



The Association for
Frontotemporal Degeneration

FIND HELP • SHARE HOPE

Frontotemporal Degeneration (FTD)

Misdiagnosed and Misunderstood

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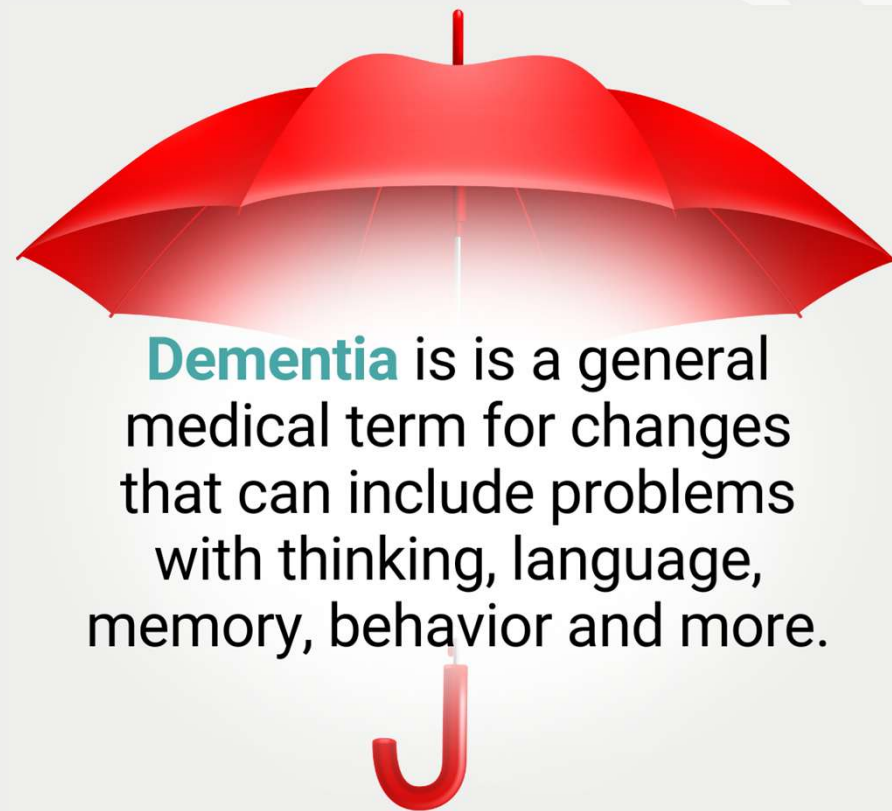
My Story Is Personal, But I'm Not Alone



The Dementia Umbrella

Some of the most common causes of dementia are:

- Alzheimer's Disease
- Lewy Body Dementia
- Frontotemporal Degeneration (FTD)
- Vascular Dementia
- Mixed Dementias



What is FTD?

A type of dementia
caused by a family
of disorders

Leading cause of
dementia in those
younger than 60

Genetic cause
found in
approximately 20%
of those diagnosed

Changes in behavior,
personality,
communication or
movement are common
symptoms

Takes an average
of 3.6 years to
achieve diagnosis

Large caregiver burden
due to age of onset
and symptomology

FTD: A Cluster of Complex Disorders

also called: frontotemporal dementia, frontotemporal lobar degeneration or Pick's Disease

Progressive Behavior/ Personality Change

**Behavioral Variant FTD
(bvFTD)**

Progressive Communication Change

**Primary Progressive
Aphasia (PPA)**

Subtypes:

- Nonfluent/Agrammatic Variant
- Semantic Variant
- Logopenic Variant

Progressive Motor Function/ Movement Change

**Corticobasal Syndrome
(CBS/CBD)**

**Progressive Supranuclear
Palsy (PSP)**

**FTD + Motor Neuron
Disease (ALS-FTD)**

Diagnosing FTD

- **Probable Diagnosis:** Clinical Diagnosis
 - Imaging(MRI, FTDG-PET)
 - Neuropsychological testing
 - Evaluation of symptoms
- **Definitive Diagnosis:** Autopsy or Genetic Test

DIAGNOSTIC CHECKLIST
Behavioral Variant Frontotemporal Degeneration (bvFTD)

FOR YOU: Changes in behavior, mood, or personality
Check off each box next to symptoms that you or a loved one have experienced. Bring this form to your next appointment with a health care provider or ask if they would like to review it ahead of your visit. This form is not a substitute for a diagnosis by a medical professional.

APATHY

- ☐ Loss of interest in work, hobbies, or relationships
- ☐ Not tending to personal hygiene
- ☐ Loss of initiative

SOCIALLY UNACCEPTED BEHAVIOR

- ☐ Saying things that are uncharacteristically rude or offensive
- ☐ Uncharacteristic touching, sexual behavior, or violation of others' personal space
- ☐ Shoplifting or impulsive purchasing
- ☐ Unexpected aggression or agitation

DECLINES IN EXECUTIVE FUNCTIONS

- ☐ Difficulty planning
- ☐ Questionable financial planning and decision-making
- ☐ Making repeated mistakes at work

LACK OF INSIGHT

- ☐ Blaming others for consequences of behavior

COMPULSIVE BEHAVIOR

- ☐ Repeating words or phrases
- ☐ Continually rubbing hands together or clapping
- ☐ Re-reading the same book or watching the same episode of a show
- ☐ Uncharacteristic hoarding
- ☐ Walking to the same place each day

LOSS OF CONCERN FOR OTHERS

- ☐ Indifference to significant events like a death or birth in the family
- ☐ Loss of empathy
- ☐ Newfound inability to recognize others' emotions
- ☐ Frequent irritability and mood changes

CHANGES IN EATING HABITS

- ☐ Binge eating and/or excessive beverage consumption
- ☐ Only eating specific foods
- ☐ Increased or first-time use of tobacco or alcohol
- ☐ Attempting to eat non-edible objects

DIAGNOSTIC CHECKLIST
Primary Progressive Aphasia (PPA)

FOR YOU: Problems with speaking, understanding, reading, or writing
Check off each symptom that you or a loved one have experienced. Bring this form to your next appointment with a health care provider or ask if they would like to review it ahead of your visit.

SLOW, LABORED SPEECH

- ☐ Difficulty moving lips and tongue to speak (resulting in slow, labored speech and slurring)
- ☐ Omitting words when forming a sentence, especially short connecting words (i.e., "to", "from", "the", "and")
- ☐ Ordering words incorrectly in sentences; using wrong word endings, verb tenses, or pronouns
- ☐ Pauses and hesitations in speaking and extensive descriptions to explain missing words
- ☐ Characteristically speaking in shorter, simpler sentences
- ☐ Placing nouns with empty words such as "thing"
- ☐ Misunderstanding complex sentences
- ☐ Mistakes in speech sounds, such as omitting or substituting certain sounds (for example, saying a "t" sound for a "g" sound; saying "las" instead of "gas")

NAMING PEOPLE AND OBJECTS

- ☐ Missing the names of objects (this can also include substituting a name with a word, like using "car" instead of "truck.")
- ☐ Using words that do not make sense to listener
- ☐ Missing names of familiar objects
- ☐ Missing how a familiar object is used
- ☐ Missing words that are not pronounced how they are written (e.g., "know")

Behavioral

- Apathy
- Disinhibition
- Loss of Empathy
- Executive Dysfunction
- Compulsive Behavior
- Hyperorality

Language

- Changes in Word Finding
- Changes in Word Understanding
- Changes in Word Order

Movement

- Muscle Weakness
- Muscle Rigidity

FTD Treatments & Therapeutic Interventions

There is hope with current research and research participation

There is no FDA approved disease-altering or symptomatic treatment yet. But we're closer than we've ever been.

- There are effective treatments and approaches to help manage symptoms:
 - Off-label use of medications to treat symptoms
 - Families can learn to use dementia-supportive approaches to respond and provide care
 - Rehabilitative therapies: Speech Therapy, Physical Therapy, and Occupational Therapy, as well as Palliative care

Active research is looking for FTD-specific treatments, and research volunteers:

- Learn more: ftdregistry.org/find-a-study/

AFTD – From Hope to Action



AFTD envisions a world with compassionate care, effective support, and a future free of FTD.

Our mission is to improve the quality of life of people affected by FTD and drive research to a cure. We work every day to advance:



Research



Awareness



Support



Education



Advocacy

AFTD Resources for Families

HelpLine: info@theaftd.org
866-507-7222

Website: www.theaftd.org

Support: www.theaftd.org/living-with-ftd/aftd-support-groups

Grants: Respite, Travel, Quality of Life

Webinars: www.theaftd.org/category/webinars/

**Annual
Conference:** Spring/In-person and Virtual

Publications: *Help & Hope*
Partners in FTD Care
The Doctor Thinks It's FTD. Now What?



theaftd.org/living-with-ftd/resources

What About the Kids?
Understanding the Genetics of FTD

How to Get Involved



Share FTD
information
and increase
awareness



Raise funds in
support of
AFTD's mission



Join AFTD's
Volunteer
Network

*[theaftd.org/get-
involved/volunteers-
network](http://theaftd.org/get-involved/volunteers-network)*



Become an
advocate for
change!

*Sign up at
[theaftd.org/get-
involved/advocate/](http://theaftd.org/get-involved/advocate/)*

Stay Connected with AFTD Resources

Scan to sign up for
AFTD's newsletters



Contact AFTD's HelpLine

**info@theaftd.
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Questions?