

Frontal, Temporal, & Frontal Temporal Lobe Dementias (FTLDs)

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What Do You Need to Know?

- These dementias are NOT the same as Alzheimer's disease —many early symptoms are very different, although there are some similar symptoms
- Early symptoms are frequently be missed or misunderstood, even by medical professionals.
- The use of typical Alzheimer's medications may have little or no effect, and in some cases may make behaviors worse in the early stages of some FTDs
- Progression of FTLDs may look very different than other forms of dementia.
- It is possible to have a combination of FTLD and other dementias especially common is FTLD plus Alzheimer's Disease.
- It can begin at much younger ages than typical Alzheimer's (40-55 versus over 70)
- Some forms have some characteristics of Parkinson's Disease especially problems with movement – some will not
- Since it is mostly either behavior or language problems at first, it is often missed as a dementia most frequently it is mis-diagnosed as a psychiatric condition, mis-behavior, or 'mid-life' crisis.
- New learning and memory problems are generally not the first problems noted.

What Is It???

- FTLDs are a group of neurological conditions that progressively damage then destroy brain tissue, starting at the front part of the brain.
- Early detection and diagnosis combined with structured approaches to caregiving and careful use certain medications can make a difference in behavior and management of symptoms.
- A definite diagnosis can still not be confirmed until an autopsy is completed FTLD is a 'probable' diagnosis or a 'possible' diagnosis, based on symptoms and progression.
- The first type noted was first seen and discovered by Dr. Pick in 1892, but often went underdiagnosed or unrecognized in early stages, until very recently.

Other names for or diagnoses that are types or related forms of Fronto-Temporal Lobe Dementias:

- Frontal Varient Fronto-Temporal Dementia (FvFTD)
- Frontal-Temporal Dementia (FTD)
- Pick's Disease
- Fronto-Temporal Dementia with Parkinsonism (FTDP-17)
- Primary Progressive Aphasia (PPA)
- Non-Fluent Aphasia
- Fluent Aphasia
- Cortico-Basal Degeneration
- Progressive Supra-nuclear Palsy
- Amyotrophic Lateral Sclerosis—Parkinsonism-FTD Complex

Who is at Risk?

- Both men and women get these dementias. More men than women diagnosed with FTLDs, at
- Risk is higher, if there are close blood relatives with FTD, but a clear genetic link has not been identified at this time for any of the FTLDs except FTDP-17.

How Common Is It?

- It is the second or third most common form of dementia 10-20% of all cases of dementia will have a strong element or some form of FTD involved.
- When all variations are included, there are close to 1 million people with FTDs in the US.
- There are a large number of people who are misdiagnosed or undiagnosed, but are living with the symptoms of FTLDs.

How Does It Progress?

- Average length of life after symptoms appear is 5-9 years with a range of 2-20 years.
- It tends to progress from behavioral or language symptoms to a more global change in abilities and worsening functional abilities over time.
- Each of the different types of FTLD has different beginning symptoms and progress somewhat differently. See the information provided below.
- By the middle of the disease, the changes are spreading into other parts of the brain. Symptoms will generally start to include more traditional memory problems, difficulty doing personal care activities, problems with figuring out what to do and when to do it. Combined with the earlier symptoms of behavioral dis-inhibition and inability to follow social norms or expectations as well as impulsivity and inability to self-initiate purposeful activity and worsening language skills makes care provision more challenging. The person may have no speech or may not be able to produce words or speech that can be understood. The person may have no ability to make needs known and may not understand what caregivers are trying to do to help. The person may have ritualized behaviors and patterns of behavior that are difficult to understand or interrupt. The person may typically spend most time walking either alone or seeking out and touching and following another person. The person may be interested only in eating, or touching or looking at objects, people, or handles and doors. Wake-sleep cycles are usually somewhat unpredictable and combined with tendency to move around a lot make a secure and supervised setting very important during this phase of the disease. The person will also not typically be very tolerant of caregivers providing hands-on care when the care is needed and may become easily verbally or physically agitated and resistive. Judgment regarding what to eat and amount to eat and drink is often impaired as is the ability to 'wait' or 'take turns'.
- By the end of the disease, the symptoms of these conditions are often difficult to distinguish from other dementias. The person will however, tend to have less ability to produce speech or understand language than most other conditions. For many with FTLDs the progression is very rapid and what can initially seem like a behavioral disturbance, may simply be worsening of the FTLD. There are, however, some cases where there is a long delay between problems with either social skills or language and worsening elsewhere in the brain, but these cases are few. Typically, as FTLDs approach the final phases, the person will stop walking and become immobile. The person will not be able to care for themselves or make needs known. Constant physical care and supervision will be needed to limit risks of falls and injuries, encourage adequate hydration, and help with safer food intake.

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How Does It Progress? (cont'd)

• Death is typically a result of pneumonia or other infection, which the body cannot fight off even with the use of antibiotics. Pneumonia is typically caused by aspiration (food or liquids getting into the airway due to problems with eating or drinking and breathing regulation). Other infections can be localized (repeated UTIs (urinary tract infections), open pressure ulcers or wounds (caused by the inability to move or friction with repeated movements), skin injuries (when hitting a hard or sharp surfaces or skin exposure to urine or feces), or contractures (tightening and shortening of muscles that keep body parts closed together), the use of tubes or catheters (feeding tubes or urinary catheters). Still other infections can be or systemic, called sepsis, an infection in the blood stream. Other causes of death include malnutrition and dehydration, complications following falls (head injury or fractures), pulmonary emboli (clots that travel to the lungs due to prolonged immobility), or heart failure.

What *Basically* is Happening?

In this type of dementia, there are three factors that are noted. There is an accumulation of abnormal tau protein (tauopathy) AND there is major tissue scarring (gliosis) and cell destruction and death in the frontal and/or temporal parts of the brain.

- Tau protein is important in maintaining the rigid structures inside the cell that help transport nutrients and chemicals throughout the cell and down the arms of the brain cells. Normally, tau proteins help form and tie together these 'railroad tracks'. When FTLDs begin there is a change in the tau protein and rather than forming nice straight rigid tracks, it breaks down and the tracks collapse and form tangles (neuro-fibullary tangles). When this happens, the cell cannot send nourishment to all parts and it causes the cell to shrink up and die. The cells most sensitive to these losses are those in the frontal and temporal lobes of the brain. As the disease worsens, however the problem spreads throughout the brain and destroys function in most areas.
 - The second process that is going on in FTLDs is that and there is scarring of brain nerve tissue (gliosis). This scarring causes the cells to stop working correctly and makes message transmission spotty and problematic.
 - The third process is related to sudden death of many brain cells in localized areas. These cells are dying at a very high rate in the frontal or temporal areas holes then form throughout these portions of the brain (vacuolation).
 - The combination of tauopathy, scarring, and hole formation causes only certain parts of the brain to be 'hit' first. This means the person will lose only certain abilities at a much faster rate than any other part of the brain. Other parts of the brain can continue to function as they did before, making this progress at first in a very different pattern than the other dementias.
 - Because the various FTLDs are NOT ALL THE SAME, symptoms are variable and, in some cases, may involve additional problems with movement early on.

What are the Common Symptoms of Various FTDs?

Typical areas include: Behavioral, judgment, and language problems.

Frontal Lobe Dementia (FvFTD or FLD)- These individuals will show changes in the left frontal lobe first – *behavior changes*

Changes may include:

- Mis-behavior Behave or talk in ways that are not socially acceptable singing loudly in a quiet or public space, eating off others plates in a restaurant, urinating on a artificial tree in a mall, touching strangers or making comments about them, etc.
- Impulsivity Take risks and have poor judgment about safety fast or risky driving, shop lifting, mis-handling money, using weapons, over-eating, drinking excessive alcohol, damaging existing relationships, sexually over-active or aggressive
- Dis-inhibition Not able to control desires or appetites (food, drink, sex, words, actions)
- Overly friendly and humorous
- Inertia unable to 'get started' can't make decisions, can't begin tasks or activities
- Obsessive compulsive behaviors becomes fixated on ideas or actions
- Inattention unable stay focused or complete activities
- Lack of social awareness not knowing how to behave in various social situations
- Lack of social sensitivity not aware of how their behavior or words affect others
- Lack of personal hygiene does not complete bathing, dressing or grooming tasks
- Becomes sexually over-active or aggressive, or may talk about sexual subjects in inappropriate settings or use words that are 'not OK'
- Becomes rigid in thinking unable to change how a problem is approached or considered
- Stereotypical behaviors repeats the same movement or action over and over (pulls hair, taps a finger, claps, smacks lips, etc.)
- Manipulative actions picking up and handling or fidgeting with objects items they find or touching and fingering people or clothing over and over
- Hyper-orality putting things in their mouth OR eating excessive amounts of salt, fat, and sugar foods – large weight gains – compulsive eating or drinking
- Language may be impulsive but unaffected OR may be reduced or repetitive, or patterned

Temporal Lobe Dementia – (speaking and understanding language problems) – damage is first noted in the left temporal lobe of the brain

Primary-Progressive Aphasia – Non-Fluent Aphasia

- Difficulty finding the names of objects
- Hesitant production of words slowed speech or stuttering
- Not speaking or speaking very little
- Worsening of speech production over time
- Echolalia repeating words that are heard over and over
- Mis-speaking coming out with the wrong words word 'salad'
- There may also be problems understanding spoken and written words as well speaking
- Non-language skills may NOT be affected at first and the person may be able to perform other activities without difficulty at first
- There are some cases where there is not a generalized dementia that occurs although aphasia (loss of language skills) does worsen there is no other change for 10-12 years
- In all other cases, the damage spreads to other brain areas with a loss of skills in all areas
 over time

Semantic Dementia – Fluent Aphasia

- o Problems with naming items and with understanding the meaning of words
- Continued ability to produce the rhythm of speech so that it sounds like the person is saying something, but the words don't make sense
- There may be some pauses in speech, but it is limited to finding a specific word, otherwise speech is smooth and seems like it should have content
- The person may repeat their phrases and 'important' words over and over during conversations without being aware or the repeats
- Facial expressions and gestures may continue to occur during speech

Frontal-Temporal Dementia – (FTD, FTLD, Pick's Disease) – combines brain changes in the frontal and temporal lobes – there are Pick's bodies found in microscopic inspection of brain tissue after death

- Behavioral changes include impulsivity, dis-inhibition, hyper-orality, decreased attention, perseveration of speech and action, stereotypical actions and words, loss of empathy and social awareness.
- Language changes include, decreased speech production, problems with production and understanding, outbursts of song or inappropriate words or phrases, or echolalia
- o Difficulty thinking things through, concentrating on tasks, loss of problem solving
- As the disease progresses, symptoms worsen and then other problems develop that look more like Alzheimer's disease.

Frontal Temporal Dementia with Parkinsonism – Chromosome 17 (FTDP-17)

- Behavioral changes loss of initiation, dis-inhibition, obsessive-compulsive behaviors, restlessness, verbal aggressiveness, loss of personal care interests and abilities, excitability and irritability, binge eating, excessive drinking of fluids and alcohol, emotional coldness and insensitivity, repetitive actions such as clapping, pacing, or vocalizing
- Psychiatric symptoms delusions, visual and auditory hallucinations
- Cognitive decline word finding problems, problems producing words, but NOT problems understanding what others say, ability to make decisions, plan, and problem solve is affected, problems paying attention, unable to understand abstract ideas or think ahead, gradual inability to speak at all (becomes mute) over time

Cortico-Basal Degeneration – problems both in the upper and deeper parts of the brain

- Signs of parkinsonism tremors, stiffness, rigidity, poor coordination, impaired balance
- Cognitive and visual-spatial impairment not able to think through any problem or express clear reasoning, problems completing even familiar motor tasks, difficulty recognizing and using tools, objects, and utensils
- Hesitant and halting speech (like non-fluent aphasia)
- Sudden contractions of muscles resulting in spasms and sudden collapses or loss of balance and falls
- Difficulty swallowing and frequent episodes of aspiration pneumonia
- Generally rapid progression and worsening of the condition changes noted by months

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Progressive Supra-nuclear Palsy

- Movement and motor problems with balance and walking
- Problems with controlling smooth eye gaze and eye movements
- Problems closing eyes, even when trying to keep them open
- Problems with being able to make and keep eye contact
- Problems with swallowing and aspiration pneumonia early in the disease
- Apathy lack of emotions, flat and none emotional, no energy and no interests
- Irritable and angry outbursts
- Depression
- Rapidly progressing dementia spreading through the brain over months to a few years

Amyotrophic Lateral Sclerosis—Parkinsonism-FTD Complex

- Combining typical symptoms of FTD with ALS (Lou Gehrig's disease)
- The additional motor signs include:
 - Muscle weakness
 - Muscle shrinkage
 - Muscle spasms
 - Swallowing problems

Diagnostic Work-Up – What Should Be Done?

Consider seeking out a specialist in dementia evaluation, if symptoms are not typical for Alzheimer's disease, as missed or mis-diagnosis is common

- Complete physical and neurological examination
- Complete medical history and history of symptom development from the person but also family or care provider (in private setting)
- Neuro-psychological testing
- Functional abilities in attention, language, visual-spatial skills, memory and thinking/reasoning skills, fine and gross motor skills.
- Brain imaging preferably a PET scan as it will show symptoms of specific areas of functional loss before the structures shrink a lot. If a PET scan is not possible, then at least a CT or MRI scan
- Blood tests, and other laboratory tests to rule out other possibilities
 Probable FTLD should be considered if behavior and or language problems are the most noticeable changes rather than memory or mobility problems.
 It is possible for a person to have both a FTLD and Alzheimer's Disease OR for a second dementia to develop after the initial symptoms of behavioral and language problems.

Medications – Controversy and Challenges

- The most recent findings are that many medications traditionally used in dementia care (acetylcholinerase inhibitors - trade names: Articept, Execelon, and Razadyne) do not provide any benefits for people in the early to middle stages of FTLDs. This is because acetylcholine is not depleted in these individuals.
- The use of memantine (Namenda) is also being questioned at this time, although there is at least one clinical trial that is in process, so the evidence is not yet complete.

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Medications – Controversy and Challenges (cont'd)

- It has been noted that many people with FTLDs so have problems with serotonin levels (this chemical is associated with clinical depression). Therefore, there have been some studies that have looked at using serotonin selective reuptake inhibitors (SSRIs). The results are mixed, although some small studies indicate some people do seem to gain some benefit in depressive, dis-inhibition, carbohydrate craving, and compulsive symptoms, with use of these type of medicines (examples of trade names: Luvox, Zoloft, Paxil (for younger people), Anafranil, Lexapro, Celexa). These medications are also being used to treat obsessive compulsive disorders (OCD) to help manage symptoms of repetitive, hyper-focused behaviors that the person cannot stop. A possible side-effect of these medications is reduced sexual drive, which is also often a problem with FTLDs. In OCD treatments the amounts of medication used tend to be high compared to dosages used for depression only. The high doses are needed for symptom management although some people are helped at very low doses as well. Typical recommendation would be to start very low and go slow to increase the medications.
- Another anti-depressant, trazadone (Desyrel) at lower doses has been used to help with agitation and to help induce sleep, if this is problematic. This has been supported with evidence from small sample size trials.
- For problems with attention, hyperactivity, as well as sleepiness and apathy medications more typically used with ADHD and ADD have been tried. Amphetamines (such as Ritalin (trade name)) and anti-depressive agents have been tried, but there is little supportive evidence in the literature and clinical trials have not yet been completed.
- For movement problems, seen in some of the FTLDs, anti-parkinson (dopamine agonist) medications have been used, but there is little evidence that they are helpful in reducing mobility problems and they have possible side effects of increasing confusion.
- There are some clinics who are studying the effect and impact of using medications traditionally used to treat or patterns of speech.
- The most that can be offered at this time is to try and treat some symptoms
- Thinking and Behavior Aid Because actetylcholine is NOT depleted, acteylcholinesterase inhibitors (Aricept, Exelon, Razadyne) are NOT usually recommended in early stages of the condition. Namenda may be considered.
- **Emotional Distress or Depression Aid** Anti-depressants that are selective serotonin reuptake inhibitors (Ex: Celexa, Lexapro, Zoloft) are used to help depression or apathy is problematic. Possible negative side effects include drowsiness, dry mouth, nausea, trouble sleeping.
- Behavioral Control Aids anti-psychotic medications may be tried to help control irrational and compulsive behaviors that cause risk to caregivers or the person (Haldol, Respiradol, Seroquel) there are serious potential side effects the person should be monitored carefully for any signs of rigidity, writhing movements, or immobility so that medications can be stopped ASAP. In emergency management situations, tranquilizers may be used for acute problems.
- Alternative Options to Manage Distress or Anxiety Two other options are being used to help with symptoms. One option is anticonvulsant medication (Depakote) and another is an antidepressant (trazadone) that has calming features that may help with tolerating care assistance or getting to sleep with fewer side effects.

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What Should Be Done Routinely?

- Complete durable healthcare and financial power of attorney decisions and paperwork
- Complete advance directive planning and financial planning
- Develop and use daily routines that include:
 - Exercise aerobic, strengthening, coordination, and flexibility
 - Self-care modify help as skills are lost
 - Leisure activities make modifications as skills are lost
 - Work or productive activities abilities may be lost early in the disease, use of time will need to be addressed
 - Rest times breaks in the action, sleep will need to be structured in and additional caregiver may be needed at night to ensure that the primary caregiver gets rest when insomnia is problematic
 - Time away for the care partner
 - Time out of the home with friends or neighbors when mobility is adequate
- Get a speech therapy consult if language skills are being affected
- Check out Safety issues with skilled health professionals (OTs or PTs) modify the home for specific safety concerns that are identified
- Check out the need for rehabilitation for mobility and functional losses (OT, PT, Speech)
- Continue familiar activities and groups (watching versus doing) consider providing some education and training for others to help them in helping the person feel included and successful
- Look at care options and locations for possibilities as needs and abilities change
- Get counseling and support if mood and personality changes are affecting relationships and roles in the family and community

Special Treatment Considerations:

Of all dementias, FTLDs can be the most isolating and frustrating to try to provide care and support. The dramatic changes in personality, behavior and language skills make relationships and care provision much more challenging and frightening. Seek skilled guidance and support.

Early Issues

- Give up trying to make the person understand what you are feeling to thinking. Be prepared that
 the person cannot see it from your point of view or respond to your concerns in the way they
 would have previously.
- Work at trying to control access to money, drink, food, medications, or other things that the person may overuse or misuse due to the symptoms of their disease. This may require assistance from professionals or experts to help make these changes.
- If the person does something inappropriate as long as they are not in danger, Do not become angry or confrontational. Stay calm and keep your voice relaxed. Consider carrying a 'companion card' and card that can be passed to others to let them know that the person with you has a condition that affects their language and behavior.
- If the person is impulsive and behaves in ways that are not consistent with their past behaviors, consider educating those who are part of the person's social network to alert them to the possibility and to provide them with optional responses and awareness.
- If the person has job responsibilities that would put others at risk, early retirement or modifications at the job site may need to be considered for everyone's well being and safety.
- If sexual behaviors are problematic or are excessive, talk with your health provider about the symptom and ask about possible medications to reduce sexual drive.

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Early Issues (cont'd)

- Look at environmental modifications to secure selected areas, decrease access and make other
 areas more visible. An OT consult may be helpful in modifying the environment and tasks, so
 the person can still participate actively and safely.
- If there are swallowing concerns. Talk with your health provider about modifying medications to limit 'pills'. It may be possible to get some as powders, others as liquids, and some as capsules rather than pills. Also begin considering food items and their presentation. Serving meats that don't require cutting into pieces, or careful chewing. Cutting sandwiches into wedges, or moving to more 'finger' options, use of mugs for soups rather than bowls, or use of straws for liquids with covered cups. A speech therapy or OT consult may be helpful to determine some options that may help.

Middle Stage Issues

- Create daily routines and schedules that foster a balance of exercise and movement, quiet time
 and active time, slow and consistent transitions with multiple cues. Build environmental supports
 into the routines so that the person can complete personal care needs as they go from one place
 or activity to another.
- Limit language and judgment/decision making demands in all areas. Simplify routines, tasks, activities, and expectations. Provide strong and simple visual cues about what is being requested or wanted demonstrate or gesture and use props. Do things one step at a time. Give strong visual cues back so that the person knows how they are doing, what comes next. Do only the parts of the tasks that the person cannot do.
- Make sure all seating used by the person, has plenty of personal space around it so they do not
 have to be too close to others. Personal space is critical to reduce problems with too much
 contact or problems with impulsive behaviors.
- Be prepared for lots of pacing or walking. Also for efforts to eat or put thing in the mouth. Create safe and secured walking spaces and items that can be safely picked up and handled without putting the person in danger. Also be prepared to secure food sources and provide many smaller size meals to meet oral intake desires. Provide snacks that are lower in calories, are bite size and provide oral stimulation.
- When possible, the use of hand under hand techniques rather than dependent assistance is helpful, as it provides the person more information about what is being asked of them and helps them to use remaining motor abilities, even though they do not quite understand what caregivers are saying to them.

Late Stage Issues

- Consider and explore the use the acetyminephine on a regular schedule to help with possible 'pain' due to muscle discomfort, immobility, pressure areas, and joint stiffness combined with the inability to communicate needs verbally.
- Keep spaces warm and use light-weight and warm blankets.
- Keep one hand still, using a flat open palm on a shoulder or hip, while providing care with other hand.
- Keep action slow and controlled. Give information about what you are going to do. Then consider
 using limited conversation to distract the person with familiar and friendly comments OR be quiet,
 if that is their preference OR use favorite music at a low volume.
- Limit contact with the palms, soles of the feet, around the mouth and in the genital area. Make sure temperature of cloths and water is at a level that is OK for the person.
- Use two people to give care One to help reassure or monitor the person for safety and comfort, while the other performs necessary tasks.

Late Stage Issues (cont'd)

- Use bed bathing versus showering or whirlpools, if sensation is extreme and distressing.
- Do not routinely use palm mitts, or protectors, splints or foam palm supports, if there is a strong
 'grasp reflex' or palm sensitivity due to increased probability that these devices will cause greater
 closure or cause more discomfort. Instead, use forearm pillow props to keep hands from
 contacting objects, use 'hand under hand' with firm pressure in palm when care is needed and
 consider the use hand sanitizer (without alcohol) to help with hand hygiene.

Some Resources for specifically for Fronto-Temporal Lobe Dementias:

- FTD Caregiver Info Center http://ftdsupport.com/index.html
- Fronto-Temporal Dementia Association www.theaftd.org
- Mayo Clinic www.mayoclinic.org
- Family Caregiver Alliance www.caregiver.org
- HelpGuide for Pick's Disease http://www.helpguide.org/elder/picks_disease.htm
- National Institute of Neurological Disorders & Stroke www.ninds.nih.gov/disorders/dementiawithlewybodies
- Primary Progressive Aphasia http://www.brain.northwestern.edu/ppa/ and an older review article on PPA
 - http://www.uphs.upenn.edu/ftd/resources/documents/ftdprogressiveaphasiareview.pdf

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Reference and Resource List

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http://www.alzheimer.ca/english/disease/dementias-frontotemp.htm

Info from e-medicine - http://www.emedicine.com/neuro/TOPIC140.HTM
Info from Northwestern University - http://www.brain.northwestern.edu/mdad/frontal.html

Info on fvFTD -

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Info on drugs used to treat symptoms in FTD - http://ftdsupport.com/side-drugs.htm#ListofDrugs Use of SSRIs - http://www.ncbi.nlm.nih.gov/pubmed/18090429

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