FTD RESOURCES

Whether you are a healthcare professional, someone living with FTD, or a family member, these resources can help.

GENERAL FTD EDUCATION AND INFORMATION FROM AFTD

MEDICAL CENTERS WITH FTD EXPERTISE
www.theaftd.org/living-with-ftd/ftd-support-groups
Select your state at AFTD’s website to find regional medical centers familiar with FTD.

AFTD EDUCATIONAL WEBINARS
www.theaftd.org/category/webinars/AFTD
Disease symptoms, care management, and FTD research.

AFTD HELPLINE
info@theaftd.org or 866.507.7222
For families and healthcare professionals. AFTD staff can respond in over 200 languages. Printed resources available in Spanish.

SUPPORT AND GUIDANCE FOR PEOPLE WITH FTD AND THEIR FAMILIES

SUPPORT FOR PEOPLE WITH FTD
www.theaftd.org/living-with-ftd/support-for-people-with-ftd
Support groups and other resources from AFTD.

AFTD COMSTOCK GRANT PROGRAM
www.theaftd.org/living-with-ftd/resources/comstock-grants
For people with FTD, full-time family caregivers, and travel grants to attend AFTD’s Annual Conference.

AFTD’S NEWLY DIAGNOSED CHECKLIST
bit.ly/NewlyDXdChecklist
A practical list of important things to do after a diagnosis.

AFTD CAREGIVER SUPPORT GROUPS
www.theaftd.org/living-with-ftd/ftd-support-groups
Find help from others who understand.

AFTD PUBLICATIONS
www.theaftd.org/living-with-ftd/resources/publications/
• The Doctor Thinks It’s FTD. Now What? A guide for managing a new diagnosis.
• Walking with Grief: Loss and the FTD Journey: A comprehensive guide to navigating the grief that FTD imposes.
• What About the Kids? Offers sensitive, practical advice to parents to help children understand FTD.

FRONTOTEMPORAL DISORDERS: INFORMATION FOR PATIENTS, FAMILIES, AND CAREGIVERS
www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources/frontotemporal-disorders
Order this NIH booklet for information about FTD disorders.

ADVOCACY

DEMENTIA ACTION ALLIANCE
www.daanow.org
An advocacy organization dedicated to changing the stigma of dementia.

DEMENTIA ALLIANCE INTERNATIONAL
www.dementiallianceinternational.org
Support and advocacy by and for people with dementia.

DEMENTIA SUPPORT FORUM
www.dementiaforum.com
Offers online support for caregivers and people with FTD.

NATIONAL COUNCIL OF DEMENTIA MINDS
www.dementiaminds.org
Supports persons living with dementia and provides education on offering support.

FTD RESEARCH

STUDIES SEEKING PARTICIPANTS
www.theaftd.org/research-clinical-trials/featured-studies
Learn about ways to get involved in FTD research at AFTD’s website.

AFTD RESEARCH FUNDING AND GRANTS PROGRAMS
www.theaftd.org/for-researchers
AFTD grants and awards to FTD researchers.

FTD DISORDERS REGISTRY
www.ftdregistry.org
A secure electronic registry that gathers information from people living with FTD and notifies them about research studies.

INFO FOR RESEARCHERS FROM THE FTD DISORDERS REGISTRY
www2.ftdregistry.org/allied-pros-list
Researchers, clinicians, and other allied professionals can sign up to receive updates on current FTD research.
FTD RESOURCES

FTD GENETICS AND BRAIN DONATION

NO-COST GENETIC TESTING OPTIONS
www.theaftd.org/ftd-genetics/no-cost-genetic-testing
You may be able to get genetic testing for free; visit AFTD’s website to learn how.

NATIONAL CENTER FOR BIOTECHNOLOGY INFORMATION
Designed to assist health care providers and researchers navigating the landscape of genetic tests.

NATIONAL SOCIETY OF GENETIC COUNSELORS
findageneticcounselor.nsgc.org
Search for genetic counseling (in-person/via telemedicine), including those with a neurogenetic specialization.

BRAIN DONATION OPTIONS
www.theaftd.org/research-clinical-trials/ways-to-participate/brain-donation
Information on brain donation and where to begin.

NEUROBIOBANK
neurobiobank.nih.gov/donors-how-become-donor
Learn about brain donation.

RELATED DISEASE ORGANIZATIONS

ALS ASSOCIATION
www.als.org
Search “frontotemporal dementia” to learn more about ALS with FTD.

BLUEFIELD PROJECT TO CURE FTD
www.bluefieldproject.org
An academic research consortium focused on discovery research.

BRAIN SUPPORT NETWORK
www.brainsupportnetwork.org
Brain donation information and other supports.

CURE PSP
www.psp.org
Dedicated to the awareness, care, and cure for progressive supranuclear palsy and related disorders.

CURE VCP DISEASE
www.curevcp.org
Drives efforts to cure diseases related to VCP gene mutations, responsible for some cases of FTD.

NATIONAL APHASIA ASSOCIATION
www.aphasia.org
Access to research, education, rehabilitation and advocacy services.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE (NINDS)
www.ninds.nih.gov/health-information/disorders/frontotemporal-dementia
FTD information from NINDS.

NATIONAL INSTITUTE ON AGING
www.nia.nih.gov/health/topics/frontotemporal-disorders
FTD information from the National Institutes of Health.

LEGAL/FINANCIAL RESOURCES

LEGAL AND FINANCIAL PLANNING
www.theaftd.org/living-with-ftd/legal-financial-planning/
AFTD’s overview of important steps to take after an FTD diagnosis.

NATIONAL ELDER LAW FOUNDATION
www.nelf.org
The only organization accredited by the American Bar Association (ABA) to certify practitioners of elder and special-needs law.

SPECIAL NEEDS ALLIANCE
www.specialneedsalliance.org
A national alliance of special-needs attorneys.

JOB ACCOMMODATION NETWORK (JAN)
askjan.org
A service of the U.S. Dept. of Labor, JAN provides free, expert, and confidential guidance on workplace accommodations and disability employment issues.

The Association for Frontotemporal Degeneration (AFTD) is the leading U.S. nonprofit working to improve the lives of people with frontotemporal degeneration (FTD), their care partners and loved ones. We envision a world with compassionate care, effective support, and a future free of FTD.