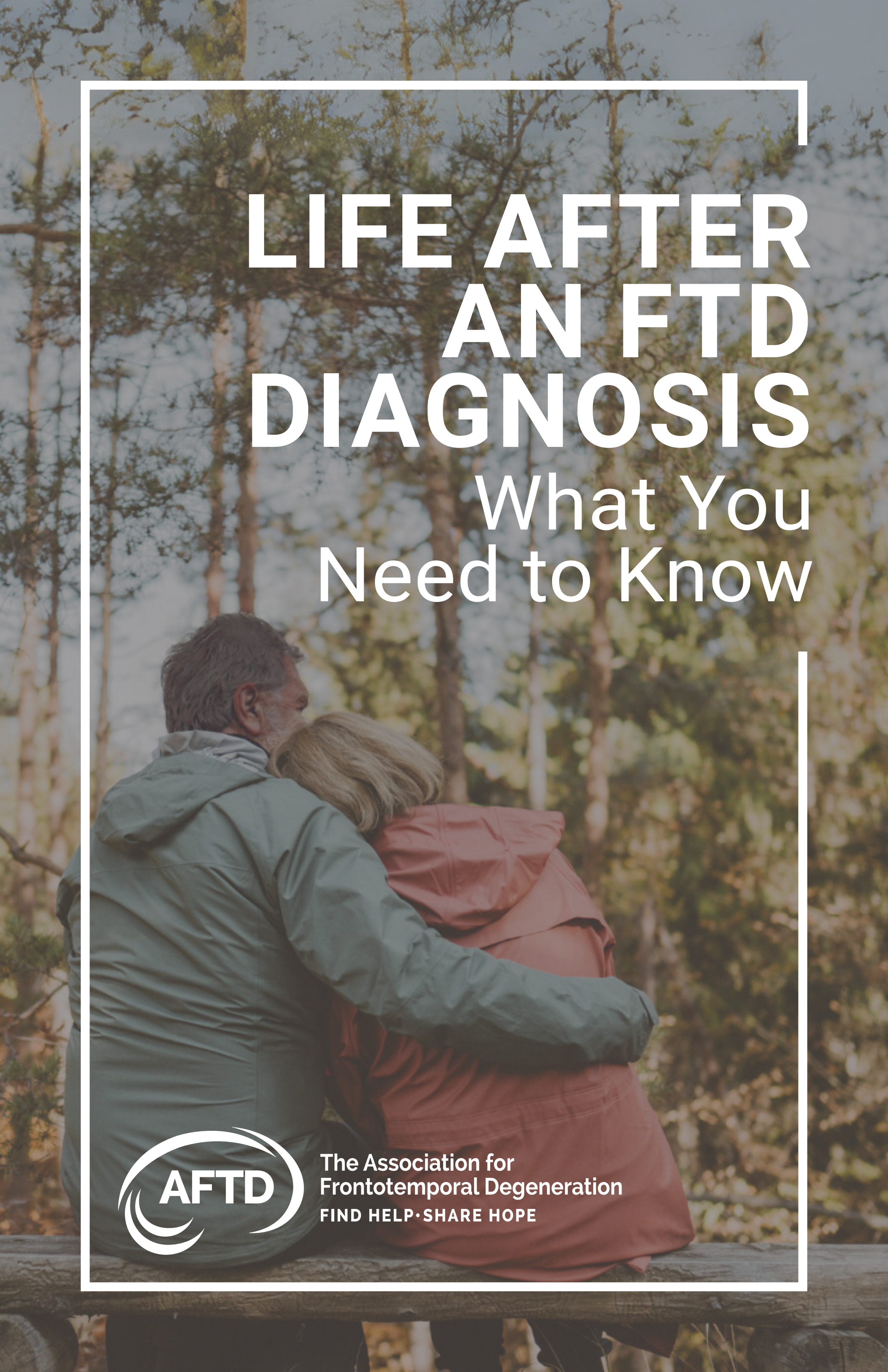


# LIFE AFTER AN FTD DIAGNOSIS

## What You Need to Know

AFTD

The Association for
Frontotemporal Degeneration
FIND HELP·SHARE HOPE

## You are not alone.

We recognize that the emotional toll of receiving an FTD diagnosis can leave you feeling overwhelmed and unsure of where to begin. Nothing can truly prepare you for a diagnosis of FTD (frontotemporal degeneration). While the diagnosis may begin to explain confusing changes in language, behavior, or personality, it also brings a wave of uncertainty and difficult questions about the future.

Too often after diagnosis, people are told there's nothing that can be done; they leave their doctor's office without hope or guidance. But that is far from the full story. You are not alone in this. The Association for Frontotemporal Degeneration (**AFTD**) is here to help. This booklet is here to support you as you begin to find your footing and discover the resources and growing community that are available to help you.

AFTD is committed to providing the information, guidance, and connection you need to navigate this diagnosis. Each year, researchers make strides toward understanding FTD and developing effective treatments. Support networks and available resources continue to expand.

It's important to take time to process your emotions, grieve, and create a plan for your own emotional care. This might include pausing before sharing the diagnosis widely and identifying a trusted inner circle to support you during this time.

While family and friends are crucial, connecting with others who understand the FTD journey can be transformative. Grief often evolves as the disease progresses, and having a support system in place can provide lifelines to help you navigate these transitions.

This booklet reflects the experiences of thousands of people affected by FTD, along with insights from professionals in the field. By taking proactive steps and building a network of support, you can navigate the challenges of FTD with greater confidence and resilience.

Sincerely,
AFTD

# Table of Contents

# I.

# Overview of FTD

FTD represents a group of brain disorders caused by degeneration or shrinking of the frontal and/or temporal lobes of the brain. It is also frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration, frontotemporal neurocognitive disorder or Pick's disease. The clinical subtypes of FTD include:

- Behavioral Variant FTD
- Primary Progressive Aphasia:
    - Nonfluent/Agrammatic variant
    - Semantic variant
    - Logopenic variant
- FTD-ALS
- Corticobasal Syndrome
- Progressive Supranuclear Palsy

Scan to view
AFTD's Disease
Overview

The most reliable estimates suggest that between 50,000 and 60,000 people in the U.S. have an FTD disorder. However, diagnosing FTD is challenging due to a lack of biomarkers and clinicians' unfamiliarity with FTD; experts in the field believe this figure may be an underestimation.

While FTD is considered a rare disease based on these estimates, awareness is growing. AFTD has built a community of families, health professionals, researchers, and policymakers advocating for greater understanding and support for everyone impacted by FTD.

While FTD disorders can occur in adults of any age, they are commonly diagnosed between the ages of 45-64. FTD therefore can have a greater impact on work, family, and finances than Alzheimer's disease, which tends to appear later in life.

## Life After an FTD Diagnosis

FTD is a progressive disease; as time passes, symptoms continue to increase and impact other areas of functioning. Often, the first indications of FTD are overlooked or dismissed as someone simply misspeaking or acting out of character. But as FTD progresses, it becomes increasingly difficult to plan or organize activities, behave appropriately in social or work settings, and care for oneself, resulting in increasing dependency. Changes to one's behavior and personality, along with difficulties in language and movement, are FTD's hallmark symptoms—unlike Alzheimer's disease, which is primarily characterized by memory loss.

FTD is often misdiagnosed as a different dementia (such as Alzheimer's), some other type of neurological disorder, or a mental health condition such as depression or bipolar disorder.

Having an accurate diagnosis is important—it helps you connect with support, resources and information, make a care plan, evaluate treatment options, and identify opportunities to participate in research. But FTD disorders are difficult to diagnose confidently.

AFTD has created diagnostic checklists to help families get an accurate diagnosis by identifying red flags to physicians. People with questions about their diagnosis should pursue a second opinion at a medical center specializing in cognitive disorders. At minimum, AFTD recommends an assessment with a neurologist, behavioral neurologist, or neuropsychologist familiar with neurodegenerative diseases. Use AFTD's Diagnostic Locator to find centers with a focus in FTD.

Scan to view
AFTD's Diagnostic
Locator

> "Around the time I was in high school, my dad started exhibiting a very odd stutter. At first, we thought it was just age, everyone does this as they age."
>
> **Mason G.**

## CAUSES OF FTD

FTD is caused by the abnormal accumulation of proteins in the frontal or temporal lobes of the brain, which leads to nerve cell death and atrophy or shrinkage of those brain regions. **The most common proteins that cause FTD are TDP-43, tau, and FUS.** These proteins can be associated with any of the FTD clinical subtypes and are not predictive of any single set of symptoms.

In approximately **60% of people diagnosed**, we do not yet understand how or why these proteins accumulate. However, the remaining **40% of people diagnosed** have a family history—blood relatives had either FTD or a related condition (such as ALS, atypical Parkinson's, a mental health condition, or language difficulties). This is called familial FTD.

Today, roughly half of those with familial FTD have an identifiable genetic cause in one of more than a dozen genes. **Variants of the *MAPT, GRN,* and *C9orf72* genes account for the majority of genetic FTD.** Several genes, including *C9orf72,* cause FTD and/or ALS. When learning about FTD, many have questions and concerns about family risk. Additional information about the genetics of FTD can be found on AFTD's website and by reaching out to the AFTD HelpLine.

## STAGES OF FTD PROGRESSION

FTD affects each individual brain differently and each case develops at its own pace and sequence, with symptoms varying in type and intensity, often even within the same FTD clinical subtype. The life expectancy of someone diagnosed with FTD is 7 to 13 years on average, but can range from 2 to 20 years after onset. FTD's progression can be broadly organized into mild, moderate, or late stages:

### Early or mild stage

- Symptoms begin to develop gradually, often in one category of functioning such as behavior and personality, language and communication, or motor symptoms.
- The person can still complete their daily routine with little assistance and may be able to compensate for early symptoms.

### Middle or moderate stage

- Symptoms begin to impact multiple areas of functioning. For example, a person whose first symptoms affected their behavior may start to experience language difficulties such as word finding.
- The person requires increasing supervision and support to complete their daily routine and personal care needs.

### Late or advanced stage

- The person is dependent upon others for their daily routine and personal care.
- Symptoms affect multiple areas including behavior, language, and motor skills.
- Swallowing issues, falls, and infections can become frequent concerns.
- Support from care professionals and hospice services is often needed to support family care partners.

# II.

# Sharing the Diagnosis

While an FTD diagnosis provides clarity, it does not ensure that others will accept and understand that FTD is the true cause of behavioral changes and other symptoms.

Everyone will bring their own history with the person diagnosed and will have their own unique reaction. Understanding an FTD diagnosis takes time, and while some relationships may be tested, others will be strengthened.

Deciding when and how to share the diagnosis is a personal choice: Those who choose to tell others what they are facing may feel empowered and find themselves better able to gain support, but family situations and support systems vary tremendously. The lack of insight that often accompanies FTD may be a hurdle; the person may not recognize their symptoms or want to acknowledge having FTD at all.

Consider first reaching out to family, friends, and others in your network who you trust will be willing to learn about the diagnosis and provide help throughout the FTD journey. Start by offering information and giving a basic outline of what you know, acknowledging that you may still have your own questions about the diagnosis. Use information and resources from AFTD and refer others to AFTD's website and HelpLine if they have additional questions. Share that AFTD's network of support is available to everyone impacted.

Before FTD is correctly diagnosed, unexplained behavioral or personality changes may create confusion, anger, and frustration among family and friends. Professional colleagues may disengage, familial relationships may become strained, and marriages may even end. Each person's experience with FTD is unique, and relationships can be affected in different ways:

**Person with FTD diagnosis**

- While some may not be aware or recognize all of the changes FTD brings, many will experience feelings of grief and loss, including changes in employment and independence, and benefit from support options.
- Peer support can help connect with others who understand. Finding ways to make meaningful contributions to family and community can ward off the isolation that diagnosed persons often feel.

> "Explaining that my mom had FTD sparked a conversation I didn't expect. Some people were genuinely curious about her experience and others commented relating to our journey. The response encouraged me to continue sharing because of how much it resonated."
>
> **Nicole P.**

**Spouses or partners of persons with FTD**

- Often the main care partner.
- Symptoms can lead to changes in companionship and intimacy. Many changes may be difficult or embarrassing to talk about with family and friends, leading to increased feelings of isolation.
- Spouses often experience role changes, including management of household tasks, decision making, and care management, that were previously shared. Some may have to consider changes in their own employment due to caregiving responsibilities.
- May experience difficult emotions including guilt, anger, loneliness, disappointment, and grief. Connect with other care partners for support and remain connected with your own health care team for your self-care and health needs. Individual counseling can help support emotional care and coping skills.
- Often navigating varying family dynamics, including in situations of second marriages where step-children may be involved as primary care partners as well.

**Young adult or adult child of person with FTD**

- A person's response to the diagnosis and changes is often shaped by the frequency of contact, amount of direct care, and their personal, work, or family situations.
- Siblings in a family may respond differently to the diagnosis and parents' needs. Each has a different relationship with their parents.
- Faces many difficult emotions including guilt or anger, concern, disappointment, and grief. Connect with support options specifically for young adults or adult children with a parent with FTD.
- May face difficult choices about postponing future goals or life changes to care for parent.

### Parents caring for an adult child with FTD

- Parents managing care face unique emotional and practical issues.
- Even if they are retired, coping with the logistics, physical demands, and financial costs of caregiving is stressful.
- Personal medical and emotional health are important to maintain.

### Families with children in the home

- Having young children or teens in the home adds many emotional, practical, and financial considerations.
- Take steps to communicate what is happening with children honestly at an age-appropriate level, and support their growth and development.
- Enlist the help of family, friends, and trusted adults to maintain balance in the family and attend to each person's well-being.

### Long-distance or secondary care partners: Siblings, extended family and friends, coworkers, colleagues

- Limited in-person contact makes it difficult to appreciate and understand the impact of FTD on the person and primary care partners.
- May have many unanswered questions if limited information is provided.
- Learn as much as possible about FTD from reputable sources and trust the main care partner's perspective. Many symptoms can be difficult to talk about and the primary care partner may be navigating more than you realize.
- May feel unsettled and not know what to do with the changing relationship. Identify a specific, practical way you can help, such as providing meals, helping with household tasks, researching resources and information, or making phone calls.
- Often difficult for the main care partner to initiate or maintain contact; a call, text, or card to say you are thinking of them is helpful.

### Ex-spouses or ex-partners

- There are some couples who may have separated or divorced, sometimes before a diagnosis has been made. This can be related to FTD's impact on personality and behavior and the often long journey to diagnosis, or may have been related to an issue separate from the changes FTD caused.
- Ex-spouses often face unique emotions and questions. They must often consider if and how they may be involved in supporting the person with FTD over time.
- Ex-spouses may be supporting adult children who are primary care partners.

> "I have learned that many of the issues I have are not unique!! They only seem that way because most individuals I am networked with are not in the world of FTD. It is such a relief to know this. This is helping me feel more empowered and much less inadequate in my struggles."
>
> **Person disgnosed with FTD**

# III.

# Adjusting to Life with FTD

Every person, family, and care partner has unique strengths and can make meaningful choices to guide the path forward on the FTD journey. While there may be moments when it all feels overwhelming, there will also be opportunities to find new meaning and shared joy. Reflect on your core values, goals, and cherished relationships—and consider ways to keep them at the center of your life.

To the right are links to lessons learned from persons diagnosed and experienced caregivers.

Lessons Learned
as a Person
Diagnosed with FTD

Lessons Learned
as an FTD
Caregiver

## HEALTH AND WELLNESS

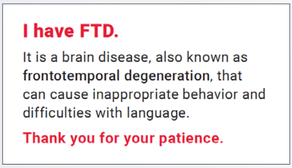
As public awareness grows and diagnostic tools improve, more individuals are being diagnosed with an FTD disorder earlier, when symptoms are still mild. While lifestyle changes cannot stop, slow, or reverse the progression of FTD, staying as healthy and active as possible can support overall physical health as well as mental and emotional well-being.

Although there is limited research on the specific benefits of healthy habits in FTD, studies in other types of dementia suggest that good nutrition and lifestyle choices may reduce the risk of heart disease and help support brain health. A “heart healthy” or “brain healthy” diet—low in saturated fats and cholesterol and rich in fruits and vegetables—can contribute to overall well-being.

Incorporating proper nutrition, regular physical activity, and stress management may help maintain a healthy weight, support healthier sleep patterns, and lower the risk of diabetes and cardiovascular issues, both of which can impact brain function. These habits may also help the unaffected areas of the brain function as effectively as possible.

## AFTD AWARENESS CARDS

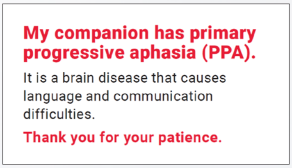
In an effort to help people with FTD and their care partners when in public settings, AFTD has created wallet-sized “awareness cards.” These cards let anyone you may encounter in public – servers, receptionists, law enforcement officials, etc. – know that the language ability and behavior of you or your loved one may be altered due to the disease.



**I have FTD.**

It is a brain disease, also known as **frontotemporal degeneration**, that can cause inappropriate behavior and difficulties with language.

**Thank you for your patience.**



**My companion has primary progressive aphasia (PPA).**

It is a brain disease that causes language and communication difficulties.

**Thank you for your patience.**

**Learn more about FTD**

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

## STAYING ENGAGED WITH DAILY ROUTINE

Staying engaged in enjoyable, meaningful, and mentally stimulating activities is important for persons living with FTD and their care partners to promote quality of life. Engagement for the person with FTD should reflect their personal interests and may need to evolve over time as abilities and needs change. Anticipate and plan for transitioning out of work—this can bring a sense of loss and disrupt daily routines and social engagement.

Finding ways to maintain social connections and adapt former interests into new, accessible activities can help preserve a sense of identity, engagement, and purpose. Volunteer activities can also provide opportunities for meaningful contribution and connection with others.

Creating predictable daily routines provides stability and comfort for both the person with FTD and their care partner. Try to maintain consistency in everyday activities like meals, household tasks, exercise, hobbies, social time, and spiritual practices.

## ADAPTING TO CHANGING NEEDS

People living with FTD often have trouble with planning, organizing, and completing tasks, so family members and friends may need to take the lead in initiating and guiding activities—while remaining flexible along the way. Because FTD can progress in unpredictable ways, being open to trying new strategies or adjusting approaches is essential.

To ensure activities remain appropriate and engaging, observe any changes in the person's abilities and increase support or supervision as needed. Adjusting your expectations—and helping others do the same—can ease frustration and promote more positive interactions. For those who don't see the person regularly, cognitive and communication challenges may not be obvious at first. The care partner's approach and attitude can help guide others in how to respond with understanding and respect.

As symptoms advance, remember that meaningful engagement doesn't have to be complex. Simply listening to music, watching birds, or spending time outdoors can provide comfort and enjoyment.

## ADDRESS SAFETY ISSUES

FTD symptoms can affect a person's safety both at home and in the community. These changes may involve behavior, communication, or physical care needs, and the needs may shift over time as different abilities are impacted. Not everyone diagnosed will engage in high-risk behaviors, but staying aware of potential safety concerns—as well as the signs and symptoms—can help inform safety planning and ensuring appropriate support.

Often, people with FTD can function well in some areas while experiencing significant challenges in others, which can make it harder to determine when additional help is needed. The person with FTD may not recognize their own declining abilities or changes in judgment and might perceive safety measures as threats to their independence, leading to frustration and resistance. For this reason, care partners can benefit greatly from the guidance and encouragement of healthcare teams, support groups, friends, and family.

## BEHAVIOR AND PERSONALITY CONSIDERATIONS

Changes in personality, behavior, and judgment are common features of FTD. These changes can be distressing, unpredictable, and often starkly different from a person's past behavior. Symptoms such as impaired self-awareness, impulse control, decision making, and loss of empathy can create safety, social, legal, and financial risks for the person and their family.

Common behavioral changes include:

- **Apathy without sadness** – A loss of interest or motivation without feeling sad, often mistaken for depression.
- **Loss of empathy** – Seeming indifferent or emotionally detached, which may upset or confuse others.
- **Behavioral disinhibition** – Inappropriate comments or actions, such as touching strangers, shoplifting, impulsive spending, inappropriate sexual behavior or in some cases, concerns related to self-harm.
- **Mood instability** – Sudden irritability, anger, or aggressive outbursts.
- **Poor judgment and executive dysfunction** – Risky decisions at work or home, susceptibility to scams, questionable financial choices.
- **Compulsive or ritualistic behavior** – Repeating words or actions, hoarding, roaming, pacing, or obsessive routines.
- **Hyperorality** – Changes in oral behavior or eating habits, including compulsive eating or drinking, especially sweets or alcohol.
- **Disorientation and confusion** – Wandering, getting lost, or appearing disoriented.
- **Lack of insight** – Difficulty recognizing or accepting their own changes, leading to resistance or blaming others. These behaviors can pose significant challenges for care partners.

As symptoms progress, increasing levels of supervision and structured support may be needed. While managing behavioral symptoms can be overwhelming, proactive planning and a strong care network can significantly reduce risk and help maintain quality of life for everyone involved.

For more information, watch the AFTD Educational Webinar “Person-Centered Care for Behavioral Variant FTD,” available on AFTD’s YouTube channel.

Scan to watch the AFTD Educational Webinar

## COMMUNICATION CONSIDERATIONS

Communication challenges are common across all forms of FTD, but they are especially pronounced in individuals diagnosed with a variant of primary progressive aphasia (PPA). These conditions impact a person’s ability to produce and understand language, with symptoms generally falling into two categories: **apraxia** (difficulty producing speech) and **aphasia** (difficulty with word recall or grammar). Many people experience a mix of both.

Common changes may include:

- Slow, labored speech
- Pauses and hesitation while speaking
- Omitting or mixing up words in a sentence
- Speaking in shorter, simpler sentences
- Difficulty naming objects or people, or relying on lengthy descriptions to replace missing words
- Trouble understanding complex sentences
- Gradual decline in speaking and comprehension, which may eventually lead to complete loss of speech

Although individuals may function independently in the early stages, growing difficulty with asking for directions, responding to emergencies, or expressing needs can present safety concerns. It’s recommended that the person wear a medical ID or alert bracelet and carry a communication card—such as AFTD’s PPA awareness cards—that includes their name, address, diagnosis, and emergency contact information.

Communication changes can lead to frustration, anxiety, depression, or social withdrawal. Supporting emotional well-being and maintaining social connections is vital. A speech-language pathologist can provide valuable support, assessing communication needs and offering strategies such as using writing pads, picture books, alternative augmentative communication (AAC) devices, voice banking, and other assistive technologies to help extend and support verbal abilities.

Scan to watch the AFTD Educational Webinar

For more information, watch the AFTD Educational Webinar "Maximizing Communication, Maintaining Connection," available on AFTD's YouTube channel.

> "Being a millennial caregiver can be incredibly isolating because it doesn't represent the quintessential American experience. It can be really difficult to find people to relate to what you're going through."
>
> **Aisha A.**

## MOVEMENT AND MOBILITY CONSIDERATIONS

Progressive changes in movement are common in several forms of FTD, particularly in conditions like **corticobasal syndrome (CBS), progressive supranuclear palsy (PSP), and FTD with motor neuron disease (FTD-ALS)**. Individuals may develop stiffness, slowness of movement, shuffling gait, tremors, balance problems, and increased risk of falls.

Symptoms may include:

*Parkinsonism-related features*

- Difficulty with balance or walking; rigidity and tremors
- Slowness or stiffness in movement
- Impaired eye movements, especially vertical (downward) or horizontal gaze, particularly in PSP
- Difficulty initiating or coordinating limb movement (limb apraxia), particularly in CBS

*Motor neuron (ALS-like) symptoms*

- Muscle weakness, twitching, or visible muscle wasting
- Trouble lifting arms, using hands, or performing fine motor tasks (e.g., buttoning, writing)
- Changes in walking stride or speed
- Drooling, difficulty swallowing (dysphagia), and slurred or slowed speech

These mobility and motor control issues can significantly affect safety and independence, increasing the risk of falls, injury, and complications like aspiration pneumonia due to swallowing difficulties. As the condition progresses, physical and occupational therapy can help people stay active and safe for as long as possible. Therapists can recommend adaptive strategies, mobility aids, and home modifications tailored to individual needs.

Additionally, movement disorder specialists can support the management of motor symptoms, while speech-language pathologists (SLPs) can offer personalized approaches to address speech and swallowing difficulties, helping to reduce choking risk and maintain proper nutrition.

For more information, watch the AFTD Educational Webinar “Person-Centered Care for Corticobasal Syndrome and Progressive Supranuclear Palsy,” available on AFTD’s YouTube channel.

Scan to watch the
AFTD Educational
Webinar

## DRIVING CONSIDERATIONS

Persons with FTD will eventually need to stop driving, but determining the right time can be challenging. Driving laws and reporting requirements vary by state, so it's important to contact your local Department of Motor Vehicles (DMV) or equivalent agency for specific guidance.

Additional points to consider:

- In many states, any individual—not just healthcare providers—can report concerns about someone's driving ability.
- Some states offer specialized programs, often through the state office on aging, that provide resources and guidance on driving safety.
- In some areas, there are driver evaluation programs offered by occupational therapists to assess a person's ability to drive.
- A dementia diagnosis may affect auto insurance, including potential increases in premiums or cancellation of coverage.

  Because of impaired judgment and insight, some individuals with FTD may continue to drive—or attempt to—even after their license has been revoked. In such cases, families need to take steps to limit access to vehicles to ensure safety.

# IV.

# Planning for Legal, Financial, and Health Insurance Issues

It is important to address legal, financial, and insurance considerations as quickly as possible so that the person diagnosed can make their wishes known and participate in planning.

## LEGAL PROTECTIONS

Consulting an attorney can help people diagnosed and their families understand their rights and protections under U.S. law.

- **Americans with Disabilities Act (ADA)** - offers protections for people with disabilities, including the right for reasonable workplace accommodations. FTD is recognized as a disability under the ADA.
- **Employee Retirement Income Security Act (ERISA)** - focuses on regulating and protecting employee retirement and health benefit plans, ensuring their proper management and accessibility to employees when they retire.
- **Family and Medical Leave Act (FMLA)** - allows eligible employees who are FTD caregivers to take up to 12 weeks of unpaid leave in a 12-month period to care for an immediate family member with a serious health condition, such as FTD.
- **Genetic Information Nondiscrimination Act (GINA)** - protects individuals from having their genetic information used to justify the denial or limitation of services.
- **Consolidated Omnibus Budget Reconciliation Act (COBRA)** - requires employees who lose coverage under their employer's group health plan to remain covered for up to 18 months, although they must pay the premium themselves, plus an administrative fee.

## LEGAL DECISION-MAKING POWERS

People living with FTD should designate someone who will ensure their wishes are respected regarding financial and healthcare decisions, including end-of-life care. It is important to discuss these options with an attorney as soon as possible after diagnosis so that the individual with FTD can participate in the process.

- **Power of Attorney (POA)** - a legal document that authorizes another person to make medical and/or financial decisions on your behalf. POAs are only enforceable if signed by an individual who is deemed legally competent at the time. Make sure that your POA is classified as durable (meaning it applies even after the individual becomes unable to make decisions) or springing (meaning it takes effect once the individual loses their decision-making ability). Otherwise, POAs can be terminated when the person becomes incapacitated. Forms and laws can vary by state.
- **Advance Directive** - Legal documents that tell medical providers and loved ones about an individual's wishes for medical treatment and services. Forms and laws can vary by state. These documents can include:
    - **Living will** – a document that shows the person's wishes regarding life-sustaining treatment at the end-of-life.
    - **Health care proxy or medical power of attorney** – designates another person to make medical decisions on your behalf.
- **Guardianships and Conservatorships** - a legal arrangement in which a family law judge appoints a third party to make decisions for an individual who is deemed unable to manage their own affairs. Laws and proceedings can vary based on your state. The incapacitated individual has no legal rights under this arrangement. This is an extreme step often involving contentious and expensive legal proceedings, and should only be considered after all other options have been explored.

## FINANCIAL ASSISTANCE

People diagnosed with FTD who live in the U.S. may be entitled to a variety of state and federal benefits. Consult an attorney and financial planner to help you understand and apply for these programs, or if your benefits are denied and you want to file an appeal.

- **Social Security Disability Insurance (SSDI)** - provides financial assistance depending on one's work history. People with FTD who have not reached retirement age should apply, and certain family members may also qualify. Everyone who qualifies will be automatically enrolled in Medicare after 24 months.
- **Supplemental Security Income (SSI)** - provides financial assistance to those with limited or no income or assets who either live with a disability or are 65 or older. Eligibility varies by state. Unlike SSDI, SSI is not contingent on work history.
- **Compassionate Allowances (CAL)** - expedites the application process for disability benefits for people with a terminal disease, such as FTD. CAL does not affect the type or amount of benefits received.

## HEALTH INSURANCE COVERAGE

Many people diagnosed with FTD lose their employer-sponsored health insurance yet are too young to qualify for Medicare. Alternative health insurance options include:

- **Medicare** - the federal healthcare program for U.S. citizens over 65, or for adults with a disability who have received SSDI for 24 months. All citizens are automatically enrolled in Medicare after turning 65, but you must apply to a Medicare program to receive benefits. Medicare does not cover the cost of long-term residential or custodial care. Visit medicare.gov to learn more.
- **Medicare Supplemental Insurance (Medigap)** - many individuals choose to purchase a Medigap policy from a private insurance company to cover care not included in Medicare. These policies may also cover Medicare premiums, co-payments, and other costs.

- **Medicaid** - a joint federal and state program providing health coverage for individuals and families below a certain income level. Eligibility, benefits, and available programs vary by state and are based on income and asset limits. Unlike Medicare, Medicaid includes programs that cover the cost of long-term residential care. An attorney can help navigate the Medicaid application process, including questions involving dual eligibility for Medicare and Medicaid.
- **Other Health Coverage Options** - For those who are ineligible for both Medicaid and Medicare, health insurance options may include coverage through a spouse's employer, COBRA (Consolidated Omnibus Budget Reconciliation Act), or a previous employer. You can also purchase a policy through the state health insurance marketplace: visit healthcare.gov to learn more.
- **Veterans Affairs (VA) Benefits** - All military veterans are eligible for healthcare through the U.S. Department of Veterans Affairs; the programs and services available depend on type of active duty and service (during wartime or in armed combat). For more information, contact your nearest VA office.
- **ALS VA Benefits** - The VA classifies some health conditions as service-related if they can be shown to be a result of active duty; these qualify for more comprehensive services. Starting in 2008, the VA presumes diagnoses of ALS to be service-related.
- **Long-Term Care Insurance** - can help pay for services to assist with daily living but it needs to be in place before health issues occur and therefore cannot be purchased after an FTD diagnosis.

> "She was not able to handle any finances, [or] pay her bills. So consequently, we had to bring her home, shut down her Pilates studio and take care of everything financially."
>
> **Caroline**

## FINDING AN ATTORNEY/FINANCIAL CONSULTANT

To find an attorney who is right for your family, use networks like the National Academy of Elder Law Attorneys or your local bar association. Be sure they practice in your state, as laws can differ throughout the U.S. You can also ask for suggestions from other care partners to find an attorney who is familiar with the needs of families with FTD. There are different types of legal/financial professionals that you can consult:

- **Elder Law Attorney** - can help with issues like Social Security and disability benefits, decision-making powers, retirement planning, and preparing documents such as power of attorney, wills, and advance medical directives.
- **Employment Law Attorney** - can help with questions about job loss due to FTD and how family members can use the FMLA to care for the person with FTD. FMLA also allows eligible employees with serious health conditions to take temporary unpaid leave if they are unable to perform the functions of their job.
- **ERISA Attorney** - can help the person with FTD preserve employee retirement and health benefits after they become unable to work.
- **Disability Attorney** - can help navigate the SSDI and SSI application processes.
- **Financial Planner** - can help organize your financial resources and explain your long-term payment options.

# V.

# Research: How You Can Help

Research is a wellspring of hope for people impacted by FTD. Over the last several years, there has been significant progress in FTD research, including advances in diagnostic evaluation, understanding of the pathology and genetics of FTD, and evaluation of potential treatments. Research participants play a vital role in that work.

People help for a variety of reasons. Contributing to research may:

- Provide you access to interventions (such as drugs, treatments, medical devices, etc.) or FTD specialists and assessments that might not otherwise be available.
- Further our understanding of how to diagnose, prevent, treat, or cure FTD in yourself and others, including future generations.
- Give you a deeper understanding of your own FTD.

There's no shortage of opportunities to participate, ranging from completing surveys from home, to undergoing regular testing to see how FTD changes over time. You and your family might take part in studies of behavioral interventions and the best ways to provide education and support to caregivers. One of the most important types of research is clinical trials.

> "I'm grateful we had the chance to take part in FTD research — it gave us a sense of purpose during a time when everything felt uncertain."
>
> **Doris L.**

## CLINICAL TRIALS

Clinical trials are a type of research conducted to determine the safety and effectiveness of new medical interventions. The last few years have seen enormous growth in clinical trial opportunities for FTD, including studies testing medications that have the potential to stop or slow its progression. Every clinical trial is different in what it asks of participants and in its potential benefits and risks.

Many current FTD clinical trials are testing interventions for genetic causes of FTD (e.g., FTD-GRN) or specific types of FTD (e.g., PSP) for which scientists have a better understanding of the cause. Learnings from these clinical trials can lead to interventions for all causes of FTD, both genetic and sporadic. To get information about which FTD clinical trials need participants, join the FTD Disorders Registry (below), or check out Clinicaltrials.gov, a public database of funded studies on a wide range of diseases and conditions maintained by the U.S. National Institutes of Health.

The best time to think about enrolling in FTD research studies is early in the disease course, when travel, tolerance for assessment, and follow-up are more feasible. You might also consider brain donation; brain tissue can help scientists develop treatments and diagnostic tools targeting the microscopic pathology that causes FTD.

Let your clinical team know if you and your family are interested in any of these research opportunities.

## GENETIC FTD TESTING

Many studies focus on genetic causes of FTD, despite research showing that about 60% of people diagnosed have no genetic cause. There are several reasons genetic research is so important. When a genetic cause is identified, scientists can be certain the diagnosis is correct. Additionally, when scientists understand the function of the gene that causes FTD, they can target the specific effects of the gene.

Genetic testing has broad research applications but can have highly personal implications. For example, results for one family member may reveal information about another relative. Nevertheless, knowing that genetic FTD is part of your family's DNA can inform many important life decisions, including career, family planning, and financial decisions.

For these and other reasons, carefully weigh the decision to test. AFTD strongly encourages consultation with a licensed genetic counselor—a medical professional who can help you think through the pros and cons as well as different avenues for obtaining genetic testing.

## JOIN THE FTD DISORDERS REGISTRY

Joining the FTD Disorders Registry, co-managed by AFTD and the Bluefield Project to Cure FTD, is the best way to learn more and stay informed about FTD research opportunities. Registry members have access to a personalized dashboard providing updates on new clinical trials and educational resources tailored to your interests. Eligible participants may also join the Registry Research Study to share their lived experience through brief surveys to further advance the science of FTD disorders.

Just signing up with the Registry is itself a powerful way to advance FTD science. Disease research is a "numbers game," with funding and scientists gravitating to studies with the broadest potential impact and largest pool of potential research participants. By joining the Registry, you're standing up and being counted. Visit FTDregistry.org to sign up!

# VI.

# Create Your Care Team

Quality FTD care involves a range of healthcare providers, but assembling a care team that works collaboratively can be challenging. Primary care partners and persons with FTD often need to coordinate multiple providers and appointments, educate others about FTD, and be strong advocates for themselves.

Care teams may include a range of specialists including a neurologist (behavioral and/or movement specialist), psychiatrist, geriatrician, and primary care provider. At times, keeping follow-up appointments might seem cumbersome, especially if they require traveling to a specialized center. However, maintaining regular appointments with a provider can ensure that you are an established patient and that your records are up to date if any changes occur. In many areas, telehealth options may be available.

It can be difficult to find health care providers with specific experience in FTD. When working with providers who do not know about FTD, share AFTD health professional resources. Find health care providers with whom you feel comfortable communicating and who listen carefully to your concerns.

Additional health care specialists can also be valuable additions to your team, including a speech-language pathologist (SLP), physical therapist (PT), occupational therapist (OT), psychologist, counselor or psychotherapist, genetic counselor, and a social worker or case manager. A social worker, case manager, or care navigator can often provide support in coordinating providers, appointments, and resources.

## TIPS FOR MANAGING MEDICAL APPOINTMENTS

Scan to download the AFTD Behavior Trtacker

- Between appointments, document any changes you observe and any concerns you may have. This will help you more effectively communicate them to your providers as they arise. Use the AFTD Behavior Tracker as a guide.
- Keep a running list of questions you want to ask at your next medical appointment. Consider bringing a trusted friend or family member to act as a second set of ears when you meet with a healthcare provider or to take notes at the appointment. If you have questions that you don't want your loved one to hear, find a way to ask them privately through a follow-up phone call or through the electronic health portal.
- There are no medications that treat FTD directly, but you may be offered one or more prescriptions to manage symptoms. Make sure to ask your prescriber about the risks and benefits and what to expect with each potential medication.
- Create a permanent and accessible healthcare file. There are apps available to help you create a personal health record of appointments, testing, and medications. Your records should include contact information for current and past healthcare providers, a history of medications used (including dosages), copies of test results, medical records, relevant legal documents, and insurance information and receipts.

## COMMUNITY RESOURCES AND SERVICES

You may not currently need support services, but finding community resources now can make things much easier down the road. Ask your personal network—friends, neighbors, local community groups, or faith-based organizations—if they have experience with support services in your area. Social workers, case managers, and local FTD/dementia groups can also help you find services. This can be an opportunity to enlist others in your network to help with researching what is available.

Many programs will not be familiar with FTD. AFTD resources can help them learn more about your specific needs. The AFTD HelpLine is also a resource for you in navigating options and for others who want to learn more about FTD.

Here are some sources of support during the FTD journey:

- **Care Coordinators.** Social workers, care managers, nurses, and other professionals can advocate for you, navigate care options, and coordinate providers on a consultation or ongoing basis. Some healthcare providers or medical centers have social workers or care navigators on staff to support patients and their families. These professionals can also be found through local agencies or paid for privately.
- **GUIDE program.** The Guiding an Improved Dementia Experience (GUIDE) model aims to support people with dementia and their unpaid caregivers. This is a pilot program offered for those with Medicare.

Scan to learn more about the GUIDE model

- **Area Agency on Aging (AAA) or Aging and Disability Resource Center (ADRC).** These local government offices can serve as an access point for a variety of long-term services, support and financial resources for older adults, persons with disabilities, and their care partners.

- **Home care services.** Home health aides assist with personal care and supervision and are paid on an hourly basis.
- **Skilled home care.** This may include a visiting nurse as well as physical, occupational, or speech therapy. These services require a prescription and may be covered by insurance.
- **Physical therapy (PT), occupational therapy (OT), and speech-language pathology (SLP).** These three disciplines offer a range of skilled support. They can provide personalized recommendations regarding exercises, assistive medical equipment, home adaptations, and communication strategies, tools, and devices.
- **Respite care.** This is a short-term care option, either at home or in a facility, that provides relief for a family care partner. AFTD's Comstock Grants help family care partners pay for respite care.
- **Adult day services/programs.** These offer structure, activities, and supervision for those with dementia and other care needs. They can be used occasionally—when the main caregiver is working, for example, or to provide respite from round-the-clock care.

- **Facility or residential care.** Considering residential care can be an emotional decision, but it may ultimately reduce stress and provide greater support for both the person living with FTD and their caregiver. Facilities offer different levels of care—assisted living, memory care, and skilled nursing—but many are geared toward people over age 65. Since facilities that specialize in dementia are more familiar with Alzheimer's disease than FTD, it is crucial to develop a relationship with staff to help them understand the specific needs and challenges of FTD.
- **In-patient psychiatric or behavioral health units.** At times, highly structured care is needed for safety, and to evaluate or adjust medication for someone who is at risk of harming themselves or others. Successful in-patient stays require close coordination between care partners, the person's medical team, and hospital staff.
- **Palliative care.** This is designed to relieve the pain, symptoms, and stress of serious illness and to improve the quality of life for the person diagnosed. It can also help with managing complex care needs. Neuropalliative care specialists are available in some areas.
- **Hospice care.** This provides coordinated, compassionate end-of-life support focused on comfort and quality of life. Many families find valuable support from hospice when their loved one becomes eligible for it.
- **Genetic counseling.** Genetic counselors provide essential support for those considering family risk and genetic testing. You can meet with a genetic counselor individually or with a family member or friend to review your family history, address concerns, choose the most appropriate testing strategy, and help you consider how the results could impact you and your family.
- **Counselor or therapist.** Consider individual, couples, or family therapy to help you cope with the feelings and changing relationships that come with FTD.

## FINDING A SUPPORT GROUP

Finding your community can make all the difference for you and your loved ones. AFTD-affiliated support groups offer a safe, moderated space where you can find resources and connect with others who truly understand your experience.

Going to your first group meeting can be intimidating. Keep in mind:

- You can meet the support group facilitator before your first meeting. AFTD-trained facilitators are warm and welcoming, and can answer many of your questions, including what to expect during a typical meeting.
- No one is required to share or respond to others who are sharing.
- The first few meetings can feel overwhelming. Group members and facilitators have been in your shoes and will help orient you.
- It’s OK if you skip a meeting, or show up to one late. FTD support group members are compassionate people and they understand your time pressures.
- Not every group is a good fit for everyone. Feel free to try multiple options until you find the group that works for you.

> "I went to my first group and shared my story,” said one AFTD support group attendee “That was the beginning of my real FTD journey, and the group saved me. As I drove away, I realized it was a sunny day and a tremendous weight had been taken from me."
>
> **Support Group Attendee**

## FTD SUPPORT GROUP AND DIAGNOSTIC CENTER LOCATOR

Scan to view the interactive U.S. map

AFTD's website features an interactive U.S. map to help you find support group that best meets your needs. To register for a national group, contact AFTD's HelpLine at 866-507-7222 or info@theaftd.org.

There are local, regional, and national support groups, with some that meet in person and many that meet virtually. There are also support groups for persons with specific caregiving needs or interests and for people diagnosed with FTD.

AFTD trains and provides resources to support group facilitators who are experienced in group dynamics. Many facilitators are, or have been, care partners of a loved one with FTD and can share local resources and support options.

# VII.

# AFTD Resources

### AFTD HelpLine

Staffed by social workers, the Helpline can provide more information on subtypes of FTD, give guidance on managing a new diagnosis, and help connect you to resources and support.

Scan to view AFTD Resources or go to theaftd.org

### Publications

A variety of booklets and resources are produced by or with AFTD input to help you on your journey.

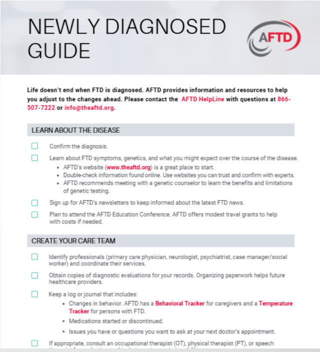
### Comstock Grants

These offer modest financial assistance to people with FTD and care partners to help maximize their quality of life. Comstock grants are available for the person with FTD, full-time family care partners, and for travel to an AFTD Education Conference.

### Awareness Cards

These printable cards let others know what FTD is and how it may impact behavior in a public setting; they're available in English and Spanish.

An FTD diagnosis can be overwhelming. AFTD's "**Newly Diagnosed Guide**" was created to help outline the steps in order to adjust to the changes ahead.



NEWLY DIAGNOSED GUIDE

**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) 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

**Recommended Reading/Viewing**

> A list compiled through recommendations from AFTD staff and family caregivers

**FTD Support Group and FTD Diagnostic Center Locator**

**FTD & Genetics**

> Learn about genetic risks association with FTD

**Glossary of FTD Terms**

## OTHER RESOURCES

**National Institute on Aging: Alzheimer's and related Dementias Education and Referral Center (ADEAR):**

> nia.nih.gov/about/alzheimers-and-dementia/about-adear-center

Clinicaltrials.gov

**Family Caregiver Alliance:**

> caregiver.org

**National Council of Dementia Minds:**

> dementiaminds.org

**Social Security Administration**

> ssa.gov

**Veterans Administration Benefits:**

> benefits.va.gov

**National Association of Elder Law Attorneys**

> naela.org

Scan to view International Resources

**AFTD would like to thank all the individuals and families affected by FTD and our professional colleagues whose collective experience is reflected in this publication.**

# Notes

# AFTD History

Helen-Ann Comstock founded AFTD in 2002, with a personal donation of $1,000. Drawing upon her experiences as a caregiver for her late husband, who had FTD, she collaborated with a team of dedicated FTD care partners and medical professionals to establish an organization focused on advancing research for FTD, providing information, education and support, and raising awareness of this rare and uniquely devastating disease.

In the ensuing years, AFTD has grown from an all-volunteer labor of love to a thriving nonprofit employing more than 50 full-time staff. The organization has emerged as a leading international expert on FTD and young-onset dementia, with a dedicated Board of Directors, a thriving volunteer network, a growing advocacy practice, and medical and scientific advisers representing the foremost experts from around the world. AFTD's work is made possible through the generous support of our donors, volunteer fundraisers and private and corporate foundations.

AFTD

The Association for Frontotemporal Degeneration

FIND HELP·SHARE HOPE

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