



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, <i>What About the Kids?</i> 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

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.



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

290 King of Prussia Road
Radnor Station Building 2, Suite 320
Radnor, PA 19087
267.514.7221 | theaftd.org