What’s Next When the Doctor Says It’s FTD?

Checking Things off the List

Pause to consider your approach.

- The path to a diagnosis is often difficult but life doesn’t end when FTD is diagnosed. Take some time to consider how you will approach living with the disease.
- Engage with people who understand FTD as soon as possible. Visit AFTD’s website and register for the organization’s newsletters (www.theaftd.org).
- Contact AFTD’s HelpLine with questions and to find support: call 866-507-7222 or email info@theaftd.org.
- Start important conversations regarding care and support. Acknowledge where perspectives are similar and different and how things may change over time as the disease progresses.
- Identify ways to adjust and keep doing the things that are most important to both the person diagnosed and to close family or friends.
- Share information about the disease and about your needs with key family and friends.
- If you have children or teens, get AFTD’s booklet, What About the Kids? and visit www.AFTDKidsandTeens.org.

Learn about the disease.

- Confirm the diagnosis.
- Learn about symptoms and what you might expect over the course of the disease.
- Start a file of key articles and resources on FTD that will help you educate others.
- Learning is ongoing. Continue to read and ask questions.
- Double check information found online. Use websites you can trust and confirm with experts.

Create your care team.

- Identify professionals (neurologist, primary care physician, psychiatrist, case manager/social worker) and coordinate the services they provide.
- Obtain copies of diagnostic evaluations for your records. Keep paperwork organized.
- Keep a log or journal of significant changes in symptoms. Prioritize issues to address with a doctor.
- Maintain a chronological record of all medications started and discontinued.
- Consult OT, PT and speech therapist for evaluation and techniques to maximize abilities.
- Explore FTD-specific supports for care partners and the person with the disease. Visit www.theaftd.org and consider phone/Zoom groups, informal connections or other options.
- Keep a list of what you need. Ask family, friends and neighbors to help.

Contact the AFTD HelpLine at 866.507.7222 or info@theaftd.org
### Address legal and financial issues.
- Consult an Elder Law attorney.
- Plan transition from employment, if still working.
- Complete legal documents (examples include Power of Attorney, living will, trusts, etc...).
- Review financial and health care programs.
- Apply for Social Security Disability (Compassionate Allowances Program).
- Determine eligibility for Veterans Administration benefits.

### Focus on wellness and a positive daily routine.
- Follow a heart-healthy diet and get regular exercise.
- Stay active with friends and interests. Adapt activities according to strengths and needs.
- Follow a regular daily routine to structure the day.
- Review and visit day programs and long-term care facilities in advance of possible placement.
- Use professional counselors to help cope with changes.
- Attend an FTD education conference. AFTD offers modest travel grants.
- Apply for AFTD's Comstock grants—these can be for care partner respite, conference travel or for a quality of life stipend for the person with FTD.

### Address safety issues.
- Assess for safety and risk regularly and make changes as needed before a crisis occurs.
- Carry complete ID with emergency contact information. Include statement about neurological disorder and/or FTD.
- Keep home environment safe and equipped to reduce risk of falls.
- Where judgment is impaired, monitor bank accounts, investments and online activity; change access as needed to protect assets.
- Use GPS monitoring or similar device if getting lost is a risk.
- Learn the laws where you live regarding driving privileges.

### Participate in research.
- Follow emerging research to understand issues important in FTD.
- Join the FTD Disorders Registry: [www.FTDRegistry.org](http://www.FTDRegistry.org)
- Become familiar with observational studies, clinical trials and opportunities to participate.
- Learn about the role of brain autopsy to confirm diagnosis and advance research.
- Plan early if interested in brain autopsy/donation.