



FIND HELP. **SHARE HOPE.**



AFTD's 2018 Annual Education Conference

Chicago Marriott O'Hare | Chicago, IL
April 13, 2018, 9:00 a.m. to 5:30 p.m.



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE





"Whether this is your first Education Conference or your involvement goes back ten years, we all have a chance today to *find help* dealing with a disease that few outside this room can understand."

Welcome to the 2018 AFTD Education Conference. As AFTD's Board Chair, I am glad to welcome you to today's event and appreciate you choosing to join us here in Chicago.

Whether this is your first Education Conference or your involvement goes back ten years, we all have a chance today to *find help* dealing with a disease that few outside this room can understand. You'll learn the most current information available from leading clinical experts, and gain practical tips and ways to manage FTD's challenges. You'll also have a chance to meet others who have firsthand knowledge of the FTD journey.

Just as critically, this Conference offers a chance to *share hope*. The health professionals and researchers on hand to present the latest developments in FTD science are working to bring a better future for all facing FTD. You will also gain new hope, both in advances being made to treat and manage symptoms of this disease, and in growing opportunities for support in our local communities. Thank you to all of the researchers, health professionals and volunteers who do so much to make that possible.

Be sure to get a color-coded ribbon to identify your local region, then take advantage of the opportunities to network and connect throughout the day, including lunch and the afternoon's Support and Networking breakout sessions. And take the chance to meet the many AFTD staff, Board members and Regional Coordinator Volunteers who are part of today's Conference. This is our opportunity to learn from you. Your suggestions are so important—and we will respond.

Throughout the day's program, you'll find ways to deal with the profound isolation so often brought on by FTD. Find a new source of support, or find out how to start your own group. Learn about other ways to volunteer—hosting a Meet & Greet or grassroots fundraising event, or educating a local facility about FTD are just a few examples.

Today, we acknowledge the collective experience, passion and inspiration of the community that built AFTD, and which drives the organization's work to this day. I hope that you enjoy the day, and that you leave feeling better prepared for the challenges that this journey can bring, and more hopeful for a future without this disease.

A handwritten signature in black ink that reads "Gail Andersen".

Gail Andersen
AFTD Board Chair

Keynote Address Sponsor

The 2018 AFTD Education Conference Keynote address is sponsored by Christopher Yurkanan in memory of his sweetheart and wife, **Chris Edmondson-Yurkanan**, who died May 23, 2017. AFTD is grateful for Christopher's generosity and drive to advocate for all who face this disease, and achieve far wider national awareness.

Chris had a generous soul, a brilliant mind, a unique style and fashion sense, a full-faced smile and an infectious laugh that is missed by many.

Over ten years ago, Chris began to show symptoms of disease and was diagnosed with Primary Progressive Aphasia. She never let the disease define her – rather, she embraced it. She and Christopher were featured together in AFTD's film *It Is What It Is* to raise awareness and increase FTD advocacy. As the disease took her ability to talk, she continued to communicate with family and friends by using smiles and touch and sweet sounds. She loved to dance with Christopher and hold his hand long after the words began to fail.

Friends and strangers alike were drawn to Chris. She had magnetic qualities that made all feel welcome and loved. Her smile brought people in – and she was truly an active and engaged listener. Her eclectic and creative outfits and kooky jewelry were her signature style.

Chris was born to Don and Blanche Edmondson on August 30, 1952, in Pasadena, California, where her father was a graduate student at Caltech. The family later moved to Austin, where she attended McCallum High School and the University of Texas. Following graduate school and a stint at Intel, she joined the faculty of the Computer Sciences Department at the



"Chris was and is an agent of change. Change is coming! She had the audacity to embrace her disease even as her life and language were dissolving around us. Remember her smile. It is her signature and symbol of hope. Mark my words: We will conquer this disease sooner, not later. ONWARD!"

– Christopher Yurkanan



University of Texas in 1984. She was a much-admired and popular faculty member there until 2007, when Primary Progressive Aphasia forced her to retire at age 55, while in the prime of her career. She delighted in mentoring students and guiding them to exciting careers. Herself a trailblazer among women in computer sciences, Chris championed young women in the field throughout her career.

Chris was active in SIGCOMM, the Association for Computing Machinery's Special Interest Group on Data Communications, which specializes

in communication and computer networks. She developed expertise in the history of internet design, publishing several authoritative articles on the technical history of the internet. She was honored to be the Executive Producer of the prestigious Turing Lecture for Vint Cerf and Robert Kahn, the "fathers of the Internet" and recipients of the 2004 Turing Award ("The Nobel Prize of Computing"). Chris was an unusual sight at the SIGCOMM gatherings – a brilliant young woman with a big smile, usually wearing purple. She garnered the deepest respect of the pioneers in the field of network computing.





About Today's Program

Welcome to the 2018 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 today, you'll notice AFTD staff, Board members and volunteers here to offer you the best available resources targeting FTD, and new ways to get involved. Stop by and introduce yourself! Offer your questions and your feedback – your input is so important to making sure that AFTD provides the leadership and support that this community deserves.

Breakout Sessions

The morning sessions (11:00 a.m.), focused on Clinical Issues, will be led by experts from Northwestern University's Feinberg School of Medicine, Rush University Medical Center, the Brain Support Network, and AFTD.

The early afternoon sessions (2:15 p.m.), focused on Care Strategies, will feature experts from Northwestern University's Feinberg School of Medicine, MemoryCare Corporation, Banner Alzheimer's Institute, Rainbow Hospice and Palliative Care, and the University of Illinois at Chicago.

The mid-afternoon sessions (3:30 p.m.), focused on Support and Networking, are led by AFTD volunteers, Board members and family care partners, who bring a depth of personal and professional experience. These sessions will help you build a network of people who understand the FTD journey, and are tailored toward people diagnosed with FTD, young adult care partners, healthcare professionals and AFTD volunteers.

For People Living with FTD

Thank you for joining us today. This year, we are offering four breakout sessions specifically for persons diagnosed. Join AFTD staff at 11:00 a.m. for a session on designing research with input from people living with FTD. At 2:00 p.m., there are two sessions for persons with FTD, as well as a networking session at 3:30 p.m. For more information, see the list of Breakout Sessions.

We have set up a quiet gathering place for persons diagnosed with FTD, should you need it. You can find it in the room Salon 10.

Networking Lunches

During lunch, you will be able to meet and network with people living in the same region as you. By wearing a color-coded ribbon, you can easily see others who live nearby; there will also be tables representing each U.S. regions should you choose to find others that way.

Health Professionals

Thank you for serving this community. Certificates of Attendance for healthcare professionals will be available after Rev. Lind's Keynote Address. Please stop by the main registration table on your way to the evening social reception, or before you leave the conference, to pick up a certificate.





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**AFTD extends sincere
gratitude to Event Host and
2018 Education Conference
Silver Sponsor:**



Cognitive Neurology and
Alzheimer's Disease Center

**Thank you, Cognitive Neurology and Alzheimer's Disease
Center, Northwestern University Feinberg School
of Medicine for your essential partnership in
this event, and your leadership
in serving this community.**



The Day's Program

8:00 a.m.

Registration

9:00 a.m.

Welcome

Gail Andersen, AFTD Board Chair

Greeting from Amy Bouschart-Callea and
Frank Callea, FTD advocates and AFTD volunteers

9:20 a.m.

The State of the Art in FTD: A Clinical Overview of the FTD Disorders

Marsel Mesulam, MD

9:45 a.m.

PPA Research: What It Is Teaching Us About Brain Function and Progression

Sandra Weintraub, PhD

10:00 a.m.

Advances in Care and Support

Darby Morhardt, PhD

10:15 a.m.

Ask the Experts – Q&A

Marsel Mesulam, MD, Sandra Weintraub, PhD,
Darby Morhardt, PhD

Facilitator: Nadine Tatton, PhD, AFTD
Scientific Director

10:45 a.m.

Break

11:00 a.m.

Breakout Sessions: Clinical Issues

12:00 p.m.

Lunch

1:15 p.m.

Speaking Up for FTD (Film and Panel Discussion)

Sharon Denny, AFTD Program Director
Panelists: Joseph A. Becker, Nancy Cummings,
Sharon Hall, Robin Riddle, Teresa Webb

2:15 p.m.

Breakout Sessions: Care Strategies

3:15 p.m.

Break

3:30 p.m.

Breakout Sessions: Support and Networking

4:45 p.m.

AFTD 2017 Highlights

Susan L-J Dickinson, MS, CGC, AFTD Chief
Executive Officer

5:10 p.m.

Keynote Address

Very Rev. Tracey Lind

5:30 p.m.

Social Reception

Attendees, Speakers, AFTD Board and Staff
are invited to attend



The Day's Breakout Sessions

Today's AFTD Education Conference features three rounds of breakout sessions. These sessions address clinical issues, outline care strategies, and offer the opportunity to gain support by networking.

11:00 a.m. Breakout Sessions: Clinical Issues

Diagnostic Evaluation Tools:

What They Can Tell You and What They Can't

Sandra Weintraub, PhD, Feinberg School of Medicine, Northwestern University

Learn about the components of a comprehensive diagnostic evaluation – including neuropsychological testing and brain imaging – and how they can inform care.

Treatment Options and Working with Your Doctor

Borna Bonakdarpour, MD, Feinberg School of Medicine, Northwestern University

Learn information on pharmacological and nonpharmacological treatments and how to work with your doctor for optimal care.

Participating in Research:

Opportunities and Advantages

Emily Rogalski, PhD, Feinberg School of Medicine, Northwestern University

Dianna Wheaton, PhD, FTD Disorders Registry

Advancing the science of FTD and developing therapies depends on study participants. Learn about types of studies and opportunities to participate.

Balance, Falls and Tremors: Motor & Cognitive Symptoms in Less-Common Forms of FTD

Zoe Arvanitakis, MD, Rush University Medical Center
Robin Riddle, MBA, Brain Support Network

There are distinct challenges when FTD presents with motor or movement symptoms. Learn about these symptoms and strategies for care.

Designing Research with Input from People Living with FTD

Matt Sharp, MSS, AFTD
Debra Niehoff, PhD, AFTD

Share experiences about participating in research and discuss how to make medical research more accessible and appealing for people with FTD.



2:15 p.m. Breakout Sessions: Care Strategies

Building Your Care Team

For Newly Diagnosed and Their Care Partners
Darby Morhardt, PhD, Feinberg School of Medicine,
Northwestern University

An FTD diagnosis is overwhelming, but it is not the end. This session will explore strategies, resources and services to help people move forward together.

Living with PPA: Practical Communication Strategies

Emily Rogalski, PhD, Feinberg School of Medicine,
Northwestern University
Becky Khayum, MS, MemoryCare Corporation

Learn about skills, tools and strategies to help maintain communication with a loved one with PPA.

Anosognosia and Positive Strategies for Care

Geri Hall, PhD, Banner Alzheimer's Institute

Lacking awareness of one's limitations or illness (anosognosia) is a hallmark symptom in behavioral FTD that can complicate diagnosis and care. Learn strategies to manage behavior and care partner stress.

Palliative Care and Easing Difficult Conversations

Nancy Flowers, LCSW, Rainbow Hospice
and Palliative Care

Initiating conversations about end-of-life care preferences can be difficult, both soon after diagnosis or when a person's health is in decline. Discuss ways to ensure care decisions remain centered on the person's wishes.

An FTD Ensemble: An Improvisational Theater Experience

For People with FTD and Care Partners
Lauren Dowden, MSW, Feinberg School of Medicine,
Northwestern University
Christine Dunford, PhD, School of Theatre & Music,
University of Illinois at Chicago

Experience improvisational performance exercises and structured activities. Learn how instincts, creativity and spontaneity can improve quality of life.

3:30 p.m. Breakout Sessions: Support and Networking

Mindfulness-Based Stress Reduction

Corey Esannason, AFTD Regional Coordinator Volunteer

FTD can be stressful and hard. Learn mindfulness-based exercises and relaxation techniques to help keep you grounded in the present.

Networking for Young Adult Care Partners Kacy Kunesh and Brian Rose, AFTD Board Members

Whether at home or at a distance, having a parent with FTD disrupts your early career and family in ways few understand. Come for informal conversation with two AFTD Board members around common experiences and needs.

Networking for Volunteers: Share Experiences and Learn about Volunteering with AFTD

Kathy Urban, Rachel Castellanos, Sarah Sozansky Beil,
AFTD Regional Coordinator Volunteers

Raise your voice for FTD! Meet AFTD's inspiring volunteers, chat about their experiences and learn ways to get involved in your area.

Networking for Healthcare Professionals

Darby Morhardt, PhD, Feinberg School of Medicine,
Northwestern University
Sandra Grow, RN

Working with people with FTD and their families brings distinct professional challenges. Connect with others around common experiences and needs.

Networking for People Diagnosed with FTD: Conversations about Living with the Disease

For People with FTD

Amy Shives, M.Ed, person diagnosed with FTD

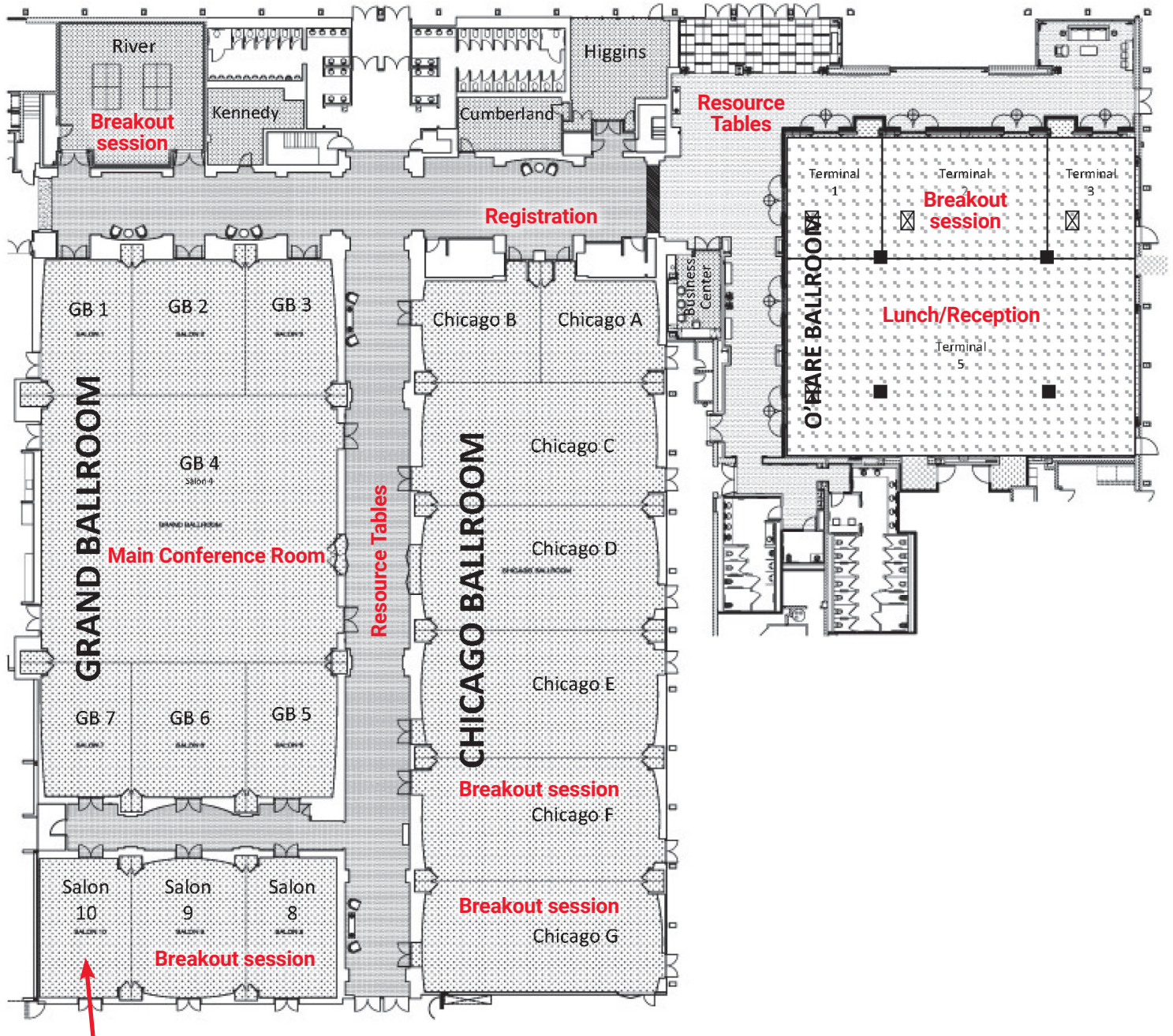
Your story is key to raising awareness of FTD. Come share your story, and hear from others who have spoken up to advocate and educate the public about FTD.

Networking for Family Care Partners

Paul Lester, Bonnie Shepherd, Beth Walter,
AFTD Board Members

Make connections with others who understand what it's like to provide care for a loved one with FTD in this networking session.

Main Floor Meeting Space



Quiet Gathering Place for
Persons Diagnosed



Speaker Bios

Gail Andersen, AFTD Board Chair, 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 31, 24 and triplets (age 20). Gail dealt with many challenges of bvFTD and found AFTD's support critical in her family's FTD journey. She is also very interested in FTD research.

Zoe Arvanitakis, MD, MS, is the Medical Director of the Rush Memory Clinic at the Rush Alzheimer's Disease Center, and a Professor of Neurological Sciences at Rush University Medical Center in Chicago, Illinois. She is a board-certified neurologist with expertise in cognition. Dr. Arvanitakis is funded by the National Institutes of Health (NIH) and conducts research on brain aging.

Joseph Aloysius Becker is the Founder and CEO of thinkfilm. He is an award-winning writer/director/producer with over 30 years in the business. Among his production credits are the Emmy Award winning series *The West Wing*, HBO's *K Street*, and *24*. Each year, Mr. Becker directs dozens of commercial spots and public service announcements for clients such as PBS, Discovery, the Centers for Disease Control and Prevention, the Global Fund for AIDS and HIV, the American Cancer Society, the National Institutes of Health and more. Becker also writes and directs documentary films for TV and has extensive experience directing corporate films related to health care, telecommunications and issue advocacy. thinkfilm recognizes its civic responsibility and has produced pro bono films for non-profit groups. In 2006, Becker

produced an award-winning film for the American Hospital Association on the response to Hurricane Katrina. He also produced *It Is What It Is* for the Association for Frontotemporal Degeneration about care partners and their loved ones with dementia. Becker's work has been recognized with the industry's highest awards, including national Emmys, Academy Award nominations and Golden Reels at the New York, Montreal, and Sydney Film Festivals.

Sarah Beil lost her father to FTD in February 2016, eight years after his diagnosis. Sarah lives in Fairfax, Virginia, where she is currently enrolled in the MSW program at George Mason University, from which she will graduate in the spring of 2019. Her professional background includes working for a law firm specializing in SSA Disability and as an analyst for the Department of Aging & Rehabilitative Services, making Social Security Disability decisions for the federal government and Medicaid decisions for the state of Virginia. Sarah has been an AFTD volunteer for the past six years, and became one of the Middle Atlantic Regional Coordinator Volunteers in 2016. She oversees Washington DC, Virginia, West Virginia, Maryland, and Delaware. Sarah's AFTD volunteer activities over the years have included participating in a Run/Walk, Food for Thought fundraising, writing for the AFTD Newsletter and overseeing our Young Adult Facebook Support Group.

Borna Bonakdarpour, MD received his medical degree from Tehran University of Medical Sciences. His doctoral research on aphasia therapy received international attention and brought him to Northwestern University for his research fellowship in aphasia rehabilitation and neuroimaging of language. Dr. Bonakdarpour completed his residency in neurology at the University of Arizona and the Florane and Jerome Rosenstone Cognitive Neurology Fellowship at the Cognitive Neurology and Alzheimer's Disease Center (CNADC). He is board-certified in neurology and behavioral neurology and his research is funded

by a five-year career development award from the NIH to study pathophysiology of primary progressive aphasia using functional and structural neuroimaging. Dr. Bonakdarpour is an active member of the CNADC clinical trials team and served as primary investigator of the CONNECT trial. He also serves as the director of cognitive neurology rotations for both neurology residents and students. In addition to academic and scientific lectures, Dr. Bonakdarpour has accepted numerous invitations to address patients, family members, physician assistants, psychology students, fellows, primary care physicians and medical specialists who care for patients with cognitive impairments and dementias. Dr. Bonakdarpour has authored more than 40 publications, including original scientific papers, reviews, and book chapters.

Rachel Castellanos holds a B.H.S. from the University of Miami and a J.D. from Saint Louis University School of Law. Before leaving her career to devote more time to family, Rachel worked in the clinical research department of a health system, and held various roles in the areas of clinical research contracts and budgets, Medicare coverage and IRB informed consents. Rachel is a care partner to her mother who was diagnosed with PPA/FTD in 2013. Rachel has been an AFTD volunteer since 2016, when she organized an AFTD Meet & Greet for those affected by FTD in the New Orleans area. In 2017 Rachel became a Regional Coordinator Volunteer for AFTD's South Central Region (AR, KS, LA, & MO).

Nancy A. Cummings possesses a BA in social work from SUNY Albany and an MBA from Sage Graduate School. She is currently the Director of the Anne B. and Leon J. Goldberg Alzheimer's Resource Center at the Alzheimer's Center at Albany Medical Center in Albany, NY. Prior to joining Albany Medical Center, Nancy spent 25 years as a Vice President, overseeing the start-up and development of assisted living communities for persons with dementia for a large not-for-profit health care system in New York. Nancy was also responsible for developing strategic initiatives across the network that would best serve persons diagnosed with Alzheimer's disease and related dementias as well as their care partners. In addition, Nancy is active in the local community with organizations that show

a commitment to improving services and supports for persons with dementia and their care partners. She is the recipient of the 2002 Professional of the Year Award from LeadingAge New York and has been a presenter on dementia care at both local and national conferences. Nancy served as an AFTD Regional Coordinator Volunteer for the Middle Atlantic states for three years.

Sharon S. Denny, MA, AFTD Program Director, leads AFTD's support and education efforts for people with FTD, their families and healthcare professionals. Her priorities include ensuring the responsiveness of core services and expanding the availability of FTD-specific resources and supports. She has introduced initiatives that address the needs of children and teens, and individuals diagnosed with FTD. For the past seven years she has led a committee of clinicians and family caregivers who produce Partners in FTD Care, an FTD education initiative for community healthcare providers. Ms. Denny has a Master's Degree in Clinical Psychology and more than 27 years of experience in program development for disability organizations. She has been with AFTD since September 2008.

Susan 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.

Lauren Dowden, MSW, LCSW is a clinical social worker at the Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine, where she works closely with individuals and families who are living with a dementia diagnosis or changes in cognition. She holds a Master's in Social Work from Loyola University Chicago specializing in mental health with a gerontology sub-specialization, and a BA in Theater Arts from Pennsylvania State University. She is also an alumna of Second City (Las Vegas) and is an adjunct faculty member at the Second City Training Center. She teaches medical improvisation to medical students at Northwestern University Feinberg School of Medicine and was an instructor at the 2014, 2015 & 2017 Woltman Inter-Professional Communications Scholars Program for medical interdisciplinary teams at Indiana University. She is also a co-facilitator for the CNADC and Lookingglass Theatre's Memory Ensemble – an improvisational workshop for individuals with dementia. As an intern at the CNADC, she co-created the first Northwestern CNADC storytelling workshop, "Don't Look Away: Using Storytelling to Give Voice, Find Connections, and Change Perceptions," which she continues to facilitate, develop and research. The storytellers from "Don't Look Away" have shared their story with over 1,000 people, including health and social service professionals, researchers, students and community members and have been featured on WTTW's *Chicago Tonight* and in *The New York Times*.

Christine Mary Dunford, PhD is Associate Professor and Director of the School of Theatre & Music at University of Illinois at Chicago. She has been an ensemble member with Lookingglass Theatre Company since 1989 where she has acted in, written/adapted and/or directed nearly three dozen Lookingglass productions, including her own adaptation of Lisa Genova's best-selling novel *Still Alice*. Christine's production received a Joseph Jefferson nomination for Outstanding New Adaptation, and was selected by the *Chicago Sun-Times* as one of the top ten plays in Chicago in 2013. Christine is co-founder (with Darby Morhardt) of The Memory Ensemble – a partnership between Lookingglass and Northwestern's Cognitive Neurology and Alzheimer's Disease Center (CNADC) – which uses improvisational performance to improve quality of life for people in the early stages of Alzheimer's disease and other dementias.

Corey Esannason, RYT, is a yoga educator and one of AFTD's Middle Atlantic Regional Coordinator Volunteers, overseeing volunteer initiatives in New York, New Jersey and Pennsylvania. Corey's mother was diagnosed with FTD in 2011. Her combined passion for movement and learning inspire her work, which provides yoga programming to adults and children throughout Westchester County in New York. With over 15 years of experience and training, Corey empowers students of all ages to continually explore, discover and grow. She is grateful for the love and support of her family and teachers and for the inspiration her students provide on a daily basis. Corey is eager to share her personal and professional knowledge with the AFTD community.

Nancy Flowers, MSW, LCSW is the Community Education Program Manager and Dementia Project Manager for Rainbow Hospice and Palliative Care. She has been a social worker, educator and manager for the past 35 years, working primarily with older adults and persons with disabilities. Nancy also served for 12 years as the Regional Ombudsman and Community Health Division Manager for the City of Evanston, where she provided consultation and education to community and long-term care facility residents, families, facility staff and social service providers on long-term care and community resources. Nancy received a Master's Degree in social work from Indiana University and is a licensed clinical social worker. She is a frequent guest lecturer at area schools of social work and a published author. She serves as board member to the Chicago End of Life Care Coalition and Three Crowns Park, and is on the National Hospice and Palliative Care Organization's (NHPCO) Social Work Steering Committee.

Becky Khayum, MS, CCC-SLP is co-founder and president of MemoryCare Corporation, a company specializing in non-pharmacological cognitive-communication interventions for people with neurodegenerative conditions. She holds an adjunct faculty position at Northwestern University, where she collaborates on research initiatives in the area of person-centered interventions for people with primary progressive aphasia. Her clinical expertise focuses on the use of functional treatment approaches and technology integration to increase life participation for individuals with aphasia and cognitive deficits.

Kacy Kunesh of Austin, TX, is an AFTD Board member and business consultant with expertise in communications, strategic growth, sales and marketing. Her international career, combined with being an avid adventurer, has taken her to 32 countries. Kacy's caregiver journey spans 12 years, starting with her mother enduring four and a half years of misdiagnoses before being correctly diagnosed with bvFTD. Kacy helped to launch AFTD's facility outreach program, the AFTD 5K grassroots event in Austin, and the AFTD Young Adult Facebook Support Group, and she speaks publicly to advocate for greater awareness of FTD and the needs of FTD caregivers. She joined the AFTD Board in 2017.

Geri Hall, PhD, ARNP, GCNS, FAAN is an advance practice nurse who has specialized in the care and management of people with dementia for the past 40 years. She developed the first theoretical framework for planning and evaluating care of people with dementia, published and spoken extensively, and served on policymaking committees. Over the last 20 years Dr. Hall has become increasingly active in the care of people with frontotemporal degeneration (FTD). She currently conducts research, counsels families, and runs two monthly support groups. She also participates on two FTD forums on Facebook: The Association for Frontotemporal Degeneration and Frontotemporal Degeneration Info and Support.

Sharon Hall is a care partner to her 95-year-old mother who has vascular dementia and lives with her and her husband, Rod, who has frontotemporal degeneration (FTD). Sharon is an active advocate for FTD, as well as an AFTD Support Group Facilitator and educator. She holds an FTD chat on caregiving.com every Monday and Saturday at 7 p.m. ET, and hosts a monthly podcast on the 4th Thursday of each month at 2 p.m. ET called "Talking FTD With Geri," with Dr. Geri Hall from Banner Alzheimer's on blogtalkradio.com/caregiving. Sharon has participated in Medicare webinars, spoken as a care partner at the NIH Research Summit on Dementia Care and Services, is active in her state Alzheimer's and Related Dementia Plan, and recently launched iCARE (Innovative Caregiving Advocates with Real Experience) together with MaryAnne Sterling, Denise Brown, Julie

Fleming and Karen Garner. This group of advocates will leverage the extensive knowledge and experience family caregivers have acquired to transform health research, health policy and healthcare delivery.

Paul Lester is the current Treasurer of the AFTD Board of Directors. He has been involved with AFTD for many years, participating in the AFTD Task Force on Families with Children and in the parents' phone support group. His wife, Arnette, passed away in 2013 at the age of 61. Mr. Lester is particularly interested in AFTD fund development.

The Very Rev. Tracey Lind is a renowned preacher and the former Dean of Trinity Episcopal Cathedral in Cleveland, Ohio. She was diagnosed with early-stage FTD in 2016. As our conference's keynote speaker, her bio is provided on page 55.

Marsel Mesulam, MD is Ruth Dunbar Davee Professor of Neuroscience and Director of the Cognitive Neurology and Alzheimer's Disease Center (CNADC) at Northwestern University. He obtained B.A. and M.D. degrees at Harvard University. He is past president of the Organization for Human Brain Mapping and past vice president of the American Neurological Association. His research has addressed the neural connectivity of the monkey brain, organization of human cholinergic pathways, representation of cognitive functions by large-scale networks, and neurobiology of dementias. He has received the Potamkin Prize for research on Alzheimer's disease from the American Academy of Neurology, the Javits Award from the National Institutes of Health, the McKnight Foundation Director's Award, and the Bengt Winblad Life Achievement Award from the Alzheimer's Association. He held the Robert Wartenberg Lectureship and the H. Houston Merritt Lectureship of the American Academy of Neurology. His textbook, *Principles of Behavioral and Cognitive Neurology*, has been part of training programs in Neurology, Psychiatry, Neuropsychology and Cognitive Neuroscience. His current research focuses on the functional imaging of neurocognitive networks, the factors that promote memory preservation in advanced age, and the treatment of dementias.

Darby Morhardt, PhD, LCSW is Associate Professor in the Cognitive Neurology and Alzheimer's Disease Center (CNADC) and Department of Preventive Medicine, Northwestern University Feinberg School of Medicine. She is director of the CNADC's Outreach and Recruitment Core of the Alzheimer's Disease Center, the Miller Alzheimer's Family Support Program, as well as clinical social work services for the Northwestern Medicine Neurobehavior and Memory Clinic. The focus of Dr. Morhardt's work has been on the impact of cognitive impairment on the individual, family and their social networks. Areas of clinical research include the experience of families living with Alzheimer's and non-Alzheimer's dementia such as frontotemporal dementia and primary progressive aphasia; the process of tailoring care to specific needs and dementia symptoms; and the development and evaluation of quality-of-life enrichment programs, support groups and other therapeutic interventions. These interventions include the award-winning Buddy Program, a unique experience that pairs persons with dementia as mentors to first-year medical students. It has been replicated in 12 universities nationally and internationally. Dr. Morhardt has participated on national, state and local advisory boards charged with developing dementia-specific clinical curricula. In her role as Outreach and Recruitment Core Leader, she is responsible for organizing the CNADC's community education and outreach programs throughout Chicago and has worked to build community-academic research partnerships with the African-American community and many limited English-proficiency communities to identify education and service needs and expand and promote research opportunities for these underrepresented groups.

Debra Niehoff, PhD, 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*.

Robin Riddle is the founder and CEO of Brain Support Network (BSN), a 501(c)(3) non-profit providing services to families dealing with four neurodegenerative disorders: Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), Dementia with Lewy Bodies (DLB), and Corticobasal Syndrome/Degeneration (CBS/CBD). BSN provides three primary services to these families: Brain donation arrangements (nationwide); caregiver support group meetings (Bay Area); and information dissemination (via web and conferences). Robin also serves as the Coordinator of the American Parkinson Disease Association (APDA) Information and Referral Center at Stanford University School of Medicine.

Dr. Emily Rogalski is a neuroscientist and Associate Professor at Northwestern University's Feinberg School of Medicine. She currently serves as Associate Director of Northwestern's NIA-funded Alzheimer Disease Center and Director of Neuroimaging. Her research falls under the broad umbrella of aging and dementia and uses a multimodal approach to investigate two aging perspectives: primary progressive aphasia (PPA) in which neurodegenerative disease invades the language network, and SuperAging in which individuals are seemingly resistant to the deleterious changes in memory associated with "normal" or more typical cognitive aging. Her investigations assist in defining the clinical and anatomical features of different dementia syndromes over the course of disease, as well as identifying genetic and other risk factors. She has also developed educational programs, support groups and Communication Bridge, a telemedicine person-centered intervention to maximize quality of life for individuals with dementia.

Brian Rose, of New York, NY, is an AFTD Board member and an Institutional Relationship Manager at Credit Suisse. His expertise is in financial statement analysis, budgeting and capital expenditure analysis. Brian's mother is afflicted with FTD and he has become an avid supporter of AFTD by organizing successful events for the annual Food for Thought campaigns. He would like to seek out best practices from his philanthropic contacts to raise awareness of FTD and gain usable knowledge for fundraising and governance. Brian joined the AFTD Board in 2017.

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 eight 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.

Bonnie Shepherd is the current Vice Chair of the AFTD Board of Directors. She retired from Hewlett Packard in 2002 after a 30-year-plus career in the computer industry. Her husband, Ned, was diagnosed with frontotemporal degeneration in 2007 and passed away in 2011. She was appointed to the Utah State Task force for Alzheimer's disease and was successful in adding related dementias verbiage to the final plan that was approved by the state legislature. Ms. Shepherd facilitates an FTD Caregiver Support group and works to educate the community on FTD and the many faces of brain degeneration.

Amy Shives, MEd, earned her masters 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 University of California at San Francisco 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 also an active alumni for 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 34 years and have two adult daughters. Their son Chester, a Cavalier King Charles Spaniel, remains in the home.

Nadine Tatton, PhD, joined AFTD as Scientific Director in June 2013. She has more than 20 years' experience as a neuroscientist in basic science and translational research, combined with technology transfer and business development expertise. At AFTD, Dr. Tatton has overseen the expansion of our competitive research grant funding to six programs including two multi-million dollar initiatives in FTD biomarkers and clinical trials.

Kathy Urban, a resident of Denver, CO, began volunteering with AFTD in 2014 after her mother passed away from FTD in 2013 at the age of 63. Since 2016 Kathy has served the organization as a Regional Coordinator Volunteer for the Southwest, which includes Arizona, California, Colorado, Hawaii, Nevada, New Mexico and Utah. Kathy works full-time at the University of Colorado School of Medicine as their Resident Physician Coordinator for Pediatrics.

Beth Walter is a member of the AFTD Board of Directors. The co-founding partner of a commercial real estate development company of 35 years and civic leader, Ms. Walter lost her husband, Mike, and four of his family members to FTD/ALS. To honor his memory, she created the Mike Walter Fund for Research to support AFTD's research initiatives. An active supporter of GRE events, Ms. Walter also founded The Walter Charitable Fund and has facilitated the "Quest for the Cure" golf tournament fundraisers since 2007, raising resources to advance research efforts and share knowledge about FTD. Ms. Walter served as AFTD's Board Chair from 2010-2013, succeeding its founder.

Teresa Webb worked as an RN Clinical Manager for a managed care facility prior to a 2010 diagnosis of logopenic PPA (lvPPA). Today, she is an active member of the Association for Frontotemporal Degeneration Think Tank, and was a Volunteer Liaison for the 2017 AFTD Food For Thought Campaign. Teresa stays active through her participation in To Whom I May Concern, a performance group where the spotlight is on the person with dementia, and the live audience listens to stories that express the feeling side of living with memory loss and confusion. She also had a starring role in the first film production of *This Is My Voice*. Ms. Webb was a presenter at the 2017 National Research Summit on Care, Services and Support for Persons with Dementia and Their Caregivers. She also co-chaired the stakeholder group People Living with Dementia, serving on the Steering and Logistic Planning Committee. Ms. Webb is founder and chair of the nonprofit Frontotemporal Dementia Advocacy Resource Network (FTD ARN). She lives in Phoenix, Arizona with her wife, their five dogs and one parrot.

Sandra Weintraub, PhD, ABCN/ABPP is Professor of Psychiatry and Behavioral Sciences, Neurology and Psychology at Northwestern University Feinberg School of Medicine and has been the Director of the Clinical Core of the Cognitive Neurology and Alzheimer's Disease Center (CNADC), funded since 1996 by the National Institute on Aging (NIA). She was one of the two Scientific Honorees recognized at the Rita Hayworth Gala of the Alzheimer's Association in 1997. She served on the Alzheimer's Disease Clinical Task Force, a special advisory committee to the NIA, to create a method for standardizing data collection at all 30 centers funded by the NIA across the U.S. She was a member of three special work groups to redefine the 2011 criteria for the clinical diagnosis of dementia of the Alzheimer type, behavioral variant

frontotemporal dementia, and primary progressive aphasia. Dr. Weintraub received her bachelor's degree from McGill University and PhD from Boston University and was on the faculty at Harvard Medical School before coming to Northwestern. She is board certified in Clinical Neuropsychology by the American Board of Professional Psychology. She directs the outpatient clinical neuropsychology service at the Neurobehavior and Memory Clinic of Northwestern Medicine, a multidisciplinary clinic dedicated to state-of-the-art diagnostic, treatment and research resources for patients with dementia and their caregivers. Dr. Weintraub has authored over 200 articles and book chapters on the neuropsychology of dementia and aging, aphasia and attention.

Dianna Wheaton, MS, PhD joined the field of FTD research in January 2016 as Director of the FTD Disorders Registry. She has more than 20 years of clinical science research experience within biochemistry and genetics, focusing on inherited neurodegenerative eye diseases. As former Director of the Southwest Eye Registry, her goal was to increase the number of diagnosed patients available for natural history studies of disease progression, conduct genetic studies to identify disease-causing genes, and identify potential patients for clinical trials. As a genetic counselor, she also provided counseling to patients and at-risk family members. She has authored numerous papers describing genes that cause retinal 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 brother's diagnosis of younger-onset dementia.

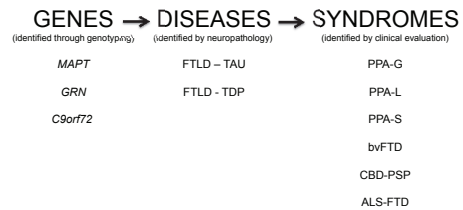
The State of the Art in FTD: A Clinical Overview of the FTD Disorders

Marsel Mesulam, MD

RAPID OVERVIEW OF CLINICAL, BASIC, AND GENETIC FACTORS IN FRONTOTEMPORAL DEGENERATION

Marsel Mesulam, MD
Cognitive Neurology and Alzheimer's Disease Center
Northwestern University Feinberg School of Medicine
Chicago, IL, USA

THE MAJOR PLAYERS

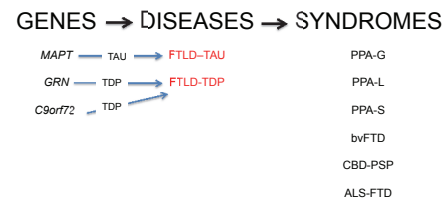


THE 23 HUMAN CHROMOSOMES

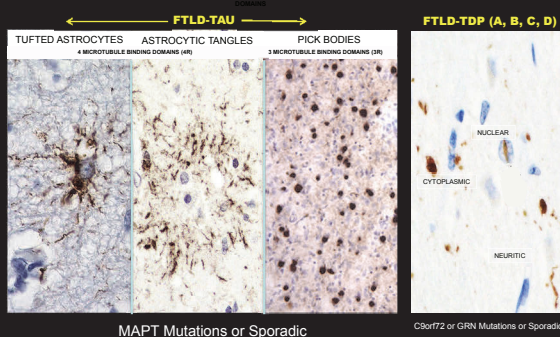
Chromosomes are made up of long strings of DNA nucleotides (bases).
There are thousands of gene pairs per chromosome, one from each parent.
There are thousands of bases per gene.
Insertion of a single incorrect base or abnormal readout of the DNA string can trigger abnormal protein accumulations.



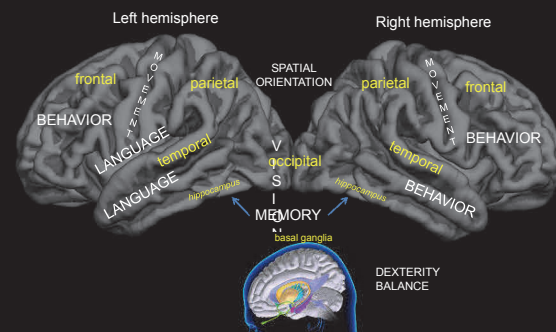
THE MAJOR PLAYERS



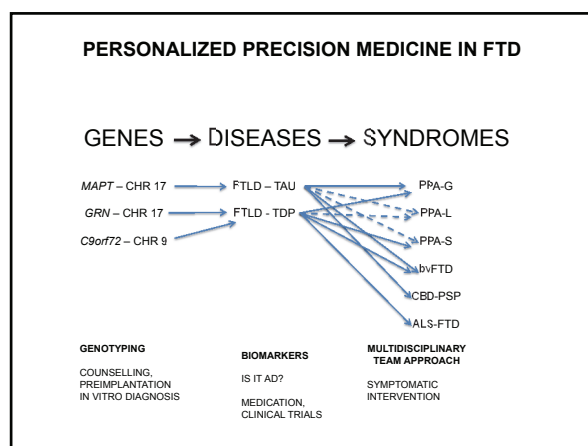
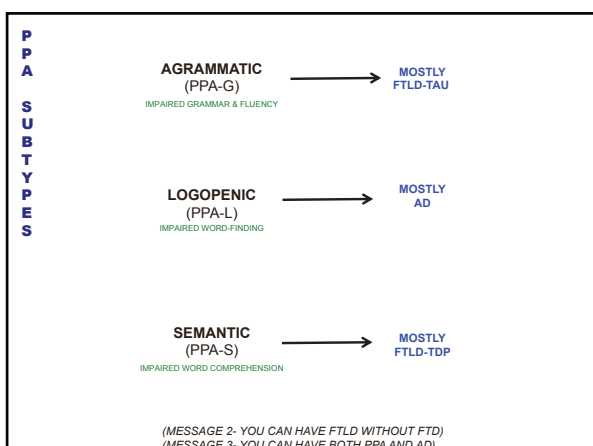
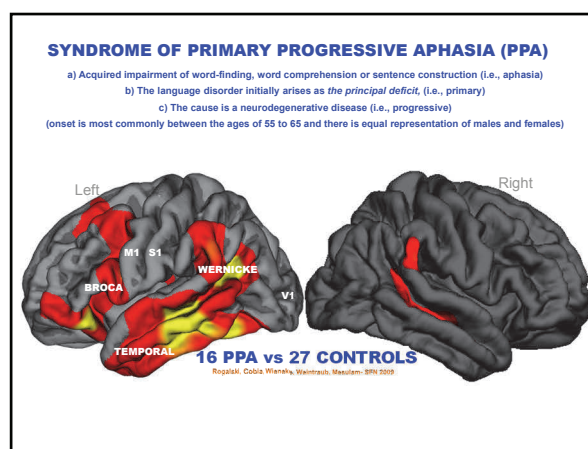
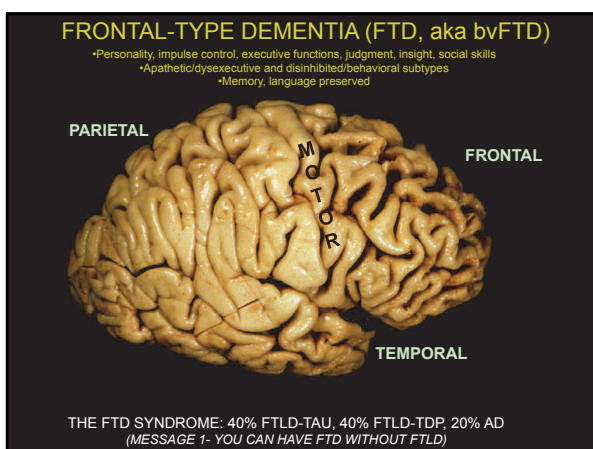
NEUROPATHOLOGIC APPEARANCE OF FTLT SUBTYPES



JOB DESCRIPTIONS IN THE HUMAN BRAIN



The State of the Art in FTD: A Clinical Overview of the FTD Disorders, cont'd.



NOTES:

PPA Research: What It Is Teaching Us About Brain Function and Progression

Sandra Weintraub, PhD

Research on Primary Progressive Aphasia: What It Is Teaching Us About Brain Function and Progression

Sandra Weintraub, PhD
Clinical Core Leader and Professor

Northwestern Cognitive Neurology and
Alzheimer's Disease Center (CNADC)

Chicago, Illinois

www.brain.northwestern.edu



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We study diseases to understand more about them in order to cure, treat or prevent them.

The study of brain diseases also teaches us how the brain functions normally, if there are risk factors for disease, and the relationships between specific symptoms and the diseases that cause them.



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Primary Progressive Aphasia: "A Language Dementia"

According to currently accepted criteria, the PPA diagnosis is made in a person with a dementia, in which language impairment (*aphasia*), caused by a neurodegenerative disease (*progressive*), is the earliest and most limiting symptom (*primary*).

* There are also memory, visuospatial and behavioral dementias.



Mesulam et al, Nature Reviews Neurology, 2014

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What is Language?

Brain processes that create words that express thoughts

Words: names of objects, colors, people, actions, adverbs, adjectives, connector words

Stringing words together expresses thoughts for the purpose of communication

Language: Speaking; understanding what others are saying; understanding words you read ; writing



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What is Aphasia?

Loss of the ability to use language (words) for communication in one or more forms:
spoken, written, sign language

Caused by damage to the brain, in areas that control language function

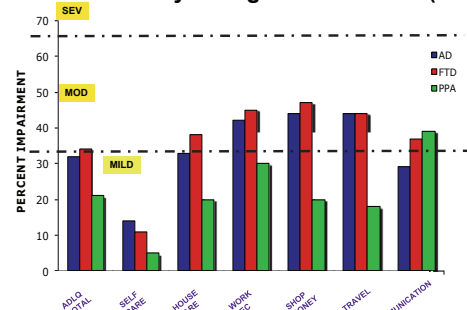
Interventions help compensate for reduced ability to communicate with words

INTERVENTIONS AIMED AT MEMORY LOSS DEMENTIA DO NOT WORK FOR APHASIA!



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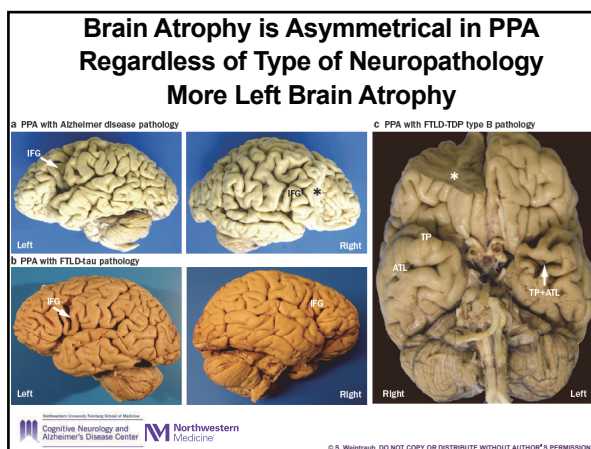
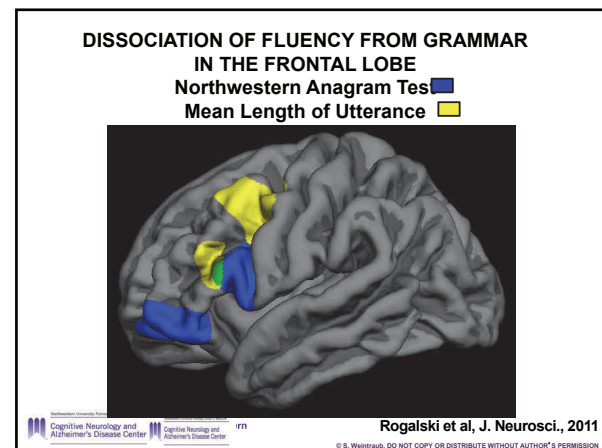
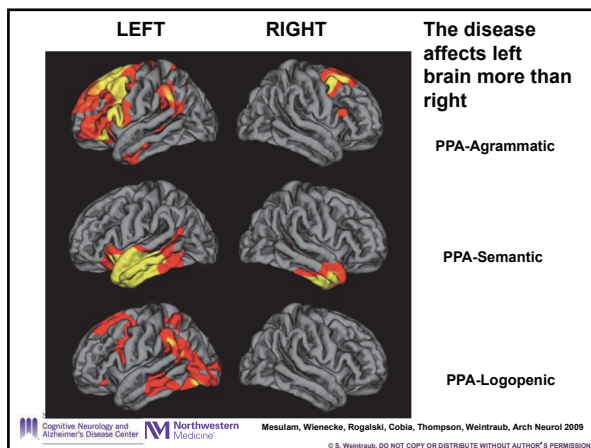
In early stages, PPA causes less functional impairment than other forms of dementia Activities of Daily Living Questionnaire (ADLQ)



Wicklund et al, 2007

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PPA Research: What It Is Teaching Us About Brain Function and Progression, cont'd.

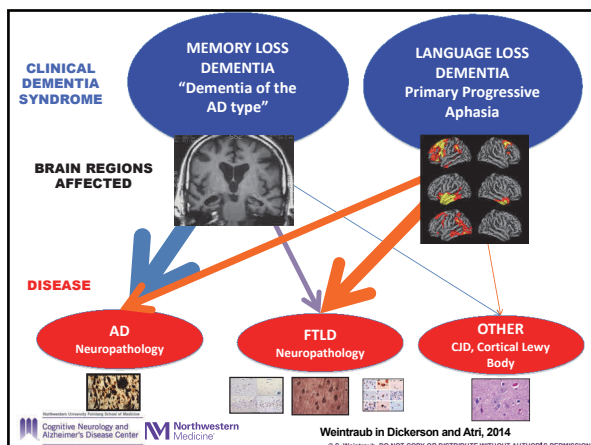


We do not have blood or cerebrospinal fluid tests for FTLD

Diagnosing PPA can help us predict what type of FTLD is in the brain or if it is more likely to be AD

Cognitive Neurology and Alzheimer's Disease Center Northwestern Medicine

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Relationship of Neuropathology to PPA Subtype

GOOD ↑ COMPREHENSION ↓ BAD	AGRAMMATIC n = 17 65% FTLD-TAU 18% FTLD-TDP 12% AD 6% DLBD & AD	LOGOPENIC n = 32 56% AD 25% FTLD-TDP 16% FTLD-TAU 3% FTLD-TDP & AD
	MIXED n = 6 67% AD 17% FTLD-TAU 17% FTLD-TDP	SEMANTIC n = 3 67% FTLD-TDP 33% AD
	BAD	GOOD

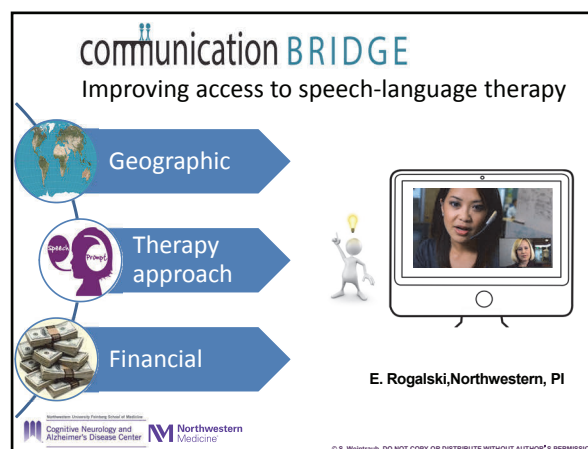
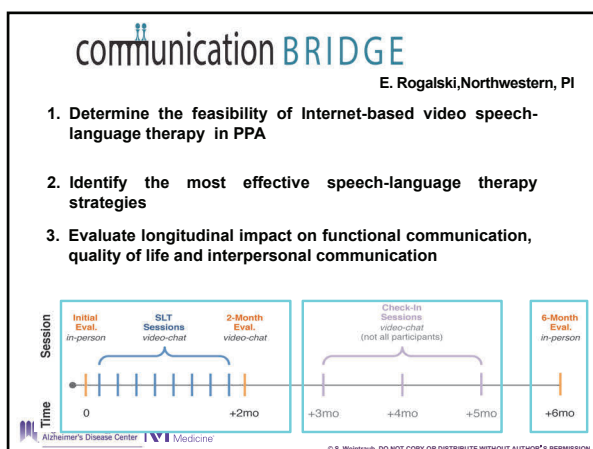
GRAMMATICALITY

Mesulam et al, Brain, 2014

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PPA Research: What It Is Teaching Us About Brain Function and Progression, cont'd.



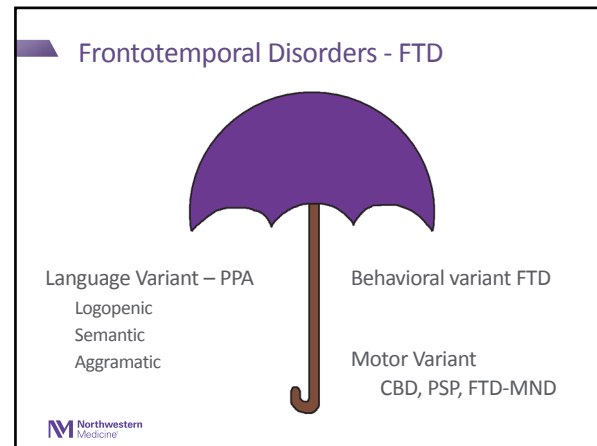
CONCLUSION

- We understand that selective brain regions are vulnerable to neurodegenerative disease.
- We can predict the type of disease causing the PPA dementia with some accuracy.
- We can tailor our interventions to support communication and change strategies as symptoms progress.
- We can educate patients and caregivers about the diagnosis and coping strategies

NOTES:

Advances in Care and Support

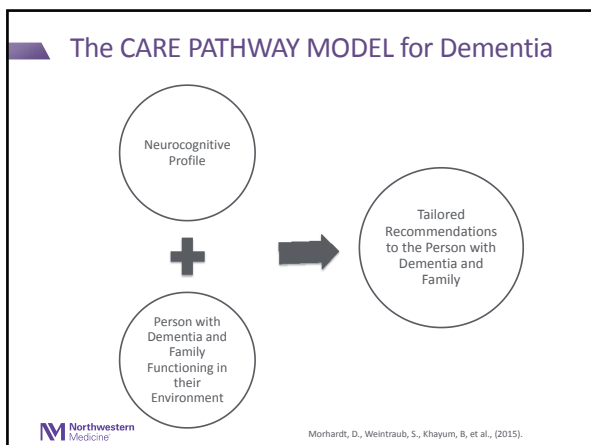
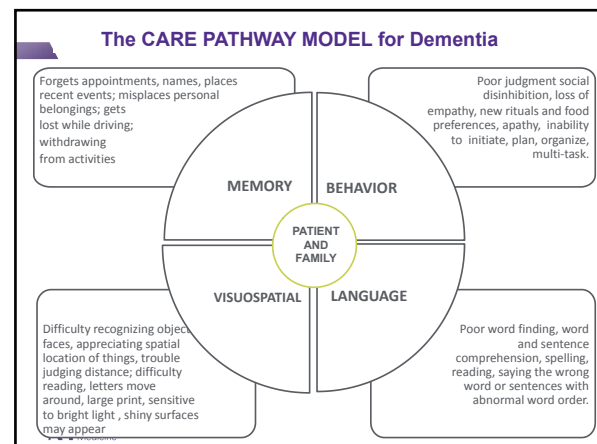
Darby Morhardt, PhD



**Support and Care for Persons with FTD and Families:
A Different Approach**

- The FTD Pathway
- How is caring for someone living with FTD different than other forms of dementia?
- Care and support for persons living with FTD and their families: What is possible?
- Using technology to support persons living with FTD and their families

Northwestern Medicine



Northwestern Medicine

FTD does not follow the same pathway as other forms of dementia

Advances in Care and Support, cont'd.

FTD: Different Pathway – Different Interventions

- FTD is not associated with memory problems
- Person & family centered approaches need to include assessment of:
 - Cognitive and functional abilities
 - Interests and preferences
 - Decision making capacity
 - Components of family functioning
 - Developmental phase
 - Illness time phase



How does FTD affect:

The person who has it?



Family Relationships



What Helps?



Different Caregiving Experience

- FTD symptoms/behaviors – loss of emotion, apathy - disruptive to relational connection and communication
- Higher levels of depression, stress and burden.
- Younger age of onset
- Difficulty obtaining diagnosis



Care and Support for Persons Living with FTD: What is Possible?

Non-medication approaches

- Family education and understanding of symptoms
- Care partner approach, attitude and expectations
- Care tailored to the person's preferences, abilities and strengths



Communication Strategies

- Adjust expectations regarding how the person expresses themselves. It's ok if not speaking grammatically. Do not over correct or interrupt.
- Verbal or visual cues for word finding or naming difficulties. Ask for gesture or demonstrations.
- In some instances try electronic communication alternatives.
- If someone has difficulty understanding you simplify your communication. Use shorter sentences, slow down, emphasize key words. Take your time.



Seek Early Speech Pathology Input

Advances in Care and Support, cont'd.

Behavior Strategies

- Apathy
 - Accept that you may need to initiate and carry conversation
 - Use positive motivation and feedback
 - Redirect / supervise to keep on task
 - Look for signs of self-neglect, safety risk
 - Capitalize on remaining strengths, abilities, preferences
- Disinhibition & Impulsivity
 - Use firm but kind limit setting to re-direct
 - Use humor
 - Use companion cards
 - Avoid rationalizing
 - Remain calm
 - Empathize with their frustration
 - Ask how you can help
 - Avoid known triggers



What do family care partners of persons living with FTD suggest?

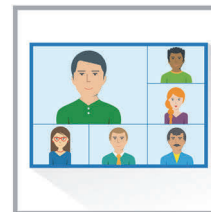
- ❖ Don't try to reason with your loved one if he or she is unable to do so.
- ❖ Choose your battles
- ❖ Modify your own expectations rather than expecting the person to be the way he or she was before...acceptance is slow but is the key to setting you free.
- ❖ If the person with FTD has impulse control difficulties, don't set them up to fail by presenting them with environmental cues that elicit problems.
- ❖ If the person is frustrated by communication difficulties, avoid placing them in situations in which communication is heavily relied upon, such as phone calls, group day programs, or large social gatherings.



Not every strategy will work for every person living with FTD and not every strategy will work every time.

Using Technology

Internet-based Videoconferencing, Support/Chat Forums/Groups



YAHOO! GROUPS



communication BRIDGE

Telemedicine randomized controlled trial for adults with mild PPA evaluating whether a person-centered treatment maximizes functional communication participation better than a dose-matched control treatment.

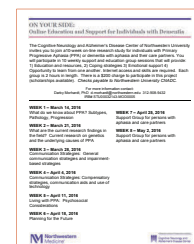
- Who?
- Individuals with a diagnosis of Primary Progressive Aphasia (PPA) and their Communication Partners
- Why?
- To better understand the effects of speech language therapy on communication abilities for individuals with PPA.
- Where?
- All components of the study take place remotely via video-conferencing.
- Key Study components:
- 5 Evaluations with a licensed speech language therapist
 - 15 Therapy Sessions with a licensed speech language therapist over the course of 1 year
 - Exercises through customized Web-Application

communicationbridge@northwestern.edu | 312-503-4012



On Your Side: Online Support and Education for Individuals with PPA and Their Families

- Feeling sense of belonging through shared experience
- Sharing compensatory strategies
- Connecting over changes/loss
- Expressing resilience/empowerment



Advances in Care and Support, cont'd.

Experiences of FTD Support Group Participants

- Sense of belonging in spite of differences in symptoms and backgrounds.
- Ability to empathize with each other's challenges with the limitations of the health care and social service systems.
- Taking the effort to try to create something positive.
- The relief to be able to share, give and receive support from others and have the ongoing professional support and information.
- A sense of hope.



NOTES:

Diagnostic Evaluation Tools: What They Can Tell You and What They Can't

Sandra Weintraub, PhD, Feinberg School of Medicine, Northwestern University

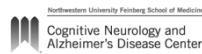
Breakout Session: Evaluation for FTLD

Sandra Weintraub, PhD
Clinical Core Leader and Professor

Northwestern Cognitive Neurology and
Alzheimer's Disease Center (CNADC)

Chicago, Illinois

www.brain.northwestern.edu



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Why is it so difficult to diagnose dementia due to frontotemporal lobar degeneration (FTLD)?

1. There are no tests (biomarkers) for FTLD in blood or other tissue
2. Many diseases can cause the same dementia- no one-to-one relationship between symptoms and disease
3. To date, the only **definitive** test for presence of a particular disease is post mortem brain autopsy to show the specific cellular abnormality



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DEFINITIONS

1. Frontotemporal Lobar Degeneration (FTLD)

A group of diseases in the brain that cause neurodegeneration (loss of brain cells):

Tauopathy (Pick's disease, corticobasal degeneration, progressive supranuclear palsy)

TDP-43 proteinopathy

FUS-opathy (rare)

2. Frontotemporal Dementia (Disorder)

The deterioration of personality and/or language and/or motor functions caused by FTLDs



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EVALUATIONS TO DEFINE THE DEMENTIA SYMPTOMS

Clinical Neuropsychology Evaluation:
What abilities are abnormal and by how much ?

Cognitive Neurology Evaluation:
What other motor and sensory symptoms are there? What do the medical tests mean?

Psychiatry Evaluation:
Are symptoms psychiatric in nature?
Can symptoms be controlled with medications?

PROCEDURES TO IDENTIFY THE DEMENTIA CAUSE

Blood Tests
Structural Neuroimaging (CT, MRI scans)
Functional Neuroimaging (FGD-PET scans)
Biomarker imaging (Amyloid PET, tau PET scans)
Electroencephalography (EEG)
Electromyography (EMG)
Cerebrospinal fluid analysis
Genetic tests

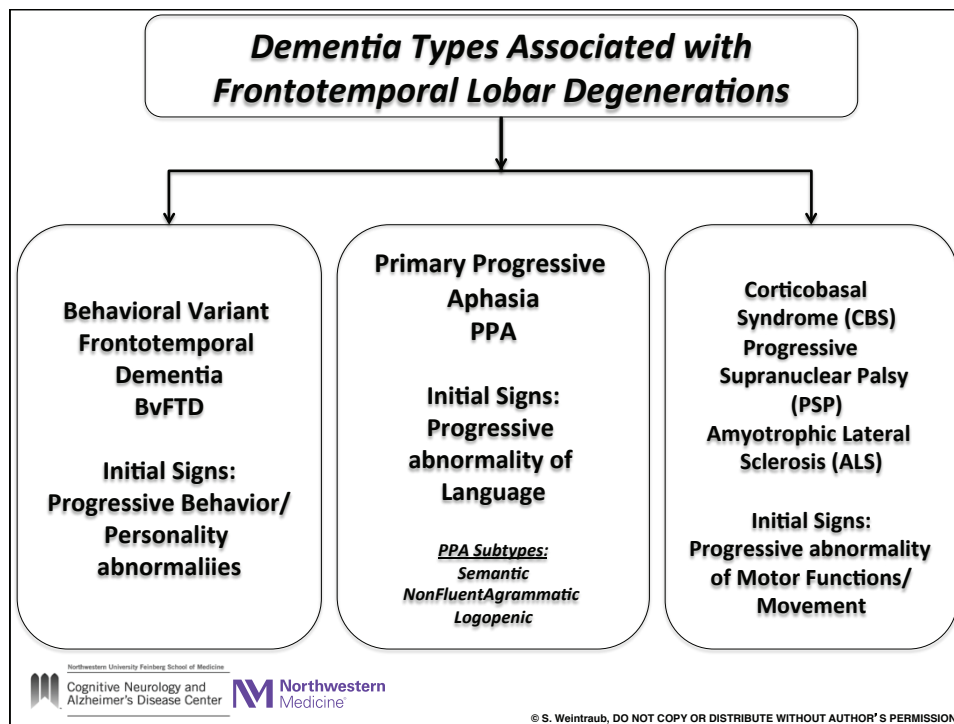
DIFFERENTIAL DIAGNOSIS

What is possibly causing the dementia ?



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Diagnostic Evaluation Tools: What They Can Tell You and What They Can't, cont'd.



DEFINE THE DEMENTIA TYPE

1. Clinical Neuropsychological Evaluation

Clinical Neuropsychologist (PhD):

- Administers and interprets objective tests of thinking abilities and behavior in comparison to standards for age and education
 - Is there decline? How much?
 - *What is the dementia type (aphasia, memory, language?)*
 - Recommendations for care based on assessment

DEFINE THE DEMENTIA TYPE

2. Cognitive Neurology Examination

Cognitive Neurologist (MD)

- Examines visual, auditory, somatosensory and motor symptoms to identify related neurological deficits
- Interprets findings of medical tests and combines them with results of neurological examination.
- Recommends medications, other treatment



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DEFINE THE DEMENTIA TYPE

3. Psychiatric Examination

- Psychiatrist (MD) clarifies the diagnosis of symptoms that can be psychiatric in origin (e.g., bvFTD symptoms are sometimes diagnosed as a "mid-life crisis.")
- Recommend medications to manage symptoms (e.g., depression, delusions, hallucinations, paranoia, obsessive compulsive behaviors, insomnia, agitation)



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IDENTIFY THE CAUSE OF THE DEMENTIA

4. Laboratory Tests:

- **Blood Tests:** are there abnormalities in the blood that can cause the brain to malfunction?
- **Structural Neuroimaging** (CT, MRI): Exclude other causes of dysfunction: strokes, brain tumors. FTLD is not visible but patterns of brain shrinkage (atrophy) can help diagnosis.
- **Functional Neuroimaging** (FGD-PET): measures brain activity/metabolism.
- **Biomarker imaging available for Alzheimer's disease:** Amyloid PET shows amyloid in the brain; tau PET is under development



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IDENTIFY THE CAUSE OF THE DEMENTIA

4. Laboratory Tests:

- **Electroencephalography (EEG):** exclude seizures as a cause a dementia. "Mad cow" disease is associated with a specific wave disturbance on EEG.
- **Electromyography (EMG):** detect abnormal electrical signals in the muscles associated with ALS (Lou Gehrig's disease)
- **CSF tests** to exclude infection, cancer, other; amyloid and tau test for Alzheimer's disease



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IDENTIFY THE CAUSE OF THE DEMENTIA

5. GENETICS/INHERITABILITY

- 30-50% report family history; the rest are "sporadic"

Genetic Mutations:

- MAPT, chromosome 17 (Tauopathy)
- GRN (progranulin) (TDP-43 proteinopathy)
- C9orf72 (TDP-43 proteinopathy)
- TBK1, VCP, CHMP2B less common

Genetic Risk Factors

- TMEM106B



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A Case Example :

Sally was 48 when her family first noticed that she was behaving oddly.

- Obsessively talking about her mother who had been institutionalized when she was 16 and had died in her 60's.
- Brought to a psychiatrist who initially diagnosed depression due to the early loss of her mother.



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Symptoms progressed over the next 2 years:

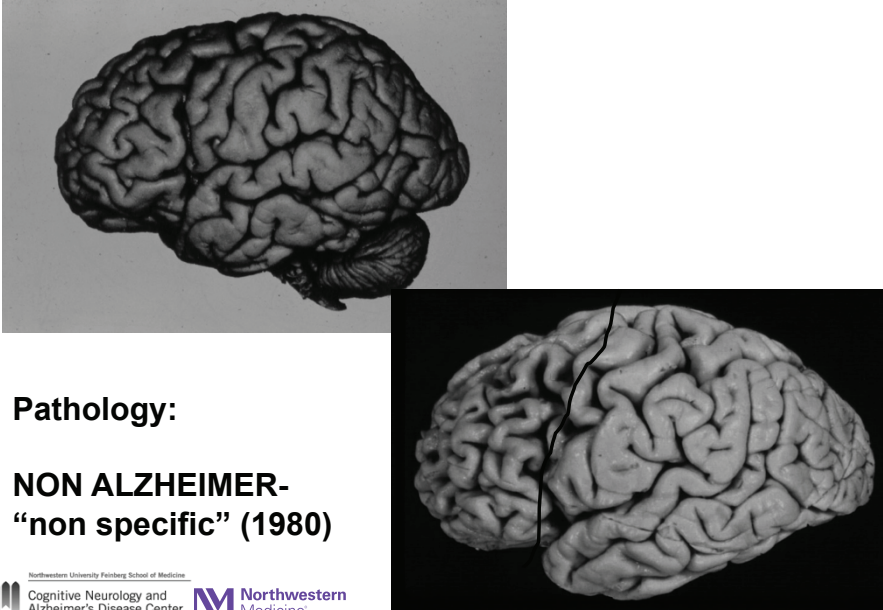
- **Worked on assembly line and let items slip** past without doing her job
- Started abusing alcohol and walking about town drunk (extremely uncharacteristic)
- Wasn't interested in her children and didn't talk to them when they came home from school (extremely uncharacteristic)
- Stopped managing usual household tasks

Neuropsychological assessment showed normal memory test scores! BUT

- Unable to focus her attention: got up from her chair often, without purpose, and wandered about the office
- Unable to reason about simple problems
- Diagnosed with bvFTD, predicted to be caused by one of the FTLDs

Diagnostic Evaluation Tools: What They Can Tell You and What They Can't, cont'd.

Behavioral Variant Frontotemporal Dementia (BvFTD)



Pathology:

NON ALZHEIMER-
"non specific" (1980)

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QUESTIONS & ANSWERS

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Treatment Options and Working with Your Doctor

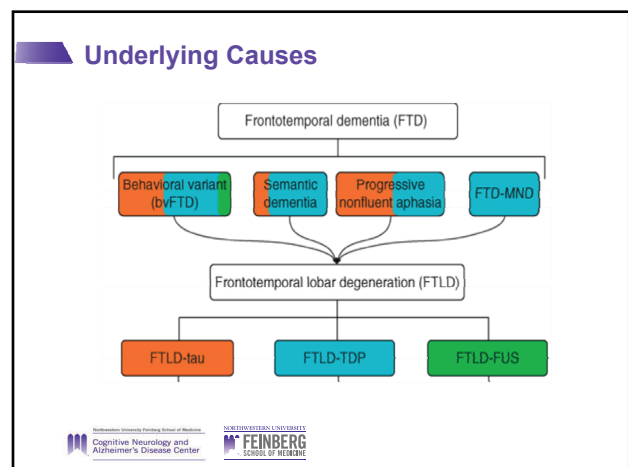
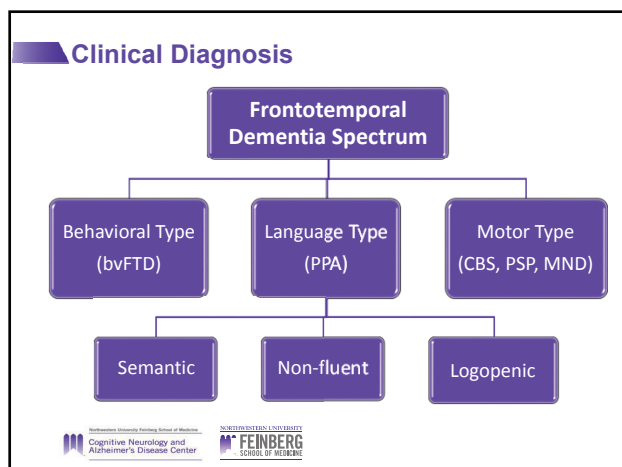
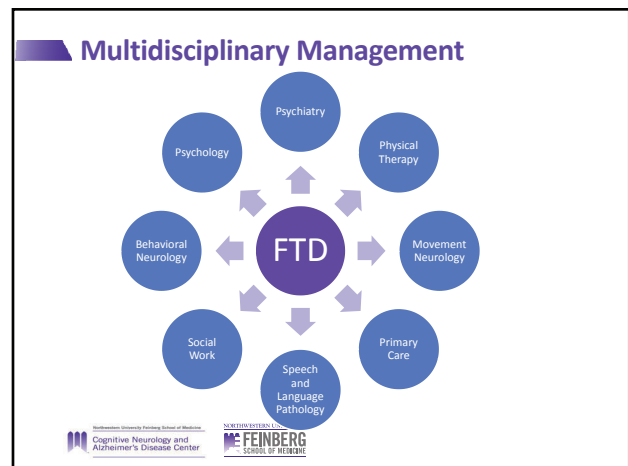
Borna Bonakdarpour, MD, Feinberg School of Medicine, Northwestern University

Treatment Options and Working with Your Doctor

Borna Bonakdarpour, MD, FAAN


Assistant Professor of Neurology
Cognitive Neurology and Alzheimer's Disease Center
Department of Neurology
Northwestern University Feinberg School of Medicine
Twitter: @bbonakda






Treatment of FTD Spectrum

- **Standard Treatments**
 - Pharmacologic treatments
 - No FDA approved drug
 - Based on open-label or case series
 - Symptomatic treatment
 - Behaviors: SSRIs: Paroxetine, Citalopram, Trazodone
 - Antipsychotics: Quetiapine, Olanzapine
 - Antiepileptics: Valproic acid, Carbamazepine
 - Cognition: Galantamine for PPA (Kertesz et al., 2008)


 Tsai and Boxer, 2016

Treatment of FTD Spectrum



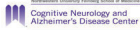
- **Standard Treatments**
 - Non-pharmacologic interventions (Merrilees et al., 2007)
 - Reward based therapy
 - Cognitive therapy
 - Speech and language therapy
 - Physical therapy
 - Life enrichment and strength-based intervention


 Tsai and Boxer, 2016

Treatment Options and Working with Your Doctor, cont'd.




 **FTLD Clinical Trials**


- **Tau stabilization**
 - **Devunetide** (Boxer et al., 2014)
 - o Phase 2/3 trial
 - o 313 PSP participants
 - o Showed that a large multicenter international clinical trial in FTD is feasible
- **Inhibit tau aggregation**
 - **Leuco-methylthioninium, LMTM, or Methylene Blue** (Wischik et al. 2016)
 - o Phase 3 trial
 - o 221 patients with FTD
 - o The study could have benefitted from spinal fluid exam to rule out Alzheimer disease for participant selection.






 **FTLD Clinical Trials**

- **Increase progranulin**
 - **Nimodipine** (Miller, IC-FTD 2016):
 - o 8-week, open-label, dose-finding study for the treatment of progranulin insufficiency from GRN gene mutation
 - o Primary outcome: plasma and CSF progranulin
 - o Strong patient selection criteria (patients with known mutation)



 **FTLD Clinical Trials**

- **Recruiting** (26 trials)
 - **AADvac 1** (anti-tau vaccine) for PPA-G
 - **tDCS** for bvFTD and PPA
 - **Low dose lithium** for behavioral symptoms of bvFTD
 - **Biomarker studies** more importantly Tau-PET
 - **GENFI** (Genetic FTD Initiative)
 - **ARTFL** (Advancing research and Treatment for Frontotemporal Lobar Degeneration)



NOTES: _____

Participating in Research: Opportunities and Advantages

Emily Rogalski, PhD, Feinberg School of Medicine, Northwestern University
Dianna Wheaton, PhD, FTD Disorders Registry

Participating in Research: Opportunities and Advantages



Is **CLINICAL RESEARCH** right for me?

Clinical research is medical research that involves **people**.

It's led to the **DISCOVERY** of every disease treatment prescribed today.

Study volunteers play a critical role in this process.

<https://www.nia.nih.gov/health/infographics/clinical-research-right-me>

Participating in Research: Opportunities and Advantages, cont'd.

Are you interested in joining a study or trial?

CLINICAL RESEARCH may be right for you if you want to:

- Help others, including future family members, who may be at risk for certain diseases
- Test new disease treatments that might work better than those currently available
- Receive regular monitoring by medical professionals

Source: <https://www.nih.gov/health/infographics/clinical-research-right-for-you>

Future Directions, Resources, and Advocacy

Be a part of the breakthrough

Research on PPA is growing

Year	Total Number of Papers
2000	25
2001	30
2002	35
2003	40
2004	45
2005	50
2006	55
2007	60
2008	65
2009	70
2010	75
2011	80
2012	85
2013	90
2014	95
2015	100
2016	105
2017	110

Logos and Resources:

- NIH** (National Institutes of Health)
- communicationBRIDGE** (communicationbridge@northwestern.edu | 312-503-4012)
- Brain Research** (www.brain.northwestern.edu)
- AFTD** (The Association for Frontotemporal Degeneration) (www.theaftd.org/)
- alzheimer's association**
- IMPACT** (International PPA Connection) (<http://www.ppaconnection.org/>)
- GENFI** (Genetic FTD Initiative) (<http://genfi.org.uk/>)
- ARTFL** (Association for Research in Frontotemporal Lobar Degeneration)
- FTD DISORDERS REGISTRY**

Participating in Research: Opportunities and Advantages, cont'd.

COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER (CNADC)

PRIMARY PROGRESSIVE APHASIA (PPA) RESEARCH PROGRAM

The CNADC is looking for individuals diagnosed with PPA for research studies on their Chicago Campus



Northwestern

Observational studies featuring:

- Advanced MRI & PET brain Imaging biomarkers
- Neuropsychological testing
- Compensation for time & travel reimbursement
- Goal: Improve diagnosis, prognosis and understanding of PPA

Interventional studies featuring:

- Specialized speech-language therapy
- Telemedicine delivery (no travel required!)
- Compensation for time
- Goal: Improve access to care, understand the usefulness of speech-language therapy

Contact:

Benjamin Rader | 312-908-9681
benjamin.rader@northwestern.edu
www.brain.northwestern.edu

NOTES:

Balance, Falls and Tremors: Motor & Cognitive Symptoms in Less-Common Forms of FTD

Zoe Arvanitakis, MD, MS, neurologist, Rush University Medical Center
Robin Riddle, CEO, Brain Support Network, www.brainsupportnetwork.org

What is parkinsonism?

Parkinsonism is a term that refers to Parkinson's Disease-like symptoms. The four key symptoms are rigidity (muscle stiffness or inflexibility), bradykinesia (slow movement), tremor, and postural instability (balance and falling). The most common parkinsonism condition is Parkinson's Disease (PD).

Parkinsonism conditions besides PD are called atypical parkinsonism disorders. These include progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD).

What are frontal lobe symptoms?

PSP and CBD are movement disorders on the frontotemporal degeneration (FTD) spectrum. This is because those with PSP and CBD can have frontal lobe symptoms. These symptoms include changes in behavior, impaired spatial reasoning, inability to understand social cues, dementia, impaired language skills, loss of empathy, and apathy.

Balance and Falls

Of all the movement symptoms in PSP and CBD, the most dangerous for the person with the diagnosis are balance problems and falls.

A bit of research has been done with PSP to show that balance can be improved with specific exercises (for the eyes and body) or physical therapy.

A lot of practical evidence exists in the PSP/CBD community that some falls can be prevented and the severity of some falls can be lessened. Approaches for accomplishing this include:

- Gait belt. The caregiver can obtain training on use of a gait belt from a physical therapist. Gait belts can lessen the severity of some falls.
- Exercise. Consider some of the exercises specific to Parkinson's Disease such as PWR! (Parkinson's Wellness Recovery!, pwr4life.org). All exercises can be done seated or with a caregiver/partner. Find a list

of PD exercise videos here:

http://parkinsons.stanford.edu/exercise_videos.html

- Physical therapy (PT), especially for walking, standing up, sitting down, and transferring. Consider some of the therapies specific to Parkinson's Disease, including LSVT-BIG therapy (lsvtglobal.com/patient-resources/what-is-lsvt-big). Talk to your neurologist about a referral to PT.
- Equipment such as a walker and wheelchair. Talk to your neurologist about a prescription for this equipment. Work with a physical therapist to find the right equipment for you.
- Training by a physical therapist. The person with a diagnosis can learn how to get up from the floor after a fall. The caregiver can learn how to assist a person in getting up from the floor after a fall.
- Home safety evaluation, often done by an occupational therapist.
- Safety equipment, especially for the bathroom.

Many of these points are addressed in the Summer 2015 issue of AFTD's Partners in FTD Care newsletter, co-authored by Robin Riddle and Phil Myers of Brain Support Network and available at www.theaftd.org/wp-content/uploads/2015/07/PinFTDcare_Newsletter_summer_2015.pdf.

Other Motor Symptoms

Occasionally, those with PSP or CBD will have tremor. If the tremor is troublesome, speak with the neurologist (or movement disorder specialist) about medication for tremor.

Many people with PSP and CBD will have rigidity. This can be quite extreme where people are stiff like a board. In some, there can be painful contractures. Medication can be tried, including Botox injections. Often the focus is on relief of pain, if present.

Balance, Falls and Tremors: Motor & Cognitive Symptoms in Less-Common Forms of FTD, cont'd.

Swallowing problems (dysphagia) are considered movement issues. Besides falls, the risk of choking or developing pneumonia from swallowing problems is a major challenge in PSP and CBD. See the same AFTD newsletter mentioned above for suggestions on how to cope with swallowing problems.

Cognitive Symptoms

Important cognitive symptoms in PSP and CBD are cognitive impairment (dementia), apathy, and

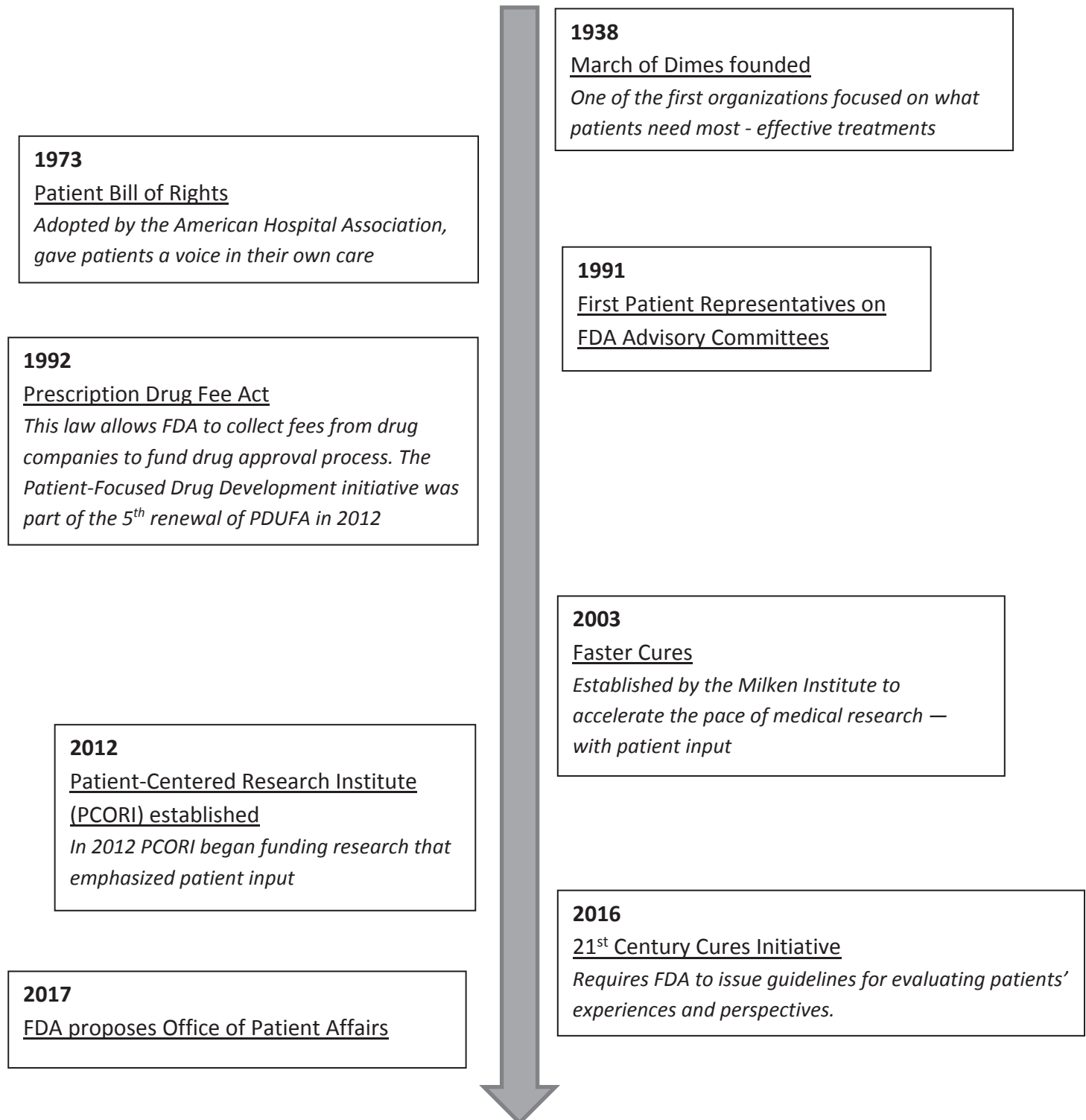
disinhibition. These symptoms don't occur in everyone with PSP or CBD. Unfortunately, the cognitive symptoms can exacerbate the motor symptoms. For example, a person with PSP or CBD may be unable to recognize that he/she is prone to falling, darts up from a chair, and starts walking without a walker. These symptoms are treated with caregiver education and support. Sometimes medication is tried for dementia symptoms.

NOTES:

Designing Research with Input from People Living with FTD

Matt Sharp, MSS, AFTD
Debra Niehoff, PhD, AFTD

“For most of history, patients were passive recipients of medical care” – and then things changed



Designing Research with Input from People Living with FTD, cont'd.

Make your voice heard: Be a co-pilot to improve clinical research

At this point in the research process:

Pre-Drug Discovery

What is it like to live with this disease?

Pre-Clinical Development

What should researchers know before starting a clinical trial?

Clinical

Putting a new treatment to the test

FDA review & approval

Is this treatment safe & effective?

You can:

Tell your story

- Participate in a researcher-initiated patient engagement event
- Join the FTD Disorders Registry
- Participate in an FDA Patient-Focused Drug Development meeting

Educate and inform

- Will this trial design work for participants and their families?
- What outcomes matter most?

Provide feedback & oversight

- What has it been like to participate in this trial?
- Serve on a Data Safety Monitoring Board

Contribute to the process

- Serve as a Patient Representative
- Benefit vs risk: a patient perspective

Want to know more?

FasterCures

An “action tank” working to accelerate medical research and promote “patient-centricity”

Reports, toolkits, videos, webinars can be found at:

<http://www.fastercures.org/>

Patient-Centered Outcomes Research Institute (PCORI)

PCORI funds patient-centered research to help people make well-informed decisions about their health care. *Accelerating Patient-Centered Outcomes Research and Methodological Research*, one of 5 funding priorities for PCORI, focuses specifically on the development of strategies to improve the way clinical studies are designed and conducted.



Food & Drug Administration (FDA)

Patient-focused Drug Development Meetings provide an opportunity for the FDA to hear directly from patients, advocates, and caregivers how a disease affects their daily lives. This information factors into the decision to approve a new medication.

<https://www.fda.gov/ForIndustry/USerFees/PrescriptionDrugUserFee/ucm453856.htm>

FDA Patient Representatives are the “voice of the patient” on FDA Advisory Committees and panels as well as in review division meetings.

<https://www.fda.gov/ForPatients/About/ucm412709.htm>

FTD Disorders Registry (FTDDR)

The Registry is an online database to collect information from those affected by all types of FTD. Persons diagnosed, (current/former) caregivers, family, and friends can join. You can also register to participate in FTDDR research.

<https://ftdregistry.org/>

Building Your Care Team

For Newly Diagnosed and Their Care Partners

Darby Morhardt, PhD, Feinberg School of Medicine, Northwestern University

A care team is a group of health and social service professionals to assist in the care for persons living with Frontotemporal Disorders (FTD) (behavioral variant frontotemporal dementia, primary progressive aphasia, corticobasal degeneration, progressive supranuclear palsy or frontotemporal disorder/motor neuron disease) and their families. Together, your team can help you navigate the various questions, concerns and uncertainties that can affect well-being and quality of life. Below is a list of possible Team members. Note that all of the professionals listed below may not be available in your area, covered by your health insurance, or familiar with FTD.

Primary Care Team:

- **What they do:** This team may consist of a medical doctor (such as an internist, geriatrician, or family medicine physician), nurse practitioner, or physician's assistant who will provide ongoing care and treatment for a variety of common medical conditions. When your primary care team suspects an illness outside the scope of their practice, they will refer you to a specialist.
- **Why they are important:** This team will still be in charge of your overall care even if you see a specialist for a particular condition. It is important to continue to see this team regularly. They can provide referrals to other clinicians.

Neurologist:

- **What:** This clinician is trained to identify and treat illnesses related to the nervous system. A behavioral neurologist is specially trained in neurological disorders that affect cognition. Behavioral neurologists are most often found in university health care settings.
- **Why:** The neurologist is typically the first to diagnosis FTD and is central to monitoring and evaluating the progression of the neurological disorder.

Neuropsychologist:

- **What:** This clinician evaluates a person's cognitive abilities using specialized paper and pencil tests which pinpoint the exact areas of cognition that are affected and to what degree.
- **Why:** These tests help the neurologist make a diagnosis or understand more specifically what may be causing the symptoms.

Psychiatrist:

- **What:** This clinician specializes in evaluating behaviors and moods of individuals.
- **Why:** A psychiatrist may prescribe medications to modify challenging behaviors and moods. A special type of psychiatrist, called a neuropsychiatrist or a geriatric psychiatrist, is specially trained in treating psychiatric problems in neurological disorders.

Social Worker:

- **What:** This clinician provides information about your particular diagnosis, linkage to local resources, individual and family counseling, advocacy, and support.
- **Why:** Social workers help patients and family members understand the diagnosis, find resources in the community and cope with changes. Social workers provide guidance and support during transitions in care throughout the disease progression.

Speech and Language Pathologist (SLP):

- **What:** This clinician sees individuals with language and other cognitive changes. They evaluate different aspects of cognition and language in detail and can make recommendations and offer compensatory strategies.
- **Why:** SLPs help the person living with FTD and their family members maintain essential communication

Building Your Care Team, cont'd.

for as long as possible. Family members should be included in the treatment sessions so they can receive education on how to facilitate communication.

Occupational Therapist (OT):

- **What:** This clinician works with individuals and family members to improve or maintain daily functioning.
- **Why:** Working with an occupational therapist can help reduce the burden on the family care partner by developing ways to modify or adapt activities of everyday life. This can be particularly helpful for individuals with visuospatial, movement or motor changes.

Physical Therapist (PT):

- **What:** A physical therapist works with individuals to maximize functioning through building strength, improving balance, preventing falls, conducting home safety assessments, and implementing physical exercise techniques tailored to each individual.
- **Why:** Maintaining the highest level of functioning possible positively impacts the quality of life for both the person living with FTD and their family.

Individual Counselor/Therapist:

- **What:** This clinician can work with either the person living with FTD or a family member to develop coping skills and work through the emotional changes brought on by the progression of FTD.
- **Why:** Counseling/therapy helps the person living with FTD and their family adapt to and cope with the significant changes that occur as a result of the diagnosis and accompanying symptoms.

Professional Care Manager:

- **What:** Professional care managers provide assistance managing, organizing and overseeing care.
- **Why:** Professional care managers facilitate transitions in care and are especially helpful for long distance caregivers and families in conflict

Palliative Care Team:

- **What:** Health care practitioners on this team promote comfort and dignity for anyone experiencing a terminal illness and can be implemented as early as the first day the diagnosis is made.
- **Why:** This care focuses on comfort and symptom relief. Hospice care, a Medicare benefit, is a form of palliative care and is implemented when a person is expected to live for six months or less.



Living with PPA: Practical Communication Strategies

Emily Rogalski, PhD, Feinberg School of Medicine, Northwestern University
Becky Khayum, MS, MemoryCare Corporation

Communication Strategies for bvFTD and PPA

What is bvFTD?

bvFTD is a clinical dementia syndrome “characterized by early and progressive changes in personality, emotional blunting and/or loss of empathy. People experience difficulty in modulating behavior, and this often results in socially inappropriate responses or activities. Impairment of language may also occur after behavioral changes have become notable.” (from AFTD website)

What is PPA?

PPA is a clinical dementia syndrome caused by neurodegenerative brain disease. PPA is defined by progressive difficulties with language processing (i.e., aphasia) that initially emerge in the absence of other cognitive or behavioral changes.

Limitations of subtyping:

The PPA subtype is based on the prominent aphasia profile. **It is important to remember that many individuals do not neatly fit into one subtype, and may have symptoms from several different subtypes.** Also, PPA is a moving target. As the disease spreads throughout the brain, symptoms from the various subtypes will emerge. It is important to look at the person’s clinical presentation of language strengths and weaknesses when developing a plan of care. The described subtypes are:

- PPA-L (logopenic variant) is characterized by the absence of grammatical difficulties, preserved single word comprehension and hesitant speech with pauses for word-finding;
- PPA-G (agrammatic/nonfluent) is characterized by agrammatism in speech, writing and/or comprehension, and preserved single word comprehension;
- PPA-S (semantic) by impaired single word comprehension and naming and preserved grammar.

A Person-centered Holistic Approach

The complexity of these diagnoses require a holistic approach, with the following variables taken into account when considering treatment strategies: (1) Clinical profile of language strengths and weaknesses, (2) Severity of symptoms, (3) individual’s hobbies, interests and communication needs, (4) individual’s motivation, along with emotional well-being, and (5) caregiver and family dynamics & involvement/support. A combination of home exercises, along with compensatory strategies may often be appropriate, with the recommended strategies frequently adjusted to meet a person’s changing communication needs as the disease progresses.

Home Exercises:

- **Rehearsal of personally relevant words:** home program designed to increase person’s word retrieval and pronunciation of words that they frequently use during daily conversation
- **Strategies to help with pronunciation of multisyllabic words:** watching a care partners lips while they say the target word together; care partner slowly fades out while person continues to say the word, writing the target words on flashcards and drawing lines between each syllable, singing or tapping the syllables out on target words
- **Script Training:** person with aphasia and caregiver are trained to type up and rehearse scripts, to increase ability to speak via telephone, tell stories or jokes, order food at a restaurant, say prayers, or explain their condition to others; For those with pronunciation difficulty: record video of script, of a mouth producing the script and over-articulating each word. The person chorus-reads the script along with the video. Scripts need to be practiced intensively (5–10x in a row, multiple days each week)

Living with PPA: Practical Communication Strategies, cont'd.

- **Copy & Recall Treatment (CART):** Written rehearsal of personally relevant words, to facilitate word retrieval or written communication of the target word
- **Personal Picture Description Task:** person with aphasia selects favorite photographs from present or past, and described them in 3-5 sentences. Key words/phrases are written on the back of the pictures to facilitate word retrieval as needed

Compensatory Strategies for Communication, Reading and Writing:

- **Self-cueing and nonverbal communication strategies:** semantic circumlocution (talking around the word), phonemic self-cueing (thinking of first letter), writing, gestures, visualization
- **Communication Partner Training:** on positive communication strategies at the conversation level (e.g., effectively cueing for increased use of semantic circumlocution by prompting "Tell me about it." or whether or not to fill in the word for the person with aphasia, based upon the person's preference)
- **Facilitating auditory comprehension:** training caregiver on strategies such as simplifying sentence structure, slowing rate or increasing use of nonverbal cues (write out key words during conversation or show a picture to help with comprehension)
- **Low-tech communication aids:** (emphasize to person and family that they need to have a "toolbox" full of different tools to help with communication; many different types of strategies and aids to help facilitate communication)
 - Communication books or boards (word or picture-based)
 - Communication wallet: (word or picture-based) portable aid so that person can easily look up important words or information during conversation
- **High-tech communication aids** – need to consider:
 - Person's motivation to use an AAC device
 - Person's fine motor and sequencing skills (Can he successfully operate a computer, TV remote or cell phone?)
 - Person's level of family support, as someone will be needed to help patient program and effectively use the device as the disease progresses
 - Out of pocket cost for the person/family
 - Trialing the use of a device in the person's home environment during functional situations
- **Writing Strategies:** Use of technology or written aids/templates to facilitate spelling and grammar.
 - Spell/grammar check on phone, tablet or computer
 - Voice Recognition Technology – to state word and have device spell word out
 - Dictionary.com or other similar websites/apps
 - Templates/written aids for writing emails, To Do lists, grocery lists, or any other functional writing task
- **Reading Strategies:** Use of technology and compensatory strategies to facilitate functional reading tasks
 - Novels: try listening to book on tape while following along with hard copy of novel
 - Pick novels you have read before, so you are familiar with the plot and characters
 - Pick novels that are shorter with less complex plots and fewer characters
 - Single Word Reading Comprehension: Highlight the word on your phone, tablet, or computer and select "define" OR type in word into Google search and it will display image and definition

Living with PPA: Practical Communication Strategies, cont'd.

- Lingraphica NewsPath – free program that offers several news articles each day. Program will read content aloud, highlight words that are displayed in large font

Use of Apps for People with PPA

- Train as early as possible and always complement with simpler strategies not involving technology, such as a communication wallet/book (Holland et al., 2012):
 - a. **Story Creator** –photo album app: can be used for communication purposes, such as telling stories
 - b. **Pic Collage** – Aid Making app: can easily make personalized communication boards or books
 - c. **Microsoft PowerPoint** – Aid Making app: can easily make communication wallets (portable aids) with this program. One slide = one page of wallet. Print 4 or 6 slides to a page, then cut out, laminate and place on a key ring
 - d. **vBox** – reading app: will read emails aloud to user
 - e. **FlipCards Pro** – quiz app: allows user to make flashcards with pictures for word rehearsal.
 - f. **Quizlet** – quiz app: allows user to make flashcards with automatic auditory cues. Can add pictures if you pay small fee for the app.
 - g. **Scene&Heard** – AAC app: easy to navigate, uses person's own pictures in different scenes
 - h. **Locabulary** – AAC app: user must be able to construct sentences when given choices
 - i. **Dynavox Compass** – AAC app: communication app, using own pictures to create scenes and scripts

Contact us for information on research opportunities, clinical care, and education opportunities:
brain.northwestern.edu | communicationbridge@northwestern.edu | 312-503-4012

NOTES: _____

Anosognosia (Lack of Awareness) and Positive Strategies for Care

Anosognosia (Lack of Awareness) and Positive Strategies for Care

Geri R Hall, PhD, GCNS, FAAN
Advanced Practice Nurse Emeritus
Banner Alzheimer's Institute

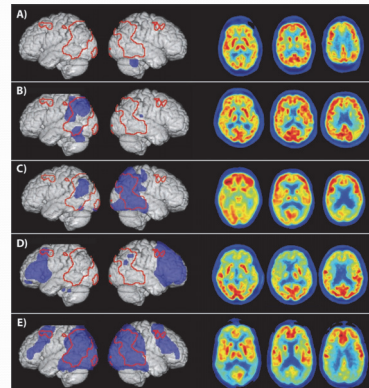
Anosognosia

- Purpose: To introduce caregivers and health professionals to symptoms of lack of awareness and other challenging behaviors
- Objectives: Following the discussion, participants should be able to do the following
 - 1) Define "anosognosia" and describe what the symptom looks like
 - 2) Describe two ways to manage "lack of awareness"
 - 3) Ask questions regarding common problems associated with bvFTD

Understanding dementia syndromes

- Dementia – An umbrella term for a set of symptoms that occur when there is damage to the "thinking, doing, understanding, and perceiving" areas of the brain
- Many diseases cause dementia. Symptoms vary by:
 - Size and location of the diseased area of the brain
 - Premorbid personality
 - Type of damage to the brain cells
 - Comorbid conditions
- FTD has a unique presentation on both scans and biopsy

FDG PET to distinguish Dementias



Anosognosia

- The inability to recognize/perceive one's limitations, abilities, & illness aka "lack of insight," a hallmark symptom of FTD
 - "Lack of insight" is the single largest reason why people with FTD refuse medications, do not seek treatment and place previously capable individuals to demonstrate risky behavior
- Two primary types of anosognosia
 - "Cognitive unawareness" factor, which loaded on items of memory, spatial and temporal orientation, calculation, abstract reasoning, and praxis (putting abstract ideas into practice)
 - the cognitive unawareness factor had more severe cognitive deficits, delusions, and apathy, but less depression
 - Decreased long-term memory
 - Associated with longer duration of illness
 - Correlates with declined cognitive test scores & language comprehension
 - "Behavioural unawareness" with factors of irritability, selfishness, inappropriate emotional display, and instinctive disinhibition.
 - Correlated significantly with higher mania and pathological laughing scores.

Anosognosia made visible



<https://www.agingcare.com/articles/anosognosia-and-dementia-top-tips-from-caregivers-20090.htm>

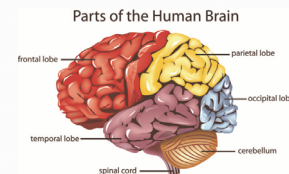
Anosognosia (Lack of Awareness) and Positive Strategies for Care, con'td.

Let's talk about loss of insight and awareness!

- How does loss of insight affect your person and yourself?
 - Person is not capable of knowing they have an illness and their abilities have changed
- This is not “denial.” It is due to a brain-based disorder
 - Damage to right parietal lobe and/or frontal lobe, the anterior cingulate and the orbitofrontal cortex.
 - Blind report they can see – even describe elaborate scenes
 - Paralyzed people report they are fully mobile

Anosognosia

- Loss of awareness is a key symptom of FTD similar to “memory loss” is to Alzheimer's disease



Caregiver strategies

- Accept the loss is more than psychological “denial.” You can not convince them they have a problem
- Therefore are often resistant to care and needs
- Combined with other losses this can be very frustrating for family, but person is relatively unconcerned
- Person will report they do activities they haven't done in years
- Person seems perfectly normal to others, including MDs
- Family may feel the person is “lying”
- Need an expert in FTD for diagnosis & care
- Routine dementia tests will be “normal”

Key strategies

- Acceptance
- Understand that explaining and reasoning are futile
- Patience
- Recognizing why you ask for certain things and asking yourself “Is this important?” Why?
- Developing alternative reasons to achieve a goal, i.e. fidgets, hiding things, etc.
- Supervise for safety and inappropriate spending



More

- Have legal forms filed in advance
 - DPOA
 - May need guardianship & conservatorship – for guardianship may need expert in FTD to testify
 - Difficult to obtain because person feels nothing is wrong
- Relationship issues
 - Anger: wanting divorce or to move out (may result in institutional)
 - Sexual behaviors: porn, advances towards others, including family
 - Caregiver wants person to “admit” to the disease resulting in anger & power struggle

Plan for safety issues

- Recognize that risk of person harming others is constant and work to protect yourself
- Remove guns & potential weapons
- Have Medic-alert alarm system for caregiver to wear at all times and use it to summon help
- Don't be afraid/embarrassed to call 911
- Identify hiding places in home and lock yourself in
- Sleep in separate bedroom with door locked
- Driving cessation & hide keys
- Continually ask “Am I safe here?”
 - If you have to pause, get out of there. If more than two times, think hospitalization and/or placement

Anosognosia (Lack of Awareness) and Positive Strategies for Care, con'td.

Making anosognosia worse

- Loss of empathy
- Narcissism
- Decreased attention/concentration
- Impulsivity
- Loss of language skills
- Loss of executive function (ability to plan, organize, and perform in order to reach a goal)

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NOTES:

Palliative Care and Easing Difficult Conversations

Nancy Flowers, MSW, LCSW, Community Education Program Manager/
Dementia Project Manager, Rainbow Hospice and Palliative Care, Mount Prospect, Illinois

NFlowers@RainbowHospice.org, 847-653-3134

This session focuses on the ways that palliative care can support family decision making for persons with FTD by facilitating conversations on care options, care preferences and potential outcomes of interventions. The session will also explore how Palliative Care teams can help families prepare for changes in patient function and navigate the grief that families experience when faced with loss.

Palliative Care

Palliative care is specialized medical care for persons living with serious illness. This approach to care provides relief of suffering through the early identification and treatment of pain and other symptoms, while also addressing emotional and spiritual concerns, and the stress of care. FTD and other dementias, may benefit from palliative care intervention as do conditions such as cancer, heart disease, respiratory disease, kidney failure, AIDS, Amyotrophic Lateral Sclerosis (ALS) and other neurological diseases.

Palliative care uses a team approach to address the needs of patients and families. Care consultations are provided by specially trained physicians, nurse practitioners, social workers and chaplains. These clinical teams work with each patient's physicians and other practitioners involved in patient care to develop a care plan that addresses pain and symptom management, and provides guidance on future directions for care.

Symptoms that benefit from palliative intervention include pain, fatigue, constipation, nausea, loss of appetite, temperature sensitivity, sleep problems, shortness of breath, and skin breakdown. In FTD and other dementias symptom management may also focus on emotional indicators of distress and discomfort: anxiety, agitation and aggressive behaviors.

Palliative care is appropriate for persons of any age and at any stage in a serious illness, and can be provided along with curative or life prolonging treatments. Medicare, Medicaid and most private insurances cover the cost of palliative care consultations, as well as hospice care.

As treatments become less effective, palliative care practitioners help guide medical caregivers and families to the most appropriate care for the person with FTD, and help identify the right time to transition to hospice. Hospice care can be initiated when a person with FTD is likely to have a life expectancy of less than six months and the family is in agreement with medical recommendations that hospice is the most appropriate option for future care.

Indications that it may be time to consider hospice include a person's inability to walk, dress or bathe without assistance, inability to communicate and incontinence. In addition, the person with FTD will have experienced one or more signs of dementia-

Palliative Care and Easing Difficult Conversations, cont'd.

The passage of the Patient Self Determination Act in 1991 made this discussion a part of the admission process of all hospitals, long term care facilities, home health agencies and hospices. On admission, health care providers are required to provide information on advance directives to each patient and family. While patients cannot be compelled to complete a health care directive, health care staff must be prepared to assist the patient and family when asked. More recent legislation requires health care providers to review existing advance directives during the admission process, to determine if the documents still reflect patient and family preferences and if the documents need to be amended to reflect any changes.

related decline in the past year including aspiration pneumonia, infection or weight loss. Once admitted to hospice, a person can remain on hospice for as long as they qualify, which will, for most persons, be until death.

Benefits of Advance Care Planning Conversations and Advance Directives

Persons with FTD, families and health care providers are often uncertain of how or when to initiate conversations about care preferences.

Ideally, advance care planning conversations occur prior to a health care crisis and at a time when persons with FTD and families have sufficient time to ask questions about medical conditions and to discuss the kind of care they want and don't want, where they want care provided and at what point treatments such as chest compression, mechanical ventilation, or artificial nutrition might be futile or unwanted. When these discussions occur during a medical crisis, persons with FTD and their families may feel pressured to make decisions more quickly than they would like or to make decisions that they are not comfortable with. This pressure may cause families to view health care providers as insensitive or adversarial.

Health care providers and other family members can help facilitate these discussions by asking about patient and family understanding of the patient's medical condition, the tests they are receiving and any fears about planned treatments. It can be helpful to ask about concerns for the future, and what information they would like from the doctor or other providers in order to make a more informed decision about care.

When one family member does not agree with other family members about care decisions, it can be helpful to ask directly about their concerns and assist them to obtain the information they need to address these concerns. Family members that have been less involved in care may have unanswered questions because they do not have a complete picture of the person's health needs.

Many things can influence health care decision making, including faith and culture. Some family members may benefit from having a chaplain, or their own priest, minister or rabbi involved in advance planning discussions. Some families may be hesitant to make a decision to stop certain treatments or to complete advance planning documents due to fear that these decisions are in conflict with their faith. Inviting a faith leader into this conversation provides a sensitive and effective way to help address patient and family concerns.

Palliative Care and Easing Difficult Conversations, cont'd.

Anticipatory Grief: Finding a Path Forward

Palliative and Hospice team members provide guidance and support in navigating decision making about FTD and other chronic and life limiting conditions. With diagnosis comes a complex array of feelings, including grief about the impact of FTD on the person, on their ability to function as an independent person and on their relationships with others. Patient and family may experience apprehension about what the future holds, and grief at the change in life as they know it. They may experience anger at the diagnosis, or disbelief, questioning its accuracy. They may experience guilt or embarrassment if they express anger at the person with FTD. They may become depressed and withdraw or may actively engage in normal activities to help get through each day. All of these feelings are common and very normal. The role of the palliative and hospice staff is to provide the education and support needed to help patients and families understand the condition trajectory and how best to navigate the condition and their reaction to it.

Grief support can include individual counseling as well as support groups for persons with FTD and caregivers, workshops and faith based support. Each person responds to change and loss in unique ways, so interventions are tailored to meet the needs of each individual and family. Education and support focuses on helping family members prepare for change, as well as to enable family members to remain connected to work and social supports that help maintain a sense of stability. Perhaps most importantly, these interventions help patients and families identify the path forward, through diagnosis and uncertainty, to a future that offers the hope of resilience.

Resources

Get Palliative Care: information about palliative care including how it benefits persons with dementia, and how to locate and choose a palliative care provider.
<https://getpalliativecare.org>

The Conversation Project: a web site that contains a specific tool kit for families of persons with dementia and other tools to help families and practitioners initiate advance care planning discussions.
<https://theconversationproject.org>

AFTD Partners in FTD Care Issue #20: Fall 2016: Comfort Care and Hospice in Advanced FTD; information and resources including support groups. Visit: In Your Region, www.theaftd.org/get-involved/in-your-region/

NHPCO CaringInfo: information on advance care planning, care giving, living with serious illness and grieving a loss. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

NHPCO (National Hospice and Palliative Care Organization): information on hospice and palliative care including how to locate and choose a quality hospice provider. Also includes information for hospice providers on caring for persons with dementia.
<http://www.nhpc.org/about/hospice-care>

National Institute on Aging: booklet on hospice and palliative care and end of life dementia care, "End of Life: Helping with Comfort and Care", <https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction>

Alzheimer's Association, Greater Illinois Chapter "Encouraging Comfort Care: A Guide for Families of People Living in Care Facilities", www.alzheimers-illinois.org

Mayo Clinic: information on end of life care, "Alzheimer's disease: Anticipating End of Life Needs", <http://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20044065>



Keynote Speaker: **The Very Rev. Tracey Lind**

The Very Rev. Tracey Lind is a newly retired Episcopal priest and city planner whose ministry has included work for social and environmental justice, interfaith relations, sustainable urban development, arts and culture, and progressive theology. Most recently, Tracey's ministry has extended to include the spiritual insights and lessons she has gained from a life complicated by dementia.

On Nov. 8, 2016, Tracey was diagnosed with primary progressive aphasia. This diagnosis hasn't stopped her from fully immersing in what life has to offer – and what she has to give.

From 2000 to 2017, Tracey was Dean of Trinity Episcopal Cathedral in Cleveland – a thriving and diverse urban congregation, a center for arts and music, and a gathering place for those devoted to Cleveland and its future. Prior to that, she was Rector of St. Paul's Episcopal Church in Paterson, New Jersey. She also worked for a decade in nonprofit management, city planning, and community organizing.

Tracey is the author of *Interrupted by God: Glimpses from the Edge*. In 2014, she presented a widely viewed TEDx Talk entitled "How I Met God in a McDonald's." She is an exhibiting photographer, an enthusiastic folk musician, an avid gardener, and an adventuresome hiker, cyclist, sailor and traveler. Tracey and her spouse, Emily Ingalls, live in an environmentally sustainable home overlooking Lake Erie in the heart of Cleveland.

To learn more about the Very Rev. Tracey Lind, read a selection of her writings, and view some of her photographs, please visit www.traceylind.com.





Support Resources from AFTD

Living with FTD is a challenge that few people truly understand.
The journey is difficult, and it can be isolating –
but you don't have to take it alone.

A core part of AFTD's mission is to help people access the assistance and support they need. The options listed on this page can help you feel less isolated, learn more about FTD care, gain coping skills, share effective strategies and access helpful resources.

AFTD HelpLine: The only helpline in the country dedicated solely to FTD, the AFTD HelpLine can connect you with the information, support and resources you need – including more information about each of the resources listed below. To get started, simply make a toll-free call to 866-507-7222, or send an email to info@theaftd.org.

Support Groups: A growing number of **in-person** FTD support groups are emerging throughout the U.S. and Canada. Support groups offer a safe space to connect with others, learn practical care tips and share resources in your community. AFTD also sponsors **web-based support groups** for people diagnosed with FTD and **telephone support groups** for caregivers including male caregivers, those caring for someone with FTD/ALS, and those caring for a spouse/partner who also have children at home.

Comstock Grants: Self-care is an essential component of effective caregiving. Through the Comstock Grant program, AFTD provides monetary support to help full-time, unpaid care partners arrange short-term respite. Travel grants help current caregivers and loved ones with FTD travel to an FTD education conference.



Facebook Groups: AFTD maintains a private Facebook group in which people affected by FTD – both persons diagnosed and care partners – can meet, share experiences, and draw support from one another. A second private group is specifically aimed at young adults – people in their 20s and 30s who have a loved one with FTD.

Informal Care Partner Connections: By using geographical data provided to us during registration, AFTD can work to match care partners who live close by or share similar circumstances. This can be an invaluable source of support for people who live far away from a face-to-face support group.



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

Find Help Online

One of the best ways to find help, resources and practical FTD knowledge is by taking advantage of online communities. Follow AFTD on Twitter for the most up-to-date information, and connect with us on Facebook to learn from others who understand this disease. You can have confidence in these sites:

AFTD Facebook Page

<https://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

<https://www.facebook.com/TheAFTDTeam1>

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

AFTD's Closed Facebook Group

<https://www.facebook.com/groups/52543721114>

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

AFTD's "Secret" Young Adult Facebook Group

To join, write: 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

<https://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.

Classy

<https://give.classy.org/AFTD>

Driven to fundraise in honor or memory of a loved one, or in response to your own diagnosis? 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

<https://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.





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, <i>What About the Kids?</i> and visit www.AFTDKidsandTeens.org .	
Learn about the disease.	
Confirm the diagnosis.	
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.	

What's Next When the Doctor Says It's FTD?, cont'd.

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.	



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



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 care partner, we encourage you to register to contribute to a better understanding of FTD's impact on individuals and their families.

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).



Partners in FTD Care

Partners in FTD Care

a quarterly newsletter for healthcare professionals

Looking for an FTD care resource to inform and empower your family and share with the health professionals you rely on? AFTD's Partners in FTD Care resource can help.

Partners in FTD Care is a quarterly AFTD publication that offers guidance for professional care providers and family caregivers using case studies and composite stories based on real-life scenarios. Developed by a team of health care experts and care partners, each edition focuses on a specific FTD care issue and suggests intervention strategies to help readers cope with the unique challenges presented by FTD.

Recent topics addressed include:

- Addressing the challenges associated with apathy, a common FTD symptom.
- Recognizing the warning signs of FTD to help ensure an accurate diagnosis.
- Using occupational therapy to help persons diagnosed to remain active in their lives.



Additional Partners in FTD Care materials, including the short documentary *It Is What It Is*, are available to be used as in-service training tools for professional caregiving staff. Family caregivers can also share this resource with their loved one's care providers – including case managers, facility staff, primary care physicians, and others – to help them provide the best care possible.

To subscribe to the Partners in FTD Care newsletter, email PartnersinFTDcare@theaftd.org, or visit www.theaftd.org/for-health-professionals/.

**AFTD's Partners in FTD Care:
Informed. Empowered. Aware.**



Are YOU Ready to Take Action and Volunteer?

You can join volunteers across the country making a difference for families facing FTD.



Lead a support group.

Conduct facility outreach.

Organize a Meet & Greet in your area.

Tell your FTD story.

Host a fundraiser.

Represent AFTD at a community event.

Together, we'll explore projects that suit your skills and interests and find the right volunteer opportunity for you.



"As an AFTD volunteer, I'm able to reach others who have FTD in their lives and show them how to find help and share hope. It feels empowering to spark these connections between people who truly understand the FTD journey."

– Kathy Urban,
AFTD Regional
Coordinator Volunteer

To learn more TODAY:

- 1) Stop by the AFTD tables and meet your Regional Coordinator Volunteer.
- 2) Join the Regional Coordinator Volunteers for this afternoon's breakout session, "Networking for Volunteers."
- 3) Visit www.theaftd.org/get-involved/volunteer-network/.





Reach Out and Find Support. Wherever You Are, You Are Not Alone.

There is a large and growing network here to help guide and support you on your FTD journey. Wherever you live, you have a chance to find support, gain coping skills, exchange resources and learn more about FTD from others who know it firsthand.



In-person FTD support groups meet regularly across the country, and many are led by an AFTD-affiliated volunteer. Join them to learn about local resources, connect with people in your community, and talk about how your life and relationships have changed. For more information on finding support, visit the AFTD Volunteers at our regional tables today, contact the AFTD Helpline, and/or visit our website.

No in-person group near you? AFTD sponsors monthly phone-based support groups for care partners. Each group has a different focus:

- language and communication symptoms
- behavioral symptoms
- caring for a spouse/partner while there are children at home
- caring for a loved one with FTD/ALS
- men's caregiver group

Persons diagnosed can access support via the online platform Zoom. These groups meet monthly and are facilitated by AFTD staff.

Contact AFTD's HelpLine for more information on remote support at **866-507-7222** or **info@theaftd.org**. However you gain support, the most important thing is to remember there is a whole community of people who know what you are going through and are here to help.

 Caregiver Support Groups
 Medical Centers with FTD Programs





Fundraising Opportunities

AFTD's Grassroots Events Program offers the chance to raise critical awareness and vital funds to support our mission.

Join the AFTD-Team today!



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



Race Season is our most active campaign, beginning in the spring and continuing into the fall months. 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.



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.



Independent Events are a great way to raise awareness and funds, year round. Do you have an idea that's not covered by the three campaigns above? 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 Grassroots Events Coordinator, Bridget Graham, to learn more about these campaigns: bgraham@theaftd.org



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/agrammatic 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

[illegible]

AFTD's 2018 Annual Education Conference

Chicago Marriott O'Hare | Chicago, IL
April 13, 2018, 9:00 a.m. to 5:30 p.m.



FIND HELP. SHARE HOPE.



The Association for
Frontotemporal Degeneration
FIND HELP • SHARE HOPE

Radnor Station Building 2, Suite 320
290 King of Prussia Road
Radnor, PA 19087

267.514.7221 - Office | 866.507.7222 - HelpLine
info@theaftd.org | www.theaftd.org