

# Genetic Counseling



Everyone with ALS should have the opportunity to meet with a genetic counselor before and after testing.

While strongly encouraged, genetic counseling is not required, and people who don't have access to a genetic counselor can still get tested.

## What is a genetic counselor?

Genetic counselors are trained to help people understand their family medical history, the genetics of ALS and the potential impacts of genetic testing.

## What should I expect during a pre-testing counseling session?

- The genetic counselor will ask about your family's history of ALS, frontotemporal demetia and other types of motor neuron diseases, movement disorders and demetias.
- Your genetic counselor will assess your risk of having an ALS-linked genetic mutation.
- You will talk about the potential personal, psychological and economic impacts of testing on both you and your family members.
- Your genetic counselor will explain the possible results and current limitations of testing.

## What will we discuss after I get my results?

- What these results may mean for both you and your family members.
- Possible next steps, including relevant clinical trials and FDA-approved therapies, if the results show a mutation is present.

## What should I ask about?

- Would genetic testing be helpful for me? Why or why not?
- What test is recommended and why?
- What will I learn from having this test?
- How will the results potentially impact me and my family?
- What won't I learn from having this test?
- Will testing and/or counseling be covered by my insurance?

If you are interested in genetic counseling, talk with your doctor.

For more information, visit [als.org/GeneticCounseling](https://www.als.org/GeneticCounseling)