FIND HELP.
SHARE HOPE.

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

A Checklist for Navigating an FTD Diagnosis

Pause to consider your approach.	
Know that although the path to a diagnosis is often difficult, life doesn't end when FTD is diagnosed.	
Engage with people who understand FTD as soon as possible. Visit AFTD's website to find resources and support (**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 about care and support and consider how things may change as the disease progresses.	
Identify ways to adjust and maintain the things that are most important to both the person diagnosed and close family or friends.	
Share information about the disease and about your needs with key family and friends.	
If you have children and teens, get AFTD's booklet *What About the Kids?* and visit **www.AFTDKidsandTeens.org**.	
Learn about the disease.	
Confirm the diagnosis as best you can. Consider traveling to an FTD center for a second opinion.	
Learning is ongoing: Continue to read about the disease and ask questions.	
Start a file of key articles and resources on FTD that will help you to educate others.	
Double-check information found online. Use websites you can trust and confirm with experts.	
Create your care team.	
Identify medical professionals and healthcare providers 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 occupational, physical and speech therapists for evaluation and techniques to maximize abilities.	
Explore FTD-specific supports for care partners and the person with the disease. Visit **www.theaftd.org** to explore support options in your state or online.	
Keep a list of what you need. Ask family, friends and neighbors to help.	

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Address legal and financial issues.	
Consult an Elder Law attorney and/or financial planner.	
Plan transition from employment, if still working.	
Complete legal documents (examples include Power of Attorney, living will, trusts, etc.).	
Review finances and make long-term plans for care.	
Apply for Social Security Disability (Compassionate Allowances Program).	
Determine eligibility for Veterans Administration benefits.	
Focus on wellness and a positive daily routine.	
Follow a regular daily routine to structure the day. Try to incorporate a heart-healthy diet and regular exercise.	
Stay active with friends and interests. Adapt activities according to strengths and needs.	
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, either online or in-person where feasible and safe for you and your family.	
Apply for AFTD’s Comstock grants—these can be for care partner respite, travel for in-person FTD conferences, or a quality of life stipend for the person with FTD.	
Address safety issues.	
Consult guidance on navigating an FTD journey during the COVID-19 pandemic on our website: **www.theaftd.org/living-with-ftd/covid-19-and-ftd/**	
Assess home environment for safety and risk regularly. Make changes as needed before a crisis occurs.	
Carry complete ID with emergency contact information. Include statement about neurological disorder and/or FTD.	
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. This resource on our website also offers useful guidance: **www.theaftd.org/driving-and-ftd/**	
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.	
Consider autopsy and/or brain donation to confirm diagnosis and advance research. Plan early if interested in brain donation for research.	