The Association for
Frontotemporal Degeneration
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Resources & Guidance for Managing Primary Progressive Aphasia

www.theaftd.org | HelpLine: 1-866-507-7222 | info@theaftd.org

Today's Topics

1

Brief overview of FTD/PPA

2

Approaches to better communication

3

AFTD resources for support

FTD: A Cluster of Complex Disorders

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

Progressive

Communication Change

Primary Progressive Aphasia (PPA)

Subtypes:

- Nonfluent/Agrammatic Variant
- Semantic Variant
- Logopenic Variant

Progressive

Behavior/ Personality Change

Behavioral Variant FTD (bvFTD)

Progressive

Motor Function/ Movement Change

Corticobasal Syndrome (CBS/CBD)

Progressive Supranuclear Palsy (PSP)

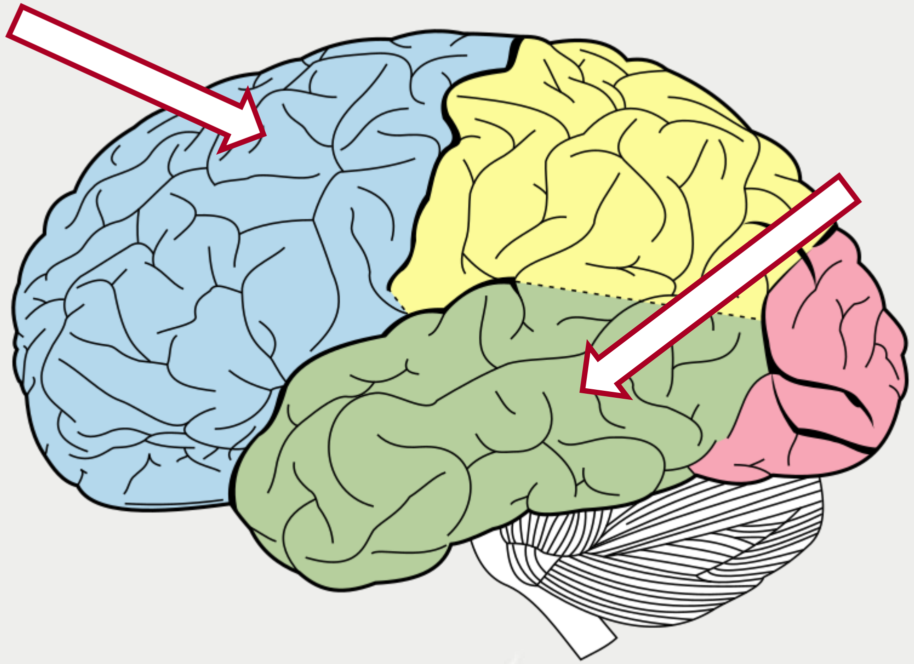
FTD + Motor Neuron Disease (ALS-FTD)

With FTD, What Happens Where?

Frontal Lobes

Prefrontal cortex

- Reasoning, decision making
- Control of behavior
- Executive functions (Planning, organizing)
- Problem solving
- Attention, concentration
- Emotional control
- Safety awareness
- Initiating action
- Physical movement



Temporal Lobes

Processing sensory information

Right Lobe

- Inhibition of speech
- Visual memory, pictures, shapes and faces, art

Left Lobe

- Verbal memory
- Understanding words and names
- Sorting new information

Signs and Symptoms of Primary Progressive Aphasia (PPA)

Nonfluent/Agrammatic

- **Agrammatism** – omitting words, errors in use of word endings, verb tense and pronouns
- Difficulty swallowing

Semantic

- **Anomia** – inability to recall names of objects
- Difficulty reading & writing words that don’t follow pronunciation or spelling rules

Logopenic

- Difficulty with finding the right word when speaking
- Difficulty with repeating phrases

Communication Approaches: The early stage of PPA

Speech language pathologist (SLP) evaluation is critical to initially and then periodically assess to:

- Create a personalized care plan which may include:
  - Alternative communication strategies and consider communication tools and devices.
  - Rehearsal lists or scripts for commonly used words or phrases that are unique to the person.

Adapt the environment and communication approaches:

- Reduce background noise and distractions
- As much as possible, use face to face communication
- Speak slowly and allow time for a response
- Use compensatory techniques, like cueing, clarifying meaning or describing the word to facilitate success, rather than "perfect" communication
- Ask for clarification is communication is unclear. Do not pretend to understand.

In the middle stage of PPA

Use scripts developed in SLP therapy to continue to discuss topics of interest in daily life”

- **Favorite activities, family, info about the diagnosis, etc.**

Simplify questions and directions:

- **Always let the person take the lead. Ask them how they want to be helped, whenever possible.**
- **Give one direction or ask one question at a time.**
- **Use questions that offer a choice rather than ones that are open-ended, like:**
  - Would you like coffee or tea for breakfast? (Instead of what would you like to drink?
  - Shall we have pizza or pasta for dinner?
  - I wonder what we should do together today. Would you like to go to the park or work in the garden?

Use affirming statements like:

- **Take your time, I can wait.**
- **We’ll figure it out. Maybe we can come back to this later.**

Seek out a neurological or neuropsychological assessment if new behavioral or movement challenges occur

In the late stage of PPA

Use multiple modalities as verbal communication becomes increasingly challenging, such as:

- **Gestures, writing single words, drawing**
- **Visual cues, picture board**

Anticipate consistent needs, when possible

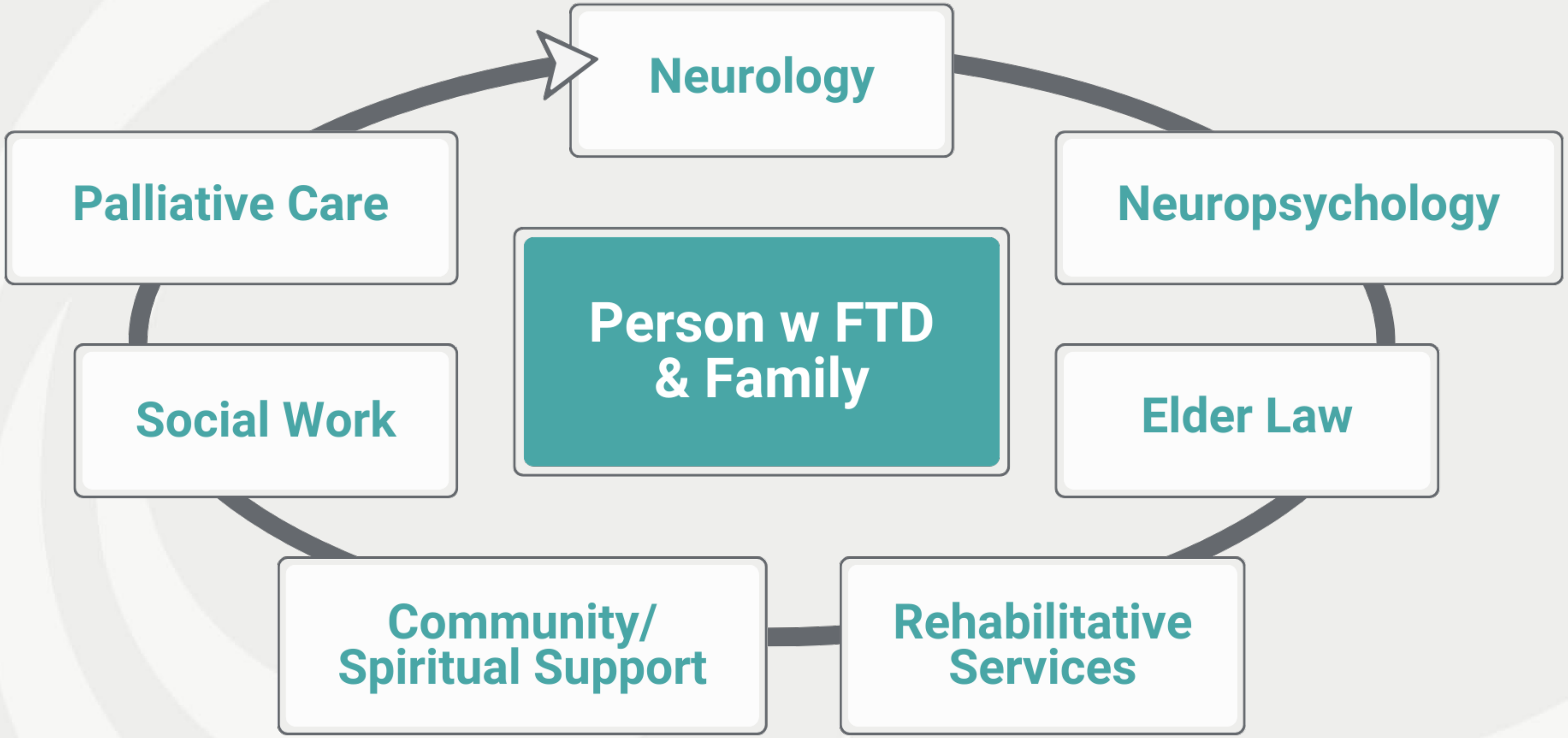
Regularly check in for comprehension or agreement

- **Nonverbal cues or confirmation that person is comfortable is communication**

Get referral to a SLP for an evaluation of swallowing or dysphagia as needed

Seek out a neurological or neuropsychological assessment if new behavioral or movement challenges occur as well as talking with medical team about hospice referral.

Building a Care Team



Person w FTD & Family

Neurology

Neuropsychology

Elder Law

Rehabilitative Services

Community/ Spiritual Support

Social Work

Palliative Care

AFTD Resources

AFTD – From Hope to Action

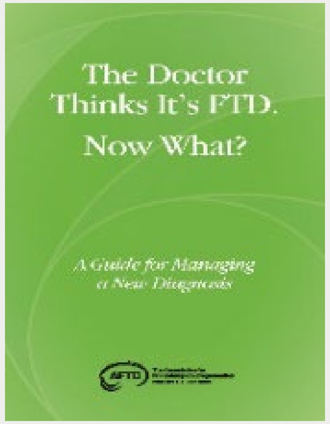
AFTD envisions a world with compassionate care, effective support, and a future free of FTD.

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:

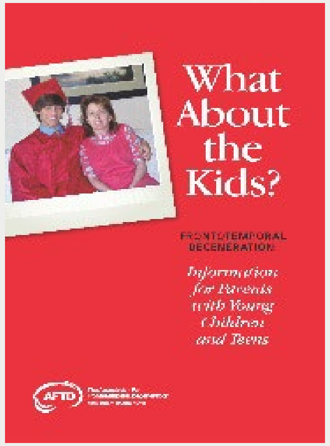
- Research
- Awareness
- Support
- Education
- Advocacy

Resources from AFTD

HelpLine	info@theaftd.org 866-507-7222
Websites	www.theaftd.org www.aftdkidsandteens.org
Publications	*Help & Hope* *Partners in FTD Care* *The Doctor Thinks It's FTD. Now What?* *What About the Kids?* *Understanding the Genetics of FTD* *Walking with Grief: Loss and the FTD journey*
Grants	Comstock Respite, Travel, Quality of Life https://www.theaftd.org/living-with-ftd/resources/comstock-grants/
Support	National and regional on-line and local in-person groups theaftd.org/living-with-ftd/aftd-support-groups

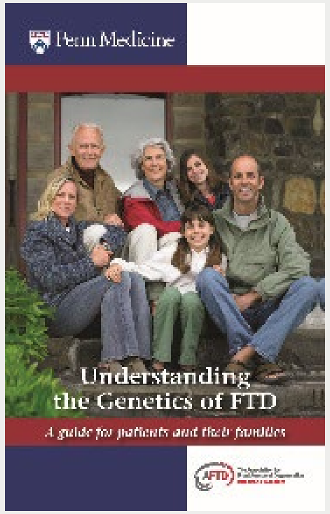

The Doctor Thinks It's FTD. Now What?

A Guide for Managing a New Diagnosis


What About the Kids?

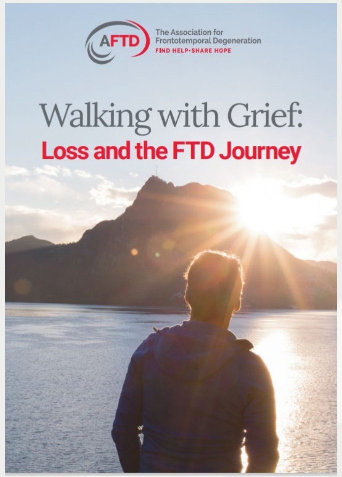
FRONTOTEMPORAL DEGENERATION

Information for Parents with Young Children and Teens


Penn Medicine

Understanding the Genetics of FTD

A guide for patients and their families


AFTD The Association for Frontotemporal Degeneration

Walking with Grief:
Loss and the FTD Journey

AFTD Resources for Managing PPA

Printed or web-based resources

Detection & Diagnosis:

PPA Diagnostic Checklist: A resource for families and healthcare providers:

- https://www.theaftd.org/wp-content/uploads/2023/09/Diagnostic-Checklist-PPA-9.23.pdf

Know the Signs and Symptoms:

- Nonfluent variant: https://www.theaftd.org/wp-content/uploads/2018/03/FTD-Signs-and-Symptoms-nfvPPA.pdf
- Semantic variant: https://www.theaftd.org/wp-content/uploads/2018/03/FTD-Signs-and-Symptoms-svPPA.pdf
- Logopenic variant: https://www.theaftd.org/wp-content/uploads/2018/03/FTD-Signs-and-Symptoms-lvPPA.pdf

Maximizing Communication Success in PPA: Winter 2016 Partners in FTD Care

- https://www.theaftd.org/wp-content/uploads/2018/03/PinFTDcare_Newsletter_Winter2016.pdf

AFTD Resources for Managing PPA

Recorded Educ Webinars

PPA: Approaches to Treatment: Session from 2024 Conference: Maya L Henry, PhD, CCC-SLP, Dept of Neurology, Univ of TX, Austin

- https://www.youtube.com/watch?v=v7Mf3XUv4Mc&list=PL0kAdIv_fhNfS7fNtIv7JveSSJXbnX-zK&index=7

Maximizing Communication, Maintaining Connection: Person Centered Care for PPA: Dr. Darby Morhardt and Dr. Emily Rogalski of Northwestern University

- https://www.theaftd.org/posts/front-page/aftd-webinar-maximizing-communication-maintaining-connection-person-centered-care-for-ppa/

What You Should Know about PPA: Emily Rogalski, PhD, Northwestern Univ, Mesulam Center for Cognitive Neurology and Alzheimer's Disease

- https://www.theaftd.org/posts/webinars/webinar-what-you-should-know-about-primary-progressive-aphasia-ppa/

AFTD Resources for Managing PPA

Support Resources

Persons Living with PPA

- **Living Well with PPA- 6 week educational support program for those newly diagnosed.**
- **Zoom Support Group for people living with FTD.**

Family Care Partners

- **Local FTD care partner supports in many areas can be found on AFTD website.**
- **Some local areas have PPA specific support groups for care partners**
- **National Zoom Support Group focused on language variants of FTD.**

Contact the AFTD Helpline for more information about any of these groups.

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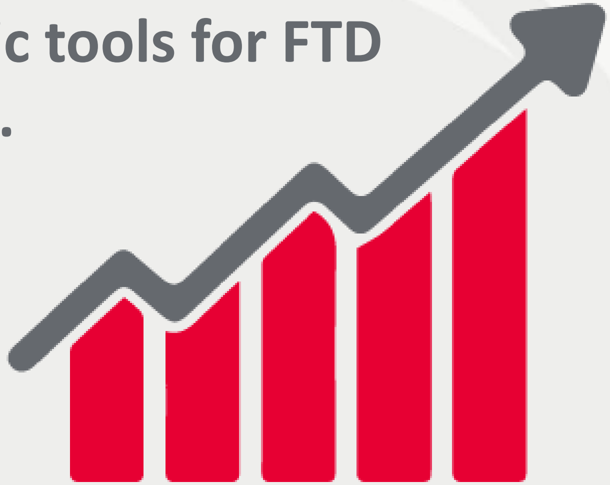
AFTD Resources for Medical and Care Professionals

- Partners in Care quarterly publication focusing on a specific issue or topic
  - Partners in FTD Care | AFTD (theaftd.org)
- Webinars and Annual Conference: Some webinars offer CEUs/CMEs
- AFTD Helpline: 1-866-507-7222 or info@theaftd.org

For additional info, go to For Health Professionals | AFTD (theaftd.org) *or contact the AFTD Helpline.*

FTD Research Opportunities

Scientists are closer than ever to new therapies and diagnostic tools for FTD and we all have a role to play in helping the research succeed.



- Many FTD clinical studies and trials are underway, seeking participants.
- Studies include experimental treatments to target FTD *symptoms* as well as potential *disease-modifying* treatments for people with sporadic and familial FTD.
- Studies also include *naturalistic/observational* studies to map the course of FTD.
- Some studies do not require the participant to know their genetic status.

Where to Learn More

Sign up for the FTD Disorders Registry: ftdregistry.org

- Co-founded by two non-profits, the Registry is a resource for persons diagnosed, families, and caregivers to participate in research.
- Healthcare providers and others may sign up to receive communications.
- The Registry provides one location to learn about research participation opportunities and share their stories to inform research design.
- Participants' personal information is NEVER shared.

Sign up for AFTD newsletters to stay informed about research opportunities and progress: theaftd.org

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

Become an advocate for change!

Stay Connected with AFTD Resources

Scan to sign up for AFTD's newsletters

Contact AFTD's HelpLine

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Questions?