

Frontotemporal Dementia (FTD): A Guide for Patients & Families

Frontotemporal dementia (FTD) is a group of brain disorders caused by progressive degeneration of the frontal and temporal lobes of the brain. These regions control personality, behavior, decision-making, language, and emotional regulation. Unlike Alzheimer's disease, early symptoms often involve behavior or language changes rather than memory loss.

Signs & Symptoms to Watch For

Common Cognitive & Language Symptoms

- Difficulty finding words or forming sentences
- Trouble understanding spoken or written language
- Reduced speech or slowed communication
- Problems with planning, organization, or judgment
- Difficulty completing complex tasks

Behavioral & Personality Changes

- Loss of empathy or reduced emotional awareness
- Socially inappropriate behavior
- Poor judgment or impulsive decisions
- Apathy or loss of motivation
- Repetitive or compulsive behaviors
- Changes in eating habits or food preferences

Typical Presentation & Progression

Early Stage

- Personality or behavioral changes
- Word-finding difficulty or communication problems
- Reduced social awareness
- Memory often relatively preserved early

Middle Stage

- Increasing behavioral symptoms
- Worsening communication problems
- Difficulty managing work or daily responsibilities
- Need for increasing supervision

Late Stage

- Severe communication impairment
- Loss of independence with daily activities
- Mobility difficulties in some cases
- Need for full-time care and supervision

Medications Used for Symptom Management

Behavioral Symptom Treatments

- Selective serotonin reuptake inhibitors (SSRIs) — may help reduce impulsivity, compulsive behaviors, irritability, and mood symptoms.
- Trazodone — sometimes used for agitation, anxiety, or sleep disturbance.

Medications Used Cautiously

- Antipsychotic medications — may be considered for severe agitation, aggression, or psychosis when safety is a concern.

Currently, there are no FDA-approved medications that specifically slow or stop the progression of frontotemporal dementia.

Diagnostic Tests Your Healthcare Team May Use

Clinical & Cognitive Evaluation

- Detailed medical history and symptom review
- Cognitive screening tests such as the Montreal Cognitive Assessment (MoCA)
- Neuropsychological testing focused on executive function and language abilities

Laboratory Tests

- Blood tests to rule out other causes of cognitive symptoms
- Thyroid function tests
- Vitamin B12 and other metabolic evaluations

Imaging Studies

- MRI or CT scans — may show shrinkage of the frontal and temporal lobes
- FDG-PET scans — may show reduced brain metabolism in frontal and temporal regions

Planning for the Future

Healthcare Planning

- Discuss goals of care early while the person can express preferences.
- Establish advance directives and a healthcare power of attorney.
- Consider specialty dementia care and long-term planning.

Legal & Financial Planning

- Assign durable financial power of attorney.
- Review insurance coverage and long-term care planning.
- Consider consulting elder-law professionals when appropriate.

Support for Caregivers

- Behavioral changes in FTD can be challenging for families.
- Establish routines, seek respite support, and connect with caregiver support groups.

National Organizations & Resources

- ✓ Association for Frontotemporal Degeneration (AFTD)
☎ 866-507-7222 | 🌐 theaftd.org — education, support groups, and caregiver resources.
- ✓ Alzheimer's Association 24/7 Helpline
☎ 800-272-3900 | 🌐 alz.org — support services and dementia education.
- ✓ National Institute on Aging (NIA)
☎ 800-438-4380 | 🌐 nia.nih.gov — research and educational resources.
- ✓ Eldercare Locator
☎ 1-800-677-1116 | 🌐 eldercare.acl.gov — connects families with local aging services.

Final Notes

- Frontotemporal dementia often affects individuals at a younger age than other dementias.
- Early recognition helps families plan for medical, legal, and caregiving needs.
- Support for caregivers is essential due to the behavioral and personality changes that can occur in this illness.