



## What to Do About... The Decision to Learn One's Genetic FTD Status

Deciding whether to learn if one has a genetic variant that will someday lead to FTD can be overwhelming. Fortunately, there are knowledgeable genetic counselors who can provide information, guidance, and resources to make that decision a little easier. Following are tips and strategies that can help healthcare professionals point families to effective genetic counseling, as well as a checklist of things that families facing FTD should be aware of before meeting with a counselor.

### Guidance for Healthcare Professionals

- Learn the importance of genetics and genetic status for individuals and families living with FTD.
- Share the link to the FTD Genetics section of AFTD's website ([theaftd.org/ftd-genetics/what-causes-ftd](http://theaftd.org/ftd-genetics/what-causes-ftd)) with persons diagnosed with FTD and family members who want to know more about whether FTD can be inherited.
- Recommend that families consider genetic counseling as a first step to answer questions about genetic status.
- Consider that a genetic counselor can evaluate the likelihood that FTD may have a genetic cause, help families think through the benefits and risks of testing, and provide ways that families can talk with other family members.
- Learn about the availability of genetic counselors in your area and be able to provide guidance to help families find one. The National Society of Genetic Counselors' website ([findageneticcounselor.nsgc.org](http://findageneticcounselor.nsgc.org)) enables families and clinicians to search for genetic counseling (in-person or via telemedicine), including those with a neurogenetic specialization.
- Learn about current FTD research opportunities via the FTD Disorders Registry ([ftdregistry.org](http://ftdregistry.org)).
- Share with families that there is currently a reason for hope for potential FTD treatments. Among other research, trials to find a disease-altering treatment based on FTD genetic status are ongoing.
- Be aware that not all sponsored genetic testing is the same and does not necessarily include pre- and post-test genetic counseling, both of which are important to ensure that those considering or taking a genetic test have all the information and support they need.
- Connect those with FTD and their families to resources to help them understand the differences in the no-cost sponsored genetic testing currently available. AFTD ([theaftd.org/ftd-genetics/no-cost-genetic-testing](http://theaftd.org/ftd-genetics/no-cost-genetic-testing)) and the FTD Disorders Registry ([ftdregistry.org/genetics-ftd](http://ftdregistry.org/genetics-ftd)) provide unbiased information specific to the benefits and limitations of current cost-free genetic testing.
- Consider making a referral to a mental health specialist, especially one who has experience with progressive neurodegenerative illness, for individuals and families who may need support to discuss their concerns and fears about deciding whether to pursue genetic counseling.



## Guidance for Individuals with FTD and Family Members

- Consider genetic counseling as a first step to answering your questions about FTD genetic status, whether you have a personal or family history of FTD, or if a past misdiagnosis could potentially be masking one.
- Know that a person can see a genetic counselor individually, or with a family member or friend.
- Consider that genetic testing is never a required part of genetic counseling.
- Assemble, as best you can, a thorough family health history before meeting with a genetic counselor. Know that FTD can present with a wide variety of symptoms and remains frequently misdiagnosed, even today.
- Reach out to other family members to confirm or learn more about your family health history.
- Recognize that a complete understanding of family history should include a history of dementia, major psychiatric conditions, or progressive challenges in movement that may have been misdiagnosed in the past within your family.
- Ask the genetic counselor about your personal genetic risk and your family risk; about future family planning, insurance, and confidentiality concerns; and for guidance on talking with other family members.
- Recognize that a person with FTD who can provide informed consent for a medical procedure is the one who decides for themselves whether to get a genetic test.
- Understand that for any person with FTD who can no longer provide informed consent, the person they have identified as their healthcare proxy or power of attorney for healthcare can provide consent for a genetic test.
- Learn about how both a genetic test and a brain autopsy can provide valuable information in relation to an FTD diagnosis. While genetic testing cannot by itself diagnose FTD, it can be used—along with an evaluation of clinical symptoms, imaging, and other assessments—to help determine if someone has FTD. A positive genetic test for an FTD gene will not necessarily determine the specific FTD disorder.
- Plan ahead if there is an interest in genetic testing when arranging for a brain autopsy, as it is not done routinely.
- Join the FTD Disorders Registry ([ftdregistry.org](http://ftdregistry.org)) to learn about current FTD research studies and how to get involved. Joining the Registry does not require research participation.

For more information on FTD genetics, please go to: [www.theaftd.org/ftd-genetics/what-causes-ftd](http://www.theaftd.org/ftd-genetics/what-causes-ftd).