

# NEWLY DIAGNOSED CHECKLIST



Life doesn't end when FTD is diagnosed. AFTD provides information and resources to help you adjust to the changes ahead. Please contact the **AFTD HelpLine** with questions at **866-507-7222** or **info@theaftd.org**.

## LEARN ABOUT THE DISEASE

- Confirm the diagnosis.
- Learn about FTD symptoms, genetics, and what you might expect over the course of the disease.
  - AFTD's website ([www.theaftd.org](http://www.theaftd.org)) is a great place to start.
  - Double-check information found online. Use websites you can trust and confirm with experts.
  - AFTD recommends meeting with a genetic counselor to learn the benefits and limitations of genetic testing.
- Sign up for AFTD's newsletters to keep informed about the latest FTD news.
- Plan to attend the AFTD Education Conference. AFTD offers modest travel grants to help with costs if needed.

## CREATE YOUR CARE TEAM

- Identify professionals (primary care physician, neurologist, psychiatrist, case manager/social worker) and coordinate their services.
- Obtain copies of diagnostic evaluations for your records. Organizing paperwork helps future healthcare providers.
- Keep a log or journal that includes:
  - Changes in behavior. AFTD has a **Behavioral Tracker** for caregivers and a **Temperature Tracker** for persons with FTD.
  - Medications started or discontinued.
  - Issues you have or questions you want to ask at your next doctor's appointment.
- If appropriate, consult an occupational therapist (OT), physical therapist (PT), or speech therapist for evaluation and techniques to maximize abilities.
- Visit [www.theaftd.org](http://www.theaftd.org) to find an in-person or virtual support group for either care partners/caregivers or persons with FTD.
- Keep a list of tasks family, friends and neighbors can help with. When they offer, say "yes!"**

## FOCUS ON WELLNESS AND A POSITIVE DAILY ROUTINE

- Follow a daily routine to structure the day that includes a healthy diet and regular exercise.
- Keep tabs on your mental health and don't be afraid to reach out for help.
- Stay active with friends and interests. Adapt activities according to strengths and needs.
- If needed, 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 REGULARLY AND MAKE CHANGES BEFORE A CRISIS OCCURS

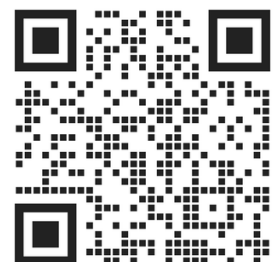
- Keep home environment safe and equipped to reduce risk of falls. Occupation or physical therapy can help you access your home for safety.
- Where judgment is impaired, monitor bank accounts, investments and online activity; change access as needed to protect assets.
- Use GPS monitoring or similar device if getting lost is a risk.
- Learn the laws where you live regarding driving privileges.
- If behaviors warrant, notify local law enforcement of diagnosis.

## ADDRESS LEGAL AND FINANCIAL ISSUES

- Consult an elder law attorney to help you complete legal documents (power of attorney, living will, trusts, etc.).
- Plan transition from employment, if still working.
- Review long-term financial plan and options if care needs increase (assisted living, nursing home facilities).
- Apply for Social Security Disability Insurance using the Compassionate Allowances program, which includes FTD as an eligible diagnosis.
- Veterans may be able to obtain benefits from the VA – [check here](#) for eligibility.
- Research day programs and long-term care facilities early for optimal planning.

## PARTICIPATE IN RESEARCH

- Join the FTD Disorders Registry ([www.FTDRegistry.org](http://www.FTDRegistry.org)).
- Participate in the ALLFTD study to support development of treatments.
- There are studies for care partners, caregivers, persons with FTD and their children. *Some clinical trials are now actively recruiting persons with FTD meeting specific criteria, with more expected on the horizon.*
- Consider **brain donation** to confirm diagnosis and advance research. Arrangements must be made well in advance.
- Visit the **Studies Seeking Participants** page on AFTD's website to learn more.



**The Association for Frontotemporal Degeneration**

[theaftd.org](http://theaftd.org) | HelpLine: 1.866.507.7222 | [info@theaftd.org](mailto:info@theaftd.org)

© 2024 The Association for Frontotemporal Degeneration