

The Doctor Thinks It's FTD. Now What?

*A Guide for Managing
a New Diagnosis*



The Association for
Frontotemporal Degeneration
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The Association for Frontotemporal Degeneration (AFTD) is a non-profit organization whose mission is to advocate for people confronting all forms of frontotemporal degeneration (FTD). AFTD's goals are to promote public awareness; provide information, education and support to people diagnosed with FTD, and their families; educate health professionals; promote research for treatment and a cure; and facilitate the international exchange of ideas.

AFTD envisions a world where frontotemporal degeneration is understood, effectively diagnosed, treated, cured and ultimately prevented.



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Table of Contents

| | |
|---|----|
| Introduction..... | 2 |
| You Are Not Alone | 3 |
| Overview of Frontotemporal Degeneration (FTD) | 4 |
| Learn About the Disease..... | 6 |
| Create Your Care Team..... | 11 |
| Legal and Financial Issues | 21 |
| Develop a Positive Daily Routine | 25 |
| Address Safety Issues | 27 |
| Gaining in Skills and Confidence..... | 29 |
| Research: The Key to Tomorrow | 30 |
| Conclusion..... | 31 |
| Checklist..... | 32 |
| Resources | 34 |



Introduction

Most often individuals encounter a diagnosis of one of the frontotemporal degeneration (FTD) disorders after a lengthy process of evaluation. While you may feel some relief that a disease is responsible for the changes that you have noticed, a diagnosis of FTD comes with many questions. The purpose of this booklet is to assist with that critical question: “Now what?”

Too often, people receiving a diagnosis of FTD have been told that there is nothing they can do. They leave with no hope and no help. However, researchers learn more each year and move closer to discovering effective treatments. Information and resources are expanding. Support is available.

Each individual and family has strengths to draw from and choices about how to approach the challenges ahead. There are many steps you can take that will shape your experience of the disease and the quality of your life. This booklet will help you start.

You are Not Alone

Approximately 50,000 to 60,000 people in the United States are diagnosed with a form of frontotemporal degeneration (FTD).

While FTD is considered a rare disease based on this estimate, awareness and understanding are increasing. The Association for Frontotemporal Degeneration (AFTD) is the nexus of families, physicians, researchers and policy makers interested in these diseases, and advocates for the entire FTD community.

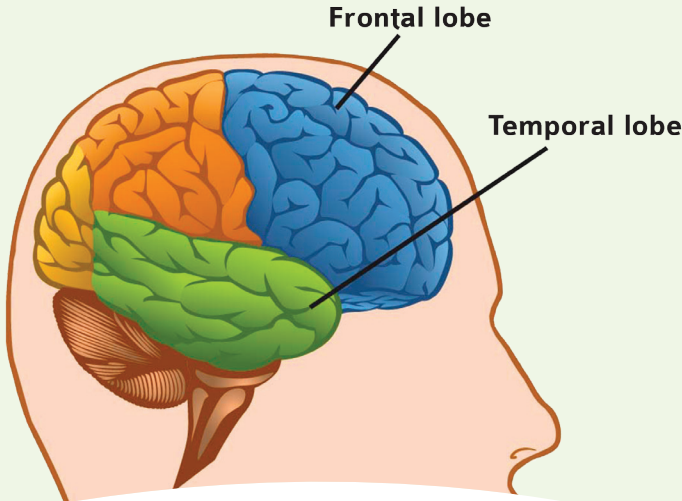
This booklet reflects the experience of thousands of individuals and families who have faced a diagnosis of FTD and the professionals who work with them. You will find suggestions for how to adjust to the changes in your life and build confidence in the decisions you make. Developing a strategic approach to the disease will help you live today fully and prepare for the future.

The most effective approach for managing FTD is not linear, but spiral. FTD is progressive and the symptoms you face will change over time. The best strategy is to address the tasks below as soon as a diagnosis is received and revisit them as your situation changes. You will bring greater confidence to your decisions as you learn more about the disease and identify new resources.

- Learn about the disease
- Create your care team (professional and personal support)
- Address legal and financial planning
- Develop a positive daily routine
- Address safety issues

"I didn't cause it. I can't change it, and I can't control it. But I do have choices about how to live each moment... I will make life as enjoyable, dignified, and meaningful as possible for as long as I can."

– Eleanor, caregiver for her husband



Overview of Frontotemporal Degeneration (FTD)

The complexity of the human brain is astounding. Our highly developed frontal and temporal lobes distinguish us from other mammals and provide the capacity to learn, analyze information, communicate and empathize with others. The tragedy of FTD is that it is these abilities – those we connect most closely with our human experience – that become most impaired.

The frontal lobes are responsible for “executive function” such as planning, organizing, prioritizing and sequencing our actions. The self-awareness that is critical for monitoring our behavior is also rooted in the frontal lobes. These skills allow us to hold back rude comments or impulsive actions and act appropriately in social situations.

The temporal lobes are involved in language and communication; they make it possible for us to speak and understand words and regulate our emotions by connecting them to objects and events. The ability to recognize faces is based in the temporal lobes.

Clinical Diagnoses

Early symptoms of FTD generally develop in one of three main areas of functioning: language and communication; personality and behavior; or movement and motor skills. *(See chart page 10-11).*

A clinical diagnosis is based on the symptoms that present first and are most prominent over the first two years.

As the disease progresses, additional areas of the brain become affected and people develop symptoms in other areas of functioning. A clinical diagnosis may change as symptoms progress. There are no treatments available currently that slow or stop the progression of the disease once it has started. A variety of medications and other interventions are used to help manage symptoms.

Clinical diagnoses that fall under the general term frontotemporal degeneration include: primary progressive aphasia (PPA), behavioral variant FTD (bvFTD), corticobasal syndrome (CBS), progressive supranuclear palsy (PSP) and FTD with motor neuron disease (FTD-MND).

Causes of FTD

The ultimate cause of FTD is unknown. Researchers have identified three proteins that are associated with one or more FTD subtypes: TDP-43, tau and FUS. These proteins are not consistently associated with any single set of symptoms or clinical diagnosis, nor is there a test available to determine which protein is responsible for disease in any one patient. Advances in genetics research have identified mutations that cause some cases of FTD, but a majority of cases are not caused by a genetic mutation. The genes and proteins associated with FTD link it to Alzheimer's disease, as well as Lou Gehrig's disease or amyotrophic lateral sclerosis (ALS).

Stages of Disease Progression

There are no clearly defined stages of FTD, since the disease can vary significantly from person to person. Clinicians classify progression broadly as mild, moderate and severe stages. During the mild stage, the person with FTD is highly functional and can manage household tasks and self-care with minimal help. In the moderate stage, the symptoms become more pronounced, and the person experiences significant deficits requiring steadily increasing supervision. This may lead to consideration of a personal care home, assisted living or nursing facility. When a person with FTD is at the severe stage of the disease, their symptoms are profound and they are extremely compromised, requiring total care.

The life expectancy of someone diagnosed with FTD is 7–13 years on average, but can range from 2–20 years.

Learn About the Disease

Learning about FTD will help you to advocate more effectively for services and support.

The more you know, the better you can prepare yourself, but the amount of information available in print and online is enormous. No one can absorb it all at once. Find some sources you can trust and keep reading and asking questions. See the Resources section of this booklet for suggestions.

Confirm the Diagnosis

It is important to have an accurate diagnosis to help you to understand symptoms, plan care, evaluate treatment options and identify opportunities to participate in research. The FTD disorders are uncommon and difficult to diagnose with confidence. People with questions about the diagnosis should pursue a second opinion at a medical center with a specialty in cognitive disorders. At a minimum, an assessment with a neurologist, behavioral neurologist or neuropsychologist familiar with neurodegenerative diseases is recommended.

There are many potential benefits to pursuing a second opinion at a specialty center or research university. However, obtaining a comprehensive evaluation at a major medical center may involve travel and can be difficult for the patient and family; weigh your considerations against possible benefits to decide what is best in your situation.

Maximize Your Doctor Visits

Quite often, people know something is wrong; however, they are not sure how to effectively convey their concerns to the physician or specialist. Your preparation can facilitate the process.

What specific problem brings you to the physician today?

Describe your observations with specific examples. The details are important. Some behaviors may seem like a memory problem, and they may be, or they may indicate a lack of concern about doing the task, e.g. “forgets to take out the trash or pay the bills.” Describe particular changes in language such as difficulty finding or using the correct words, decreased speaking or a lack of comprehension. A person who becomes disinterested in their usual routine and sits and watches TV all day may be depressed or it may be a sign of apathy that

requires further evaluation. Prioritize your concerns so the doctor knows what is troubling you the most.

Be as specific as possible about when you first noticed the change.

It is important to establish the timeframe in which cognitive and behavior changes are occurring. It may help to anchor your observations with certain events. For example, “Everything was fine last Christmas, but he completely forgot Valentine’s Day, which is something he’s never done.”

What else happened around the time you noticed the change?

Were there any illnesses or surgeries around the time changes began? Did you travel or take any significant trips? Were there work-related issues? This can be difficult to pinpoint because we often assume someone having trouble at work is stressed. The cognitive and behavioral symptoms of FTD can affect work performance and may not be recognized as a health issue.

“I knew something was seriously wrong, but it was almost impossible to make other people understand the most troubling changes. They thought I was crazy.”

– Dan, caregiver for his wife

Are there other health issues to consider?

What other medical or emotional conditions does the patient have that may be influencing the situation? Bring a list of current medications including prescription and over-the-counter drugs, herbal remedies and vitamins. Indicate the reason the medication is taken, who prescribed it, the dose, what time of day and how many times a day it is taken. Make note of any new medications or recent changes.

Did anyone else in the family have a neurological or psychiatric problem?

A family history of neurological disease may be an important consideration in the evaluation process. This may include vague family stories of someone “not being quite right.” Some details to note include: At what ages did these problems appear? How old are parents and siblings? What medical conditions do they have? If they died, what was the cause of death, at what age did this occur and was an autopsy done? Include family members such as grandparents, aunts, uncles and cousins who may have displayed neurological disease symptoms.

What should you bring or have sent to the physician's office before the first visit?

Be prepared with a list of all previous physicians you have seen (and why) that includes names/addresses/phone/fax. Send copies of the results of all lab tests completed in the last two years to the office before your visit. Include written reports of previous diagnostic tests, including EEG, brain MRI and/or PET scan, spinal fluid test results and neuropsychological testing reports. It is better if you can bring copies of brain MRI or PET scans on a disk or on film for the physician to review; otherwise they can be easily lost. Whenever possible, obtain the records from doctor visits and testing. Keep a copy for your records and make a copy to hand carry or send before your scheduled visit. Call ahead to confirm that the records have arrived, then check to make sure they are in the chart.

How do I share my concerns with the physician without upsetting my loved one?

Due to privacy rules, physicians need the patient's permission to speak privately with a family member or friend. Some families feel comfortable discussing their observations in front of the individual, while others do not. If this visit is with a new physician, consider writing a brief letter stating that you do not want to upset your

family member but wish to describe your concerns to the doctor. Ask office staff if you can accompany the individual into the exam room and mention you would like to speak privately with the doctor at some point. In the exam room, position yourself slightly behind or to the side of the individual. When the person answers a question incorrectly, you can shake your head to indicate that you disagree with the response without interrupting the exam. The physician can follow-up with you privately later or you may wish to make a separate appointment with the doctor.

What if we run out of time?

If you were unable to get all of your concerns addressed in the time allotted for the appointment, ask if you can schedule another appointment to complete this evaluation.



| Types of Frontotemporal Degeneration (FTD) | |
|--|---|
| Clinical presentation | Considerations |
| Progressive behavior/personality decline | |
| Behavioral variant FTD (bvFTD) Also known as Pick's disease or frontotemporal dementia | <p>Decreased empathy and self-awareness may affect interest in others and mutual relationships.</p> <p>Lack of behavioral control and cognitive decline can lead to self-care and safety issues.</p> <p>Compulsions and impaired impulse control can cause inappropriate social behaviors, such as overeating and uncontrolled drinking.</p> <p>Poor judgment and decision making combined with a lack of self-awareness may result in financial and legal trouble. Monitor finances closely.</p> <p>Disorientation and confusion may lead to wandering and getting lost.</p> <p>Increasing levels of supervision and companion care are often needed.</p> <p>Remove dangerous tools, firearms and other hazards. Control access to junk food (i.e., sweets, alcohol, credit cards and the Internet).</p> |
| Progressive language decline | |
| Primary progressive aphasia (PPA) Subtypes of PPA include: -Agrammatic PPA -Semantic PPA -Logopenic PPA | <p>Gradually increasing difficulty in speaking and/or understanding language.</p> <p>Speech therapy can extend verbal abilities and provide training and advice on tools and strategies; communication tools, like writing pads, picture books, and electronics can help.</p> <p>Self-awareness and executive functions remain relatively intact in people with PPA, which contributes to frustration and feelings of loss.</p> <p>The inability to communicate may result in withdrawal and isolation; attention to risk of anxiety and depression is important.</p> <p>As symptoms progress, people may become mute and unable to communicate.</p> <p>Changes in executive function and behavior are common as the disease progresses and affect other areas of the brain.</p> |

| Continued | |
|---|---|
| Clinical presentation | Considerations |
| Progressive motor decline | |
| Progressive supranuclear palsy (PSP) | <p>A lack of motor control and decreased mobility may impact overall health in various ways that require adapting and accommodation.</p> <p>Many people with movement disorders also experience cognitive and behavioral decline.</p> <p>Physical and occupational therapy can help people remain active and healthy for as long as possible.</p> <p>Some Parkinson's disease medications can be used to manage symptoms such as rigidity or tremors.</p> <p>Medical equipment such as walkers, wheelchairs or hospital beds can help maintain independence and may be covered by public and private insurance policies.</p> <p>There are programs to help afford home modification like ramps and stair lifts.</p> |
| Corticobasal syndrome (CBS) | |
| FTD with parkinsonism | |
| FTD with amyotrophic lateral sclerosis (FTD-ALS) | |

Create Your Care Team

People can live for many years with FTD and benefit from a broad range of treatments and therapies. You will likely have to engage many different providers over time. Quality health care depends on finding the right health professionals, advocating for services, arranging payment and following up.

Medical Professionals

Healthcare systems can be disjointed; navigating them may be time-consuming and frustrating. Very often it will fall on the primary caregiver to anchor the effort, but he or she will need support and assistance from others. Be ready to help doctors and healthcare professionals do their best by educating them about FTD. Below are suggestions for identifying a team and managing care:

- Use a single point of contact for healthcare providers. It is easiest when one person in a family is the point of contact for all providers. Keep your phone numbers, e-mail addresses and other contact information as consistent as possible and if you must change your



address or contact number, be sure to take advantage of whatever forwarding services are available.

- Build a comprehensive medical team. Each of the following providers may play an important role depending on needs: primary care physician, neurologist, psychiatrist or geriatrician, movement disorders specialist, speech and language pathologist, physical therapist, occupational therapist, psychologist and social worker or case manager.
- Your primary care doctor is key. Access to specialists is most often through primary care. A physician who has experience with FTD can make a tremendous difference in the care a patient receives and in the caregiver's confidence, but may be difficult to find. A physician with whom you communicate well and who is open to learning about FTD can be equally effective.
- Maintain a consistent schedule of routine healthcare. Having FTD may make it difficult for the person to understand or communicate changes in their physical well-being. Routine problems like the common cold or a toothache can trigger changes in behavior that appear to be the result of FTD, but are unrelated and easily treatable. Additionally, planning, scheduling and participating in office visits may elicit resistance, confusion and anxiety from someone with FTD. Establishing as much routine and consistency as possible around these necessary events can reduce the potential stress for everyone involved and result in higher quality care.

- Keep a diary. Tracking changes between office visits will help your doctor to manage symptoms as effectively as possible.
- Be strategic about medication use. Currently there are no medications to treat the disease but doctors can prescribe a variety of drugs to treat the symptoms. You are in a better position to monitor medications than your doctor. It is important to understand why a medication is prescribed and what specific problem it is expected to address so you can report back on the effectiveness of anything your doctor prescribes. There will be ups and downs with daily functioning that may not be related to the medications so it is important stay on a new one for at least 4-6 weeks to assess whether or not it is helping. It is preferable to discontinue medications that no longer address a problem.
- Keep paperwork organized and accessible. Request records routinely. Create a permanent and accessible healthcare file. It should include lists of current and past healthcare providers' contact information, current and discontinued medications and dosages, copies of medical records and relevant legal documents, and insurance information and payment receipts. Storing medical records you do not need is much easier than attempting to obtain old records you end up needing down the road.
- Develop an FTD education file. Request or make extra copies of information or articles about FTD that are especially relevant for you. Give healthcare providers, other professionals, and family and friends the information they need to understand your situation.

Community Services

There is a wide array of community services that can assist you with managing daily care. You may not need them now, or at all, depending on your particular situation, but becoming familiar with resources and

"We're all trying to help Dad from different parts of the country. I'm his 'executive assistant.' My job is to keep paperwork, appointments and the rest of the family organized."

– Bob, father diagnosed with FTD and living alone

service providers before you need them will make transitions in care easier. A social worker or geriatric case manager can be a valuable ally to help identify suitable services.

- **In-home care services** – Home healthcare can provide services on an hourly basis for assistance with personal care, physical or occupational therapy. Companion services may offer short-term respite for the main care provider.
- **Augmentative communication** – People with language impairment may benefit from picture and symbol communication boards and electronic devices to help express themselves. A speech-language pathologist (SLP) can evaluate communication strengths and needs and recommend compensatory strategies. Speech therapy can help people maintain language abilities for as long as possible and is a valuable resource to consider.
- **Assistive equipment** – If physical symptoms impair mobility, assistive equipment such as walkers, wheelchairs, Hoyer lifts or hospital beds may be necessary. A physical or occupational therapist can evaluate mobility and strength and recommend adjustments to minimize the risk of falls. Look for state or federal health programs to help assess your home environment and pay for necessary modifications or durable medical equipment.
- **Adult day services** – Day programs offer daily structure, activities and supervision. They are an important service for people who are active, for when the main caregiver is working, or to provide regular respite from round-the-clock care. Some programs are designed for people with dementia.
- **Residential care** – Many people with FTD benefit from care in a residential facility. This can be a difficult transition to consider, but in many situations the facility may offer both the person with FTD and the caregiver the best quality of life. Facilities are generally designed for people over the age of 65, but accept people younger. A personal care, assisted living facility or a specialized dementia care program may be the best option for people with private resources. Skilled nursing facilities accept Medicare and Medicaid.
- **In-patient psychiatric or behavioral health unit** – At times, the highly structured care of a hospital is needed to evaluate or adjust medication for someone with agitated or aggressive behavior. A high level of coordination between family, physician and unit staff is important for effective transitions.

- **Hospice care** – Many families that access hospice when their loved one is eligible find benefit and comfort. Hospice offers a coordinated array of services including palliative medical care and a compassionate approach to end of life.
- **Counselor or therapist** – Professional assistance can be valuable to cope with the losses, changing relationships and increased stress that come with FTD. Consider individual, couples' or family therapy depending on your situation and need.

Family and Friends

Family situations and support systems vary tremendously. Before diagnosis, the gradual development of unexplained symptoms may create confusion, anger and frustration among family and friends. Professional colleagues may disengage. Family relationships may become strained; marriages may end before disease is identified as the culprit.

While receiving a diagnosis adds clarity, it does not ensure understanding or acceptance of the disease by others. Understanding is a process that takes time. Turn first to those who will listen and learn.

No one can manage FTD without help.

The rate of progression and specific symptoms that an individual with FTD will face cannot be predicted. However, over time the person's need for assistance will increase. The main caregiver's need for assistance will increase as well.

It is a personal decision when and what to tell people about the diagnosis. People who tell family and friends what they are facing often feel empowered and may be able to mobilize assistance more easily.

- Some people pull the whole family together for a meeting to educate them about FTD and ask for assistance. Others write a letter outlining the situation, and still others prefer to talk with just a few people one on one.
- It is good to be open from the start. Offer information and give a basic outline of what you know, decide how much depth and detail is needed and provide resources for people to learn more. It is important for friends and family to be able to identify the disease, but everyone processes difficult information in their own way.

- Not everyone will understand equally. Each person has a unique relationship with the person diagnosed and will have their own reaction. Be patient and be ready to provide more information when the opportunity presents itself.
- Discuss important and sensitive topics early for the greatest possible participation of the person with the disease.

For the Person with FTD

A diagnosis of FTD does not change what you enjoy and value in life. The doctor's words do not change what you can or cannot do. Getting a diagnosis causes a change in perspective. It prompts you to think about how you want to live and reevaluate your wishes for the future.

Although you may feel alone as you begin to face this diagnosis, there are many people that can help.

- Identify family, friends and professionals whom you trust and who are willing to learn about your diagnosis and provide help as your needs change.
- Be practical. Plan for help with medical appointments, meals and household tasks, finances and paperwork, transportation and companionship.
- Your experience of the disease is unique. It may be difficult to express what you notice or how you feel. Find the outlets you need through talking with people close to you, or through creative arts or hobbies.
- You can do things you like, but may have to do them differently. Adapt activities to fit your strengths and minimize areas of difficulty to continue to enjoy your interests and time with family and friends.

"I was diagnosed 6 ½ years ago and have never met anyone else with FTD, until now. It's amazing to realize other people know what it feels like to have this."

– Howard, diagnosed with bvFTD



- You may want to share your experiences with others who have been diagnosed with FTD. Some people use online support. A few caregiver groups and medical centers have programs for people with FTD. Some people write blogs about their experiences.
- Local communities may have programs for people with early-stage Alzheimer's disease. These education and support groups can be helpful for some people with FTD.
- People with FTD who are interested in support should let family, local providers and AFTD know in order to advocate for the development of more opportunities.

For Caregivers

The more assistance and support you have, the better. There are so many needs that arise along the way with FTD, that having people with different abilities and availability is really helpful. Consider what is most important for you to do and where others can help. Taking a team approach will relieve the burden of anyone needing to do everything and will ensure good care.

- Trust your instincts. You know yourself and your situation best. Many people will offer advice, but you will know which makes the most sense.
- Give yourself permission to practice, make mistakes and try again. No one is prepared for challenges that come with FTD. Experiment with new approaches; if it does not work, try something else.
- Ask people to help. Family, friends and colleagues may not know how they can help unless you tell them. When someone offers you help, say "yes."

- Make a list of what needs to be done and match people to tasks according to their skills, interests and availability. Consider which tasks you like to do and which are the most laborious. Some things to consider include: managing medical appointments, caring for children or teens and driving them to activities; preparing meals; household maintenance; finances and paperwork; and companionship.
- Develop a broad support system. FTD does not just affect the person with the disease, but impacts everyone around them. Each person in the family will have different needs and ways of coping.
- Join an FTD support group. Other FTD caregivers can be a lifeline; they understand that your questions, daily challenges and concerns differ from those of people with Alzheimer's or other types of dementia.
- Find support that fits your needs. Face-to-face groups, online support, groups that meet by phone and individual connections to other FTD caregivers in your area are all options. Do not stop looking until you find what you need.
- Respite can be a life-saver. Schedule regular activities by yourself or with friends purely for your own relaxation or enjoyment. It is important.
- Invest in those who listen and try to understand. Not everyone responds to a profound change as you would hope or expect. Some people you think you can count on will disappoint you. Acknowledge your disappointment and focus on those who are there for you.
- Nurture your spirit. Your faith community may be an important source of understanding and assistance.
- Refer to the Resources section in the back of this booklet for some organizations and resources that can help.

"Other FTD caregivers might be the only ones who really "get it," but they truly do understand. I felt that right away."

– Sally, caregiver for her husband

| Each person's experience with FTD is unique. Relationships are affected in different ways. | |
|---|---|
| Relationship | Considerations |
| Person diagnosed | <p>People with PPA, movement disorders and some with bvFTD are aware of changes and feel the losses deeply.</p> <p>Often feels isolated and scared with few opportunities to meet others with FTD.</p> <p>Needs ways to contribute to family, community, etc., to feel productive.</p> <p>Some FTD supports are starting; early stage Alzheimer's and other dementia groups may be helpful.</p> |
| Spouse or partner | <p>Often the main caregiver and person most emotionally close to the person diagnosed.</p> <p>Behavior, personality and language symptoms change the relationship contributing to tremendous loss in companionship and intimacy.</p> <p>Faces many difficult emotions including guilt or anger, loneliness, disappointment and grief. Acknowledge and address them as they occur.</p> <p>Responsibility for all household management, decision making and care management can overwhelm the caregiver who does not have help.</p> <p>Maintaining a positive outlook and satisfaction in the relationship is possible when the caregiver has support and assistance.</p> |
| Adult child/ long distance caregiver | <p>An individual's response is shaped by the frequency of contact, amount of direct care, and their personal, work or family situations.</p> <p>Siblings in a family may respond differently to the diagnosis and parent's needs. Each has a different relationship with the parent.</p> <p>Faces many difficult emotions including guilt or anger, concern for the well parent, disappointment and grief. Acknowledge and address them as they occur.</p> <p>May face difficult choices about postponing future goals or life changes to care for parent.</p> |

| Continued | |
|---|---|
| Relationship | Considerations |
| Parent with young children of an affected spouse | <p>Having young children or teens in the home adds many additional emotional, practical and financial considerations.</p> <p>The well parent becomes a single parent to the children and caregiver for the spouse or partner.</p> <p>Take steps to communicate with children honestly at an age-appropriate level, and support their growth and development.</p> <p>Enlist the help of family and friends to maintain balance in the family and attend to each individual's well-being.</p> <p>Facility placement may be considered earlier for family reasons.</p> |
| Parent caring for adult child | <p>Parents managing care face unique emotional and practical issues.</p> <p>Often in retirement, coping with the logistics, physical demands and financial demands of caregiving is stressful.</p> <p>Personal medical and emotional health is important to maintain.</p> <p>Often feel isolated and poorly understood by peers who don't know about FTD.</p> |
| Extended family and friends | <p>Limited in-person contact makes it difficult to appreciate the impact of the disease on the individual and caregiver.</p> <p>Learn as much as possible about FTD from reputable sources and trust the main caregiver's perspective.</p> <p>May feel unsettled and not know what to do with the changing relationships. Identify a specific, practical way you can help.</p> <p>Often difficult for the main caregiver to initiate or maintain contact; a call or note to say you are thinking of them is helpful.</p> |

Legal and Financial Issues

A variety of legal and financial considerations accompany an FTD diagnosis. Some, such as decision-making powers or disability benefits, may be topics you have not considered before. Other more familiar issues include financial planning, or health insurance and retirement benefits. All of them become more pressing and complicated by the onset of FTD. Because FTD is a progressive disease that impairs thinking and decision making, it is important to address these issues early.

Below is a general introduction to some of the issues to consider:

Elder Law

Many of the legal questions that arise can be addressed by an elder law attorney regardless of the age of the individual diagnosed with FTD. Elder law is a specialty field that includes social security and disability benefits, decision-making powers and guardian or conservatorship, as well as tax law related to retirement planning. An elder law attorney can help you prepare legal documents such as power of attorney, and wills or advanced medical directives. Elder law attorneys often work closely with financial planners who have expertise in retirement.

Labor or Employment Law

If the person is still working at the time they are diagnosed, it may be helpful to consult with an employment and/or Employee Retirement Income Security Act (ERISA) lawyer. ERISA is the area of law that applies to the benefits employers must offer their employees. Talking with an ERISA lawyer can help you preserve benefits the person with

“Nobody wants to have these difficult conversations, but I’m really glad we did. It is important to do so early, because the disease will take your opportunity away.”

– Sue, caregiver for her father



FTD receives through an employer after he or she becomes unable to work. Employment lawyers can help with questions regarding losing a job because of the disease and the rights family members have under the Family Medical Leave Act (FMLA). In Canada, contact your Employment Standards Branch in your province or territory.

Finding an Attorney

Employment and elder law include a mix of federal and state/provincial laws. It is important to talk with an attorney who specializes in these areas and practices in your state in order to best address the issues as they apply to your individual situation. While these laws apply to everyone regardless of their specific diagnosis, some characteristics of FTD can present unique and complicated issues. You can find an attorney through an existing network such as the National Academy of Elder Law Attorneys in the United States. It may be necessary for you to educate an attorney about FTD to receive the best counsel. Provide articles and resources you know and trust to make this easier.

The best way to find an elder law or employment attorney who has worked with people confronting FTD is to ask other caregivers for suggestions. An FTD caregiver support group or individual caregivers in your area may be able to provide suggestions. Such recommendations offer a starting point; you must determine if the attorney can meet your needs.

Decision Making Powers

People with FTD will eventually need someone to act on their behalf to make financial and healthcare decisions. There are a variety of options that allow people to make legally binding decisions on behalf of another. They range from powers of attorney and advance directives for healthcare to guardianship proceedings. All of these require that the individual with FTD participate in the process. As FTD progresses, it will become increasingly difficult for the person with FTD to express their wishes for end of life care and make sound decisions about who will represent their best interests. It is important to discuss your decision-making options with an attorney as soon as possible after a diagnosis is made.

Power of Attorney (POA)

A power of attorney is a legal document that allows you to authorize an individual to act as your agent and manage your personal affairs. POA can be as simple or as complicated as you want it to be. It can apply to either medical or financial decisions or both, depending on state laws. POA is terminated if the individual becomes incapacitated unless it is durable (written to stay in effect after an individual becomes unable to make their own decisions), or springing (written to take effect after an individual becomes unable to make their own decisions). POA can be written and signed in an attorney's office but is only enforceable if signed by an individual who is legally competent. Challenging the legality of POA on grounds of competency typically involves a guardianship hearing.

Advance Medical Directives or Living Wills

A living will is a legal document that states an individual's wishes for medical treatment and other healthcare services. A living will cannot be used to appoint someone to make healthcare decisions. The relationship between a living will and POA (and which takes precedence) varies from state to state. For example in some states, they can be combined in a single document and other states require two separate documents.

Guardianship or Conservatorship

Guardianship or conservatorship is a legal decision made by a family law judge after hearing a court case. It is an expensive and contentious process with all parties entitled to their own qualified legal representation. Guardianship decisions not only assign an

individual the right to act on behalf of another, but also remove all the legal rights an individual has as an adult. Guardianship should only be considered after other options are explored.

Public Benefits

There is a variety of state and federal benefits to which people diagnosed with FTD may be entitled. An elder law attorney can help you to understand and apply to these programs, and especially to appeal after a denial of benefits. A financial planner can help you organize your resources when applying for state healthcare programs and review your options for paying for care over the long term.

Social Security Disability Benefits (SSDI)

In the United States, people under the age of retirement who have been employed and are diagnosed with FTD should apply for disability benefits from Social Security. What programs you are eligible for and the level of benefits you may receive will vary depending on your work history. Anyone who qualifies for disability benefits will be automatically enrolled in Medicare after 24 months.

Compassionate Allowances Program

Compassionate Allowances is a Social Security program in the United States that expedites the applications process for disability benefits for people with a terminal disease. Through Compassionate Allowances, anyone with a properly documented FTD diagnosis, including bvFTD, PPA, CBS and PSP will have their application marked for an expedited medical review process. Compassionate allowances only speeds up the application process; it does not affect the type or amount of benefits people may receive.

Medicare

Medicare is the federal healthcare program for United States citizens over the age of retirement. All citizens are automatically enrolled in Medicare after they turn 65 but in order to receive benefits you must apply to the Medicare program that best meets your needs. Medicare does not offer a plan that covers the cost of long-term residential care. To learn more about Medicare, contact your local Social Security office.

Medicaid

Medicaid is the federal healthcare program for people below a certain income level. Medicaid programs may receive federal funds but are managed by the state government. Each state varies in the Medicaid programs available and the eligibility criteria for services will vary from program to program. Unlike Medicare, Medicaid includes programs that cover the cost of long-term residential care. It is possible for people on Medicare to also be eligible for some Medicaid programs. An elder law attorney can be particularly helpful in applying for Medicaid services, especially when there are questions of dual Medicare-Medicaid eligibility.

Benefits for Military Veterans

The Veterans Administration (VA) offers a broad range of benefits to veterans of the United States armed forces and their families. All veterans are eligible for healthcare through the VA, but the programs and the services available will depend on the type of active duty performed and whether or not a veteran served during a time of war or was involved in armed combat. For more information, contact the nearest VA office.

Veterans Administration Benefits for ALS

The VA classifies injuries and some health conditions as service-related if they can be shown to be a result of active duty. Veterans with service-related injuries or health conditions qualify for more comprehensive services. Starting in 2008, the VA presumes amyotrophic lateral sclerosis (ALS) to be service-related. Veterans with ALS and their families are eligible to receive all benefits and services available to those with a service-related health condition.

In Canada

There are several resources listed in the back of this booklet for information on the Canadian Pension Plan (CPP), the Disability Tax Credit and for information on the Canadian healthcare system.

Develop a Positive Daily Routine

As public awareness and diagnostic tools improve, more people are diagnosed with an FTD disorder in the early stage when symptoms are mild. It is important to stay healthy and active to reduce the impact of symptoms as long as possible. No lifestyle change will stop

the progression or reverse the disease. However, items that promote overall physical health, and mental and emotional well-being are positive practices for all, including those with FTD.

Health and Wellness

Research supports the benefits of proper nutrition and healthy habits in the reduction of heart disease and protection of brain functioning. A “heart healthy” or “brain healthy” diet is one that is low in fat, low in cholesterol and high in fruits and vegetables that contain antioxidants. Proper nutrition, regular exercise and stress management can promote weight control and help to prevent diabetes and heart disease, which affect brain functioning. These habits will not reverse the disease process once it has started, but may allow undamaged parts of the brain to function at their best.

Maintain a Regular Routine

Many people with FTD benefit from following a regular daily routine. Predictable patterns and activities provide an important framework for both the person with FTD and the caregiver. Include daily living activities such as meals, household tasks and errands; physical activity; hobbies; social interaction and spiritual development. Sleep disturbance in FTD is common. Including exercise and activity each day can help to promote a regular sleep pattern.

Stay Active

It is important for people with FTD to stay engaged in enjoyable and stimulating activities of their choosing. The “formula” is to maintain social relationships as much as possible and adapt interests, accomplishments and memories into activities that match the person’s current functioning. For example, if competitive poker or bridge was a favorite social activity, playing a more casual or simpler version with fewer rules if needed can engage the person, connect with that part of his past and provide a meaningful way to interact with others.

Flexibility is the Key

There is a multitude of ways for a person with FTD to stay involved. Activities should be personalized according to a person’s interests and current abilities. Difficulty in planning, organizing and carrying out activities is common with FTD, so family and friends must take the lead. Be willing to experiment with different ideas or approaches to see what works.

Adjust your expectations and help family and friends to do so as well. The thinking and communication challenges a person has may not be apparent to those with less regular contact. Others will learn from the caregiver’s example. While you may not be able to do things as quickly or easily as before, activities can be adapted and still provide enjoyment.

As symptoms progress, it may become necessary to discontinue some activities. The activity should bring enjoyment to the person with FTD. If a particular task becomes too difficult or stressful as abilities change, it is time to reevaluate and adjust. An activity can be as simple as listening to music or watching the birds outside, as long as it brings enjoyment.

Address Safety Issues

Each clinical presentation of FTD has symptoms that can compromise a person’s safety at home and in the community. The risks associated with the initial area of impairment (behavior, language, movement) will change over time as disease spreads to other brain circuits and areas of functioning. Not everyone will experience the same risks. Become aware of possible safety considerations so you will not be caught off-guard.

The person with FTD may resist accepting reduced independence or may not be aware of declining abilities or judgment. When these

behaviors are the result of disease, the person will not be able to change or control them when they are pointed out or they are asked to do so. Those closest to someone with FTD have a responsibility to assess safety issues recurrently and act to keep the person and those around them safe.

Communication

People with primary progressive aphasia (PPA) develop difficulties in using spoken and written language and in understanding word meaning. People with PPA generally do not experience behavior or personality changes until later stages of the disease, so they may be able to function quite independently. As communication becomes more impaired, the inability to effectively ask for directions if lost, respond to emergency situations and express needs becomes a safety consideration. People not familiar with PPA may think the person is intoxicated or needs emergency medical care. Make sure to carry a card that says the person has PPA and lists name, address and emergency contact information. The person affected should wear a medical ID or medic-alert bracelet.

Decision-making and Judgment

People with behavioral variant FTD (bvFTD) often experience impairments in self-awareness, decision-making and judgment. Loss of these skills can lead to a variety of behaviors that start gradually and have significant risk. The person does not intend to create difficulty. They are not aware of the potential consequences of actions or decisions. Someone who enjoys running or biking may become less attentive to traffic rules or take extremely long outings without water or a sense of where they are. A parent of young children may not moderate their playful rough-housing and overpower a child. Someone who has always been thrifty may buy multiple new cars or a new home without discussing it with their spouse. An independent business owner may use payroll funds for a risky investment or respond to Internet investment scams. Do not ignore your concerns. Assess the level of risk and take action as needed: increase supervision, monitor or close financial accounts, enlist the help of others. External action is needed to reduce potential risk.

Risk of Falls

People with corticobasal syndrome (CBS) or progressive supranuclear palsy (PSP) may develop stiffness, slowing of movements, a shuffling gait, tremors, balance problems and falls. When movement problems



are present, a physical therapy evaluation can identify interventions and assistive equipment to reduce the risk of falls. There are many ways to address strength and flexibility, and maximize daily activities.

Driving

When a person with FTD should stop driving is a question all families must eventually face. There is no single answer that applies to each family or individual. The laws concerning what doctors treating people with dementia can or must do vary from state to state, as do the laws that apply to driving privileges. To learn the details in your state, you should contact the appropriate agency, usually the department of motor vehicles or equivalent division. Some states have special programs that offer information or guidance on this question which are often developed in collaboration with the state office on aging.

Gaining in Skills and Confidence

There are many challenges that come with a diagnosis of FTD. They present difficult but valuable opportunities to become a more confident and effective caregiver. Following are some things to keep in mind as you go along:

- **Don't take it personally.** FTD robs people of their self-control and ability to make rational decisions. Challenging, disturbing and problematic behaviors are symptoms of the disease and not deliberate actions or personal attacks. Recognizing this can be


critical to learning how to cope with the behaviors and responding appropriately.

- **Frontotemporal degeneration is rare.** Well-meaning friends and health providers may label all dementia as Alzheimer's and treat anything that does not fit their understanding of that disease as a psychiatric condition like depression or obsessive-compulsive disorder. Advocate for what you need; each individual interaction increases awareness.
- **Be practical in assessing what you need.** The clarity of diagnosis, names of subtypes and language related to FTD can be confusing. There is overlap in research, treatment and resources with Alzheimer's and other related disorders. Pay attention to what works and what does not work for you and be prepared to advocate for what you need. The person is more important than the name of the disease.
- **Trust yourself.** You are advocating for someone with a serious medical condition who deserves respect and competent care. You will know them differently than physicians or other providers. Ask questions and speak up; your opinion is valuable and needs to be heard. Stay open to the perspectives of involved family members and friends, but trust the decisions you make as a primary caregiver.
- **Take care of yourself.** You are in it for the long haul. Pace yourself, and find ways to reenergize and stay well. Do not permit the toll of the disease to grow.
- **Join an FTD support group.** The people you meet will understand.

Research: The Key to Tomorrow

Research is at the heart of hope for people with any rare disorder. As scientists discover the causes of disease and apply that knowledge to the development of treatments and a cure, they create a brighter future. Research requires the collaboration of many different individuals, including scientists, study volunteers and financial donors.

There has been significant progress in FTD research over the last decade, including advances in diagnostic evaluation, understanding of the pathology and genetics of FTD, and identification of targets for treatment intervention. Studies are also investigating behavioral intervention strategies and the best ways to provide education and support to caregivers. None of these studies could be completed without the participation of patients and caregivers.

A photograph of a man and a young boy sitting on a black bench in a room. The man, on the left, is wearing an orange button-down shirt and brown trousers. He is looking down at his hands, which are clasped together. The boy, on the right, is wearing a white t-shirt and white trousers. He is looking down at his hands, which are also clasped together. In the background, there is a black grand piano, a lamp with a white shade, and a framed picture on the wall.

Participating in research is one way to access specialized care and connect with a network of the most knowledgeable doctors in the field. Consider enrolling in research studies early in the disease course, when travel, tolerance for assessment and follow-up are possible. While opportunities may exist as the disease progresses, participation may become increasingly difficult. Brain donation or brain autopsy are often available to those who participate in observational studies. Also, as clinical drug trials expand, people connected with a research center may be notified of studies for which they may be eligible.

Conclusion

There is nothing that totally prepares you for FTD. A diagnosis may explain troubling changes in language or behavior, but FTD also brings many unanswered questions about the future. While no one can provide many specific answers, you do not face these questions alone. There is a growing community of informed, knowledgeable and caring people – professionals and caregivers – who understand and are ready to help.

FTD brings devastating losses that are felt in different ways by each family member or friend. The challenge is to create a strategy for moving forward. This booklet offers touchstones to which you can return frequently as the disease progresses. They will start you on a path that promotes compassionate care for each person with FTD and sustains each person in their life. Keep asking for what you need and remain open to help in all its forms. Hope lies in our response to one another.

Checklist

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| Learn About the Disease | |
| Confirm the diagnosis. | |
| Learn about the disease symptoms and what you might expect. | |
| If you have children or teens, get AFTD's booklet <i>What About the Kids?</i> | |
| Share information with key family and friends. | |
| Start a file of key articles and resources on FTD that will help educate others. | |
| Visit AFTD's website and register for the newsletter (www.theaftd.org). | |
| Contact AFTD's Helpline with questions: 866-507-7222 or info@theaftd.org . | |
| Learning is ongoing. Continue to read and ask questions. | |
| Create Your Care Team | |
| Identify professionals (neurologist, primary care physician, psychiatrist, case manager/social worker) and establish coordination. | |
| Obtain copies of diagnostic evaluations for your records. Keep paperwork organized. | |
| Keep log or journal of significant changes in symptoms. Prioritize issues to address with doctor. | |
| Maintain chronological record of all medications started and discontinued. | |
| Consult OT, PT and speech therapist for evaluation and techniques to maximize abilities. | |
| Join an FTD caregiver support group. Visit www.theaftd.org and ask about phone groups, informal connections or other options. | |
| Explore peer support for the person with FTD. Initial online and other efforts are starting. | |
| Keep a list of what you need. Ask family, friends and neighbors to help. | |
| Address Legal and Financial Issues | |
| Consult an Elder Law attorney. | |
| Plan transition from employment, if still working. | |
| Complete legal documents (Power of Attorney, living will, will, etc.). | |
| Review financial and health care programs. | |
| Apply for Social Security Disability (Compassionate Allowances Program). | |
| Determine eligibility for Veterans Administration benefits. | |

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| Develop a Positive Daily Routine | |
| Follow a heart-healthy diet and get regular exercise. | |
| Stay active with friends and interests. Adapt activities according to strengths and needs. | |
| Follow a regular daily routine to structure the day. | |
| Review and visit day programs and facilities in advance of possible placement. | |
| Use professional counselors to help cope with changes. | |
| Attend an FTD education conference. AFTD offers modest travel grants. | |
| Apply for AFTD's respite grant. | |
| Address Safety Issues | |
| Assess for safety and risk regularly and make changes as needed before a crisis occurs. | |
| Carry complete ID with emergency contact information. State that the person has a neurological disorder. | |
| Keep home environment safe and equipped to reduce risk of falls. | |
| Where judgment is impaired, monitor bank accounts, investments and online activity; change access as needed to protect assets. | |
| Use GPS monitoring or similar device if there is any risk the person may get lost in the community. | |
| Learn the laws where you live regarding driving privileges. | |
| Participate in Research | |
| Follow emerging research to understand issues important in FTD. | |
| Become familiar with observational studies, clinical trials and opportunities to participate. | |
| Learn about the role of brain autopsy to confirm diagnosis and advance research. | |
| Plan early if interested in brain autopsy/donation. | |

Resources

The Association for Frontotemporal Degeneration (AFTD)

Radnor, PA
1-866-507-7222 (toll free) or 267-514-7221
www.theaftd.org

Comprehensive information, education, support, resources and advocacy specific to FTD.

National Institute on Aging Alzheimer's Disease Education and Referral Center (ADEAR)

Silver Spring, MD
1-800-438-4380 (toll free)
www.nia.nih.gov/alzheimers/topics/other-dementias#frontotemporal

Information and publications on dementia and caregiving for families, caregivers and professionals.

ClinicalTrials.gov

www.clinicaltrials.gov

A registry and results database of publicly and privately supported clinical studies from around the world. Provided by the US National Institutes of Health.

Social Security Administration, Disability Benefits

www.ssa.gov/pgm/disability.htm

The US government's website on Social Security Disability Programs. Includes section where you can apply for disability or appeal a decision on a previous application.

Veterans Administration Benefits

www.va.gov/healthbenefits

Provides information on the healthcare benefits available to all veterans of the US armed forces.

National Association of Elder Law Attorneys

www.naela.org

Includes search engine to locate attorneys who are members of the National Academy.

Disease Information

ALS Association

www.alsa.org

Provides information pertaining to programs and services, resources, research, education and advocacy surrounding ALS.

CurePSP

www.psp.org

Offers information, videos, and support resources specifically for PSP, CBD and related brain diseases.

National Aphasia Association

www.aphasia.org

Includes aphasia resources, materials and tools.

WE MOVE

www.wemove.org

Provides web-based information and resources related to all types of movement disorders.

Canadian Resources

Canadian Pension Plan

Disability Benefits

www.servicecanada.gc.ca/eng/sc/cpp/disability/disabilitypension.shtml

Provides a monthly taxable benefit to contributors who are disabled and to their dependent children.

Frequently Asked Questions regarding Canada's pension plan

www.servicecanada.gc.ca/eng/sc/cpp/disability/disabilitypension.shtml

Health Canada

www.hc-sc.gc.ca/hcs-sss/index-eng.php

Provides information on Canada's publicly funded health care system, known as Medicare.

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Notes:

For additional copies of this publication or further information contact:

AFTD
info@theaftd.org
267-514-7221 / 866-507-7222

**Frontotemporal degeneration is an umbrella term
that includes the following clinical diagnoses:**

Behavioral Variant FTD or Frontotemporal Dementia

Primary Progressive Aphasia

Progressive Supranuclear Palsy

Corticobasal Syndrome

FTD with Motor Neuron Disease



**The Association for
Frontotemporal Degeneration**
FIND HELP • SHARE HOPE

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