

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/aftd-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/aftd-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.dementiaallianceinternational.org

Support and advocacy by and for people with dementia.

FTD SUPPORT FORUM

www.ftdsupportforum.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

www.ncbi.nlm.nih.gov/gtr

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.