The Association for Frontotemporal Degeneration
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# AFTD's 2019 Annual Education Conference

**Los Angeles Airport Marriott,**
**Los Angeles, CA**
**May 3, 2019, 8:45 a.m. – 5:30 p.m.**

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**For their generous sponsorship of the 2019 AFTD Education Conference, AFTD would like to thank the following:**

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**"No matter where you stand on this path, know that you are in a room filled with people who understand the challenges that FTD can bring to a family."**

Dear Friends,

On behalf of AFTD's Board of Directors, I welcome you to today's Education Conference. Though this Conference has grown and evolved significantly since we first gathered in 2010, one thing has remained constant. Gathering here together has always been a way to find help in facing the reality of FTD, and to share the profound hope that can grow when so many people facing this disease assemble in one place.

Some of you may be at the start of your FTD journey, and we are glad and grateful that you have found us. No matter where you stand on this path – whether you are a person living with FTD, a care partner or caregiver – know that you are in a room filled with people who understand the challenges that FTD can bring to a family.

AFTD strives each day to help members of this community find help and share hope. We offer help in the form of support groups, Comstock Grants for care partners and persons diagnosed, and the latest in FTD information. And our growing research efforts seek earlier diagnosis, the development of disease-modifying treatments, and ways to advance hope for a cure.

AFTD seeks a world with compassionate care, effective support, and a future free of FTD. The program for our 2019 Conference reflects that vision. We have gathered leading experts to update us on the latest in FTD research, and have brought together health professionals, family members and persons diagnosed to offer perspectives on caregiving, support, and research. Martha Madison, who balances a thriving career as an actor with the responsibility of caring for her mother, will offer a keynote address that highlights the lessons she's learned during her decade-long FTD journey.

In designing this conference, we have worked with community input to ensure that everyone's needs are recognized, represented and respected. We also look forward to learning how we can better serve you in the future. Please take this occasion to speak with AFTD staff, Board members, Regional Coordinator Volunteers and other attendees throughout the day. Your suggestions help us to serve this community better.

I hope that you find today's conference engaging and informative, and that you feel the support and hope that comes from being part of a group of people that understands. Thank you again for joining us here in Los Angeles.

Sincerely,

Gail Andersen

Gail Andersen
Chair, AFTD Board of Directors

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# About Today's Program

Welcome to the 2019 AFTD Education Conference. We have planned an informative and engaging day of programming. Here are some of the special features we'd like to bring to your attention.

## Resource Tables

As you move about the conference, you will notice AFTD staff, Board members and Regional Coordinator Volunteers here to offer you the best available resources targeting FTD, as well as new ways to get involved. Please don't hesitate to say hello! AFTD strongly values constituent input. Your questions and feedback help to ensure that we are serving the needs of the people facing this disease.

## For People Living with FTD

Thank you for joining us today. Each year, people living with FTD play a larger role in the planning and presentations of the day. You are encouraged to attend sessions of your interest throughout the day. Two breakout sessions are specifically tailored for those diagnosed with FTD: "Adapting to FTD: A Discussion for Persons Living with FTD" at 2:50 p.m. and the "Forum for People Living with FTD" at 4 p.m.

Throughout the day, the Susan Suchan Room will be available as a gathering place for people with FTD. The room, located in the Scottsdale room, is named in memory of Susan Suchan, a friend and advocate who died in January 2018. If you need help finding the room or have other questions, please ask anyone wearing a "Need Help: Ask Me" button.

## For Health Professionals

Thank you for attending the AFTD Education Conference. We appreciate your desire to learn more about this too-little-understood condition. Certificates of Attendance will be available following the closing session at the end of the conference. Please see AFTD Program Manager Matt Sharp at the registration table at the end of the conference to obtain your certificate.

## Keynote Address

Actor, producer and FTD care partner Martha Madison will deliver our 2019 Keynote Address (11:30 a.m.). Martha is best known for her role as Belle Black on *Days of Our Lives*. Her mother Barbara was diagnosed with behavioral variant FTD in 2008, at age 56, and has been living with multiple sclerosis for more than 25 years. In the wake of her mother's diagnosis, Martha has become a dedicated FTD advocate. Her full biography can be found on page 59.

## Lunch & Regional Networking

Standard box lunches will include turkey, ham & Swiss cheese, and vegetarian options. If you requested a special lunch when you registered, you may pick up your meal at the table with the "Special Requests Only" sign. During lunch (12 p.m. to 1:15 p.m.), you will have the opportunity to meet and network with others from your region. By wearing a color-coded ribbon, you can easily identify others who live nearby. To network at lunch, look for the tables representing each U.S. region. People with FTD are welcome to eat in the Susan Suchan Room after picking up their lunch if they prefer.

## Breakout Sessions

Our afternoon sessions will focus on Clinical Issues (1:15 p.m. to 2:30 p.m.), Care Strategies (2:50 p.m. to 3:50 p.m.), and Open Q&A and Networking (4:00 p.m. to 4:50 p.m.). See pages 7 & 9 for room assignments.

## What Are Your Lifelines?

All participants are invited to the final conference session, "What Are Your Lifelines?", at 5 p.m. Audience participation is encouraged in this fast-paced look at some of the ways people facing FTD find help and share hope. Look for opportunities to share information about your own lifelines today!

## Social Reception

Conference attendees and speakers are invited to join AFTD staff and Board members for an informal social gathering following the day's events (5:30 p.m. to 7:30 p.m.).

## Livestreaming and Audio Recordings

Plenary sessions will be livestreamed. Breakout sessions will be made available as audio recordings.


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OUR MISSION

is to develop therapies that

**empower the immune system**

to cure neurodegeneration

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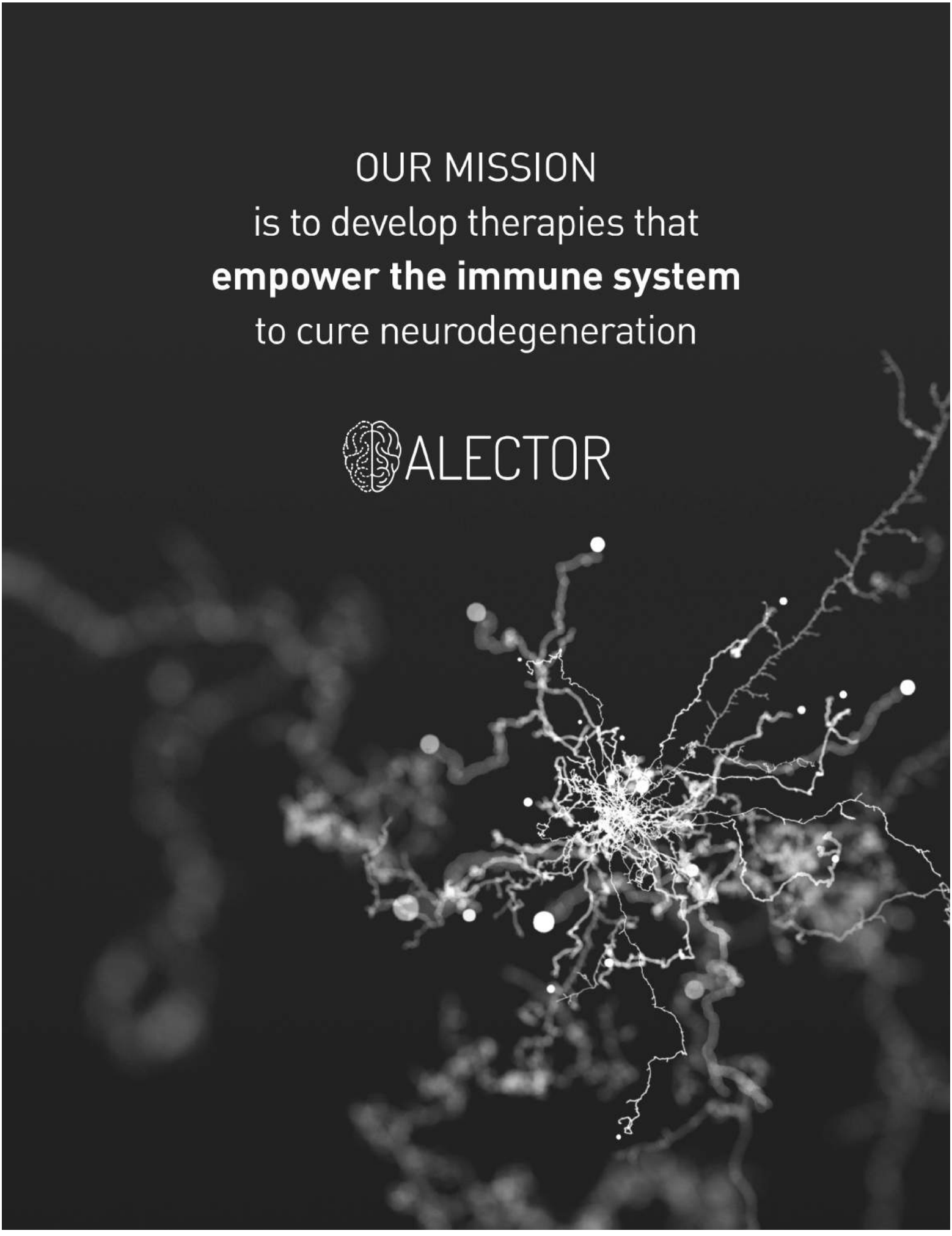

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# The Day's Program

**8:00 a.m.**

**Registration**

**8:45 a.m.**

**Welcome**
Gail Andersen, AFTD Board Chair
Amy Shives, MEd, AFTD ThinkTank

**9:00 a.m.**

**Advances in Understanding FTD**
Mario Mendez, MD, PhD, UCLA
Jamie Fong, CGC, UCSF

**9:40 a.m.**

**Perspectives on Research**
Kimiko Domoto-Reilly, MD, UW
Elvira Jimenez, PhD, UCLA
Dianna K.H. Wheaton, MS, PhD, CHES
Anne and Ed Fargusson

**10:20 a.m.**

**Break**

**10:40 a.m.**

**Perspectives on Care and Support**
Mary Guerriero Austrom, PhD,
Indiana University School of Medicine

Mary O'Hara, LCSW, Rocky Mountain
Neurobehavioral Associates

Laurie Scherrer
Chuck Anastasia

**11:15 a.m.**

**Providing Help, Advancing Hope:**
**AFTD's 2019 – 2022 Strategic Plan**
Susan L-J Dickinson, MS, CGC

**11:30 a.m.**

**Conference Keynote Address**
Martha Madison, Actor, *Days of Our Lives*

**12:00 p.m.**

**Lunch**

**1:15 p.m.**

**Breakout Sessions: Clinical Issues**
Please see page 7 for details

**2:30 p.m.**

**Break**

**2:50 p.m.**

**Breakout Sessions: Care Strategies**
Please see page 9 for details

**4:00 p.m.**

**Breakout Sessions: Open Q&A and Networking**
Please see page 9 for details

**5:00 p.m.**

**What Are Your Lifelines?**
Ben Freeman, AFTD

**5:30 p.m. to 7:30 p.m.**

**Social Reception**
Continue your conversations: Join speakers, AFTD Board members, staff and attendees for an informal reception following the conference.

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## The Day's Breakout Sessions

This afternoon's breakout sessions will address clinical issues, outline care strategies, and offer the opportunity to gain support by networking.
Room assignments accompany each listing in parentheses.

### Clinical Issues – 1:15 p.m.

**Managing Behavioral Variant FTD (Salon 1 & 2)**
Chuang-Kuo Wu, MD, PhD
Marianne Sanders, RN
Amy and George Shives
Jill Shapira, PhD, RN, facilitator

*Explore behavioral variant FTD from four distinct and complementary perspectives – from the clinical perspective, a care-and-support perspective, and from a person diagnosed and care partner.*

**Managing Primary Progressive Aphasia (Atlanta)**
Ahmad Sajjadi, MD
Maura Silverman, MS, CCC/SLP
Tracey Lind and Emily Ingalls
Mary O'Hara, facilitator

*Explore PPA from four distinct and complementary perspectives – from the clinical perspective, a care-and-support perspective, and from a person diagnosed and care partner.*

**Managing ALS/FTD & Movement Disorders (Chicago)**
Gabriel Leger, MD
Jamie Fong, CGC
Miki Paul, PhD
Debra Niehoff, PhD, facilitator

*Explore the physical and cognitive challenges of ALS/FTD, progressive supranuclear palsy and corticobasal degeneration from clinical, genetic and caregiving perspectives.*

## Care Strategies – 2:50 p.m.

**The Doctor Thinks It's FTD. Now What? (Atlanta)**
Christy Turner, CDP, CDCM, CCSI
Marianne Sanders, RN

*For those who are facing a new diagnosis, this session will help you understand FTD and start planning for care.*

**Developing Communication Teams and Tools (Boston)**
Maura Silverman, MS, CCC/SLP

*Having PPA does not mean you have nothing to say. This session will focus on finding alternative means of communicating when language is lost.*

**Developing Environmental & Behavioral Strategies (Salon 1 & 2)**

Jill Shapira, PhD, RN, Sue Hirsch, MA, and Sandi Grow, RN, AFTD Partners in FTD Care Advisors

*This session will demonstrate how to use a problem-solving approach to develop creative and individualized strategies to address challenging behaviors due to FTD.*

**Loss and Grief in FTD (Chicago)**
Bridget Moran-McCabe, MPH, AFTD
Elaine Rose, AFTD Volunteer

*The experience of loss and grief is complicated. This session will discuss coping with this unique and personal experience.*

**Adapting to FTD: A Discussion for Persons Living with FTD (Dallas)**

Matt Sharp, MSS, AFTD
Amy Shives, MEd

*This session will feature a panel of people living with FTD discussing how to compensate and overcome challenges in daily life. This session is led by and is for people living with the disease. Any care partners who attend will be asked to listen rather than speak.*

## Open Q&A and Networking – 4:00

**Forum for Young Adults (Atlanta)**
Gabriel Leger, MD
Jamie Fong, CGC
Elivra Jimenez, PhD
Mary O'Hara, LCSW, facilitator

*If you're in your 20's or 30's and have a family member diagnosed with FTD, you're bound to have questions. Here's an opportunity to interact with experts as well as peers with similar concerns.*

**Forum for Care Partners (Salon 1 & 2)**
Chuang-Kuo Wu, MD, PhD
Mary Austrom, PhD
Maura Silverman, MS, CCC/SLP
Jill Shapira, PhD, RN, facilitator

*There's never enough time to talk with professionals who have expertise in FTD. This session offers care partners an additional opportunity to ask your questions and hear the concerns of peers.*

**Forum for People Living with FTD (Dallas)**
Kimiko Domoto-Reilly, MD
Ahmad Sajjadi, MD
Marianne Sanders, RN
Matt Sharp, MSS, facilitator

*Come ask professional FTD experts your questions. This session offers people living with a diagnosis an opportunity to meet with medical, research and dementia experts to discuss questions and care needs.*

**Engaging with AFTD for Healthcare Providers (Boston)**
Sharon Denny, MA, facilitator

*Learn about how AFTD can support your work with people with FTD and their families, and join us to continue to increase awareness of FTD, shorten time to diagnosis and improve the quality of care available.*

**Find Help, Share Hope: The Power of Social Media Storytelling (Chicago)**
Lauren Gauthier and Bridget Graham, facilitators

*Join AFTD's Online Community Coordinator and Special Events Manager to explore how you can leverage social media to increase awareness and understanding of FTD.*

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# Is Proud to Support the AFTD Education Conference

## Don't miss this year's events!

**Buffalo Trace Charity Open Colorado**
**August 24, 2019**
**Colorado National Golf Club**
**Broomfield, CO**

**Buffalo Trace Charity Open New York**
**August 15, 2019**
**The Seawane Club**
**Hewlett Harbor, NY**

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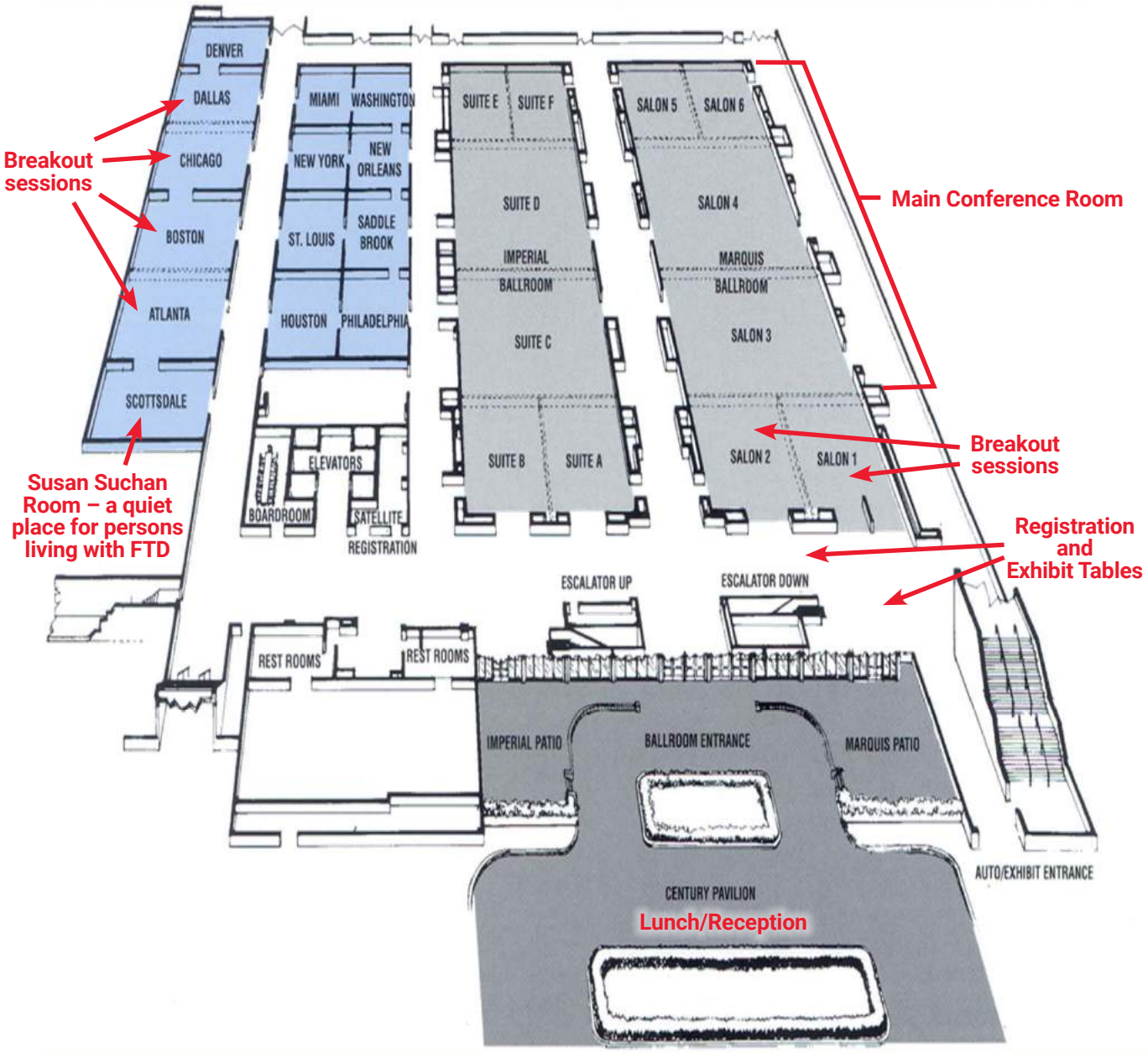
## BALLROOM LEVEL - MEETING SPACE



# Advances in Understanding FTD

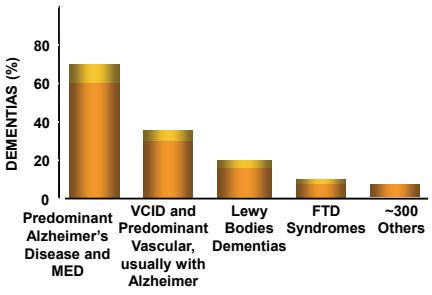
**Mario Mendez, MD, PhD**

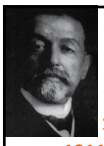
## Frontotemporal Degeneration: An Update

**AFTD Educational Conference Los Angeles 2019**


Mario F. Mendez, M.D., Ph.D.
Departments of Neurology and Psychiatry & Biobehavioral Sciences,
David Geffen School of Medicine, University of California at Los Angeles;
and
Section of Neurology, V.A. Greater Los Angeles Healthcare Center,
Los Angeles, California USA


## PART 1: FTD Syndromes



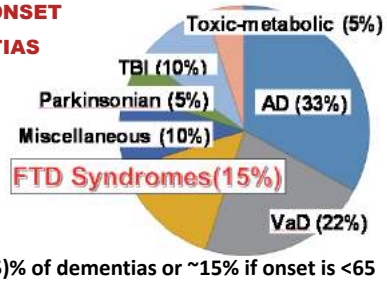



## Brief History of FTD

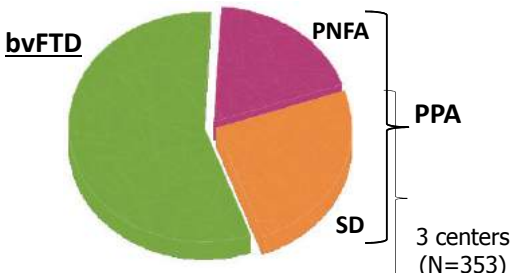
1892 Arnold Pick described first FTD patient
1911 Alzheimer described pathology:
Silver-stained Pick bodies→

DARK AGES
1993+ *Renaissance*: Epidemiology, Clinical Criteria
1997 *Age of Tauopathy*: abn. *tau*, FTDP-17, MAPT gene
2006 *Age of TDP-43 and* progranulin gene
2008-9 *Expanded genetics and path: TARDBP gene, FUS*
2011 *C'9orf72 and interface with ALS and psychosis*
2015 Multicenter funding for clinical trials in FTD

**EARLY-ONSET DEMENTIAS**

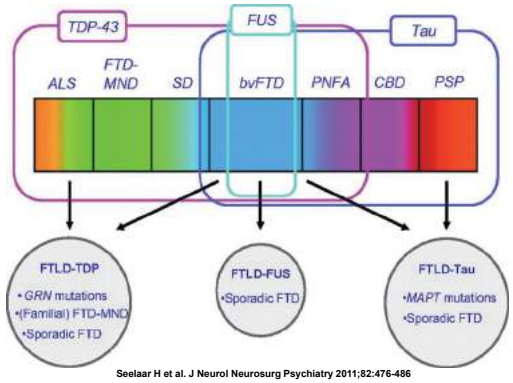



1. ~8 (5-15)% of dementias or ~15% if onset is <65
2. FTD:AD-~1:65-70 overall or 1:2-3 if <65; 1:1 if <60
3. Onset 57-58 (20-80+); no significant sex difference
4. BvFTD duration 7.6yrs (3-10), longer for PPA, SD




Johnson et al. Arch Neurol. 2005;62:925-930

NEURODEGENERATIVE SPECTRUM OF FTD-RELATED SYNDROMES



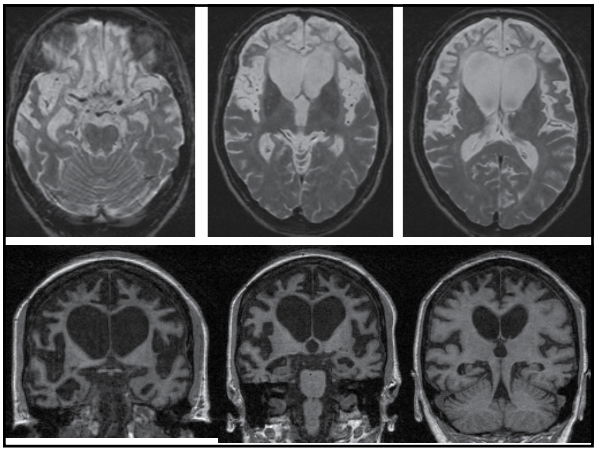

Seelaar H et al. J Neurol Neurosurg Psychiatry 2011;82:476-486

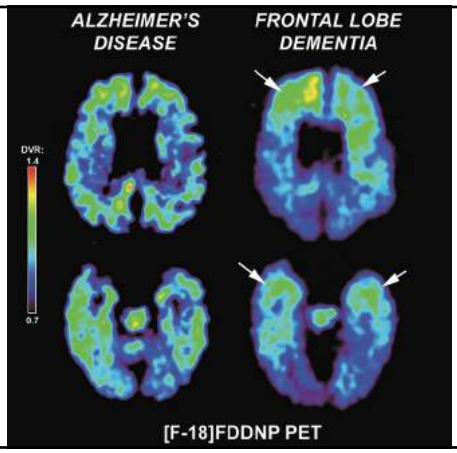
**Intl Consensus Criteria for bvFTD**

**Neurodegenerative Disease (progressive)**

**Possible bvFTD** (3 of A-F present) ("Probable" if additional neuroimaging)

- **A. Early behavioral disinhibition**
- **B. Early apathy or inertia**
- **C. Early loss of sympathy or empathy**
- **D. Early perseverative, stereotyped or compulsive/ritualistic behavior**
- **E. Hyperorality and dietary changes**
- **F. Neuropsychological profile (all 3 present)**





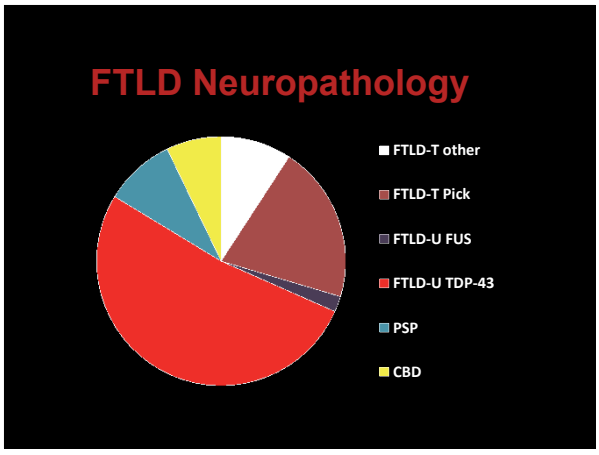

## Neuropathology and Genetics

**Variable Neuropathology termed "Frontotemporal Lobar Degeneration" (FTLD):**

All have frontotemporal regional neuronal loss, microvacuolarization, and neuronal inclusion bodies with abnormal protein deposits -primarily hyperphosphorylated tau or transactive response DNA-binding protein tau k43 (TDP-43)

**Variable Genetics: 33% or more have suggestive FHx**

13% caused by an autosomal dominant gene – C'9orf72, PRGN, MAPT, VCP, CHMP2B, TARDBP




| Mutation | C'9orf72 (12%) | MAPT (2-11%) | PGRN (5-10%) |
|---|---|---|---|
| Age of Diagnosis | 56 | 52 | 62 |
| Clinical | FTD-ALS | FTD, PSP, CBD | FTD, PPA, AD, CBD |
| MRI | Mild dorsal, occipital, cerebellar | Classical frontotemporal | Assymetric frontotemporal |
| Unique Clinical | Tremor (cerebellar?), ALS, Thalamic? | Symmetry, suicide, addiction | Overlap with AD |
| Unique Biology | RNA-mediated | 4r tauopathy | Haplo-insufficiency, Links to AD? |

*FROM BRUCE MILLER, MD, UCSF*

## BvFTD is characterized by Altered Social Behavior

- Altered social behavior affects the psychological well-being and social life of families and caregivers.
- Understanding altered social behavior is critical for behavior management
- Accommodating the behavior in a calm, safe environment while providing education and support for the caregiver, is more important that extinguishing the behavior

## Major Social Behavior Disturbances in BvFTD

1. Detachment: unmotivated, apathetic, "inertia"
2. Disinhibition: violate social norms/manners
3. Altered interpersonal connection or loss of empathy
4. Altered communication

## Objectives

**The ultimate objective: to m*aintain or enhance quality of life***

- What are the social behavior disturbances of FTD?
- What is their impact on patients?
- What is their impact on families and caregivers?
- What are non-drug management strategies?
  - Behavioral
  - Environmental
  - Caregiver
  - Educational

## What is the impact on patients?

- Loss of independence
- Loss of role outside home (eg, occupation)
- Loss of role in family
- Social isolation and exclusion
- Decreased overall sense of self/identity

## What is the impact on families?

- Altered balance between patient needs and family needs
- Altered family roles
- Ambiguity about the future and how to plan
- Family resilience and tensions about caregiving
- Children–discussing and helping them cope

## Non-Drug Strategies for Intervention

**Nonpharmacological interventions are more likely to be effective in managing behavioral symptoms than drugs** (Ayalon et al, Arch Intern Med 2006;166:2182-8)

•Environmental adaptations

•Behavior management

•Caregiver training

•Education

## Before anything, Check for Causes

**FTD impairs their ability to communicate their needs or report physical health issues or other causes of altered social behavior.**

- Check for unmet needs, eg, hunger, urge to urinate
- Make sure that even "mild" pain is managed
- Evaluate medical illnesses
- Evaluate medications and recent dosage changes
- Rule-out covert anxiety or depression

## Think Proactive and Reactive Tools

- **PROACTIVE**
  - Plan ahead, the entire day and individual activities
  - Anticipate potential problems
  - Let others know of potentially altered social behavior
  - "Carer's card" to hand people in public that explains FTD
  - Plan environmental modifications
- **REACTIVE**
  - Have behavioral and other techniques ready to use
  - Invest others in preparation to respond when needed

## Behavior Management
**(Repeat, Reassure, Redirect)**

- Approach with smile and a calm, soft, reassuring manner–avoid arguing
- Refocus them by distracting with conversation or objects
- Modify or eliminate potential triggers and frustrations
- Initiate enjoyable activities and comforting techniques
- Establish regular schedule, routine, sleep-wake cycle

## Disengagement or Apathy

**Apathy has the most impact on marital relationship** (du Vugt et al., 2003)

- Provide structure - more effective than free time
- Offer or direct to individual or small group activities
- Do not force them; let them passively participate
- Ensure tasks are simple so that they can complete
- At onset, explain activities in simple language

## Disinhibition

**In Germany, behavioral disturbances were predominant reason for hospital admission among 58 patient with FTLD included FTD** (Ibach et al, Dement Geriatr Cogn disord 2004;17:269-73)

- Identify trigger for disinhibition and interventions
- Avoid confrontation; gently redirect to another activity
- Reduce environmental stimulation
- Involve other family members and caregivers
- If disruptive, inform others, include what does or does not work

## Altered Interpersonal Connection

**FTD caregivers report a loss of emotional attachment leading to isolation and anger due to behavioral symptoms** (Massimo et al, Geriatr Nurs 2013;34:302-6)

- Rethink expectation of emotional feedback; offer empathy without expecting reciprocity
- Provide them information about others' perspectives
- Encourage families to share what they did together
- Share moments of connection and special events
- Instruct others so they don't expect validation

## Altered Communication

**Many have little verbal output and single or short phrase answers and others are excessively talkative and jocular.**

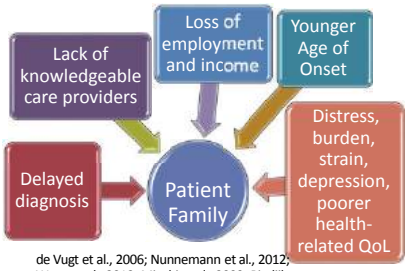
- Approach with calm, patient, pleasant tone of voice
- Reduce competing stimulation and distractions
- Use the same terms consistently for care issues
- Other forms of communication: touch and lead, hand motions, props, picture, sing, short written words
- Technology–iPads with communication apps and software programs like Proloquo2Go(www.proloquo2go.com)

## Environment

- Create a safe, calm, and predictable environment
- Eliminate confusing, noisy, cluttered, or overstimulating environments
- Simplify social situations and number of people
- Provide safe wandering and ambulation
- Family may choose familiar public places

## FTD Family Caregiving

(Darby Morhardt, PhD, LCSW
Northwestern University)




de Vugt et al., 2006; Nunnemann et al., 2012; Wong et al., 2012; Mioshi et al., 2009; Riedijk et al., 2006; Diehl-Schmid et al., 2013

## Caregiver

**Worse strain, emotional distress and lower perceived control among bvFTD caregivers. Levels of depression for FTD caregivers are twice that of AD caregivers** (Wong et al, 2012 AMP 20;724-8) (Mioshi et al, Dement Geriatr Cogn disord 2009;27:76-81).

- Practice caregiver wellness, self-care, and forgiveness
- Find balance: spend time together AND time apart
- Have realistic expectations
- Reach out and talk to others about what is happening
- Support groups with other caregivers of those with FTD

## Education

- Education and coaching are effective in minimizing negative outcomes from behavioral symptoms
- Courses on behavior management
- Caregivers also benefit from courses on home safety, problem solving, stress reduction, health
- Coaching via phone calls regarding caregiver stress

**I hope that this information helps you.**
**Thank you very much for your attention.**

# Advances in Understanding FTD

**Jamie Fong, CGC**

**TAKE-HOME POINTS**

**BACKGROUND**

- About 50% of people with FTD have **no** known single gene cause of their diagnosis. They usually have no family history of the condition. This is sporadic FTD.
- About 40% of people with FTD have at least one relative with a related neurodegenerative disease. This is familial FTD.
- About 10% of people with FTD have symptoms due to a single gene change or mutation. This is genetic FTD.

**WHAT CAN I DO?**

If you are concerned about a genetic form of FTD in your family, you should:

- **Gather information.** Investigate your family history. Who in the family has neurodegenerative disease? Which relative with disease is living or deceased? What was the diagnosis? How old was your relative at first symptom? What were the relative's symptoms, especially early in the disease? At what age did your relative pass away? Did the deceased relative undergo brain autopsy?
- **Discuss genetic testing with your relative living with symptoms (or their surrogate/decision-maker)**. If no FTD-causing gene has already been identified in your family, the best person in whom to start genetic testing is your relative living with symptoms. Not all relatives or their surrogates/decision-makers will be comfortable discussing this. Approach your relatives respectfully and with sensitivity.

Has your relative living with symptoms already had FTD genetic testing? If yes, what was the result? If no, would this be something they would consider?

*Reasons a reluctant relative living with symptoms should consider genetic testing:*

1. *May clarify FTD risk for other family members*
2. *May answer the question, "Why did this happen?"*

If genetic testing cannot begin with a relative living with symptoms, there are limitations to first testing healthy people in the family. Skip to the next step for more information.

- **Contact a genetics professional.** Preferably one who is familiar with genetic FTD. A genetics professional can discuss with you the options for genetic testing. Genetics professionals include genetic counselors and medical geneticists. Genetic counselors who are familiar with genetic FTD are often affiliated with medical centers comprising the research networks called ARTFL (pronounced "artful") and LEFFTDS (pronounced "left-eez"). Alternatively, you could identify a genetic counselor through the National Society of Genetic Counselors.

ARTFL (Advancing Research and Treatment for Frontotemporal Lobar Degeneration) **https://www.rarediseasesnetwork.org/cms/artfl/About-Us**

LEFFTDS (Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects) **https://www.nia.nih.gov/alzheimers/clinical-trials/longitudinal-evaluation-familial-frontotemporal-dementia-lefftds**

National Society of Genetic Counselors
Select "Find a Genetic Counselor"
**https://www.nsgc.org**

Consider participation in research. If your relative living with symptoms is able-bodied, they might be eligible to participate in research. Healthy people who have a known FTD-causing gene in their family are eligible to participate in research. Healthy people who do not already have a known FTD-causing gene in their family are eligible to participate in research if they have 2 or more relatives with FTD or related condition.

Check out the following websites for information about FTD research studies that might be right for you.

The Association for Frontotemporal Degeneration
**https://www.theaftd.org**

FTD Disorders Registry
**https://ftdregistry.org**

ClinicalTrials.gov
**https://clinicaltrials.gov**

# Perspectives on Research

**Kimiko Domoto-Reilly, MD**

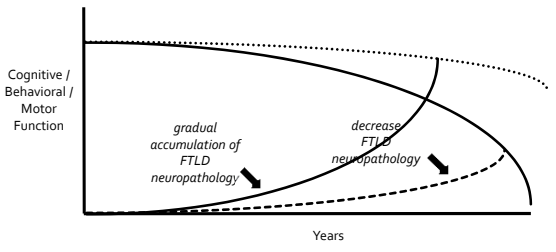
## Types of Research Studies

- Longitudinal
  - Follow participants over time
- Observational
  - Collect information
    - Daily activity questionnaires, family history, cognitive testing, neurologic examination
    - Biospecimen: blood, cerebrospinal fluid, skin biopsy
- Interventional ("Clinical Trial")
  - Participants are given an investigational treatment
    - drug, cognitive training, transcranial magnetic stimulation
  - Typically a portion of participants are given placebo / sham treatment

## FTLD-specific measures are needed

- Cognitive and behavioral scales
- Biofluid measures
  - Blood, cerebrospinal fluid
- Imaging measures
  - Structural (MRI), functional (FDG-PET, fMRI), molecular (PET)
- Role of Biomarkers
  - Diagnostic
  - Prognostic
  - Monitor change over time and response to treatment

## Research Targets




- Understand natural history
  - "calibrate" tools for monitoring
- Risk/protective factors
  - Genetics
- Treatment
  - Disease modifying

**NOTES:**

# Perspectives on Research

**Elvira Jiminez, PhD**

## Overview

- Why participate in FTD research?
- Common participation concerns
- Types of research opportunities available for FTD patients and their caregivers
- What to expect during a typical research visit
- How look for research studies

## Why do we do FTD research?

- FTD research provides the opportunity to understand the disease, its symptoms, its changes and how it affects family and caregivers.
- It is necessary in advancing treatments, services and technology.
- For participants– it may provide sense of meaning and purpose within this devastating disease.

➢ **Many of our research participants often state that they want to help others and contribute to science.**

## Common Concerns and Questions

- What is the purpose of the study?
- What are the study's procedures?
- What can I expect on the day of a research visit?
- How long will the research last?
- How do I benefit?
- Will my information be kept confidential?
- How will the results be disseminated? Can get results of the study?
- Do I have to pay for participating?
- How will the investigator benefit ? conflicts of interest ?
- Why should I volunteer?

➢ **Research Consent form, provided with most research studies** usually addresses many of the concerns by participants

## Types of Research Opportunities

- There is a wide range of studies that you can participate in
- Research studies range in time commitment and/or personal burden
- The primary type clinical studies are:
  - Observational clinical studies
  - Clinical trials
  - Registries
  - Brain Donations

## What to expect on the day of the visits

- Not much preparation before the visit is needed
- There is travel time– most studies take place at study sites
- There is time investment– depending on the type of research study the visits may be from 1-4 hours
- Examples of study procedures include paper-and-pencil testing, caregiver/study partner questionnaires, brain scans, genetic testing
- Participants are provided breaks in between procedures and as requested
- Mealtime breaks are scheduled based on participants' preferences
- Additional support staff is available to assist with impaired participants
- Not every question or procedure has to be completed – some times participants can ask to skip a question or task that makes them uncomfortable/frustrated
- The research visit can be stopped at any time if the participant no longer wants to participate or does not feel well

➢ **Not every situation is the same -- most visits are tailored to address specific needs of research participants.**

## How do you find research opportunities?

- Ask your providers
- clinicaltrials.gov
- Association for Frontotemporal Degeneration (theaftd.org)
- Research Institutions (e.g., universities, industry research sites)
- Community events
- Internet/ Social media
- Support groups

# Perspectives on Research

**Dianna Wheaton, MS, PhD**

FTD DISORDERS REGISTRY

Participating in Research

May 3rd, 2019

AFTD 2019 Annual Education Conference

*FTD Disorders Registry LLC*
*Dianna K.H. Wheaton, MS, PhD, CHES*

## *FTD Disorders Registry LLC*

Founded as an independent, non-profit entity March 2015 by AFTD & the Bluefield Project.

**Mission:** *To facilitate and advance research into the spectrum of FTD disorders.*

**Goal:** *To create and curate a patient/caregiver registry to serve as* ***a resource for the entire FTD disorders community,*** *including persons diagnosed, their families, caregivers, clinical care providers and researchers.*

## *Registry Format*

- **Contact Registry-** *International*
  - Access to informational updates & e-Newsletters

*Community organizing & communication*

- **Research registry-** *U.S. & Canada*
  - Informed consent to participate
  - Password-protected account
  - Coded identifier assigned to protect privacy

*Health outcomes research & study recruitment*

## *Opportunity to participate*

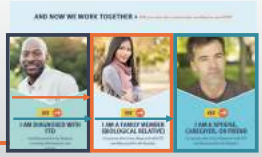
Fewer barriers than traditional research

- Broad enrollment groups
- Participate from home
- Have a voice
- Contribute to science

## *Target Population*

**Who can Join?**

- Persons diagnosed with FTD → *bvFTD, PPA, PSP, CBD, FTD-ALS*
- Current or former spouse, family members, caregivers or friends



**FTD diagnosed person**
*Self-enroll or with helper*

**Biological family member**

**Spouse/Caregiver/Friend**

**NOTES:** _____

# Perspectives on Research

## A Participant's Perspective

**By Anne and Ed Fargusson**

Research has a human face. Anne and I, along with many others, are that human face. Diseases like frontotemporal degeneration often take away the human face. The disease itself attacks a person's identity, belonging, and purpose. The results of the disease are devastating to the patient and the patient's family and friends.

Research is a way to help. While it is unlikely that the research that we participate in will benefit us directly, to us materially, it does provide a sense that we still can make a difference. It does restore some level of dignity that, in spite of this horrible disease, we can still contribute; we still have value. By contributing to research, our life and our experience can be of benefit to others. It is not all a waste. While this disease and its consequences are horrible, maybe through research others can be helped. By believing that we are helping others, we are helped.

We have been going to UCSF for the past 13 years participating in various research projects. It's difficult to even remember all the names. As Anne says, you can:

"Explore with me my experience of being a research participant over all these years – from PET scans to Nutella sandwiches. Most research is government-funded with the attempt of discovering the cause of FTD along with the genetic component. You need to know the cause before you find a prevention, arrest the progression, or a cure. Because of this, this leads to all kinds of studies. Some even seem bizarre: How many sandwiches you can eat in one hour. Eye exams looking at dots. Pretend to lose a key to see how you would emotionally respond. Just to name a few. And of course, medical and cognitive testing."

The two big studies we have been part of are ARTFL and LEFFTDS – important longitudinal studies funded by the National Institutes of Health to better understand the progression of FTD. We have also contributed to some caregiver studies, AFTD's Economic Burden Study and are part of the FTD Disorders Registry.

It all adds up. We encourage everyone who is affected by FTD – and who can participate in studies – to do so. It is an important way to contribute to the work towards a cure and also to give meaning to the experience we are going through.

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## FTD Family Caregiver Research

Mary Guerriero Austrom, PhD
Wesley P Martin Professor of AD Education
Department of Psychiatry
Outreach and Recruitment Core
Indiana Alzheimer Disease Center
Associate Dean for Diversity Affairs
Indiana University School of Medicine

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## Acknowledgments

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- DEMA Study supported by NINR 1R21 NR013755-01

I have biases like everyone else.

I have no conflicts of interest or financial relationships to disclose.

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## Overview

- Research on FTD, persons with FTD and their caregivers is growing.
- Intervention research vs examining burden and stress
  - Tailored Activity Program (O'Conner et al., 2017)
    - OT intervention with individualized activities for CG to engage the person with FTD in meaningful activities
  - Focus group study of FTD caregivers and brain donation (Austrom, Dickenson, Denny et al., 2011)
    - Identify barriers to research participation and brain donation and how to communicate with CG
- bvFTD and PPA Caregiver Needs Assessment (Austrom, Morhardt et al., 2018)
  - Describe this work and share early findings

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## Background

- Caregivers of persons with frontotemporal disorders (FTD) have unique challenges and needs.
- They show higher levels of stress, depression and burden than those caring for persons with Alzheimer's disease.
- The clinical profiles and pathologies associated with FTD are heterogeneous and characterized by <u>two main phenotypes</u>:
  - a progressive deterioration in behavior, emotion, and interpersonal conduct known as behavioral variant FTD (bvFTD);
  - and a decline in language skills; known as primary progressive aphasia (PPA).

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## Study Aims

There is an abundant literature regarding the experience of caregiving for persons with AD, however, there are very few studies examining the experience of caring for persons with FTD and none that have compared behavior and language variant caregivers. This qualitative study elicited the lived experience of caregivers specifically related to:

- Process of obtaining diagnosis
- Most challenging things participants had to deal with supporting/caring for the person with the diagnosis (PWD)
- What helped or hindered coping and day to day living
- What advice caregivers would offer healthcare providers

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## Methods and Sample

**Semi-Structured Qualitative Interviews:**

- Conducted 1X1, face-to-face or by phone
- All interviews were audio-recorded and transcribed. (Video-recorded: IN)
- Multiple, intentional readings of transcripts for content analysis and development of emerging themes.
- Researchers discussed emergence of themes noting areas of agreement/disagreement and similarities and differences between profiles

**Sample:**

- Purposive sampling was used to recruit caregivers (5) of persons with bvFTD (Indiana U) and (5) PPA (Northwestern U)

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## Emerging Themes

***Diagnosis Journey***

- Obtaining an accurate diagnosis was difficult and lengthy, multi-year process; with bvFTD taking an average of X more years than PPA.
- Finding knowledgeable healthcare providers, including neurologist, neuropsychologists, psychiatrists and other was a challenge for most

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## *Diagnosis Journey*

*We kept treating … and managing symptoms… and symptom management was what allowed us to keep moving through the journey. We treated depression and we added another antidepressant. We added mood stabilizers, and they kept covering us for a season, but we just kept pursuing it,[the diagnosis] because the symptoms just kept expanding, which we now understand was the fact that it's a progressive disease. (F4)*

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***Most challenging aspects of caregiving***

- Experiencing difficult and uncomfortable emotions: loneliness, depression, fear,
- Adapting to changing roles related to PWD inertia, lack of insight, and personality changes
- Experiencing significant financial and legal challenges; with bvFTD caregivers engaging legal remedies that changes marital/family structure to protect future
- Grieving developmentally non-normative losses due to younger age of onset

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## *Challenges of caregiving*

*You start to lose yourself. I can see that. One of my sisters says I've closed off a lot. I don't like to talk about this and sometimes I don't want to talk. I'm never not sad. (P1)*

*" I didn't get a chance to tell my mom goodbye, because I no longer have a mom.." (F1)*

*[the lawyer] was really careful to explain that it was a legal separation that would be dismissed after everything was done, that it wasn't a divorce, that we wouldn't have to file divorce papers or anything like that. After I understood it I'm like okay this is the system they have set up. (F5)*

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***Key coping strategies***

- All respondents identified support groups, individual counseling as essential avenues to talk and learn about the disease
- Develop a life outside of the diagnosis and the PWD
- Get respite care earlier rather than later
- Gain knowledge about diagnosis
- Develop good self-care habits

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## *Key coping strategies*

*I think the support groups helped me understand what I'm going to be dealing with… hearing these stories….I'm a nicer person since I've been in therapy. (P5)*

*I have learned there is a next stage and that is giving yourself permission to think personally has only come about in the last 3-4 months where there is less guilt involved claiming your life… and I feel guilty a lot of the time. (P2)*

*My PPA support group most helpful. Monthly meeting was helpful but in the beginning I sat there in disbelief – there's no way that he will be incontinent, or have these behaviors. I sure learned quickly from my PPA sisters – some things were the same way, but others were not. (P4)*

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### *Advice for Healthcare Providers*

- Without exception all respondents advise the neurologist and neuropsychologist to speak with care partner one-on-one, without the PWD present
- Provide a "roadmap" or "checklist" of what information needs to be provided for diagnosis and noting progression
- The concept of the progressive nature of the illness was not understood until far later in the diagnosis.
- Refer to social work early on to help with understanding of diagnosis, resources, and coping

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### *Advice for Healthcare Providers*

*I think there have been so many little episodes where I want to share information that would be helpful but I'm worried I don't want to share it in front of J. Some days – I want to have in some of these initial meetings with the neurologist – have some time alone with the doctor….I think a checklist given to the family prior to an appointment would be helpful to the family. It would help families stay on track with relevant information, give families a preview of what they will most likely be facing, and reassure them that they didn't leave out any key information when they are meeting with the doctor/practitioners. (P5)*

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## Conclusions and Next Steps

- Preliminary analysis of in-depth interviews of bvFTD and PPA caregivers reveal both similarities and differences within the caregiving experience.
- Further analysis of this narrative data and further research is needed to more fully understand the experience of FTD caregivers and guide health care professionals in the development of appropriate interventions.

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MEDICAL MANAGEMENT


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## Pharmacological Interventions

- Do have a place in the care and treatment of PWD
- Should be carefully considered once non-pharmacological interventions have been exhausted
- Most beneficial when used in combination with non-pharmacological interventions
- A plan to discontinue pharmacological interventions must be implemented after 3 – 6 months as many BPSD will resolve

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## Care vs. Cure

Just because we cannot cure FTD, doesn't mean we don't care.

# Perspectives on Care & Support

**Mary O'Hara, LCSW**

**Research in FTD Care**

## Perspectives on Care: You Are Not Alone – Where to Begin Finding Guidance & Support

**STEP ONE**

- Request a referral for resource navigation (social worker, care/case manager, local social service agencies).
- Determine the most helpful way for you to learn/educate yourself about the diagnosis and caregiving.
- Prepare yourself to be the one to educate others about the diagnosis and caregiving.

**BEGIN LEGAL AND FINANCIAL PLANNING**

- Meet with an Elder Law Attorney to discuss Legal and Financial Planning.
- If under age 65, apply for Social Security Disability Insurance (SSDI).
- If working, begin to plan transition from employment.
- If eligible, inquire about Veterans Benefits.
- If you have Long Term Care Insurance, find out what your plan provides.
- Begin discussing future care options and financial resources available to pay for care.

**CONSIDER SAFETY**

- Carry an "I have PPA/bvFTD card" that briefly explains the diagnosis to others.
- Consult with an Occupational Therapist for a home safety evaluation.
- Consult with a Physical Therapist for changes in balance, gait, falls, motor abilities.
- If judgment is impaired, monitor bank accounts, credit cards, investments, internet
- Request a driving evaluation from physician and begin discussions around this transition
- Enroll in Medic Alert ID program (**www.medicalert.org** or 800.432.5378).
- Discuss using the "Find My Phone" smartphone tool.
- Remove or safely store any firearms in the home.
- Regularly evaluate safety of person staying alone ("What would you do if there was a fire?").
- If there are disagreements around these safety issues, seek the help of professionals on your care team (physicians, social workers, nurses, care managers, etc.) to assess for safety and suggest ways to help with adjustment to the changes. Call upon friends and family members to be part of these transitions as well.

**ADAPT COMMUNICATION**

- Request a referral for a Speech and Language Pathologist (SLP) to learn additional ways to communicate (gestures, pictures, communication books).
- Prepare for conversations to take more time. Don't give too much information at once. Speak clearly and in an adult manner.
- Minimize noise, stimulation and the number of people in a conversation at a time.
- If helpful to the person living with PPA/bvFTD, offer suggestions or give fewer choices.
- If you need a behavior to stop use Redirection or Distraction to draw attention elsewhere.
- If there are disagreements, avoid arguing or attempts at convincing.

**TAKE THINGS DAY BY DAY**

- Establish a predictable and familiar daily routine.
- Stay engaged with favorite activities for as long as possible. Simplify or modify, as needed.
- Encourage regular exercise, healthy diet & stay socially connected, but not to the point that doing this causes family member /care partner stress. The disease can cause apathy and affect a person's initiative/motivation.
- Be willing to try different services, interventions and resources- don't assume they will not work/help.
- If bvFTD behaviors cause distress, use the D.I.C.E. approach to problem solve a response. The D.I.C.E. approach is a process that helps care partners manage the behavioral and psychiatric symptoms of dementia (BPSD). It stands for Describe Behavior, Investigate Causes, Create a Plan, Evaluate Plan (Kales et al., JAGS 2014). For more information, visit: **http://www.programforpositiveaging.org**
- Request a referral for a geriatric psychiatrist if there are changes in mood.
- Keep a log of changes in behavior and communication to share with providers.
- At the end of the day, take a moment to think about what went well that day, what strengths remain, and where there were moments of connection.

**FIND YOUR WAY**

- Tell someone. Consider how and when to share with family, friends, neighbors, employers.
- Consider individual counseling for support around feelings of grief, guilt, sadness, anger, loneliness, fear.
- Only YOU know what helps you stay calm & anchored. Set intentions to regularly access what fills you up.
- Find a breathing exercise that works for you and begin a relaxation breathing practice that you can access when feeling frustration, stress or anxiety in difficult moments.
- Ask for help with specific tasks. For example, can someone bring over dinner, shovel snow, offer a ride, regularly check-in or visit weekly?
- Seek support & guidance from The Association for Frontotemporal Degeneration (AFTD) at **www.theaftd.org** or 866-507-7222.
- Find opportunities for respite /breaks from providing care. Access The AFTD Respite Care Grant ($500/per family/year). For more information, visit **www.theaftd.org**
- Join an FTD/PPA support group to meet others living with a diagnosis and connect with the FTD / PPA Community Online Resources found at **www.theaftd.org/get-involved/in-your-region**
- Living with FTD/PPA can be an ongoing practice of Acceptance, Patience, Forgiveness and Loss. You are simultaneously holding on and letting go. You are forced to adapt, change and bend your branches in ways you didn't imagine. You are not alone and the support you access will help you find your way.


Adapted with permission from the Northwestern University Mesulam Center for Cognitive Neurology and Alzheimer's Disease, Chicago, IL **www.brain.northwestern.edu**. Newly Diagnosed Check list from 2012 FTD/PPA Conference. Additional Contributions from S. Barnard, K.Gomes, B. Sheldon, A. Cerveny and C. Seymour

## Pointers for FTD Care Partners

**By Chuck Anastasia**

Establish a multi-faceted care plan to maintain the best possible quality of life for the person with FTD and to set priorities and guide the daily choices we must make as care partners. For example:

1. Develop and maintain routines.
2. Get as much exercise as is practical.
3. Eat a healthy diet.
4. Stay socially engaged & intellectually stimulated.
5. Use medications under the direction of an expert doctor to manage symptoms.

We pursued activities and decisions that fit our care plan, and avoided choices that did not. These guidelines simplified our daily planning and helped reduce procrastination and indecision.

Seek help early though adult day programs & home companions, and communicate openly and honestly with them about our loved one's needs. Open communication with her care team built trust and helped me recognize when it was time to consider long term care.

Rather than focusing on why this happened to us, we tried to make the best of our situation. We participated in a research study at Mass General Hospital, where VJ donated her brain for FTD research. This is one of the most important ways we can help stop FTD.

Stay connected to other caregivers through online & in-person support groups for practical tips, and encouragement.

I immersed myself in inspirational audio books, and relied on my faith for strength. Reading and hearing about other families coping with dementia and other challenges helped me understand and anticipate the disease trajectory and prepared me for what was to come.

I was motivated by strong caregiver role models. There are a few "ordinary heroes" that I've known personally over the years, who devoted themselves to long term care of family members. Taking notice of other strong caregivers coping with very difficult circumstances, gave me confidence that I could also do it.

Taking time for daily exercise helps care partners take care of ourselves. I bike when the weather is warm and walk in the winter. I maintained my early morning exercise routine when VJ could be left alone at home, but as her illness progressed I had to use an elliptical walker in our basement. We used an inexpensive wireless call button so she could alert me when she got out of bed while I was working out, but in the late stages this became ineffective, and was another clue that it was time to consider long term care.

**Challenges faced as an FTD Care partner:**

Making the decision to be very open with family & friends about this disease made it easier for us to cope. The stigma of dementia, and desire not to upset family members and friends made it tempting to try to keep serious illnesses to ourselves. However, keeping secrets is a burden that causes stress, and creates a barrier to people who would help if they understood what we are coping with.

I've always been respectful of authority and expertise, so it was a challenge for me to be assertive and ask probing questions of the professional care team, when I didn't understand, or felt like they didn't recognize our needs. I overcame my inclination to defer to the experts and advocated assertively when VJ's needs weren't being met.

Adapting our activities and routines to our loved-one's evolving abilities and needs: When we establish routines that work for a time, it can be frustrating when our loved one's needs change and we need to recognize and adapt our routine to their changing ability.

Making the decision to have a loved-one admitted to long term care is one of the most difficult decisions any care partner will face. The day VJ was admitted, I walked out of the facility crying to myself, "What have I done?" but this was soon followed by a profound sense of relief, and I felt like a weight was lifted off me. I visited VJ for 3 to 6 hours every day, for just over 3 months she was in long term care. The staff in these facilities has an incredibly difficult but important job. I tried to learn their names, and treat them with the respect they deserve. I learned what to do and not to do in the nursing home and actively participated in VJ's care and feeding. Despite the challenges, we also had uplifting experiences in the nursing home.

## Pointers from Someone Living with FTD - Encourage, Empower, Enable and Engage

**By Laurie Scherrer**

**Empower to unleash the maximum potential – even if that is only a smile**

- Continuously: Engage, Enable and Encourage
- Eliminate as much stress as possible

**Observe what triggers confusion, disorientation or behaviors**

- Create tools and strategies to overcome the obstacles and challenges and find ways to adjust
- Perhaps I'm sensitive to noise or over stimulations – get earplugs and sunglasses
- Provide social interaction
- Talk to me – not about me.
- **Look directly at me and ask my opinion** – even if I can't answer

**ENABLE rather than disable**

- Provide assistance to work through tasks – yes it takes longer
- The more you do for me – the less I can do for myself
- Find tools to assist with tasks – (i.e. a modified spoon or tags on sheets)
- Maintain a routine as much as possible
- Communicate with visual and audio to improve processing

**Encouragement and Motivation inspire to do more**

- Provides a "feel good" positive attitude for both people
- Helps focus on the goal
- Stimulates productivity through a desire for approval

**When you can't control what's happening, challenge yourself to control the way you respond to what's happening.**

**NOTES:** _____

# Clinical Issues: Managing Behavioral Variant FTD

**Chuang-Kuo Wu, MD**

## Managing Behavioral FTD (bvFTD)

Chuang-Kuo Wu, MD, PhD
University of California, Irvine

## Overview of bvFTD

- Behavioral variant (predominant) – Frontotemporal dementia (bv-FTD; in short, frontotemporal dementia – FTD): one kind of presentation of "frontotemporal lobar degeneration (FTLD)". The other kind is the language variant (predominant) – FTLD (so called Primary Progressive Aphasia – PPA)
- A relatively ***rare***, ***young-onset*** (younger than 65) ***neurodegenerative*** disorder (progressive brain cell loss predominantly affecting frontal and temporal lobes)

## Clinical Symptoms

- Cognitive symptoms – impaired executive function (dysexecutive syndrome) – "frontal lobe syndrome"
- Behavioral symptoms – outstandingly bizarre actions; out of character
- Emotion and affect – blunt; lacking sympathy and empathy – personality change
- Unusual eating behavior or sexual behavior
- Changing from one extreme to the other
- Lacking self-regulation and insight

## Diagnostic Evaluation

- Every patient with bv-FTD has a unique story because of his/her education, job and social status.
- Although there is a set of diagnostic criteria (revision after revision over the past 30 years), it is not easy to diagnose patients with bv-FTD. Often patients would take 2 to 3 years to receive the diagnosis.
- On the other hand, some patients can be given the wrong diagnosis of bv-FTD if there are conditions that can be mimicking bv-FTD.

## Diagnostic Evaluation

- In order to make a proper diagnosis of bv-FTD, the clinician has to spend time to interview the family members/friends/colleagues who have known the patient well over the years.
- It is very important to survey or rule out common medical conditions that mimic bv-FTD, such as alcohol/substance abuse, traumatic brain injury, stroke, brain tumor and psychiatric disorder.
- Brain scans (head CT or brain MRI) are crucial for establishing the diagnosis of bv-FTD --- objective evidence of atrophy (shrinkage; brain cell loss) in frontal and temporal lobes.
- Functional brain studies, like SPECT or PET, can be used but they often are NOT covered by insurance plans. And they are NOT always reliable.

## Diagnostic Evaluation

- Some patients have main features of bv-FTD; yet their brain MRI and/or head CT studies do not show objective evidence of atrophy in the frontal and/or temporal lobes over the years of follow-up. Be cautious! Need a second opinion.
- Professor Hodges reports "bv-FTD phenocopy syndrome" or so-called "non-progressive FTD".

## Complex Terminology

- Over the years, there are following terminology – frontal lobe syndrome, Pick's disease, dysexecutive syndrome, frontotemporal dementia, bv-FTD/bv-FTLD, temporal lobe predominant – FTD, Semantic dementia and Primary progressive aphasia (PPA).
- Based on research, majority of patients with bv-FTD are "sporadic" in nature (meaning unknown cause of several altered proteins in brain cells). Few bv-FTD patients are caused by the particular mutations of several genes.
- At times, it is also difficult to tell bv-FTD from young-onset Alzheimer's disease.

## Progression

- Because bv-FTD is a neurodegenerative disorder, the brain will continue to lose brain cells and progressively spread the changes into other brain regions over the years. Therefore bv-FTD patients will continue to lose cognitive skills, including language, memory, motor and visual functions.
- Although bv-FTD does not directly affect heart rate, blood pressure and breathing, this disorder inevitably makes the patients to be vulnerable to dangers, to lose ability to take care of themselves and to cause care-providers a lot of stress because of lacking empathy and impaired insight.

## Management

- There is NO cure for bv-FTD at the present time.
- Management – the family and caregivers need to learn about this disorder so that they can form their way and plan to provide the care.
- Patients with bv-FTD need a principal "custodial" person to protect and provide the care (legal guardian or legally-appointed representative) .
- There are some psychiatric medicines that can be prescribed selectively by psychiatrists or neurologists for some behavioral issues or neurological symptoms.

**NOTES:**

# Clinical Issues: Managing Behavioral Variant FTD

**Marianne Sanders, RN**

## Managing Behavioral FTD – Takeaways

**By Marianne Sanders, RN**

Caring for a loved one diagnosed with bvFTD revolves around his or her changes in behavior, poor judgment and lack of awareness of their illness, and the safety concerns you have for them.

Challenges include becoming familiar with this rare disease while providing the supervision and support needed to keep your affected family member safe and content, while still maintaining your other responsibilities such as a job, household finances, household chores, and child care. Multiple medical appointments must be scheduled and attended. Understanding and adjusting to the changes in the relationship with your loved one will be one of your greatest challenges, along with accepting that their uncharacteristic behaviors are part of the disease and not intentionally meant to injure you.

Setting up a strong medical team is an important resource for management of the challenging behaviors, as well as for understanding how these behaviors are symptoms connected to brain changes.

Finding support is essential to both you and affected loved one. Become familiar with AFTD resources online, join a support group, and attend educational conferences about FTD when possible. Check the AFTD website (**www.theAFTD.org**) for support groups in person, online or by phone in your area. This is where you will find others on a similar journey. Consider talk therapy or supportive counseling as a way to navigate stress. Reach out to close family members and friends for help and support.

**NOTES:**

# Clinical Issues: Managing Behavioral Variant FTD

**Amy Shives, MEd, a person living with FTD**

**THE FIRST STOP: SYMPTOMS AND DIAGNOSIS**
Everyone that is traveling this journey of dementia has their own unique story. That being said, people going through the difficult symptoms, diagnosis, and life adaptions, appear to have more in common than not.

- We have unexplained changes in every aspect of our lives.
- We must adapt to these changes when we are feeling the most vulnerable we have ever felt.
- We must deal with the people in our lives responding to us. Family, coworkers and friends are all confused thus they may not be able to be as supportive as we need them to be.
- Getting a diagnosis is a long and difficult process. Often it takes years of effort and resources to tackle obtaining one. Most people do not have the resources necessary to learn what their problems can be attributed to. Not knowing what is wrong with you as your life falls apart is devastating.

**THE SECOND STOP: WHAT DO I DO NOW?**
One of the many things we do is search to find ourselves in this new place in our lives. This is the first stage of grief. We have to go home and let the diagnosis sink in. It is very important to allow yourself to do that. Some people with bvFTD don't know they have a disease, but many of us do. This flies in face of people telling you to hurry and get your affairs in order. Instead, we need to experience first stage of grief in own surroundings, with our loved ones. You don't need to be in panic that you are going to die immediately. Allow yourself that time.

Then you need to work through the details of having a brain disease. This is on-going. Minute by minute, day by day working through details never stops as the disease progresses. It wasn't in our plan to change our lives this way. You need to address financial questions. Who earns the income? How old are the kids? Are there kids in college? Finances. Marriage and family relationships. Friends. There are decisions you need to make. Whatever dreams you had about retirement, if you had them are out of question. You need to adjust your behavior.

Then there is care giving. If you don't have long-term care insurance you can't get it after a diagnosis. One spouse can die and someone's left. You need to address these questions. Those decisions evolve. Watch the kids' behavior. They will be growing into understanding of the disease and care giving at their own developmental level. They may not want to talk to the person diagnosed. That's hard. The dynamics in communication in the family change. You never get to stop working through the details. You're always adapting until the end. When nothing is decided, then there you are.

Having a diagnosis doesn't speak to how ill – or well – I am. Everyone gets diagnosed at different stage of disease. But an earlier diagnosis lets me be more involved.

**THE THIRD STOP: STAYING THE COURSE, SO AS TO NOT FALL OFF THE TRAIN**
It is necessary for us, the people with dementia, to continue to live our lives as we see fit for ourselves. Someone else's lifestyle, beliefs, and attitudes cannot be taken on as our own.

As people, we all have our own identities that grows and change with circumstances. Of course this remains true lifelong. We are people with dementia. WE ARE PEOPLE WITH A DISEASE. WE ARE NOT THE DISEASE.

As much as is possible, we attempt to live our lives post-diagnosis as other people do. With all that comes with being a person tackling life. Having self-knowledge, and thinking about the issues is good for one's health. If you can do it, a self-assessment, is helpful. Some questions one might ask themselves:

- How is my time best used for my optimal health? What balance is best for me?
- Would volunteering at a valued environment be a positive activity?
- Do I need alone time? Do I need naps? Do I need a creative outlet?
- Is exercise in some form a goal?
- What nutritional guidelines do I want to consider?
- Do I need to assess my relationships and possibly let some of them come to a natural end.
- How can I establish new relationships and interests?
- Do I want to seek out support such as counseling, peer support, online support, AFTD support?
- Do I want to pursue becoming an advocate for people with FTD?
- Do I need assistance in communicating with my family about issues I might have?

An individual assessment is crucial. Talking with trusted people in your life is usually the best place to start. It is incumbent upon loving care partners to realize that they too have incredible changes to adapt to. Utilizing the list of self-assessment strategies, is also useful for the care partner. If the person with FTD lacks awareness, the care partner must assess safety concerns and care needs. They should seek help from a trusted person to help with communication and take that away from dyad. Then check for their own mental health, seek help for themselves through a counselor, spiritual person, or by seeking someone else out.

**THE FOURTH STOP: WE ARRIVE AT THE KNOWLEDGE THAT THERE IS NO ONE STATION TO DEPEND UPON AS A CONSTANT IN OUR LIVES**

Life of course is a moving target. People with dementia who have increasingly broken brains have their own additional moving target to deal with.

It's natural that people seek security in what is known to them. Unfortunately, life doesn't allow us to remain in such safe surroundings and not have change inflicted upon us. It would be comforting if we could know that at some point in our disease process we will have gone through the grief, set everything up, felt all the feelings, and have arrived at a peace of mind that allows us to find comfort in knowing there's no more work to be done. But we don't get to let anything go, because dementia is a moving target. It doesn't let you land in a safe stagnant place. You go through the process and get to contentment, but then changes again. This is true for everyone in life, but it's harder if you have a broken brain.

It is crucial that people with dementia and their care partners realize that the person with FTD is not doing the behaviors from dementia TO the care partner. The behaviors that have resulted from the disease are not directed to the care partner personally. The care partner must realize this fact for all concerned. The behaviors are a byproduct of FTD.

# Clinical Issues: Managing Primary Progressive Aphasia

**Ahmed Sajjadi, MD**

## *Primary Progressive Aphasia*

S.Ahmad Sajjadi MD, PhD
Assistant professor of Neurology
University of California, Irvine

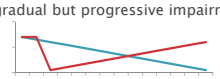
## I have no disclosures

## Outline

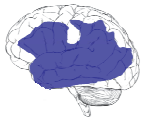
- Introduction and importance of early diagnosis
- PPA subtypes
- Treatment
- Research

## Primary Progressive Aphasia (PPA)

- Insidious onset and gradual but progressive impairment of language




- Due to degeneration of brain language areas



- First described Europeans in 1893 (verbal deafness)
- Modern era interest in the condition started in 1970s

## Demography

- Under-diagnosed condition
- As frequent as behavioural variant FTD
- Affects males and females equally
- Largely non-hereditary (a minority have genetic mutations)
- Not only limited to younger population

## Diagnostic challenges

- Insidious onset
- Insensitive tools
- Lack of biomarkers
- Evolving clinical picture

## Importance of early diagnosis

- Disease modifying therapies are most effective early on
- Providing an explanation for the perceived problems
- Safety of the patients and the wider community
- In advance care and financial planning for the families

## PPA subtypes

## Importance of further classification

- Different presenting complaints
- Various evolving patterns
  - Life expectancy
  - Type of disability (motor, behaviour, ...)
- Implications on care needs, independence, driving, ...
- There is a relationship between clinical presentation and underlying pathology

Now: Symptomatic Rx for some patients
Future: Pathology specific disease modifying treatments

## PPA subtypes

- Semantic (svPPA)
- Non-fluent/agrammatic (nfvPPA)
- Logopenic (lvPPA)
- Progressive supranuclear gaze palsy (PSP)
- Corticobasal degeneration (CBD)

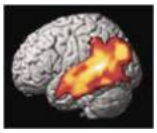
## Semantic variant

- Fluent subtype
- break down of knowledge
- Initially presents with anomia
- Behavioral features develop with progression

## Non-fluent variant

- Non-fluent, effortful speech
- Phonological errors due to apraxia of speech
- Grammatical mistakes
- Frequently evolves to movement disorders PSP and CBD

## Logopenic variant



- Word finding pauses
- Phonological errors
- Impaired repetition of sentences
- Commonly due to Alzheimer's disease pathology

## Pharmacological treatments

- No cure!
- Symptomatic treatments for
  - Depression & obsession
  - Other behavioral impairment
  - Insomnia
  - Movement disorder

## Non-pharmacological treatments

- Life style modification
  - Exercise
  - Diet
- Speech and language therapy
  - Early stages of the disease
  - Later stages of the disease
- Non-invasive brain stimulation (evolving filed)

## Research

- Heterogeneous condition
- Due to more than one type of pathology
- Evolving course
- Lack of clinical trials

Importance of activism / advocacy groups

## Thank you

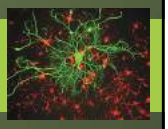
» ssajjadi@uci.edu

**NOTES:**

# Clinical Issues: Managing Primary Progressive Aphasia

**Maura Silverman, CCC, SLP**

## Panel Discussion: Managing PPA



**Considerations for connections**

Maura English Silverman, MS, CCC/SLP
AFTD Education Conference
May 1, 2019

## What we hear…

Speech Therapy? My husband can't even talk anymore…

Look, I work all day, the last thing I can do when I get home is help her with her speech homework!

He can't even follow simple directions, … we are way beyond communication strategies!

Silverman 2019

## What we know…

Speech Therapy? My husband can't even talk anymore…

Look, I work all day, the last thing I can do when I get home is help her with her speech homework!

He can't even follow simple directions, … we are way beyond communication strategies!

There's nobody to talk to anymore anyway …our friends don't understand.

I'm too tired. Period.

He put shaving cream on his toothbrush, … can you help with that???

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## Communication…a definition

Communication:
- The imparting or exchanging of information or news.

***… that's it???***

Silverman 2019

## Communication … a better definition

Communication:
- The act of purposeful engagement with another.
- The mutual sharing of ideas, thoughts, and feelings.
- A verbal, or nonverbal, connection

*It connects strangers, may lead to finding love, and even prevents wars in some cases*
*(Odessey, Sofia Gratas Mar 6, 2017)*

Silverman 2019

## Think about it this way…

Molly's Movement Inspires, educates and gives back to caregivers dealing with Dementia, Alzheimer's and other life struggles. Thanks for joining the movement.

About Molly's Movement
www.MollysMovement.com

Watch the Journey on YouTube
https://www.youtube.com/c/joejoe


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## What parts of communication did Joe miss?

- *The ability for his mom to order her own Frosty?*
- *The need for him to repeat his question over and over or provide clarifying information?*
- *Her speech clarity or intelligibility?*

Most importantly… knowing what he really misses…what is really lost with aphasia and dementia is the fodder for what we can do to help a family!!

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## Some Guiding Principles:

- Know the WHO (Getting to know you, personality/hobbies/story)

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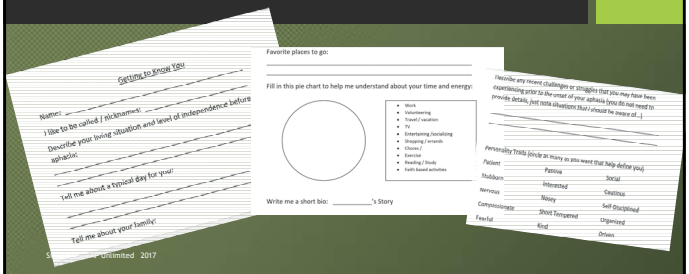
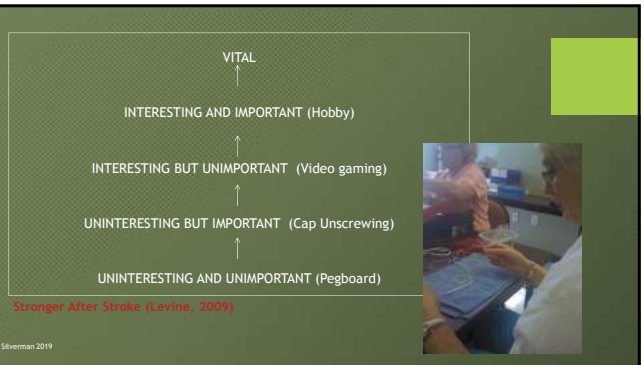
## Getting to know you…




Silverman Unlimited 2017

## Stronger After Stroke (Levine, 2009)

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## Modify task / Level of Cueing for Participation

- Know the WHO (Getting to know you, personality/hobbies/story)
- Maintain Independence and Purpose
  - What CAN someone do?
  - What levels of support do they need to do it?
  - What would give them purpose and pleasure?

***Don't throw the baby away with the bathwater…***


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## Some Guiding Principles:

- Know the WHO (Getting to know you, personality/hobbies/story)
- Maintain Independence and Purpose
- Accessible communication and memory supports/props

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## Some Guiding Principles:

- Know the WHO (Getting to know you, personality/hobbies/story)
- Maintain Independence and Purpose
- Accessible communication and memory supports/props
- Identify Communication Barriers
  - Ask (and re-ask) the individual/family "Tell me about the last communication breakdown" or "A situation that caused a lot of frustration."
  - Consider the continuum, life span, timeline of the individual and how those barriers will change → thus your intervention will adapt.

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| Challenge / Barrier | Potential Causes or Influences | Potential Solutions Compensatory and Rehab/Stimulation |
|---|---|---|
| | | |

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| Challenge / Barrier | Potential Causes or Influences | Potential Solutions Compensatory and Rehab/Stimulation |
|---|---|---|
| * putting shaving cream on the toothbrush … | "Executive Functioning"<br><br>* task organization, sequencing and problem solving | * Picture sequence taped to the bathroom mirror |

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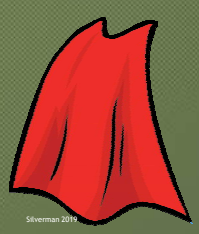
## Don a CAPE and let's do this…

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| | |
|---|---|
| C | Connecting People |
| A | Augmentative & Alternative Communication |
| P | Partner Training |
| E | Education and Resources |

*Special Thanks to Roberta Elman, PhD and* ***Megan Vu***

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## C: Connecting Individuals/Families with PPA

Online Support Groups:
- Primary Progressive Aphasia Support Group (Facebook Group)
- Aphasia Recovery Connection: Family / Caregivers Group

Websites:
- Association for Frontotemporal Degeneration (AFTD)
- Mesulam Center for Cognitive Neurology and Alzheimer's Disease
- National Aphasia Association /Aphasia Access

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## MORE Connections:

Local Support Groups:

Programs:
- Aphasia Programs (i.e. TAP Unlimited (ie. communication groups)
- Area Medical Centers / Universities
- Day Programming:
  - programs of interest at local library, senior center, adult day programs, faith based programs and other meetups

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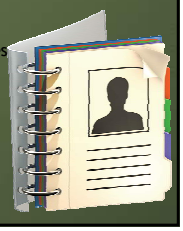
## A: Augmentative and Alternative Communication

Any and all tools, aids, props or supports that can be utilized to improve access to, and use of, communication.

- "I have aphasia" cards, visor cards, ID bracelets, phone notes
- Communication booklet/wallet or apps on the phone with information on the individual's "story" and things that are typically challenging to remember/access.
- Environmental modifications; pictured cue cards (ie. Sequenced pictures on bathroom mirror)



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## A: Augmentative and Alternative Communication

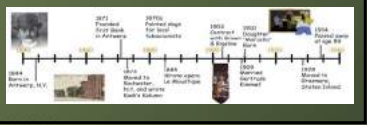
**Photo Button Phone**

Road ID; medic-alert; Lauren's Hope

**Photo 365**

Silverman 2019

## Telling your story



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## P: Partner Training

1) **Who do you train?** Any and all Communicative Partners
2) **When do you train them?** OFTEN
3) **How do I know where to start???**

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## P: Partner Training

1) **Who do you train?** Any and all Communicative Partners
2) **When do you train them?** OFTEN
3) **How do I know where to start???**

ASK!

*What was the last communication challenge you had?*

*Tell me about a really frustrating conversation or exchange…*

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## P: Partner Training

Any and all Communicative Partners …

- Organic training / REAL Interactions
- Formal training with SLP for identified individuals or groups
- Use of social media formats, email lists, Caring Bridge, etc.
- Keep an ongoing "live" notebook for challenges
- Prep for all appts with appropriate supports.

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## E: Education and Resources

YOU are not alone!

- THIS AFTD conference
- Dementia Capable Programs (DCC) / Aphasia Friendly Businesses
- Area presentations (i.e. Adult living communities)
- Give Care
- Better Conversations with Aphasia (training module)


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**NOTES:**

Maura English Silverman, MS, CCC/SLP
Triangle Aphasia Project, Unlimited
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Cary, NC 27511
info@aphasiaproject.org
maura@aphasiaproject.org
Website:
www.aphasiaproject.org

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**NOTES:**

## Tips for Living with PPA

**By Rev. Tracey Lind and Emily Ingalls**

**The Basics**

- Manage your PPA as a chronic condition – not a terminal illness
- Healthy diet
- Daily exercise
- Meditation
- Quality sleep
- Smart technology
- Live in the moment
- Express gratitude
- Try not to worry

**Eating Out:**

- Before you go out to a restaurant, look at the menu online and decide what you want to eat
- If you can't get a menu online, decide what sort of meal you want (chicken, fish, salad) so that when you are handed a menu you have already narrowed down the choices
- Avoid restaurants with lots of noise and screens, such as sports bars.
- Find a table in a quiet corner if possible

**Dressing**

- Create a capsule wardrobe so that you only see a limited number of items in your closet and they all go together
- Decide what you want to wear the night before
- Keep it simple

**Language**

- Use descriptive work-arounds when you can't recall a word
- Be upfront about language difficulties -- ask people to give you time to finish your sentences
- Manage and curtail number of conversations during the day
- Give yourself word assignments to practice
- Use Google dictionary and thesaurus
- Listen to books when reading gets hard
- Be patient and forgiving with yourself

**Name recall**

- When you meet someone say "It's nice to see you," even if you're not sure you've ever met the person
- Ask people their names (begin by saying yours)

**Travel**

- Ask to pre-board airplanes
- Carry a card in your wallet to show to TSA (and others) if you're having trouble speaking
- Ask TSA for special assistance (if you need it)
- Use Lyft and Uber if driving becomes an issue
- Prepare and carry a complete and detailed itinerary
- Pre-arrange where you will be met at the airport

**Time Management**

- Consider using an Apple Watch or iPhone Calendar
- Set alarms and alerts
- Establish a daily schedule and try to stick to it
- Create a playlist of your life so that others will know your personal tastes when you can no longer communicate

**THE PLAYLIST OF YOUR LIFE**

On the journey of dementia (especially FTD-PPA), in all likelihood, there will come a time when one is unable to use language to communicate. In anticipation of this time, we recommend making a list of the music, films, poetry, food, and television shows you enjoy so that when you're no longer able to communicate with language, your caregivers, friends and family will know your personal taste. We believe this should be a part of any good advance directive for those with cognitive challenges. Here are some suggestions to get you started:

- Inspiration for music and song choices:
- Make you smile
- Bring tears to your eyes
- Relaxes you
- Help you to focus
- Sing around a campfire
- Doing chores
- Exercise
- Falling asleep
- Road trip
- Rush hour
- Going on vacation
- Childhood
- Junior and senior high
- First date, dance or kiss
- Falling in love and breaking up
- Wedding
- "That summer"
- Inspiration
- When you're sad, lonely or depressed
- Holiday music
- Hymns
- Classical favorites
- Jazz music
- Broadway tunes
- The song you want to hear as you take your final breath

**Spiritual Inspiration**

- Scripture passages
- Poems
- Prayers

**Film, Television and Radio**

- Favorite movies and television shows
- Types of film and television (drama, comedy, action, thriller, documentary)
- News broadcasters and commentators
- Television/radio that you really dislike

**Fiction, Non-fiction, or Both**

- Flowers and Plants

**Sports, Games and Hobbies**

**Colors, Smells, and Sounds**

**Animals and Pets**

**Food**

- Favorite breakfast, lunch, dinner
- Snacks – salty, sweet or both?
- Desserts and cookies
- Soups and Sandwiches
- Drinks
- Comfort meals, foods and recipes
- Food and drink that you really don't like

**Clothing**
- Sleepwear
- Favorite sweater or sweatshirt
- Tops and bottoms
- Socks and shoes

**Places – Parks, Restaurants, Stores**

**Friends and family**
- Visit with you when you're not able to go out
- Be with you at the end of your life

**Bucket List Items (still not fulfilled)**

**What makes you anxious? What makes you calm?**

**How do you like to be touched? How do you not want to be touched?**

**Temperature preferences**

**Personal habits and daily routine**
- When you awake and go to sleep
- Preferred meal time
- Bathing and tooth brushing (what's your favorite soap, shampoo and toothpaste)
- Preferred exercise
- Do you like to be alone or with other people

**NOTES:**

# Clinical Issues: Managing ALS-FTD and Movement Disorders

**Gabriel Leger, MD, and Jamie Fong, CGC**

**Overview:**

Frontotemporal Dementia (FTD) is a complex progressive neurodegenerative disorder. Signs and symptoms that may appear as initial manifestations, and their progression to involve other domains or systems, can vary considerably from patient to patient. Difficulties can range from isolated changes in behavior and cognition, including language, to more multisystemic difficulties that include changes often seen in Parkinsonian (slowness or movements, falls, stiffness) and neuromuscular (muscle weakness and atrophy, respiratory failure) disorders.

These diverse outcomes are usually (but not always) determined by the underlying pathology and are strongly influenced by gene abnormalities (if present). Diagnostic labels such as behavioral variant FTD, PPA, PSP, CBD, FTD/ALS are often used.

In this session we will explore these different presentations and discuss the critical importance for a multidisciplinary approach to compassionately address the complex varying needs of each patient.

**COMMON PRESENTATIONS OF ALS WITH FTD**
(from Partners Spring 2018 issue)

ALS can present in myriad ways, with weakness in any segment of the body. Roughly 75% of patients present with limb weakness, 25% present with bulbar weakness (trouble speaking or swallowing), and a small number present with respiratory insufficiency. Similarly, FTD can manifest early on as a predominantly behavioral syndrome or as a disorder of language; these patterns of disease can look very different. Both ALS and FTD can have variable disease courses as well.

Unsurprisingly, ALS with FTD presents and develops in many different ways—no two cases are the same. Here are some examples of persons diagnosed:

- A 58-year-old man develops walking difficulty due to stiffness in his leg. His wife reports that subtle personality changes, which she first noticed five years ago, have now begun to cause problems at his job.
- A 61-year-old man, already diagnosed with severe bvFTD, is referred by a cognitive clinic for further neuromuscular evaluation because of new onset right-hand weakness.
- A 53-year-old woman with dysarthria and hand weakness, whose sister has ALS, shows a lack of insight into her disability along with inappropriate public affection to her husband in the doctor's office during an examination.
- A 69-year-old man presented with dysarthria and over the course of two years began to exhibit anarthria (no audible speech) and developed a need for a feeding tube and power wheelchair. He then developed a language disorder that manifested in his writing: He confused "yes" and "no," showed a lack of grammar ability and made frequent spelling errors.

ALS is unpredictable—it can first manifest in any part of the body, then spread in a variety of patterns. One common presentation is when weakness starts in one arm: It will then spread to the opposite arm, then to the leg on the side of the body where it initially started. But it is harder to predict when respiratory or bulbar muscles may become involved. In both ALS and FTD, the speed of progression can be variable and is hard to predict. The best predictor of rate of progression is the patient's individual history, as rate of progression tends to remain constant within an individual.

**A SHARED GENETIC MUTATION**
(from Partners Spring 2018 issue)

The discovery in 2011 that the C9orf72 gene mutation can cause both frontotemporal degeneration (FTD) and amyotrophic lateral sclerosis (ALS) has transformed a long-held belief that ALS is purely a neuromuscular disorder and that FTD is purely a cognitive or behavioral form of dementia. It is now recognized that the C9orf72 gene is the most common gene causing hereditary FTD, ALS, and ALS with FTD. We also now know that several other genes can cause both diseases. FTD is a progressive brain disease that causes changes in behavior, personality and language dysfunction due to loss of nerve cells in the frontal and temporal lobes. ALS is a neurodegenerative disease in which loss of upper motor neurons (located in the brain) and lower motor neurons (located in the brainstem and spinal cord) can lead to paralysis, dysphagia,

dysarthria and respiratory failure. Describing the clinical syndrome where both FTD and ALS occur in the same person has been an area of active research, and our knowledge of the underlying genetics, pathology and clinical features is still unfolding. ALS is mostly commonly associated with behavioral variant FTD. However, as our case study illustrates, primary progressive aphasia (including both the non-fluent agrammatic and semantic variants) have been reported in association with ALS.

**A CARE PARTNER'S PERSPECTIVE ON ALS/FTD by Miki Paul, PhD**

Read Miki's account of caring for her husband in AFTD's Partners in FTD Care Spring 2018 issue. Below is a list of her favorite books on caregiving that were helpful for her when she cared for her husband:

**What If It's Not Alzheimer's: A Caregiver's Guide to Dementia**, by Gary Radin and Lisa Radin

*Amyotrophic Lateral Sclerosis, A Guide for Patients and Families*, by Hiroshi Mitsumoto, MD

*Passages in Caregiving*, by Gail Sheehy

*The Best of Us*: A Memoir, by Joyce Maynard

*The Wild Edge of Sorrow*, by Francis Weller

*MDA ALS Caregivers Guide by MDA*, ALS division

*Fried, Why You Burn Out and How to Revive*, by Joan Borysenko, PhD

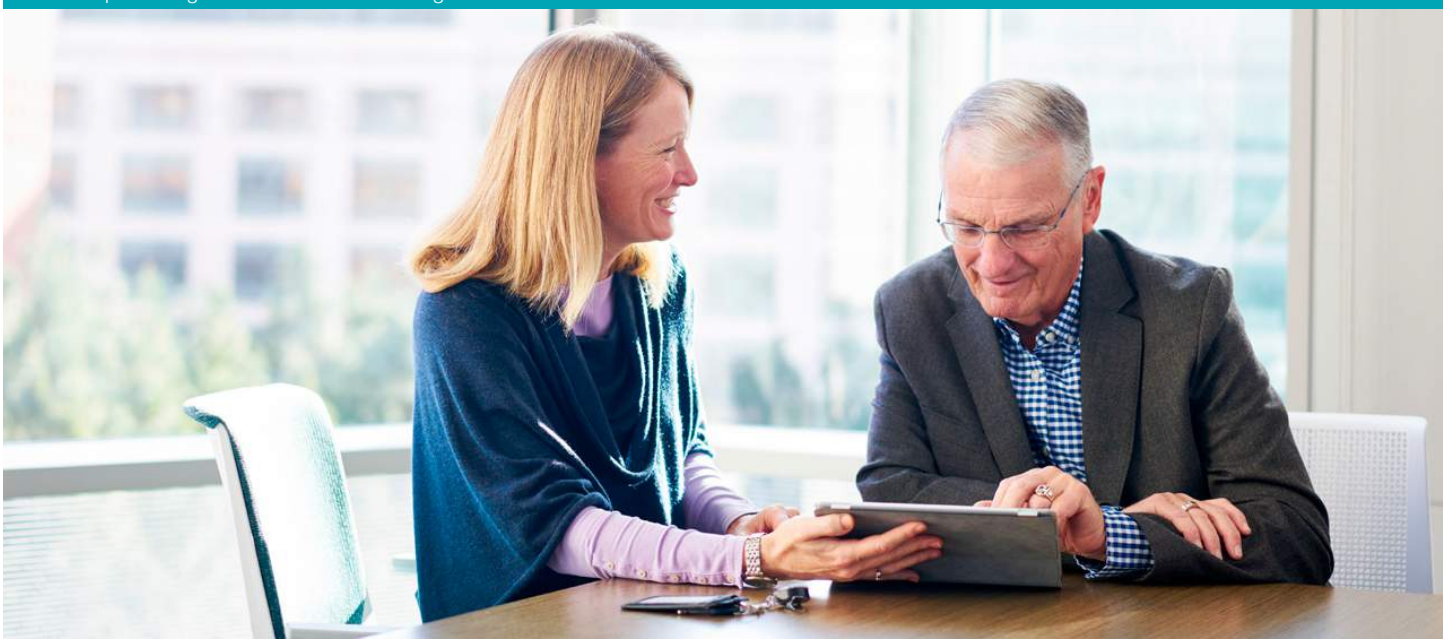
*How to Survive the Loss of a Love*, by Harold Bloomfield, MD, Melba Colgrove, PhD, Peter McWilliams

*Meditations for Caregivers: Practical, Emotional, and Spiritual Support for You and Your Family*, by Barry Jacobs, PsyD and Julia Mayer, PsyD

*Every Note Played*, by Lisa Genova, PhD (even though it is a fictional account of caregiving a person with ALS as well as what it feels like for a person having ALS, the scientist author interviewed numerous families and patients coping with ALS. This book is useful to share with friends/families to increase their understanding of what you and your loved one are going through)

**NOTES:**

A patient's guide to Genetic Counseling



## What is genetic counseling?

The goal of genetic counseling is to provide education, support, and guidance about the genetic causes of illnesses and about the options for genetic testing. Genetic counseling helps patients and families make informed decisions about genetic testing, determines what genetic testing results mean, and adapts to the impact of genetic information.

## Who provides genetic counseling?

Genetic counseling is provided by trained medical professionals. Genetic counselors or physicians (usually medical geneticists but also other physicians with genetics training) can provide genetic counseling. The genetic counselor or physician should have dementia expertise.

## What do genetic counselors do?

Genetic counselors can:

- Ask you about your family medical history
- Determine the risk you have to develop genetic disease
- Explain how genetic conditions are passed down in families
- Provide information about specific genetic conditions
- Provide information about genetic testing options and help you decide what is best for you and your family
- Discuss reproductive options
- Help you order genetic testing, if appropriate
- Inform you of the results of genetic testing, if ordered, and help with their interpretation
- Provide supportive counseling about your response to results
- Refer you to medical specialists, patient organizations, support groups, and other resources

For more information, please visit the National Society of Genetic Counselors (NSGC) website: nsgc.org

## Why would my doctor refer me to a genetic counselor?

- Your doctor suspects you have a genetic form of dementia
- Your doctor suspects your family member(s) has a genetic form of dementia
- You have little to no information about your family history and are worried about a genetic form of dementia
- You are planning to have a child and have questions about genetic disease

## What questions could I ask a genetic counselor?

- Does dementia run in my family?
- If my family member has dementia, might I get it? If yes, should I get tested?
- If I have dementia, are my family members more likely to get it?
- Is there genetic testing for dementia? If yes, what are the benefits and limitations of testing? How will I pay for it?
- What kind of information would genetic testing for dementia give me?
- What is the process of getting a genetic test?
- How can knowing about my genetic risk help me?
- Are there risks associated with genetic testing?
- Could genetic testing results affect my health care coverage?

## What will happen during my appointment with a genetic counselor?

The first genetic counseling appointment usually lasts one hour, although this can vary depending on your family history, your risk for genetic disease, and your questions. Follow-up appointments are scheduled as needed, including an appointment for reviewing results, if genetic testing is ordered. In general, the first appointment will include the following:

- The genetic counselor will discuss your family's medical history. This includes questions about:
  - Who are all the members of the family
  - Who in the family has or had dementia
  - The type(s) of dementia (if known) in the family and how the family member(s) with dementia was diagnosed
  - Age(s) at first symptom of family member(s) with dementia
  - Age(s) at diagnosis of family member(s) with dementia
  - Whether or not medical records of the family member(s) with dementia could be obtained
  - Whether or not brain autopsy of the deceased family member(s) with dementia was done
- Using your family history information, the genetic counselor will talk about the likelihood of a genetic cause of dementia in your family.
- The genetic counselor will explain causes and symptoms of genetic forms of dementia.
- If genetic testing is available, the genetic counselor will discuss the benefits, risks, and limitations of testing. She will tell you about the genetic testing process.
- If genetic testing is appropriate, the genetic counselor may order testing for you or may refer you back to your physician to order testing. The clinician who orders your genetic testing will receive results. You will not receive results directly from the laboratory.
- The genetic counselor will discuss what genetic test results might mean for you or your family, including possible emotional effects.
- The genetic counselor will help you find ways to adapt to genetic test results. She may refer you to other providers or resources for additional support.

## Does my health insurance cover the cost of genetic testing?

It depends on your insurance policy. If you wish to learn the extent of coverage of the cost of genetic testing, you should contact your insurance carrier directly. The genetic counselor may have information about the cost of genetic testing but may not know the extent of your insurance coverage.

# Care Strategies: The Doctor Thinks It's FTD. Now What?

**Christy Turner, CDP, CDCM, CCSI, Marianne Sanders, RN**

**Key points for people facing a new diagnosis and their families:**

1. When you make an irrevocable decision to "always bring The Good Stuff" (respect, kindness, love, empathy, and compassion) to every interaction with both yourself and your person, you're setting up both of you for the best possible outcome in every situation. Using The Good Stuff with yourself smothers that nasty little voice in your head. Using it with your person allows you to keep communication positive.

2. A difficult yet crucial mindset shift for families of newly diagnosed people is moving from searching for answers to living with them. The "win" of solving the puzzle of what's been going on and finally getting a correct diagnosis runs into the reality that FTD can last up to 25 years. A mindset shift allows "My person is living with FTD," to become a part of everyday life rather than the sole focus of each day. Families who report feeling most successful are those who keep in mind the possible length of the condition and plan accordingly, use support systems, and continue maintaining an identity independent of "family care partner or person living with FTD."

3. One of the many benefits of embracing person-centered care is it allows you to move through this diagnosis with a framework for decision-making. Your criteria is simply what's best for your person, specifically, versus what's best for an institution or other third party.

4. Medical team members could include any combination of the following disciplines: primary care physician, behavioral neurologist, psychiatrist, neuro psychologist, social worker, nurse, speech language pathologist, occupational therapist, physical therapist, geriatric care managers, home health aides, palliative care and/or hospice teams and potentially adult day or full time facility-based services.

5. Every member of the care team has a role to play, some throughout the progression, others at specific intervals. The most important members of your care team are you and your family. Being part of a team means you are not alone on this journey. Leaning on professionals for guidance in care decisions can help. Speaking with other families affected by FTD via support groups or online forums about how they have utilized professionals could also help you gain insights.

6. FTD is a rare disease and most professionals not working in FTD-specific clinics may not know about it. Providing them with some background, such as AFTD's provider letter or website is often enough to get them caught up so they can best help you.

7. Preparing for appointments can make a more successful outcome. The logistics of getting you and your person there can be a challenge. Taking a few minutes before to ensure you have what you need can really help. Once you leave a medical professionals office – you need to shift back into logistics of getting home. Having notes to refer to later is crucial. A few suggestions include:

   - Keep a running list of questions in a notes section on your phone between visits (or a notebook designated for appointments kept in a high traffic area).
   - A week or two before the visit: put some observational notes into your phone/notebook – any areas of decline, new triggers or behaviors, swallowing problems; if taking medications any changes (good or bad) since last visit, etc.
   - Have a plan for what works best for you to take notes while in the appointment; asking the clinicians to slow down so you can get everything, especially if there are any "next steps" or follow up referrals. Repeat back what you think you heard to make sure you are all on the same page.

8. Understanding what's happening in your person's brain--and that it's entirely outside their control--allows you to focus on your person's strengths and abilities and keep a more positive and realistic mindset.
9. Have difficult conversations with your loved one living with FTD as early as possible. The unknown progression of FTD is very difficult to navigate. As much as you and your person are able to discuss things like living wills, facility care, in-home support, finances etc. the easier those decisions will be when/if the time comes.

**NOTES:** _____

# Care Strategies: Developing Communications Teams and Tools

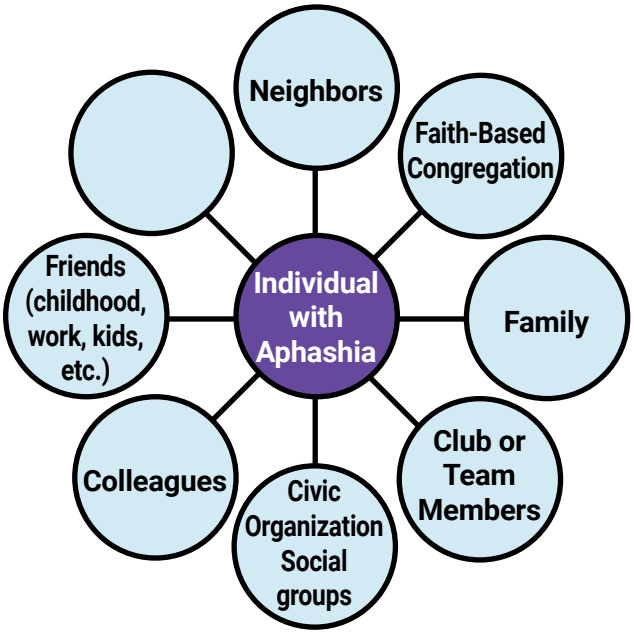
**Maura Silverman, SLP**

**Objectives:**

- Describe Communication Support Teams (CST) as a model to augment programming and broaden community for an individual with PPA/Aphasia
- Demonstrate ways of developing individualized communication supports for cognitive and linguistic challenges.

**Communication Support Teams:**
Communication Support Teams were developed by TAP Unlimited to provide an accessible and innovative program model for individuals with aphasia. The person/family centered approach to programming has its foundation in care team models and can be individualized for a person's needs along the continuum of care/PPA journey.

**Communication Supports**:
Identifying communication barriers is an essential component to determining effective, efficient communication aids. An aid, or a support, can be likened to an assistive devise that someone utilizes for challenges with ambulation or independent living skills. The goal is to select the least restrictive, most flexible tools that are modifiable as needs change.




| Challenge/Barrier | Potential Causes or Influences | Potential Solutions Compensatory and Rehab/Stimulation |
|---|---|---|
| | | |

# Care Strategies: Developing Environmental and Behavioral Strategies

**Jill Shapira, PhD, RN, Sandra Grow, RN, Sue Hirsch, MA**

**Problem-Solving Approach**

**1. Aims**

- Identify problematic behaviors in behavioral variant (bv)FTD
- Understand importance of non-pharmacological interventions
- Learn principles of problem-solving approach in home and residential community settings
- Become familiar with resources

**2. Overview of problematic behaviors**

- bvFTD is a neurological disease caused by an impairment in the frontal lobes of the brain
- Possible symptoms of bvFTD are personality changes, apathy, and a progressive decline in socially appropriate behavior, judgment, self-control and empathy
- If the behavior is unsafe for the person or others: contact medical team
- If the behavior is related to a medical illness, pain, or changes in medication: contact medical team
- Consider impact of specific behaviors on caregiver's anger, frustration, sadness

**3. Problem-Solving Approach**

- While challenging symptoms commonly occur together, focus on specific behaviors separately, one at a time
- Consider role of impairment in frontal lobes in contributing to behavior and possible solutions
- Recognize caregiver/staff's emotional approach as key in managing behaviors

**A. *Identify and define problem***

- State the specific problem as clearly as possible.
- Are you concerned about the physical safety of your loved one/resident or others?
- How often does the behavior occur (several times each day, weekly, less than once/week)?
- Can you identify possible triggers: environmental factors (noisy location, unfamiliar place), time of day, presence of other individuals, physical condition (medical illness, changes in medications, pain), caregiver and others stress, emotions, or actions?
- What have you already tried to manage this behavior?
- How troubled are you about the behavior for your loved one/resident (mildly, moderately, severely)?
- Does this behavior affect others emotionally (mildly, moderately, severely) (i.e., caregivers, other residents, and/or their families)?

**B. *Brainstorm possible solutions***

- List all ideas that pop into your head, regardless of whether it is feasible or not.
- Be creative and consider all options.
- Ask family, friends, support group members for suggestions.
- Schedule meeting to involve residential staff members.
- Refer to AFTD resources.

**C. *Evaluate the options***

- Weigh the pros and cons of each possible solution by asking which of these possibilities will be best for the person with FTD and the best for family caregivers and/or the residential community.
- Eliminate alternatives that are not manageable or realistic.

**D. *Make a plan and do it***

- Create a written plan of care.
- Be as detailed as possible.

**E.** ***Evaluate the outcome***

- Was the solution effective? Did the behavior stay the same, get somewhat better, or improve? Did the frequency of the behavior change?
- Did the caregiver/staff's thinking or feeling about the behavior change? Is there more or less willingness to accept the behavior?
- Does the existing plan need to be revised, or is a new plan needed?

**Resources:**

Specialized information and support from AFTD
Website: **www.theaftd.org**
Helpline: 866-507-7222

Partners in FTD Care Newsletters:

- Issue #1: Fall 2011: Behavioral Variant FTD
- Issue #2: Winter 2012: Communication Strategies in FTD
- Issue #11: Spring 2014: Why Does He Act Like That? Aggressive Behaviors in FTD
- Issue #13: Fall 2014: The Loss of Empathy and Connection in FTD
- Issue #14: Winter 2015: Changes in Eating and Managing Related Compulsive Behaviors
- Issue #23: Winter 2018: Understanding and Managing Apathy to Improve Care in FTD
- Issue #25: Winter 2019: Everything is Just Fine: Anosognosia in Frontotemporal Degeneration

**AFTD Educational Webinars**

August 27, 2018
**Webinar: What You Should Know about Behavioral Variant FTD (bvFTD)**

Dr. Nupur Ghoshal from Washington University in St. Louis explores aspects of bvFTD that all health providers, persons living with FTD, and their families should know. Her presentation addresses clinical signs and symptoms and the latest in bvFTD diagnosis and treatment.

May 25, 2017
**Webinar: bvFTD Subtypes: Divergent Anatomy, Divergent Behavior**

The third edition of AFTD's educational webinar series explores how different physical dysfunctions within the brain correspond to symptoms of the four distinct sub-types of behavioral variant FTD (bvFTD).

January 12, 2017
**Webinar: A Care Paradigm for Persons with Frontotemporal Degeneration**

Presented by Dr. Alvin Holm, this AFTD educational webinar explores how FTD treatment benefits from an integrated and comprehensive approach. Learn how symptom-specific therapies, wellness management and environmental support can help caregivers manage FTD care more effectively.

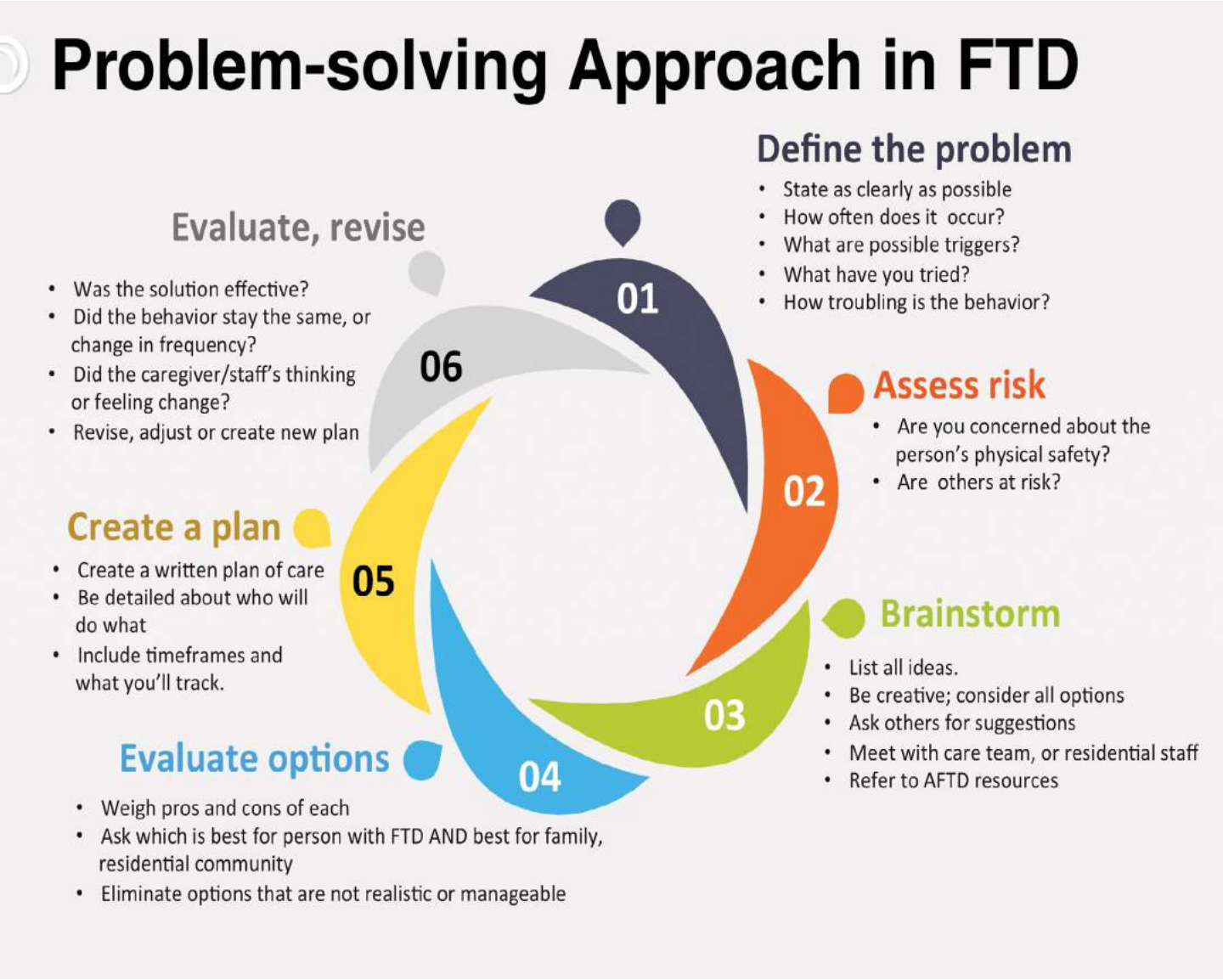
**Additional resources**

National Institutes of Aging:
**https://www.nia.nih.gov/health/what-are-frontotemporal-disorders**

Savvy Caregiver Program: The Savvy Caregiver program is a 6 week training program for caregivers of someone with Alzheimer's disease or related dementias. Caregivers learn to develop and adjust strategies and approaches for effective care giving. Provided locally by various dementia care organizations.

## Care Strategies: Developing Environmental and Behavioral Strategies

**Jill Shapira, PhD, RN, Sandra Grow, RN, Sue Hirsch, MA**




# Care Strategies: Loss and Grief in FTD

**Bridget Moran-McCabe, MPH, Elaine Rose, AFTD Volunteer and Former Care Partner**

**Key points for grief and loss in FTD:**

Much like the FTD journey, everyone's grief experience is different. Grief is an expression of the love you hold for the person affected by FTD. Everyone has had different relationships and styles of expressing that love so there is no right or wrong way to grieve.

Through the years, care partners have shared with us their FTD journey, which included their grief journey. Below are insights AFTD has heard care partners share, as well as quotes from volunteers who helped create AFTD's newest resource (coming soon) on grief and loss. We hope this session reinforces for you that you are not alone and that others, who have struggled with similar thoughts and feelings, have been able to find their new normal.

**Care partner share:**

- *It's a roller coaster ride every day where no two days are the same.*
- *Some become really sad; others solider on; even others go into denial and won't talk about it. There is no room for perfectionism in this journey. I knew the process would be about making decisions and that some of my decisions might not be the right ones. I gave myself permission to do the best I could.*
- *It's not what you want and the process may not be how you want it to play out but you will get through it. There is hope for a new, different life.*

With FTD, we lose our loved ones in small ways as the disease progresses. Skills, once easily mastered by our person living with FTD, will diminish and we may not have the space or capacity to reflect on these losses while in the caregiving role. This anticipatory grief is an emotional challenge no matter when it all catches up with us.

**Care partner share:**

- *The most difficult part is the long goodbye. Cancer can be a long goodbye but, in this situation (FTD), it is not so much cancer of the body but cancer of the soul.*
- *My person is not the person who we knew and it can be hard to recognize them as we knew them.*
- *I was like a machine going through the days. I became numb.*
- *I'm most proud of how I found my way through this. I think I did the best I could for him. His family is grateful to me for that. I would do it the same way if I had to do it again.*
- *I don't know how it sounds to others, but I don't care. I think I did a damn good job.*

FTD can be a long journey for some. In the process, family and friends may retreat or disappear altogether. Finding your new normal takes time. Stay open to new routines, mantras, rituals and experiences. Seek out a supportive community - whatever that means for you. AFTD has several options for support: in-person, online or via phone. Maybe yoga, meditation or other forms of you-centered activities work for you. Be open to experimenting with ways to help yourself, help your person living with FTD, and form a community.

**Care partner share:**

- *Taking one step at a time when there are a million shifting steps isn't always practical. The demands are so constant it may be difficult to remember this is all very hard and very sad. Try to remember that (or have someone remind you of it) and be patient with yourself and your loved one. Meanwhile, you begin to grieve for the life you thought you would have and the things left unsaid. Build coping skills and as you are able embrace this new normal.*

- *Experiences vary when it comes to support from friends and family. Some must reconcile a troubled or unresolved history with our loved one. If a familial genetic link is identified, fear of how this will affect your family shifts your ability to help.*
- *Family and friends have their own grief process. If denial is part of that, it makes it difficult. Most of our friends have disappeared. Things changed. They're different and I'm different. They can't comprehend what I have been through. Very few of them have had that kind of reality in their lives. Now I have a new community of friends.*

Regardless of where you are on this difficult FTD journey, know that you are not alone. Reach out to AFTD to get connected with others who are coping with a similar situation.

**Care partner share:**

- *You must have hope that you are going to come out of this. You're not going to come out the same, but you are going to come out of this.*
- *At some level you feel a transformation that is soul stretching. I'm not someone who thinks suffering is good for us, but it does somehow cause a deep transformation.*
- *I created a wall and methodically went about my business of caregiving. I was distracted all the time. I never knew what each day would bring.*
- *I just kept going forward and tried to get the family to understand that we had no control over anything except our reactions.*

**NOTES:**

# Care Strategies: Adapting to FTD

**Amy Shives, MEd, Matt Sharp, MSS**
**Graphics by Laurie Scherrer**


When you can't control what's happening, challenge yourself to control the way you respond to what's happening

The more independence you give up and allow other people to take care of - the more dependent you will become on others. Change your thought process from "I can't do this anymore" to "How can I accomplish this task (what changes or modifications can we make to assist me)."

Build your passion to fight back! Sometimes the passion within us drives us to continue fighting. Get involved in advocacy work to educate about dementia. Contact theaftd.org and Dementia Action Alliance at daanow.org to get started.


Communicate visually as well as audibly as much as possible. Dementia slows down processing time being able to see and hear helps clarify the communication. Use video chats rather than telephone, write down tasks, and ask restaurants for a written list of specials.

- There are many things, like noise, stress, over-stimulation or lack of sleep that can aggravate or enhance confusion and agitation. With observation and patience, you may be able to recognize what triggers these symptoms in you. Once you recognize the triggers you may be able to find ways to lessen their impact. For example, use earplugs when in a store or restaurant to reduce the noise, keep gatherings small to avoid over-stimulation, and when needed take an afternoon nap.
- Maintain as much of a routine as possible (especially morning and evening). Make a list of routine tasks in the order they are done and check them off as completes; i.e. scrub teeth, get washed, get dressed, etc.. A routine can help to establish an automatic reaction and reduces some of the "think work" required during periods of confusion.


- It is OK to take some time to grieve for your losses and accept that life will change. Most people need to experience this after diagnosis and again as their abilities change. In addition to grief, you may experience shock, anger, denial and sadness. These are normal reactions that can help you come to terms with your disease and help you to move on.
- You will have good moments when you feel "normal" and think you should go back to work and you will have bad moments when the world is a fog (dementia daze zone). You may feel confused and disoriented and find it difficult to think and then the fog will go away (at least for a while). It is OK to admit you are having a bad day.
- Encouragement provides a "Feel Good" Positive attitude for everyone. It helps you focus on the goal and stimulates productivity through a desire for approval.


- Stay active and socialize with friends old and new. Once you curl up into yourself it is hard to get out. There are a number of groups that offer video chats with other people living with dementia so you can socialize, ask questions and encourage each other. Dementiamentors.org offers a mentor program so you can have weekly chats with someone living with dementia.
- Enjoy life, friends, family and activities for as long as you can.
- Talk to me – not about me.
- Look directly at me and ask my opinion – even if I can't answer
- In order to be Empowered;
- I must be **Encouraged – Enabled – Engaged**

FIND HELP.
SHARE HOPE.

## Keynote Speaker: Martha Madison

Martha Madison is an actor, wife, mother and FTD advocate. She is best known for her role as Isabella "Belle" Black on *Days of Our Lives*, and for the digital daytime drama series *Winterthorne*, for which she received a Daytime Emmy Award nomination. Martha's television career spans nearly 20 years and includes guest-starring roles on *Criminal Minds*, *Without a Trace*, *Law and Order: Criminal Intent*, *General Hospital* and *One Mississippi*.

Martha's FTD journey began in 2008, when her mother Barbara Baggs learned she had behavioral variant FTD at age 56. In the wake of her mother's diagnosis, she has become a dedicated FTD advocate, appearing in a public service announcement for AFTD, delivering the message "Think It's Alzheimer's? Think Again." She and her sisters recently ran the 2018 Dallas Marathon under AFTD's banner, raising awareness and funds to support our mission. She further highlighted her experience as an FTD care partner in a September 2018 interview with *Soap Opera Digest*.

"AFTD has been such an important resource for my family during my mom's FTD journey, and for so many families around the country," Martha says. "It's a privilege to be able to support them and the important work they do."

A Texas native, Martha currently lives in Dallas with her husband and daughter.

To learn more about Martha, her career and her family's FTD journey, please visit her personal website, **marthamadison.com**.

FIND HELP.
SHARE HOPE.

# Speaker Bios

**Chuck Anastasia** of Bristol, Rhode Island, is an AFTD volunteer. He was the primary care partner and advocate for his wife, VJ, from her first symptoms in 2012 through her diagnosis of FTD/CBS in 2013, until she was admitted to long-term care in November 2018. She died peacefully under hospice care in February 2019. Chuck educated himself on FTD and caregiving best practices through in-person and online courses and support groups. His gratitude for families who shared their FTD experiences motivates him to help others on the FTD journey. He co-facilitated a breakout session about online support at the 2017 AFTD Education Conference. Chuck and VJ spoke at a 2017 patient information day for a Boston pharmaceutical company that is researching FTD. They also shared their story through an awareness video, *VJ & Chuck*, which premiered at AFTD's Hope Rising benefit in 2017. Chuck became an FTD support group facilitator in February 2019.

**Gail Andersen,** AFTD Board Chair, of Mason, OH, retired from Procter & Gamble after a 31-year career. After her retirement in December 2013, she joined the AFTD Board, of which she became Chair in spring 2016. Ms. Andersen has brought important experience in strategic planning and project management to the organization's Board. Previously, she served on AFTD's Task Force for Families with Children. Gail's husband Larry died in 2012 at the age of 56. His bvFTD symptoms began at age 43, and she was raising young children from his FTD onset to diagnosis and admission to a long-term care facility. The couple's children are currently 33, 25 and triplets (age 21). Gail dealt with many challenges of bvFTD and found AFTD's support critical in her family's FTD journey. She is committed to furthering FTD research.

**Mary Guerriero Austrom,** Ph.D., is associate dean for diversity affairs and professor of clinical psychology, as well as the Wesley P. Martin professor of Alzheimer's disease education, at Indiana University School of Medicine. Dr. Austrom's research and teaching interests include dementia, the science of aging and caregiver education. Her current research projects focus on how caregivers and care partners of people with FTD choose whether to participate in research studies, and how caregivers of people with dementia approach end-of-life decision making. Dr. Austrom received her Ph.D. from York University in Toronto.

**Sharon S. Denny,** MA, AFTD Senior Director of Programs, joined AFTD in September 2008. Over the past decade, she has led strategic development of support and education efforts for people with FTD, their care partners and families, and healthcare professionals. Under her leadership, AFTD has expanded its HelpLine and built a national network of support groups facilitated by AFTD-affiliated leaders. She has created a national volunteer program and led efforts to include people living with FTD in AFTD's mission. An advocate for high-quality, responsive services, she has introduced initiatives to address the needs of families with young children and teens, and directed *Partners in FTD Care*, an education initiative for healthcare professionals and families. She has an MA in Clinical Psychology from West Chester University and a BA in psychology from the College of the Holy Cross.

**Susan L-J Dickinson,** MS, CGC, AFTD Chief Executive Officer (CEO), joined AFTD in February 2008. A certified genetic counselor, she brings more than two decades of experience facilitating communications among lay, scientific and medical communities. Under her leadership, AFTD has expanded dramatically in scale and impact, from a $400,000 organization with a part-time staff of three to a $5 million organization with 20 full-time staff. During her tenure, AFTD has expanded programs to meet and advocate for the needs of FTD families, and invested in specific strategies to advance FTD research and drug development, including two multi-year, multi-million dollar research initiatives targeting FTD diagnosis and treatment. She holds

an MS in genetic counseling from Arcadia University and a BA in biology and psychology from Swarthmore College.

**Kimiko Domoto-Reilly,** M.D. completed her neurology residency and fellowship training at the joint Harvard program based at Brigham and Women's Hospital and Massachusetts General Hospital. She then served as a clinical and research staff neurologist in the MGH Frontotemporal Dementia Unit. Dr. Domoto-Reilly joined the University of Washington in 2014, and sees patients at the Memory & Brain Wellness Clinic. She is the Outreach, Recruitment, and Engagement Core Leader of the UW Alzheimer's Disease Research Center. Dr. Domoto-Reilly conducts research in the Alzheimer's Disease Research Center as well as the Integrated Brain Imaging Center, with a focus on investigating how multimodal imaging can provide insight into the clinical manifestations and pathologic underpinnings of frontotemporal degeneration.

**Anne Fargusson** spent her career as a registered nurse with a Bachelor of Science in Nursing. She earned an Enterostomal Therapist certification in wound and ostomy care and a certification to place PIC lines. About 14 years ago Anne was diagnosed with behavioral variant FTD, and about four years ago became part of a gene study where it was determined that she has the *C9orf72* genetic mutation. Twenty-two years ago, her father died of complications related to FTD. Since then, Anne has taken part in research studies at the UCSF Memory and Aging Center and is active in FTD advocacy and raising awareness. Anne is here with her husband, Ed. They have identical twin sons, both of whom are Emergency Department Physicians.

**Ed Fargusson** is the assistant to the president of the Northern California Conference of Seventh-day Adventists. Previously, he served as director of Human Resources. Prior assignments for Ed have included associate director of Public Affairs and Religious Liberty, and pastoring in various churches in Northern California for over 20 years. Ed holds a Master of Divinity Degree from Andrews University and a B.A. in Theology from Pacific Union College. He and Anne Fargusson have been married since 1981. The Fargussons make their home in Sacramento, California.

**Jamie Fong** is a genetic counselor at the UCSF Memory and Aging Center. She has worked as a genetic counselor since 2008, providing clinical care and support to families at risk for inherited conditions. At the UCSF Memory and Aging Center, she provides genetic counseling to individuals and families with or at risk of frontotemporal dementia and other neurodegenerative conditions. She also facilitates a telephone support group for adult children caregivers of people with frontotemporal dementia. She lectures frequently about genetic counseling in dementia care, and leads medical student discussion groups about bioethics. She is a member of the National Society of Genetic Counselors, and a diplomate of the American Board of Genetic Counseling. She holds a master's degree in genetic counseling from Sarah Lawrence College, and a bachelor's degree in molecular and cell biology from University of California, Berkeley.

**Ben Freeman** joined AFTD as Development & Communications Director in February 2015. He has more than ten years of experience in nonprofit development and communications, and past background in IT and technology systems. For a decade, he served as Development Director for the Paraprofessional Healthcare Institute, helping to scale its work to improve care for elders and people living with disabilities. Ben works with AFTD's staff, Board, and community to raise awareness, expand the organization's visibility, and strengthen its impact and sustainability.

**Lauren Martin Gauthier,** AFTD Online Community Coordinator, joined AFTD in August 2017. Lauren has spent the majority of her 17-year career in the nonprofit sector, where her primary focus has been on marketing and social media management. In her previous roles, she developed social media strategy; created and implemented innovative and successful marketing campaigns; and grew the digital audience, influence, reach and impact of multiple organizations. As Online Community Coordinator, Lauren works to deepen AFTD's engagement with its community through social media, e-newsletters and other forms of digital communications.

**Bridget Graham,** AFTD Special Events Manager, joined AFTD in October 2015 as Grassroots Events (GRE) Coordinator and assumed her current position in January 2019. She holds a B.S. in Speech Communication from Millersville University of Pennsylvania. As GRE Coordinator, Bridget expanded and refined AFTD's national network of grassroots events, managing national branded campaigns and independent, host-driven events that collectively raised more than $1 million in support of AFTD's mission. In her current role, she oversees AFTD's annual Hope Rising Benefit and manages major branded fundraising events throughout the year, while also supervising the overall GRE program.

**Sandra Grow** is a registered nurse with nearly four decades of experience; she currently works part time as a Quality Nurse at the Ohio Anesthesia Group. In 2007, her husband Karl – a former air traffic controller in the U.S. Air Force and Air Force Reserve and a U.S. postal worker – was diagnosed with FTD. Sandra's involvement with AFTD dates back nearly 10 years. She has co-facilitated a support group in Akron, co-presented a webinar with AFTD Senior Director of Programs Sharon Denny, and is a current advisor to AFTD's Partners in FTD Care initiative. In 2018, she joined AFTD's Board of Directors.

**Susan Hirsch** has worked in the gerontology field for more than 35 years. She has specialized in dementia care during her 31 years of employment with HCR ManorCare. Her current position is Education and Development Group Specialist, where her responsibilities include developing, implementing, and supporting specialized dementia services (including training materials) in memory care communities. In the field of dementia, she has collaborated on several research studies and presented nationally on dementia-related topics, including frontotemporal degeneration. She has served as a support group leader, is a past Board Member of the Central Pennsylvania Chapter of the Alzheimer's Association, and is currently serving on the Pennsylvania Health Care Association AL/PC Board. Sue is also an advisor for AFTD's Partners in FTD Care initiative. She earned her master's degree in Psychology/Gerontology from Hood College.

**Emily Ingalls** spent more than 20 years in commercial real estate and project management. She was an early proponent of sustainable buildings. In 2000, she championed the "greening" of Trinity Cathedral in Cleveland, helping to create the city's first sustainable building. Emily is now Chief Logistics Officer, responsible for managing a life and home turned upside down by dementia. She has served on several Northeast Ohio civic boards, including the Nature Center at Shaker Lakes and Facing History and Ourselves. She is an avid gardener, a beginner birder and an aspiring cook. Emily has a BA from Swarthmore College in Pennsylvania and an MBA from Cleveland's Case Western Reserve University.

**Elvira Jimenez,** Ph.D., MPH works for the David Geffen School of Medicine at the University of California's Department of Neurology, coordinating dementia research. She has over 15 years of experience directing clinical projects investigating frontotemporal dementia, early-onset Alzheimer's disease and traumatic brain injury. Her research focus is on constructing a grounded theory for early-onset-dementia caregivers. She has co-authored more than 35 peer-reviewed articles. She is also involved in health services research working for the Center for the Study of Healthcare Innovation, Implementation & Policy (CSHIIP) at the West Los Angeles VA.

**Gabriel Léger,** M.D. trained in Montreal at McGill University, where he completed a residency in Neurology and a fellowship in Movement Disorders at the Montreal Neurological Institute. In 2003, he completed a second fellowship in Behavioral Neurology and Neuropsychiatry at the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University in Chicago. His training completed, he became Assistant Professor and Director of the Neurology Residency program at the University of Montreal until 2011, when he joined the Cleveland Clinic's Lou Ruvo Center for Brain Health in Las Vegas. At the Cleveland Clinic, he directed their fellowship program in Behavioral Neurology and Neuropsychiatry and an FTD and young-onset dementia clinic. He joined the neurosciences faculty at UCSD and the Alzheimer's Disease Research Center (ADRC) in July 2018, where he directs clinical trials in the treatment of Alzheimer's disease and is helping to create a new multi-disciplinary memory disorders clinic.

**The Very Rev. Tracey Lind** is a retired Episcopal priest and city planner whose career has included work for social and environmental justice, interfaith relations, sustainable urban development, arts and culture, and progressive theology. Most recently, her ministry has extended to include the spiritual insights and lessons she has gained from a life complicated by dementia. During her 17-year tenure as Dean of Cleveland's Trinity Episcopal Cathedral, Rev. Lind led the establishment of Greater Cleveland Congregations and a number of other faith-based and civic initiatives. She is also the author of *Interrupted by God: Glimpses from the Edge* and currently serves on the boards of the Episcopal Church Pension Fund and Judson Retirement Services; she is also a member of the AFTD Think Tank.

**Martha Madison** is an FTD advocate and an actor best known for her role as Isabella "Belle" Black on *Days of Our Lives*. Her mother was diagnosed with behavioral variant FTD in 2008. As our conference's keynote speaker, her biography is provided on page 59.

**Mario F. Mendez,** M.D., Ph.D., is a behavioral neurologist who focuses on the clinical aspects of frontotemporal dementia, primary progressive aphasia, posterior cortical atrophy, and other neurodegenerative conditions. His training is in internal medicine, neurology, neurobehavior, and experimental psychology. Dr. Mendez completed an internal medicine residency at USC-LAC Medical Center and briefly practiced medicine before returning to do a neurology residency at UCLA. Currently Dr. Mendez is the Director of Neurobehavior at the VA Greater Los Angeles and Professor of Neurology and Psychiatry at UCLA.

**Bridget Moran-McCabe,** MPH, AFTD Support Services Manager, joined AFTD in May 2015. She holds an MPH from Drexel University. In a career spanning more than 15 years, Bridget has worked to develop new programs and research projects serving vulnerable populations, such as those with terminal illnesses, people experiencing homelessness, children who have experienced trauma, and individuals contemplating suicide. She now works to develop and sustain AFTD's network of support: providing leadership and training to our wonderful volunteers who allow groups to come together and share their stories, learn ways to advocate, and gain much needed coping skills and strategies. She also works collaboratively with staff and volunteers to provide new avenues for support and resources, and believes until there is a cure for FTD, bearing witness and creating a space for those affected to tell their story is the most important support we can offer FTD families. She is honored to work with all who are sharing their time and talents to do so.

**Debra Niehoff,** Ph.D., joined the Association for Frontotemporal Degeneration in 2015 as Research Manager, with responsibility for coordinating AFTD's grant programs. She received a PhD in pharmacology from the Johns Hopkins University and a B.S. degree in psychology with honors from Carnegie Mellon University. Before coming to AFTD, Dr. Niehoff served on the faculty at Bucks County Community College, where she developed and supervised one of the first two-year neuroscience degree programs in the country. She also has over 20 years of experience in scientific and medical communications and is the author of two books, *The Biology of Violence: How Understanding the Brain, Behavior and Environment Can Break the Vicious Circle of Aggression* and *The Language of Life: How Cells Communicate in Health and Disease*. As a result of her expertise on the neurobiological origins of violent behavior, Dr. Niehoff has served as a guest instructor for the FBI's Critical Incident Response Group and a member of the editorial board for the journal *Violence and Gender*.

**Mary O'Hara,** LCSW is a Licensed Clinical Social Worker with over 14 years of experience working with individuals and families living with dementia. She has worked in a Skilled Nursing Facility, at The Alzheimer's Association, and as the Assistant Director of Education at Northwestern University's Cognitive Neurology and Alzheimer's Disease Center. She has focused much of her career on supporting families living with FTD and PPA. She is currently in private practice in Denver, CO, offering support to family caregivers and people in the early stages of a dementia diagnosis. She also co-facilitates the Denver FTD/PPA group.

**Dr. Miki Paul,** Ph.D. is the facilitator for the only national monthly support group (by phone) for care partners of family members with FTD-ALS, to which she brings her experience as a former caregiver for her beloved husband, who had the dual diagnosis. A psychologist by profession, she has a practice of In-Your-Home Counseling/Psychotherapy Services for the Emotional Well-Being of Older Adults in the San Francisco Bay Area. Dr. Paul won the highest national award by the American Psychological Association for Distinguished Contribution to the Practice of Psychology. She was awarded the $10,000 Sunshine Peace Award for her 22 years of volunteerism in the domestic violence movement. Her claim to fame is having her entire collection of psychology books used as props in the psychologist's office in the movie *Tin Cup*. On her own time, she enjoys playing mandolin in the San Francisco Mandolin Orchestra.

**Elaine Rose's** husband, Bob Matusiak, was diagnosed with bvFTD in 2007 when he was 55 years old. He also developed aphasia, Parkinsonian tremors and impaired motor abilities. He spent the last five years of his life at Arden Courts, a dementia care facility, and died in 2015. Shortly after Bob was moved to Arden Courts, Elaine and the facility marketing director developed a support group for FTD families. Elaine continues to co-facilitate their monthly meetings. She also volunteers as a liaison for AFTD's Food for Thought campaign and contributes as a writer and editor for AFTD materials. Bob and Elaine have two children, both married; one granddaughter, about to turn 1; and, at this writing, another granddaughter due to arrive soon.

**S. Ahmad Sajjadi,** M.D., Ph.D. is a cognitive neurologist with special interest in frontotemporal dementia. Following his M.D. and to pursue his research interests, he completed a Ph.D. at the University of Cambridge in the UK, studying neuropsychological and MRI characteristics of primary progressive aphasia. Dr. Sajjadi is currently an assistant professor of neurology at the University of California, Irvine where he consults with patients suffering from different types of dementia with an emphasis on FTD. He also continues to conduct research into ways to improve the diagnosis and prediction of underlying pathology in primary progressive aphasia.

**Marianne F. Sanders,** RN is a clinical nurse research specialist in brain health and memory at University Hospitals Cleveland Medical Center since 1993. She is the coordinator and independent rater for Alzheimer's disease and other dementia clinical trials. Marianne has co-facilitated an FTD support group in Cleveland since 2008. She also facilitates the Savvy Caregiver Program, a six-week course of two-hour classes designed to provide caregivers with the tools they need to understand and manage the memory loss and behavioral symptoms common in dementia.

**Laurie Scherrer** was diagnosed with early onset Alzheimer's and FTD in August 2013 at the age of 55. Unable to continue a professional career, she turned her focus towards helping others during their dementia journey. Laurie is on the Dementia Action Alliance Advisory Council and several work groups. She is a Dementia Mentor and a Purple Angel, and is active in many support groups. Laurie is frequently a co-host and panel member for Alzheimer's Speaks Radio, and has been featured in documentaries and articles published in the *New York Times*, *AARP*, *PBC* and the *Reading Eagle*. On her website, dementiadaze.com, Laurie shares her experiences to help other persons diagnosed and their care partners explore ways to live beyond dementia. She and her husband Roy work hard to identify the obstacles that trigger Laurie's challenges and symptoms and then figure out what adjustments they can make to overcome the barriers. "We don't automatically accept that I CAN'T do things anymore -- instead we try to figure out HOW I CAN do them."

**Jill Shapira,** Ph.D. graduated from UCLA as a Nurse Practitioner in 1976 and helped develop the UCLA Neurobehavioral program. Jill quickly realized how devastated families become when faced with behavioral changes in their loved ones. She completed a doctoral program in medical anthropology at UCLA to further her understanding of the social and cultural impact of challenging behaviors on both family and nursing home caregivers. For 15 years, Dr. Shapira collaborated with Dr. Mario Mendez at UCLA. They specialized in caring for individuals with frontotemporal dementia and young-onset Alzheimer's disease and their families. Jill designed innovative behavior management strategies and coordinated various clinical research projects. While Jill retired from UCLA

to enjoy her four grandchildren, she remains connected to her clinical roots through voluntary activities. She is a founding member of the AFTD Partners in FTD Care task force, which develops best practices for care partners and healthcare professionals.

**Matthew Sharp,** MSS, AFTD Program Manager, earned his Master of Social Services degree from Bryn Mawr College's Graduate School of Social Work and Social Research in 2009, making a transition from his career in the natural sciences, which included 8 years in the ornithology department of the Academy of Natural Sciences in Philadelphia. He joined the organization in December 2009 and is now responsible for AFTD's HelpLine, a key service for providing information and support to those directly impacted by the disease. Matt also spearheads AFTD's involvement in the National Alzheimer's Project Act (NAPA) and the development of the organization's growing advocacy efforts.

**Amy Shives,** M.Ed., earned her master's degree in education from Western Washington University in Bellingham, WA. Her career included employment as a Child Therapist in social service agencies prior to her position at Community Colleges of Spokane, where she was a tenured counseling faculty member for 25 years prior to a diagnosis of FTD. Amy is a volunteer at the UCSF Memory and Aging Center where she is enrolled in longitudinal research studies for FTD. She is a founding board member of Dementia Alliance International (DAI), and a current board member of Frontal Temporal Dementia Advocacy Resource Network (FTD ARN). She is a member of the AFTD Think Tank for persons diagnosed, and was a member of the 2019 AFTD Education Conference Planning Committee. She is also a past member of the National Alzheimer's Association Early Stage Advisory Group, where she has spoken nationally on dementia issues. Amy grew up with a mother who had unrecognized FTD challenges. She and her husband George have been married for 35 years and have two adult daughters. Their son Chester, a Cavalier King Charles Spaniel, and his new brother Tommy the kitten remain in the home.

**Maura English Silverman,** M.S., CCC/SLP has always been passionate about helping others. In her role as Executive Director of the Triangle Aphasia Project, Unlimited, Maura is able to help those whose communication has been robbed by stroke or brain injury. She created the organization 16 years ago to allow individuals to receive programming for as long as they needed it. The local grassroots program has gotten national recognition, including receiving the American Stroke Association's award in 2019; Maura, meanwhile, has received the *Triangle Business Journal's* Healthcare Hero award and Aphasia Access's inaugural Innovator Award. She serves on national and international aphasia committees, publishes and speaks on aphasia, neuroplasticity and community engagement. Her husband, four sons, mom, and dog Joy are her "Why." In her spare time she enjoys serving the community through Meals on Wheels, 100 Women Who Give a Hoot, Esteamed Coffee, and personal health and fitness.

**Nadine Tatton,** Ph.D. joined AFTD as the Scientific Director in June 2013. Dr. Tatton provides oversight for AFTD's expanding program of competitive research grants which include postdoctoral fellowship and pilot grant programs to support early career researchers. She provides strategic leadership for our FTD Biomarkers Initiative and on our partner programs with the Alzheimer's Drug Discovery Foundation (ADDF) which include TreatFTD grants for early phase clinical trials, Accelerating Drug Discovery for FTD and the newly created Diagnostics Accelerator for biomarkers. Dr. Tatton is lead organizer for the FTD Treatment Study Group conference which brings together international experts from industry, academia and government agencies with a focus on developing treatments for FTD. Dr. Tatton received her PhD from the University of Toronto, Department of Physiology with a specialty in neuroscience.

**Christy Turner** is an educator, public speaker and dementia expert based in Portland, Oregon. She is the founder of DementiaSherpa.com, a website that provides information, resources and support for persons with dementia and their loved ones. A Certified Dementia Practitioner, Certified Dementia Care Unit Manager and Cognitive Stimulation

Instructor, Christy has worked privately as a consultant and with numerous memory care, assisted living and skilled nursing facilities. She has spoken at local and national conferences and gatherings, and teaches at Chemeketa Community College in Salem, Oregon. Christy's experiences as a care partner for seven family members with dementia influence her belief that every person living with dementia deserves to be treated with dignity, respect, kindness and love.

**Dianna K.H. Wheaton,** M.S., Ph.D., CHES joined the field of FTD research as director of the FTD Disorders Registry in January 2016. She has more than 20 years of clinical science research experience and genetic counseling for patients and at-risk family members. She has authored numerous papers describing genes that cause neurodegenerative eye disease and the associated clinical symptoms, participated as co-investigator for interventional clinical trials, and acted as principal/co-investigator for genetic epidemiology studies. Her research commitment was refocused to neurodegenerative dementia disorders after her father's diagnosis of a temporal brain tumor and her brother's diagnosis of younger-onset dementia. Dr. Wheaton currently directs FTD Disorders Registry operations working directly with persons diagnosed with FTD and their families, and leading outreach efforts to lay and health professional communities. She also actively works with clinicians, researchers and organizations interested in using the Registry to answer important research questions and to support clinical trials.

**Chuang-Kuo Wu,** MD, PhD, is professor of neurology at University of California, Irvine's School of Medicine. Dr. Wu is a board-certified neurologist with subspecialty board certifications in behavioral neurology and neuropsychiatry and vascular neurology. His clinical interests include frontotemporal dementia, primary progressive aphasia, Alzheimer's disease, Lewy body dementia, Parkinson's disease with dementia, vascular dementia, mild cognitive impairment and strokes. Dr. Wu earned his medical degree at China Medical College in Taichung, Taiwan and completed an internship and a residency in neurology at Boston Medical Center. He then followed up with a fellowship in Geriatric Neurology/Dementia at UC San Diego Medical Center. Dr. Wu has published a variety of original research papers, conducted drug trials for various dementia disorders and provides his expertise in comprehensive patient care for persons diagnosed with dementia at UCI Health.

**NOTES:**

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# Available on Our Website

AFTD strives to be a hub for information about how to live with FTD from every angle.
In addition to the material discussed today at the AFTD Education Conference,
you may find the following informational informational resources, available at **theaftd.org**, helpful.

## What Is FTD?

The What Is FTD? section of our website provides a comprehensive disease overview, touching on how FTD differs from other forms of dementia and how the condition progresses. You can also find information on FTD subtypes, genetic factors and answers to frequently asked questions.

## Managing FTD

As public awareness and diagnostic tools improve, more people are diagnosed with an FTD disorder in the early stage, when symptoms are relatively mild. It is important to stay healthy and active to reduce the impact of symptoms as long as possible. While no lifestyle change will stop the progression or reverse the disease, steps can be taken to manage symptoms to the best of your ability. The Managing FTD section of AFTD's website suggests ways to approach activities of daily living and how to manage common symptoms.

## Genetics of FTD

Approximately 40% of people with FTD have a family history of the disease. Learning about the genetics underlying the condition can help you plan for your own care, and help your family down the line. The Genetics of FTD section of AFTD's website provides background on commonly observed FTD genetic mutations, and how to address this topic with health professionals.

## Booklets

AFTD has created informational booklets to help people with FTD and their loved ones. These titles, including *Understanding the Genetics of FTD* and *The Doctor Thinks It's FTD. Now What?*, are available to download free of charge on AFTD's website.

## Partners in FTD Care

Published quarterly, the Partners in FTD Care newsletter offers a deep dive into the challenges that arise regularly in FTD care, including medical, financial and personal concerns. Back issues can be found on the AFTD website. Some topics include:

- Family Participation in FTD Research
- When the Diagnosis Doesn't Fit: Challenges in Diagnosing FTD
- An Evolving Understanding of ALS with Frontotemporal Degeneration
- Easing the Transition: Residential Long-Term Care in FTD

## Educational Webinars

AFTD partners with leading experts in FTD care and research to address the pressing topics surrounding these conditions. Our Educational Webinars provide important information and context for diagnosis, disease management and life with FTD. These resources can be streamed live as they happen or watched in archived versions on our YouTube channel (www.youtube.com/theAFTDorg). Past webinar topics include:

- What You Should Know About Primary Progressive Aphasia (PPA)
- The FTD Disorders Registry and How It Can Advance Research
- The Journey to an FTD Diagnosis
- An Overview of FTD Genetics and the Role of Genetic Counseling

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# Support Resources from AFTD

**AFTD HelpLine:** AFTD's HelpLine is a unique resource – it is the only helpline in the country devoted entirely to FTD. Whether you or a loved one has been newly diagnosed, or if you have been living with the disease for years, the HelpLine can offer the information and support that you need. To start, make a toll-free call to **866-507-7222**, or send an email to **info@theaftd.org**. A knowledgeable member of the AFTD staff will assist you in finding help.

**Support Groups:** Support groups offer a safe space to connect with others, learn practical care tips and share resources in your community. AFTD–affiliated support group facilitator volunteers receive ongoing training, and have access to the most up-to-date information in the field. AFTD also provides web-based support groups for people living with FTD and telephone support groups for care partners, including male care partners, those caring for someone with dually diagnosed with ALS with FTD, and those caring for a spouse/partner who also have children in the home. No matter how you choose to gain support, connecting with others who understand FTD can be a lifeline.

**Comstock Grants:** AFTD's Comstock Grant program provides monetary support to care partners and persons diagnosed in the form of three different grant types. Full-time, unpaid care partners can arrange short-term respite by using money from the Respite Grant. Travel Grants, meanwhile, help defray the costs of travel to an FTD education conference. The newest Comstock Grant, the Quality of Life Grant, helps a person diagnosed with an FTD disorder to access services or supports that improve their quality of life.

**Facebook Groups:** AFTD maintains a private Facebook group in which people affected by FTD – both persons living with FTD and care partners – can meet, share experiences and draw support from one another. A second "secret" group is specifically aimed at young adults in their 20s and 30s who have FTD present in their lives. See page 69 for information on how to join.

**Informal Care Partner Connections:** FTD care partners interested in finding other care partners who live nearby can provide their location to AFTD, which we will use to match you to others in your area. These connections can be invaluable, particularly to those who live in a region that is currently without an in-person support group. Contact **info@theaftd.org** to get involved.


**Remember to:**
Register with
**www.theAFTD.org**
for regular updates

## Finding Help Via Social Media

Connect with AFTD on the following online platforms to ensure that the help, information and support you need is just a click away.

### AFTD Facebook Page
**www.facebook.com/TheAFTD**

AFTD's Facebook page keeps followers updated on area events, research findings, and the latest FTD news, stories, articles and opportunities to engage AFTD's mission.

### AFTD-Team Facebook Page
**www.facebook.com/TheAFTDTeam1**

The AFTD-Team Facebook page allows members to stay connected and current with the latest AFTD grassroots fundraising opportunities, campaign news, events and volunteer opportunities.

### AFTD's Closed Facebook Group
**www.facebook.com/groups/52543721114**

AFTD offers a closed Facebook group, where members can share personal experiences and respond to discussion topics in a safe online setting.

### AFTD's "Secret" Young Adult Facebook Group
To join, send an email to **youngadults@theaftd.org**

AFTD's Young Adult Facebook group serves as a supportive space for people in their 20s and 30s who have a loved one with FTD. To join, email youngadults@theaftd.org and include the email address you used to open your Facebook account. You will receive a group invite within one week.

### Twitter
**twitter.com/AFTDHope, @AFTDHope**

AFTD's Twitter feed offers research updates, information on new AFTD opportunities, and the latest in FTD-related news and information.

### YouTube
**www.youtube.com/TheAFTDorg**

Access resources, educational materials and messages of hope through AFTD's YouTube channel, which provides easily accessible visual content for persons diagnosed, care partners and caregivers, and the AFTD community.

### Instagram
**www.instagram.com/theaftd**

You can follow AFTD's Instagram pages for information, messages of hope and educational content about FTD.

### Classy
**give.classy.org/AFTD**

Are you driven to fundraise in honor or memory of a loved one, or in response to your own diagnosis? Have you been inspired to take part in a grassroots event and fundraise in support of AFTD's mission? AFTD's Classy online fundraising platform is a sharply designed, easy-to-use way to tell your story, and engage supporters.

### World FTD United
**www.worldftdunited.net**

AFTD is a member of this international coalition of organizations and health professionals, which works to provide support to everyone affected by FTD around the world.

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# What's Next When the Doctor Says It's FTD?

## Checking Things off the List

| | |
|---|---|
| **Pause to consider your approach.** | |
| The path to a diagnosis is often difficult but life doesn't end when FTD is diagnosed. Take some time to consider how you will approach living with the disease. | |
| Engage with people who understand FTD as soon as possible. Visit AFTD's website and register for the organization's newsletters (**www.theaftd.org**). | |
| Contact AFTD's HelpLine with questions and to find support: call **866-507-7222** or email **info@theaftd.org**. | |
| Start important conversations regarding care and support. Acknowledge where perspectives are similar and different and how things may change over time as the disease progresses. | |
| Identify ways to adjust and keep doing the things that are most important to both the person diagnosed and to close family or friends. | |
| Share information about the disease and about your needs with key family and friends. | |
| If you have children or teens, get AFTD's booklet, *What About the Kids?* and visit **www.AFTDKidsandTeens.org**. | |
| **Learn about the disease.** | |
| Confirm the diagnosis as best you can. Consider traveling to an FTD center for a second opinion. | |
| Learn about symptoms and what you might expect over the course of the disease. | |
| Start a file of key articles and resources on FTD that will help you educate others. | |
| Learning is ongoing. Continue to read and ask questions. | |
| Double check information found online. Use websites you can trust and confirm with experts. | |
| **Create your care team.** | |
| Identify professionals (neurologist, primary care physician, psychiatrist, case manager/social worker) and coordinate the services they provide. | |
| Obtain copies of diagnostic evaluations for your records. Keep paperwork organized. | |
| Keep a log or journal of significant changes in symptoms. Prioritize issues to address with a doctor. | |
| Maintain a chronological record of all medications started and discontinued. | |
| Consult OT, PT and speech therapist for evaluation and techniques to maximize abilities. | |
| Explore FTD-specific supports for care partners and the person with the disease. Visit **www.theaftd.org** and consider phone/Zoom groups, informal connections or other options. | |
| 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 (examples include Power of Attorney, living will, trusts, etc…). | |
| Review financial and health care programs. | |
| Apply for Social Security Disability (Compassionate Allowances Program). | |
| Determine eligibility for Veterans Administration benefits. | |
| **Focus on wellness and 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 long-term care 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 Comstock grants—these can be for care partner respite, conference travel or for a quality of life stipend for the person with FTD. | |
| **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. Include statement about neurological disorder and/or FTD. | |
| 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 getting lost is a risk. | |
| Learn the laws where you live regarding driving privileges. | |
| **Participate in research.** | |
| Follow emerging research to understand issues important in FTD. | |
| Join the FTD Disorders Registry: **www.FTDRegistry.org** | |
| 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. | |

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## Are YOU Ready to Take Action and Volunteer?

Join volunteers across the country making a difference for families facing FTD.


**Lead a support group.**

**Organize an informal gathering in your area.**

**Represent AFTD at a community event.**

**Host a fundraiser.**

**Tell your FTD story.**

Your Regional Coordinator Volunteer will work with you to determine the right opportunity that meets your interests and availability.

## To get started TODAY:

- ✓ Stop by the AFTD tables and meet your Regional Coordinator Volunteer.
- ✓ Visit **www.theaftd.org/get-involved/volunteer-network** to learn more about AFTD's National Volunteer Network.
- ✓ Complete the Volunteer Form online at **www.theaftd.org/volunteer-with-aftd** and your Regional Coordinator Volunteer will contact you by email.

*"Volunteering with AFTD has been a silver lining that I never knew existed on this FTD journey. It has created a sense of empowerment in a very disempowering situation. The community and relationships I have built as a result of volunteering are a true sense of comfort, and I am forever grateful for them."*

– Corey Esannason,
AFTD Middle Atlantic
Regional Coordinator
Volunteer

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# FTD Disorders Registry

## Join the Registry. Tell your story. Advance the science.

FTD DISORDERS REGISTRY®

A shared vision between AFTD and The Bluefield Project to Cure Frontotemporal Dementia, the FTD Disorders Registry allows anyone affected by FTD to share their stories with the research community, fueling hope for effective treatments and therapies.

Whether you are living with FTD yourself or you are a family member or care partner of someone who is, we encourage you to register to contribute to a better understanding of FTD's impact on individuals and their families. The FTD Disorders Registry currently includes data from more than 2,200 individuals, including 400 people living with one of the diseases.

The FTD Disorders Registry is both a Contact Registry and a Research Registry. All who join will receive periodic news and FTD research updates by email. Research participants will receive notifications to participate in surveys.

We hope you will consider becoming part of the Registry. Visit **www.ftdregistry.org** to learn more and sign up.

*The Contact Registry is open to international enrollment, but to register for the Research Registry and participate in research you must be a resident of the U.S. or Canada and at least 18 years old (19 in those states and provinces where the age of majority is 19; Alberta, Saskatchewan, and Newfoundland and Labrador are currently excluded).*

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# Engaging with AFTD: For Healthcare Professionals

Forming active partnerships with healthcare professionals is a crucial component of AFTD's mission. FTD experts within the medical and social services community are among our most trusted sources of information, and help to inform key AFTD resources such as Partners in FTD Care. Professionals across health care disciplines can find information and resources to strengthen their work on behalf of people with FTD and their families.

These include:

## "For Health Professionals" on AFTD's Website

Healthcare professionals unfamiliar with FTD can get answers at the AFTD website. A special section compiles information on Clinical Presentations, Diagnosing FTD, and Treating FTD.

## Partners in FTD Care

Whether a primary care physician or a Memory Care team leader, AFTD's Partners in FTD Care newsletter can support your work. Guest experts join AFTD staff and the all-volunteer Partners in FTD Care Advisory Committee to compile information and care strategies into an in-depth newsletter for healthcare professionals as well as family caregivers and care partners. Sign up at: **info@theaftd.org**.

## AFTD Educational Webinars

Launched in 2016, the Educational Webinar series features prominent speakers addressing issues in FTD. Each runs for about an hour and features a question-and-answer segment with the speaker; all the webinars are archived at theaftd.org.

## Volunteer Opportunities

Healthcare professionals are among some of AFTD's most dedicated volunteers. If you are moved to share your expertise by facilitating a support group, doing facility outreach, hosting a Meet & Greet, or representing AFTD at a conference or another event in your local community, you are encouraged to contact AFTD Volunteer Manager Kerri Keane at **kkeane@theaftd.org**.

## Do you need information you don't see? Or have suggestions for increasing awareness among your peers?

Contact AFTD's HelpLine for information or resources that will help you to serve clients or advocate on their behalf: **866-507-7222** or **info@theaftd.org**.




**AFTD 2019 Annual Education Conference**
**Los Angeles, CA**

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# Fundraising Opportunities

THE AFTD-TEAM

With Love AFTD CAMPAIGN

**With Love** is a virtual campaign held each February, based on the day dedicated to love, Valentine's Day. Create a fundraising page through our online platform and share your story of love. Anyone impacted by FTD is encouraged to take part. Join us in a show of force—the force of love—against FTD.

THE AFTD TEAM

**Race Season** is our most active campaign -- and now it lasts year-round! AFTD links up with race hosts across the country and forms teams for local community members to participate. Walk or run, there's a race for everyone, from a 5K to a marathon! Join us at AFTD's tent at each race, where there will be opportunities for team members to gather and connect, and for newcomers to learn.

AFTD's Food for Thought
www.theaftd.org

**Food for Thought** is a fundraising campaign focusing on food and FTD education. Held the last week of September and first week of October, FFT encompasses World FTD Awareness Week. During this time, people across the world host bake sales, restaurant benefit nights, happy hours and much more.

AFTD

**Independent Events** are a great way to raise awareness and funds, year round. Do you have an idea that's not covered by the above three campaigns? AFTD supports community members by helping them plan and execute successful events from their own imaginations. Past independent events have included golf tournaments, races, product sales and many more.

## Make your voice heard...

Contact AFTD's Special Events Manager Bridget Graham
to learn more about these campaigns: **bgraham@theaftd.org**

*Welcome to the team!*

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# Glossary of Key Terms

**Anosognosia** — An impaired ability to accurately understand – or even to be aware of – one's own illness.

**Apathy** — Lack of interest in previously meaningful activities or self-care.

**Aphasia** — An acquired brain disorder characterized by the loss of the ability to speak, write or understand what others are saying.

**Apraxia** — An inability to carry out purposeful activities, even if the person still has the muscle strength needed to do so. Apraxia of speech, in which the affected person has difficulty producing the movement of the lips and tongue needed to talk, is a symptom of nonfluent/agrammmatic PPA. *Limb apraxia* is a symptom of corticobasal syndrome.

**Behavioral neurology** — A subspecialty of neurology devoted to the neural basis of behavior and cognition. Behavioral neurologists are trained in the diagnosis and treatment of neurodegenerative disorders, including FTD.

**Behavioral variant FTD (bvFTD)** — The most common form of FTD, behavioral variant FTD is characterized by changes in personality, apathy, and disinhibition, as well as a decline in judgment, self-control, and empathy.

**Biomarker** — A physiological characteristic that can be objectively measured as an indicator of underlying biological or pathological process. (For example, high blood pressure is an indicator of heart disease.) The identification of FTD biomarkers to guide diagnosis and drug development is a critical research priority.

***C9ORF72*** — A specific mutation of this gene on chromosome 9, known as a *hexanucleotide repeat*, is the most common genetic cause of both FTD and ALS. The *C9ORF72* mutation is associated with an abnormal accumulation of the protein TDP-43, which is involved in RNA metabolism.

**Clinical diagnosis** — A diagnosis based on signs, symptoms, and medical history, in conjunction with laboratory tests or imaging procedures, but without confirmatory pathology. A clinical diagnosis of FTD can only be confirmed post-mortem by examining brain tissue for characteristic pathological features.

**Corticobasal syndrome (CBS)** — One of the movement-predominant FTD disorders, CBS is characterized by the loss of voluntary movement, rigidity, and uncontrollable muscle contractions. People with CBS may also exhibit behavioral and language symptoms common to other forms of FTD.

**Dementia** — Often used incorrectly as a synonym for Alzheimer's disease, "dementia" is a general term that indicates significant impairment in multiple aspects of cognition (e.g., memory, language, visuospatial function, attention, executive function, social understanding) severe enough to restrict the ability to carry out typical daily activities.

**Disinhibition** — An inability to control or suppress an immediate, impulsive response to a situation. For example, the affected person may blurt out a rude comment or engage in risky, even dangerous, behavior.

**Dysphagia** — Difficulty swallowing, which can lead to gagging or choking.

**Executive function** — Refers to a set of advanced cognitive skills that control and regulate behavior, including planning, strategizing, self-monitoring, judgment, reasoning, attention, and abstract thinking.

**Frontal lobe** — One of the four major subdivisions of the brain's outer layer or cerebral cortex, located at the front of the brain near the forehead. The frontal lobe plays important roles in executive function, voluntary movement, and emotional regulation.

***GRN*** — The gene that encodes the protein *progranulin*, which plays a role in several important cellular functions, including the regulation of inflammation. Mutations in the *GRN* gene, one of the most common causes of hereditary FTD, lead to a reduction in progranulin referred to as *progranulin haploinsufficiency*.

***MAPT*** — The gene that encodes the microtubule-associated protein tau. Mutations in the *MAPT* gene are one of the more common causes of inherited FTD and result in abnormal accumulations of tau.

**Neuroimaging** — A collective term for procedures that enable visualization of the structure or function of the brain and spinal cord, including changes associated with FTD and other brain disorders. Examples include CT, PET and MRI scanning. Advances in neuroimaging are fueling important advances in our understanding of FTD disease mechanisms as well as biomarker discovery and development.

**Neuropsychological testing** — Diagnostic procedures that utilize pencil-and-paper-type questionnaires and activities to test cognitive functions, such as memory, concentration, attention, and problem solving as well as visuospatial, math, and language skills.

**Parkinsonism** — Motor symptoms commonly observed in Parkinson's disease, such as tremors, rigidity, abnormally slow movement, and difficulty maintaining balance. These symptoms (but not other symptoms of Parkinson's disease) are also observed in two movement-dominant FTD disorders, corticobasal syndrome and progressive supranuclear palsy. As a result, these diseases are sometimes referred to as *atypical parkinsonism*.

**Pathological diagnosis** — A diagnosis made by examining affected tissues under a microscope to identify characteristic changes. Post-mortem pathological diagnosis confirming the presence of abnormal aggregation of FTD-associated proteins (tau, TDP-43) is currently the only way to know for certain that the affected individual had FTD.

**Primary progressive aphasia (PPA)** — The umbrella term for a group of FTD disorders characterized by the progressive loss of the ability to speak, read, write, or understand spoken language. Three types, or variants, of PPA can be differentiated:

- *Semantic variant PPA (svPPA)*, in which the affected individual loses the ability to recall the names of objects and the meanings of words
- *Nonfluent/agrammatic PPA (nfvPPA)*, in which the individual retains the meanings of word but loses the ability to produce speech, use words correctly, or construct grammatically correct sentences
- *Logopenic variant PPA (lvPPA)*, in which the affected individual experiences difficulty recalling words and omits or substitutes sounds in words, making it difficult for listeners to understand what they are saying

**Progressive supranuclear palsy (PSP)** — A movement-predominant FTD disorder characterized by a progressive inability to move the eyes, especially vertically, as well as difficulties with balance, coordination, and movement of the muscles controlling the mouth and throat.

**Sporadic** — Refers to FTD cases in which the affected individual has no known family history of FTD disorders.

**Tau** — One of the brain proteins that forms abnormal accumulations in FTD; approximately 40% of people with FTD have FTD-tau. In healthy brain cells, tau stabilizes microtubules that maintain the internal structure of axons.

**TDP-43** — One of the proteins in the brain that forms abnormal accumulations in FTD. Approximately half of people with FTD have FTD-TDP-43; it is also the protein that accumulates in the majority of ALS cases. Mutations in the gene encoding TDP-43, *TARDBP*, are a rare cause of hereditary FTD and also cause hereditary ALS.

**Temporal lobe** — One of the four major subdivisions of the brain's outer layer or cerebral cortex, located on either side of the brain behind the ear. The temporal lobes play important roles in language, hearing, memory, and emotion.

# Notes

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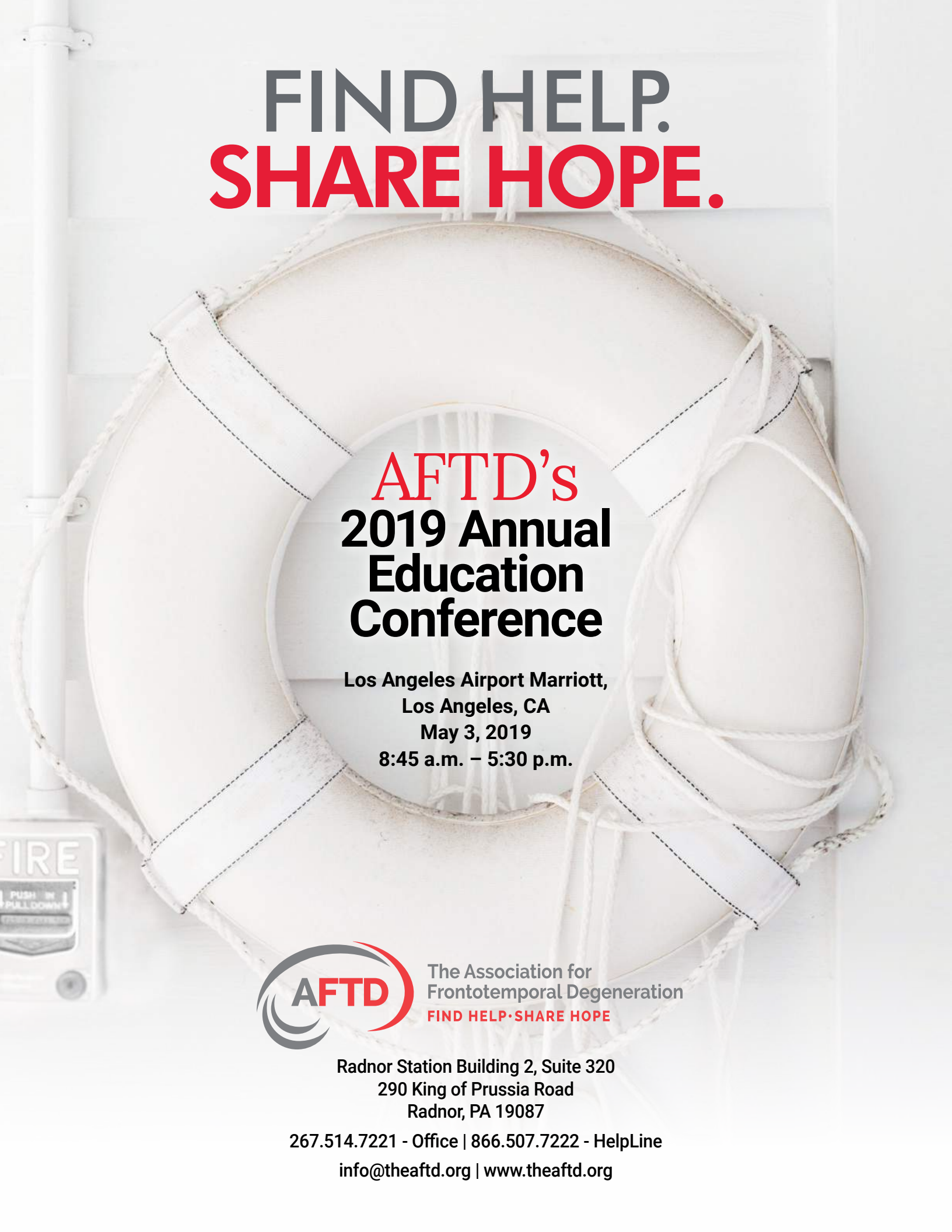

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## AFTD's
## 2019 Annual Education Conference

**Los Angeles Airport Marriott,**
**Los Angeles, CA**
**May 3, 2019**
**8:45 a.m. – 5:30 p.m.**

AFTD
The Association for Frontotemporal Degeneration
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