of developing ALS, you may feel relieved — but if you find out that a family member does have a higher risk, you may feel a sense of survivor's guilt at the same time.

If you choose to share genetic testing results with your family members, they may have strong feelings about your results and their own risk of developing ALS or related conditions. Keep in mind that you're not alone — your genetic counselor can share guidance to support you through difficult conversations with family and friends.

Tips for communicating with your family

Here are some helpful tips for sharing information with your family, if you choose to.



You are not alone. A genetic counselor can help you every step of the way. Genetic counselors are also available for other family members who want to discuss their risks.



You are in control. You can decide whether you want to share your results and with whom.



Practice what you want to say. Write down a list of things you want to cover. You don't need to have all the answers, and you don't need to explain everything in one sitting.



Find the right time. Make sure you and the person you are telling are not distracted or in the middle of something. A quiet space with undivided attention is best.



Consider writing a letter or email, if having a conversation may be too difficult. Genetic counselors can also write letters that explain the testing, the results, and their meaning that you can share with your family.

You know your family best and their preferred way of communicating about ALS and other related conditions.

How much does genetic testing cost?

While genetic testing has historically been expensive, the costs have significantly decreased over time. Your genetic counselor can provide you with testing options and help gather information about anticipated costs. Some genetic testing companies may work with your insurance company to cover the cost, too.

You can also ask your counselor about programs that provide genetic testing at no cost to people with a family history of ALS or related conditions.



Additional Resources

End the Legacy

A patient-led organization dedicated to the needs and interests of the Genetic ALS & FTD community

www.endthelegacy.org

Light the Way

Sano Genetics has built a new online platform that offers no-cost genetic education, counseling, testing, peer support, and connections to research opportunities.

sanogenetics.com/light-the-way

The Association for Frontotemporal Degeneration

Their mission is to improve the quality of life of people affected by FTD and drive research to a cure.

www.theaftd.org

ALS TDI Trial Navigator

Provides a resource to search for clinical research that is currently enrolling people that have a known genetic connection to ALS and are not symptomatic along with people that do not know their genetic status.

www.als.net/als-trial-navigator

Notes

Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more, visit lesturnerals.org.

ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics are offered monthly. To learn more, visit:

alslearningseries.org.

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Support Groups

We facilitate support groups to provide people living with ALS, their caregivers and families the opportunity to share their experience.

To find out more, visit: lesturnerals.org/support-groups.

