



Genetic Counseling

This material is provided by UCSF Weill Institute for Neurosciences as an educational resource for health care providers.



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 genetic causes of illnesses and about options for genetic testing. Genetic counseling helps providers, patients, and families make informed decisions about genetic testing, interpret information derived from the results, and adapt to the impact of genetic information.

What do genetic counselors do?

Genetic counselors can:

- Obtain and review your patient's family medical history
- Assess whether or not your patient is at risk for genetic disease
- Explain how genetic conditions are inherited
- Provide your patient with information about genetic conditions
- Offer guidance to help your patient make informed choices or life plans
- Discuss reproductive options
- Provide information about genetic testing options and help your patient decide what is best for him/her and his or her family
- Facilitate the ordering of genetic testing, if appropriate
- Disclose genetic testing results to patients and their families and help with their interpretation
- Provide supportive counseling about your patient's response to the results
- Provide your patient with referrals to medical specialists, advocacy, support networks, and other resources

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

Why would you refer your patient to a genetic counselor?

A referral to a genetic counselor would serve your patient in many situations:

- You are concerned your patient has a genetic form of dementia
- You are concerned your patient's family member has a genetic form of dementia
- Your patient has a family member who was diagnosed with a genetic form of dementia
- Your patient has limited information about his/her family history and is concerned about a genetic form of dementia
- Your patient is considering having a child and has questions about genetic disease

Questions your patient could 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 at risk to get it?
- Is genetic testing available for dementia? If yes, what are the benefits and limitations of testing? How will I pay for it?
- What kind of information could genetic testing for dementia give me?

- What does the genetic testing process involve?
- How could knowing more about genetic risk help me?
- Could I be exposing myself or my family to discrimination based on genetic information?
- Could genetic testing results affect my health care coverage?

What will happen during an appointment with a genetic counselor?

An initial genetic counseling session usually lasts an hour; however, this can change based on the patient's family history, risk for genetic disease, and questions the patient may have. Follow-up sessions are scheduled as needed, including results disclosure, if genetic testing is ordered. In general, the appointment will entail the following:

- The genetic counselor will obtain a detailed family history. This includes questions about:
 - Who are all the members of the family
 - Who in the family has or had dementia
 - The types of dementia (if known) in the family, and how the affected family member was diagnosed
 - Age(s) at which the affected family member(s) began having symptoms and/or was diagnosed
 - The availability of medical records documenting the diagnosis of the affected family member
 - The availability of brain autopsy results confirms the diagnosis of a deceased family member with dementia
- Using family history information, the genetic counselor will talk about the likelihood of genetic etiology for the dementia in your patient's family.
- The genetic counselor will explain the cause and symptoms of genetic forms of dementia.
- If genetic testing is available, the genetic counselor will discuss the benefits and risks of testing. The genetic counselor will also discuss the limitations of genetic testing.
- If genetic testing is appropriate, the genetic counselor may order testing for your patient or refer back to you to order the test. The clinician who orders genetic testing will receive the results.
- The genetic counselor will talk about the emotional and cognitive impact of results with your patient. S/he will discuss the implications for the patient's family members.
- The genetic counselor will help your patient identify adaptive strategies for living at risk, and in certain situations, to uncertainty surrounding whether or not your patient or his/her family member will develop dementia.
- A genetic counselor will help refer your patient to support resources for patients and families facing dementia.

Does health insurance cover the cost of genetic testing?

Your patient may wish to contact his/her insurance carrier about whether or not genetic counseling and testing is covered under his/her policy. The genetic counselor will have information about the cost of genetic testing but may not know the extent of your patient's insurance coverage. If your patient has Medicare or Medicaid as his/her primary payer, s/he may have limited coverage of the cost of genetic testing.