NEWLY DIAGNOSED CHECKLIST

Life doesn't end when FTD is diagnosed. AFTD provides lots of 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 symptoms and what you might expect over the course of the disease.
  - AFTD's website (**www.theaftd.org**) is a great place to start.
  - Double check information found online. Use websites you can trust and confirm with experts.

☐ 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 the services they provide.

☐ Obtain copies of diagnostic evaluations for your records. Organizing paperwork will help future health care providers.

☐ Keep a log or journal that includes
  - Changes in behavior
  - Medications started or discontinued
  - Issues that you want to address with a doctor

☐ If appropriate, consult an occupational therapist (OT), physical therapist (PT), or speech therapist for evaluation and techniques to maximize abilities.

☐ Care partners need support too! Visit **www.theaftd.org** to find an in-person or virtual support group.

☐ **Keep a list of things family, friends and neighbors can help with. When they offer, say "yes!"**

FOCUS ON WELLNESS AND A POSITIVE DAILY ROUTINE

☐ Follow a regular daily routine to structure the day.
☐ Follow a heart-healthy diet and get regular exercise.
☐ 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.
☐ 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 using the Compassionate Allowances Program that includes an FTD diagnosis 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**)
☐ Participate in the ALLFTD study to support development of treatments.
☐ There are studies for care partners, caregivers, persons with FTD and their children. *Clinical trials for persons with FTD are now available for small group of persons with FTD, with more expected on the horizon.*
☐ Consider brain autopsy to confirm diagnosis and advance research. Arrangements must be made well in advance.
☐ Visit the Studies Seeking Participants page on **www.theaftd.org** website to learn more.

The Association for Frontotemporal Degeneration
theaftd.org | HelpLine: 1.866.507.7222 | info@theaftd.org