



# A Patient's Guide to Genetic Counseling

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for patients.



**UCSF** Weill Institute for Neurosciences  
Memory and Aging Center



## What is genetic counseling?

The goal of genetic counseling is to provide education, support, and guidance about the genetic causes of illnesses and about the options for genetic testing. Genetic counseling helps patients and families make informed decisions about genetic testing, determines what genetic testing results mean, and adapts to the impact of genetic information.

## Who provides genetic counseling?

Genetic counseling is provided by trained medical professionals. Genetic counselors or physicians (usually medical geneticists but also other physicians with genetics training) can provide genetic counseling. The genetic counselor or physician should have dementia expertise.

## What do genetic counselors do?

Genetic counselors can:

- Ask you about your family medical history
- Determine the risk you have to develop genetic disease
- Explain how genetic conditions are passed down in families
- Provide information about specific genetic conditions
- Provide information about genetic testing options and help you decide what is best for you and your family
- Discuss reproductive options
- Help you order genetic testing, if appropriate
- Inform you of the results of genetic testing, if ordered, and help with their interpretation
- Provide supportive counseling about your response to results
- Refer you to medical specialists, patient organizations, support groups, and other resources

For more information, please visit the National Society of Genetic Counselors (NSGC) website: [nsgc.org](https://www.nsgc.org)

## Why would my doctor refer me to a genetic counselor?

- Your doctor suspects you have a genetic form of dementia
- Your doctor suspects your family member(s) has a genetic form of dementia
- You have little to no information about your family history and are worried about a genetic form of dementia
- You are planning to have a child and have questions about genetic disease

## What questions could I ask a genetic counselor?

- Does dementia run in my family?
- If my family member has dementia, might I get it? If yes, should I get tested?
- If I have dementia, are my family members more likely to get it?
- Is there genetic testing for dementia? If yes, what are the benefits and limitations of testing? How will I pay for it?
- What kind of information would genetic testing for dementia give me?
- What is the process of getting a genetic test?
- How can knowing about my genetic risk help me?
- Are there risks associated with genetic testing?
- Could genetic testing results affect my health care coverage?

## What will happen during my appointment with a genetic counselor?

The first genetic counseling appointment usually lasts one hour, although this can vary depending on your family history, your risk for genetic disease, and your questions. Follow-up appointments are scheduled as needed, including an appointment for reviewing results, if genetic testing is ordered. In general, the first appointment will include the following:

- The genetic counselor will discuss your family's medical history. This includes questions about:
  - Who are all the members of the family
  - Who in the family has or had dementia
  - The type(s) of dementia (if known) in the family and how the family member(s) with dementia was diagnosed
  - Age(s) at first symptom of family member(s) with dementia
  - Age(s) at diagnosis of family member(s) with dementia
  - Whether or not medical records of the family member(s) with dementia could be obtained
  - Whether or not brain autopsy of the deceased family member(s) with dementia was done
- Using your family history information, the genetic counselor will talk about the likelihood of a genetic cause of dementia in your family.

- The genetic counselor will explain causes and symptoms of genetic forms of dementia.
- If genetic testing is available, the genetic counselor will discuss the benefits, risks, and limitations of testing. She will tell you about the genetic testing process.
- If genetic testing is appropriate, the genetic counselor may order testing for you or may refer you back to your physician to order testing. The clinician who orders your genetic testing will receive results. You will not receive results directly from the laboratory.
- The genetic counselor will discuss what genetic test results might mean for you or your family, including possible emotional effects.
- The genetic counselor will help you find ways to adapt to genetic test results. She may refer you to other providers or resources for additional support.

## Does my health insurance cover the cost of genetic testing?

It depends on your insurance policy. If you wish to learn the extent of coverage of the cost of genetic testing, you should contact your insurance carrier directly. The genetic counselor may have information about the cost of genetic testing but may not know the extent of your insurance coverage.