

C Partners in FTD Care

A quarterly newsletter for
healthcare professionals

Fall 2022

FOR HEALTHCARE PROFESSIONALS: WHAT FAMILIES NEED AFTER AN FTD DIAGNOSIS

INTRODUCTION

FTD is a “scary, huge diagnosis,” as FTD care partner Reesa notes in the interview below. Without adequate information and support, it can feel even scarier. Healthcare professionals play a significant role in ensuring that the newly diagnosed and their care partners are equipped with everything they need to navigate the FTD journey as successfully as possible. Learning about the disease, and what to expect and prepare for, is critical. Healthcare professionals can also help families learn about support groups and guide them to finding specific legal and

financial planning resources. Many families gain a sense of hope and purpose from participating in clinical trials. Healthcare professionals can highlight the potential benefits of participation.

What follows is an interview with James, who is living with a primary progressive aphasia (PPA) diagnosis, and his wife and full-time care partner, Reesa. They discuss getting their diagnosis, the information and supports they received upon diagnosis, and what resources they wish they had gotten as they began their FTD journey.



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JAMES AND REESA'S STORY

AFTD: When were you diagnosed with PPA and how long did it take?

James: It took two years to get fully diagnosed. Sadly, it's getting a bit worse. I was only losing a few words at a time and now I'm losing lots of them. But thankfully my company offered disability benefits, so even though I lost my job, thank goodness we've had financial assistance.

Reesa: James was having some memory and sleep problems about four years ago and went to his doctor. They ended up diagnosing him with high stress, gave him some medications for that and suggested counseling. But he continued to have issues with word-finding and memory.

We then saw a neuropsychiatrist who suspected PPA and recommended UCSF [the University of California, San Francisco] to get a formal diagnosis. In April 2020 we met

with UCSF, and they diagnosed him with the semantic variant of PPA. At that point, James's work was beginning to suffer. He's a former researcher and journalist – reading, writing, and public speaking were all part of his job. PPA affects exactly those things. We were told that James should stop working. They also told us the disease is progressive – no treatment, no cure. That certainly was a lot – it was a lot. We both had been working our whole careers, and all of a sudden everything was upside-down.

AFTD: When you were diagnosed, were you given any information about the disease?

Reesa: Our doctor and her team explained PPA because we had never heard of it. They referred us to several places – AFTD being one of them – to learn more. Then they recommended speech therapy as well as some of the clinical trials we're now part of.

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THE VALUE OF SUPPORT ON THE FTD JOURNEY

Frontotemporal degeneration (FTD) can be an isolating and stigmatizing disease for people living with a diagnosis and their families. The young age of onset, disinhibited behavior, and loss of autonomy are a few factors that can bring isolation. Care partners of people with FTD experience greater overall burden, stress, and depression than care partners of people with more typical, late-onset forms of dementia such as Alzheimer's disease (Tookey et al., 2022), as FTD often comes at a time when there may still be kids at home, care partners juggling full-time jobs, and limited financial resources.

Finding FTD-specific peer support can help to moderate aspects of FTD that are especially isolating and challenging. Care partners and persons living with FTD alike express appreciation for connecting with others who understand FTD. "It is nice to be with others who are going through a similar experience, and to know you are not alone," said Randy Ledbetter, a member of a support group run by an AFTD volunteer. Gary Radin, an AFTD support group volunteer, said that "support groups provide an opportunity to exchange practical advice, offer emotional support, and share

key resources." Having a community that understands what you are experiencing is key in coping with an FTD diagnosis and living with the disease.

Having a community that understands what you are experiencing is key in coping with an FTD diagnosis and living with the disease.

No one should have to face an FTD diagnosis alone. AFTD maintains a network of almost 75 in-person and virtual support groups throughout the country, run by AFTD-trained volunteers, that support care partners. In addition, AFTD has two national support groups for people living with FTD, and several groups developed for people in specific situations, such as having young children at home. AFTD's network of support groups can be found at theaftd.org/living-with-ftd/aftd-support-groups or by reaching out to the AFTD HelpLine at 1-866-507-7222 or info@theaftd.org.

Reference:

Tookey, S., Greaves, C.V., Rohrer, J.D. et al. Exploring experiences and needs of spousal carers of people with behavioural variant frontotemporal dementia (bvFTD) including those with familial FTD (fFTD): A qualitative study. *BMC Geriatr* 22, 185 (2022). <https://doi.org/10.1186/s12877-022-02867-1>

FTD OVERVIEW

Frontotemporal degeneration (FTD), which refers to a group of progressive neurological diseases affecting the brain's frontal and temporal lobes, is the most common cause of dementia for people under age 60. The FTD disorders are characterized by gradual deterioration in behavior, personality, language, and/or movement, with memory usually relatively preserved. FTD may also be referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease.

Clinical FTD diagnoses include behavioral variant FTD (or bvFTD), primary progressive aphasia (PPA), corticobasal syndrome (CBS), progressive supranuclear palsy (PSP), and ALS with FTD.

Specific symptoms and the course of disease can vary significantly across individuals, even within the same subtype.

Although the age of onset can range from 21 to 80, the majority of FTD cases occur between 45 and 64. The young age of onset substantially increases its impact on work, relationships, and the economic and social burden faced by families.

FTD is frequently misdiagnosed as Alzheimer's disease, depression, Parkinson's disease, or a psychiatric condition. On average, it currently takes 3.6 years to get an accurate diagnosis. There are no cures or disease-modifying treatments for FTD, and the average life expectancy is 7-13 years after the start of symptoms.

AFTD: James, did you feel adequately prepared for your PPA journey after receiving your diagnosis?

James: I definitely appreciated the insights they gave us about this disease and the things I needed to do to keep my brain healthy. I was so glad that they said to keep my brain healthy I should do lots of walking and running, because I already do those on a pretty regular basis.



Reesa: We got more resources during follow-up sessions. We meet with a neurologist every six months. They've talked about exercise and switching to a Mediterranean diet for brain health. They told us that James's food preferences might change, and that he may develop different food cravings as the disease progresses.

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LEGAL AND FINANCIAL PLANNING: WHAT'S DIFFERENT ABOUT FTD?

Due to FTD's typically younger age of onset, employment, health insurance, finances, and saving for retirement can all be impacted at a critical wage-earning period in one's life. Legal and financial matters should be considered and addressed as soon as possible following an FTD diagnosis.

FTD is currently a terminal disease, with no cure or disease-altering treatment. Providers should encourage families to pursue legal consultation and complete legal documents as early as possible to maximize the ability of the person diagnosed to participate in both short-term and long-term decision-making. Far too often families are told "to get their legal and financial matters in order," as if death is imminent. But as the FTD diagnostic process improves, with earlier diagnoses being made, people with FTD are increasingly able to participate in planning, and find it empowering. As the disease progresses, the person diagnosed will be less able to articulate their choices and preferences, so it is critical to get their input early on to ensure that their wishes are acknowledged.

Legal and financial planning is complicated, with rules and regulations differing by state. This article provides a broad overview of the unique legal and financial challenges that families with FTD can face. Most clinicians and healthcare providers already know of the

(see PLANNING, next page)

AFTD: What do you get out of support groups that's been helpful? Is it primarily emotional support; is it practical information?

Reesa: The most amazing thing has been just learning from other people who are going through the FTD journey, whether they are farther along or at the same place. We're both in support groups; James is actually in more than I am. Two of the groups are really just sharing things we've learned and talking about how we're coping. Another group will have doctors talk about research or new findings, or they might have a speech pathologist.

We've also gotten together with people in our support group socially, had potlucks and things like that. You kind of need people who understand what you're going through. As close as your family and friends are, unless you're actually going through it, it's just hard to understand.



AFTD: What about managing your finances and legal matters following the diagnosis? Were you provided with any information about what you need to do, who you need to contact?

Reesa: We were given some resources that we used as an overall to-do list. But the "how" part – no, that's harder. We became very expert at trying to navigate disability, both state and federal.

We were fortunate that we already had a financial planner, and she referred us to an estate attorney who had experience working with people who have dementia. As far as navigating the employment aspect, we've heard stories about people needing to contact employment attorneys if the employer is resistant to offering disability. James's employer was wonderful about it, but we've heard that's not always the case.

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important documents – durable power of attorney for finances and for health care, wills and living wills, trusts, etc. – that ensure one's medical and financial wishes are followed if one cannot speak for themselves. Such documentation is especially important for families living with FTD. Visit www.theaftd.org/living-with-ftd/legal-financial-planning for additional information.

FINDING AN ELDER LAW OR DISABILITY ATTORNEY

With FTD, the combination of impaired judgment, increased impulsivity, and decreased self-awareness can leave both the person diagnosed and their primary caregivers legally and financially vulnerable. An elder law or disability attorney is the best person to advise families on the protection of finances and consideration of health and long-term care expenses, as well as wills, powers of attorney, and/or guardianship. The National Elder Law Foundation (nelf.org) can help families locate an elder law attorney, while special needs or disability attorneys can be found through the Special Needs Alliance (specialneedsalliance.org).

FTD's symptoms can leave both the person diagnosed and their primary caregivers legally and financially vulnerable.

Families can also use AFTD resources such as our "Provider Letter" to help a legal advisor to better understand FTD and their family's challenges and needs (theaftd.org/wp-content/uploads/2021/05/Provider_Letter_Caregiver.pdf).

MEDICAL LEAVE OF ABSENCE FROM EMPLOYMENT

The initial presenting symptoms in FTD – affecting behavior, executive function, language, and/or movement – vary by individual, but FTD inevitably brings change and decline in cognitive functioning. As the disease progresses, the person affected may experience increasing difficulty in planning or organizing activities, behave inappropriately in social or work settings, or have trouble communicating with or relating to others.

(see PLANNING, next page)

AFTD: What sorts of clinical trials or research are you involved in?

Reesa: We've been involved in a number of studies. One of them was a speech therapy trial that James is still part of. We're part of an annual ALLFTD study. We're also in some wearable studies, where James wears a smartwatch that tracks his sleeping and other biometrics. He just started a drug trial.

"Our philosophy is just to say yes to [every research and clinical trial opportunity] because we want to be known by the researchers in the field."

James and I are on the same page on this – our philosophy is just to say yes to everything because we want to be known by the researchers in the field. I know that you've got to stay visible, and you need to keep rattling cages. The enthusiasm and the care of the people in the research setting has been amazing. They're young, they're excited, and they want to help. They're grateful to have a subject; we're grateful to have that interaction. It's been very rewarding.

AFTD: What were some resources that you didn't get initially that, looking back, would have really helped in the early days?

Reesa: If I had one wish it would be to have a meeting post-diagnosis with the entire care team, an hour where we could take our time, ask questions, get referrals. Give us a list: "Here are some people who are familiar with PPA; here are speech pathologists who are familiar with PPA." It would also be great to meet another couple or a family that is also living with FTD. Having a conversation with another family that has also gotten this news would be amazing: "You've been diagnosed too – now what?"

Healthcare professionals who understand the questions and adjustments that come with an FTD diagnosis can significantly shape a family's FTD journey.

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Changes in job performance or interpersonal issues at work often appear before a diagnosis is made. Symptoms that families notice at home will likely also be observed by colleagues or customers at work.

If the person with FTD symptoms or a diagnosis is still employed, families should consider whether requesting a medical leave of absence from employment is in their best interest. The Family and Medical Leave Act (FMLA) allows people to take up to 12 weeks of unpaid leave annually for family and medical reasons with continuation of group health insurance coverage. This may prevent an employer from terminating someone while they are in the process of getting a diagnosis or for taking the time needed to follow up on additional tests or medically necessary activities following a diagnosis.

DISABILITY AND REASONABLE ACCOMMODATION ON THE JOB

Due to greater general awareness of FTD, many people are being diagnosed earlier in the disease process, when there may be more options to continue to work. An individual's decision to stay at or leave their job should factor in their current abilities, an understanding of the disease, and the level of risk inherent in the person's position or responsibilities. Disclosing one's diagnosis is a personal decision; however, doing so could reduce the risk of the person being terminated. Additionally, being able to continue working can help one maintain a routine, mental stimulation, and access to benefits such as health insurance.

If a family decides to disclose an FTD diagnosis to the employer of the person affected, they can state that the person has a neurological condition and request reasonable accommodations through a formal written request with the help of a provider. The websites of the Americans with Disabilities Act (ada.gov) and the Job Accommodation Network (askjan.org) have samples and guidance for this request. Accommodations may include increased supervision, increased reminders, or additional time off for appointments.

WORKING WITH FTD CAREGIVERS: AMBIGUOUS LOSS AND FTD

By Mary O'Hara, LCSW

Pauline Boss, PhD, created the concept of ambiguous loss to explain a loss that lacks closure, clarity, and predictability. Ambiguous loss in FTD refers to the complicated experience of watching someone slowly lose their emotional and cognitive abilities while they remain physically present. This confusing experience complicates grief and can result in a caregiver's feelings of hopelessness, anxiety, guilt, depression, and uncertainty. Ambiguous loss freezes the grieving process and can block the family caregiver's ability to cope. If ambiguous loss isn't acknowledged or tended to, it compounds a caregiver's stress and may eventually affect their ability to provide effective FTD care.

Grieving and caregiving both take enormous energy. A family member caring for a person with FTD must do both. In death, loss is easily recognized; we allow people time and space to grieve, and offer our support as they try to gain a sense of closure. But in FTD, losses can begin long before death, and closure is therefore elusive. FTD caregivers are expected to tend to their loved ones while they are grieving; they do not have the time, permission, or opportunity to openly mourn. Understandably, FTD caregivers might not realize they are grieving, as they are forced to set those feelings aside to effectively perform the demanding tasks of daily care.

The emotional confusion caused by ambiguous loss can affect a caregiver's sense of confidence and competence, impacting their ability to make decisions, follow through with tasks, and take steps that are in the best interest of their loved one's health – or their own. This explains why family caregivers are sometimes unable to follow the recommendations of professionals. Know that caregivers are not intentionally ignoring your guidance; rather, simply getting through the day may be overwhelming for them.

While it can be frustrating when caregivers seem unable to take recommended actions to help their loved ones and themselves, it is important to recognize this as a normal part of their grief and to help them to name their experience. Educating families about ambiguous loss can help them understand what is happening and why they feel emotionally conflicted. Often, families are relieved to know there is a name for what they are experiencing. Getting them to understand how to build resilience can help them find ways to move forward and remain attentive to present needs and moments of joy.

Because of FTD's specific symptoms and its progressive nature, grief accompanies ambiguous loss and contributes to a significant portion of caregiver stress. Caregivers who get support in naming, understanding, and tending to these feelings stand to benefit as they continue their journey.

Learn about tasks to help build resilience on the next page.

PARTNERS IN FTD CARE ADVISORS

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts, and family caregivers. Advisors include:

- **Sandi Grow, RN**, former FTD caregiver, AFTD Board member
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AFTD extends special thanks to James and Reesa for generously sharing their story.

For permission to reprint this material in whole or in part, contact Esther Kane, AFTD Director of Support & Education, at ekane@theaftd.org. To join the Partners in FTD Care mailing list, or to view the full archive of back issues, visit www.theaftd.org/for-health-professionals/partners-in-ftd-care

WORKING WITH FTD CAREGIVERS (continued)

TASKS TO HELP BUILD RESILIENCE

Building resilience in the face of ambiguous loss can be helped by these six tasks:

1. ADJUSTING MASTERY

Recognize what we cannot control. Making a list of what you can and cannot control can be useful.

2. RECONCILING IDENTITY

“Who am I now that this happened? What is lost? What remains?” – make a list of each. “Can I stop comparing myself to the person I used to be? Can I stop clinging to what should have been? How can I begin to feel good about who I am?”

3. RECOGNIZING AND NORMALIZING AMBIVALENCE

Talking about ambiguous loss helps us legitimize it, and allows others to recognize our grief. This task involves recognizing that seemingly opposite modes of feeling can co-exist: heartbreak and gratitude; a lack of closure (and its attendant anxiety) and the anticipation of moving forward with new relationships and interests; grief for a future that will never come and hope for a new beginning.

4. REVISING ATTACHMENTS/RELATIONSHIPS

Building resilience requires building a community by forging new relationships with others who understand FTD. But it also requires reaching out to your existing community in an open way, by no longer hiding or downplaying the fact that FTD has become part of your life. Excessive avoidance limits our ability to find your way forward in a life changed by loss. By being more open and direct, we can change our relationship to FTD.

5. FINDING MEANING

Celebrate what remains. Creativity builds resilience. Opening yourself to new activities can prevent being locked into loss. Doing a values-focused exercise can help begin the search for meaning that is rooted in your values.

6. DISCOVERING NEW HOPE

Try to find hope to be able to live with the loss and still have a good life. Is there any post-traumatic wisdom that you can take from this experience?

REFERENCES AND RECOMMENDED READING:

Ambiguous Loss. www.ambiguousloss.com.

Boss, Pauline. *Loss, Trauma, and Resilience: Therapeutic Work with Ambiguous Loss*. 2006, New York: WW Norton & Company.

Boss, Pauline. *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief*. 2011, San Francisco: Jossey-Bass.

Managing Ambiguous Loss and Grief. www.alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/managing-ambiguous-loss-grief.

A PIVOTAL MOMENT IN FTD RESEARCH

Research into FTD has gained momentum in recent years, with numerous active clinical trials, observational studies, and other notable scientific advancements. Many promising therapies that seek to improve symptom management or slow down or stop disease progression are currently in development, as are urgently needed diagnostic tools and biomarkers. The promise is palpable, particularly for a fatal progressive disease with no currently approved treatments.

However, a pressing new concern has emerged. Will there be enough participants to allow this research to continue? At this pivotal moment, diagnosing physicians and healthcare providers can play a critical role in opening the door to research opportunities for persons diagnosed and their families.

Healthcare providers can play a critical role in opening the door to research opportunities for persons diagnosed and their families.

Approximately 40% of people diagnosed with FTD report a family history of related disorders, with 10% representing a genetic autosomal dominant transmission (Sirkis et al., 2019; Ramos et al., 2020). The demand for research participants is most critical for people with FTD caused by these genetic variants, particularly FTD cases caused by a variant in the *GRN* gene (FTD-GRN). The underlying pathophysiology in genetic cases is relatively better understood than in apparently sporadic cases, where there is no known familial relationship. Many FTD clinical trials, as well as observational studies, are specifically recruiting people with FTD-GRN (see **Table 1**).

Research participation opportunities are available for people diagnosed with all FTD clinical subtypes (behavioral variant FTD, primary progressive aphasia, progressive supranuclear palsy, corticobasal syndrome, and FTD-ALS), past and current caregivers, biological

relatives of people with FTD, and people with sporadic FTD. Current research opportunities vary widely in eligibility criteria, duration, types of interventions, and remote participation options.

Volunteering for research enables participants to access interventions, specialists, and assessments that may not be available as part of their routine medical care. Research participation can bring insights about their or their loved one's condition and allow them to play a more active role in their health care. Participating in research is also an opportunity to partner with researchers to bring us closer to better diagnostics, treatments, and even a cure.

Healthcare providers often serve as important connectors to research information for people living with FTD. Those who are aware of – and can make referrals to – research opportunities can help further FTD research. Persons diagnosed consider their clinicians' opinions one of the most important factors in deciding whether to try a new treatment (Association for Frontotemporal Degeneration, 2021). They also typically have ongoing relationships with their providers, and therefore a high degree of trust – essential elements in decision-making around research participation (Taft et al., 2019). Enrolling in research early in the disease progression is also important, as trials often target people in the earliest stages of FTD. Crucial trials will fail if they cannot recruit enough participants.

In addition to discussing traditional research opportunities early on, families should also be aware of genetic counseling (www.theaftd.org/ftd-genetics/no-cost-genetic-testing) and brain donation options (www.theaftd.org/research-clinical-trials/ways-to-participate/brain-donation), topics that can be difficult to discuss but are important for families to learn about.

Resources exist for both healthcare providers and families to stay informed of current research opportunities. People diagnosed with FTD, care partners, family members, and friends can enroll in the FTD Disorders Registry.

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The Registry is designed to inform this community about research opportunities and match people to appropriate studies actively seeking participants (ftdregistry.org). Registry participants retain full control over their identifying information, which is never shared. Healthcare providers can also sign up for the FTD Disorders Registry newsletters, which provide key updates in FTD research (www2.ftdregistry.org/allied-pros-list).

Families and professionals can also sign up for AFTD newsletters to stay informed about research opportunities and progress (theaftd.org). Additionally, families should consider finding out if they are eligible for ALLFTD, a multisite natural history study that is fundamental to enhancing our understanding of FTD (allftd.org).

Scientists are closer than ever to new FTD therapies and diagnostic tools. We all have a role to play in helping the research succeed.

DRUG	COMPANY	INDICATION
AL001	Alector	FTD-GRN and asymptomatic GRN carriers clinicaltrials.gov/ct2/show/NCT04374136?term=al001&draw=2&rank=3 or click here
WVE-004	Wave Life Sciences	FTD/ALS caused by C9orf72 variant clinicaltrials.gov/ct2/show/NCT04931862?term=focus-c9&draw=2&rank=1 or click here
PR006	Prevail Therapeutics	FTD-GRN http://clinicaltrials.gov/ct2/show/NCT04408625?term=pr006&draw=2&rank=1 or click here
PBFT02	Passage Bio	FTD-GRN http://clinicaltrials.gov/ct2/show/NCT04747431?term=PBFT02&draw=2&rank=1 or click here
TPN-101	Transposon	FTD/ALS caused by C9orf72 variant http://clinicaltrials.gov/ct2/show/NCT04993755?term=tpn-101&draw=2&rank=1 or click here
DNL593	Denali	FTD-GRN http://clinicaltrials.gov/ct2/show/NCT05262023?term=dnl593&draw=2&rank=1 or click here

Table 1. A sample of trials currently recruiting for people with genetic FTD (as of July 2022)

REFERENCES:

The Association for Frontotemporal Degeneration (2021). *Frontotemporal Degeneration (FTD): A Voice of the Patient Report*. https://www.theaftd.org/wp-content/uploads/2021/10/AFTD_Voice-of-the-Patient-Report-10.27.2021.pdf

Ramos, E. M., Dokuru, D. R., Van Berlo, V., Wojta, K., Wang, Q., Huang, A. Y., et al. (2020). Genetic screening of a large series of North American sporadic and familial frontotemporal dementia cases. *Alzheimer's & Dementia*, 16(1), 118–130.

Sirkis, D. W., Geier, E. G., Bonham, L. W., Karch, C. M., & Yokoyama, J. S. (2019). Recent advances in the genetics of frontotemporal dementia. *Current genetic medicine reports*, 7(1), 41–52. <https://doi.org/10.1007/s40142-019-0160-6>

Taft, T., Weir, C., Kramer, H., & Facelli, J. C. (2019). Primary care perspectives on implementation of clinical trial recruitment. *Journal of clinical and translational science*, 4(1), 61–68. <https://doi.org/10.1017/cts.2019.435>

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

DEMANTIA ACTION ALLIANCE

www.daanow.org

An advocacy organization dedicated to changing the stigma of dementia.

DEMANTIA 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 DEMANTIA 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.