Care.
Connection.
Discovery.

AFTD 2017 Annual Education Conference

Sheraton Inner Harbor Hotel | Baltimore, MD
May 5, 2017, 9:00 a.m. to 5:30 p.m.

AFTD
The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

As of 4/24/2017

AFTD Education Conference 2017
HOPE
Baltimore, MD

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“Learn as much as you can today about FTD care. Take the opportunity to find connection with others here today. Keep with you a spirit of discovery – focused on how research can advance treatments and a cure, and on finding new resources to better manage FTD and gain support.”

Dear Friends,

As AFTD’s Board Chair, it is my honor to welcome you to our 2017 Education Conference. For all those living with an FTD diagnosis, and for the many caregivers and family members reading this: thank you for choosing to be here with us today.

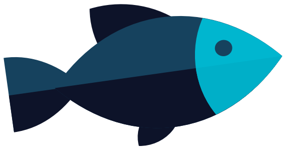
I encourage you to take the themes of this conference to heart. Learn as much as you can today about FTD care. Take the opportunity to find connection with others. Keep with you a spirit of discovery – focused on how research can advance treatments and a cure, and on finding new resources to better manage FTD and gain support.

To the researchers and health professionals in attendance: On behalf of all of us here whose lives have been touched directly by FTD, thank you for being here with us on our journey.

This is also a day of discovery for AFTD’s Board and staff. By learning your perspectives, we gain vital knowledge to inform our work. So be sure to connect: Tell us how you’re doing and how we can better serve your needs.

I also challenge you to look for areas where you could become more involved – whether by leading a support group, by hosting a fundraiser, by joining the FTD Disorders Registry, or in the countless other ways that volunteers drive AFTD’s work.

I know all too well the feeling of isolation that an FTD journey brings with it. Finding and becoming part of AFTD’s community was of tremendous importance to me and my family. My hope is that you will leave today feeling more hopeful and supported – and with a clearer idea of your own essential role in the work to **#endFTD.**



Warm Regards,

Gail Andersen

Gail Andersen
AFTD Board Chair

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About Today's Program

Welcome to the 2017 Education Conference!
There are some special features we'd like to call out about today's program.

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

In response to feedback from prior Conference attendees, we're offering a wider range of breakout session options than ever before.

- The morning sessions (10:45 a.m.), focused on **Clinical Issues**, will be led by experts from Penn FTD Center, Johns Hopkins University, and Geisinger Health.
- The early afternoon sessions (2:00 pm), focused on **Care Strategies**, will feature experts from Johns Hopkins, Thomas Jefferson University, and Rainbow Hospice & Palliative Care.
- The mid-afternoon sessions (3:15 p.m.), focused on **Support & Networking**, are led by AFTD volunteers, who bring a depth of personal and professional experience. These sessions will help you to take charge of your and your family's FTD journey, and find new ways to connect with others online and in-person.

For People Living with FTD

Thank you for joining us today. Three breakout sessions throughout the day – designed and convened with assistance from people living with this diagnosis, are stronger and richer because of your participation.

These sessions will be held in the **Potomac Room** on the 3rd Floor. Need a break in a quieter space? This room will be open and available throughout the day.

Young Adult Lunch

Anyone joining today in their 20s or 30s is encouraged to join AFTD Grassroots Events Coordinator Bridget Graham and AFTD Volunteer Kati Woodford for a networking lunch. Be sure to take part – share your experience and offer your invaluable perspective on ways you are navigating a parent's, a loved one's or a friend's FTD journey.

Health Professionals

Thank you for serving this community. Certificates of Attendance for healthcare professionals will be available after Dr. Amjad'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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Table of Contents

Care.
Connection.
Discovery.

AFTD is grateful to acknowledge:

2017 AFTD Education Conference
Event Host

JOHNS HOPKINS
MEDICINE

**Thank you, Johns Hopkins Medicine,
for your collaboration and leadership.**

The Day's Program

8:00 a.m.
Registration

9:00 a.m.
Welcome
Gail Andersen, AFTD Board Chair

Greeting from Sheryl Whitman, an AFTD community member and person with FTD

9:15 a.m.
A Clinical Update and Overview of FTD Disorders
Chiadi Onyike, MD

9:45 a.m.
FTD Disorders Registry
Dianna Wheaton, PhD

10:00 a.m.
Ask the Experts – Q&A
Chiadi Onyike, MD, Dianna Wheaton, PhD
Facilitator: Nadine Tatton, PhD,
AFTD Scientific Director

10:30 a.m.
Break

10:45 a.m.
Breakout Sessions:
Clinical Issues

11:45 a.m.
Lunch

A Young Adults Networking Session will be offered
Bridget Graham, AFTD Grassroots Events Coordinator and Kati Woodford, AFTD Volunteer

1:00 p.m.
Promoting Dialogue:
Persons w/ FTD & Care Partners
(Panel Session)
Lisa Gwyther, LCSW

2:00 p.m.
Breakout Sessions:
Care Strategies

3:15 p.m.
Breakout Sessions:
Support & Networking

4:15 p.m.
Break

4:30 p.m.
AFTD 2016 Highlights
Susan L-J Dickinson, MS, CGC
AFTD Chief Executive Officer

4:50 p.m.
Keynote Address
Halima Amjad, MD

5:30 p.m.
Social Reception
Harborview Ballroom, 2nd Floor
Attendees, Speakers, AFTD Board and Staff are invited to attend

2nd Floor:

Breakout Rooms

Social Reception

KEY

Room 1 - Severn Gallery
Room 2 - Severn Room
Room 2A - Severn Room I
Room 2B - Severn Room II
Room 2C - Severn Room III
Room 3 - Camden Gallery
Room 4 - Camden Room
Room 4A - Camden Room I
Room 4B - Camden Room II
Room 5 - Harborview Gallery
Room 6 - Harborview Ballroom
Room 6A - Harborview Ballroom I
Room 6B - Harborview Ballroom II
Room 7 - Board Room
Room 8 - Sassafras
Room 9 - Loch Raven Gallery
Room 10 - Loch Raven Room
Room 10A - Loch Raven Room I
Room 10B - Loch Raven Room II

3rd Floor:

Registration

Plenary Sessions

Sessions for Persons Diagnosed (**Potomac Room**)

KEY

Room 1- Potomac Gallery
Room 2 - Potomac Room
Room 3 - Patapsco
Room 4 - Chesapeake Gallery
Room 5 - Chesapeake Ballroom
Room 5A - Chesapeake Ballroom I
Room 5B - Chesapeake Ballroom II
Room 5C - Chesapeake Ballroom III

The Day's Breakout Sessions

This year, in response to feedback from attendees,
AFTD's Education Conference will offer more breakout sessions than ever before.

10:45 a.m. Breakout Sessions: Clinical Issues

Demystifying Diagnosis of FTD: How Evaluation Can Inform Care
Maya Lichtenstein, MD, MHSc,
Peter Stewart, PhD, Geisinger Health

Brain-Behavior Relationships: Why Does He Act That Way?
Lauren Massimo, PhD, CRNP
Penn FTD Center

Medications and Non-Pharma Approaches to Treatment
David Irwin, MD
Penn FTD Center

FTD Research: The Value of Studies and Opportunities for Involvement
Ann Fishman, Sarah Lawrence and Weiyi Mu, CGC
Johns Hopkins University

Building Bridges: Communicating with Partners About Care Needs and Challenges
For People with FTD
Matt Sharp, Teresa Webb

2:00 p.m. Breakout Sessions: Care Strategies

Navigating Key Care Decisions in FTD
Mary Anne Wylie, RN, Johns Hopkins University, FTD Clinic

Enhancing Quality of Life Through Activities
Catherine Piersol, OTR, Thomas Jefferson University

Communication Strategies and Emerging Research in PPA
Kyrana Tsapkini, PhD, Johns Hopkins University
Stephanie Grasso, M.A., CCC-SLP, Doctoral Student,
The Aphasia Research and Treatment Lab, The University of Texas at Austin

Comfort Care and End of Life Considerations
Nancy Flowers, MSW, LCSW, Rainbow Hospice & Palliative Care

Moving Forward with an FTD Diagnosis
For People with FTD
Rod Hall, Matt Sharp, Diana Winoker

3:15 p.m. Breakout Sessions: Support & Networking

Mindfulness-Based Stress Reduction Exercises
Corey Esannason, AFTD Regional Coordinator Volunteer

Making a Difference: Share Experiences and Learn Opportunities as an AFTD Volunteer
Sarah Sozansky Beil, AFTD Regional Coordinator Volunteer

What About the Kids? Meet Others Facing FTD with Kids & Teens in the Home
Shana Nissen, AFTD Volunteer

Connecting with Online Friends
For Caregivers
Sharon Denny, Sharon Hall

Connecting with Online Friends
For People with FTD
Matt Sharp

Speaker Bios

Halima Amjad, M.D., M.P.H. is an Assistant Professor of Medicine in the Division of Geriatric Medicine at Johns Hopkins University. As our conference's keynote speaker, her bio is provided on page 56.

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 29, 22 and triplets (age 19). 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.

Sarah Sozansky Beil is a Virginia-based AFTD Regional Coordinator Volunteer, coordinating volunteer efforts in Middle Atlantic states of Delaware, Maryland, Washington D.C., Virginia and West Virginia. Sarah works as a claims adjudicator/analyst for the Virginia Department of Aging and Rehabilitative Services. Sarah conducts AFTD's quarterly facility outreach training for volunteers. She lost her father to FTD in 2016.

Sharon S. Denny, M.A., 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 six 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 26 years of experience in program development for disability organizations. She has been with AFTD since September 2008.

Susan Dickinson, M.S., C.G.C., Chief Executive Officer (CEO), joined AFTD as Executive Director 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 $3 million organization with 15 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 M.S. in genetic counseling from Arcadia University and B.A. in biology and psychology from Swarthmore College.

Corey Esannason, R.Y.T. yoga educator and one of AFTD's Middle Atlantic Regional Coordinator volunteers, coordinating efforts in New Jersey and Pennsylvania. Her mother was diagnosed with FTD in 2011. Her combined passion for moving and learning inspire her work, which provides yoga programming to adults and children throughout Westchester County, NY. With more than 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, her teachers and the inspiration her students provide her with on a daily basis. Corey is excited to share her personal and professional knowledge with the AFTD community.

Ann Fishman, M.B.A. has been a Research Coordinator at the Johns Hopkins School of Medicine for 5 years. She coordinates Johns Hopkins's participation in the multicenter research study Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL). She is also participating in a new project at Johns Hopkins to give individuals with FTD and their families a voice, gaining their perspectives on what aspects of the disease would need to change for a treatment to be considered a success.

Nancy Flowers, M.S.W., L.C.S.W. 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.

Stephanie Grasso, M.A. is a speech-language pathologist and doctoral student mentored by Dr. Maya Henry in the Aphasia Research and Treatment Lab at the University of Texas at Austin. Her research interests pertain to the manifestation of neurologically based communication disorders within the context of bilingualism. Stephanie's research also focuses on expanding the evidence base for speech-language interventions in individuals with primary progressive aphasia. She uses neuroimaging techniques to inform variability in treatment responsiveness in these populations. She graduated with a B.A. in Communicative Disorders from the University of Redlands, and an M.A. in Communication Sciences and Disorders from the University of Texas at Austin.

Lisa P. Gwyther, M.S.W., L.C.S.W. is a social worker with 40 years of experience working with people living with dementia and their families. An Associate Professor in the Duke Department of Psychiatry, she directs the Duke Family Support Program. Lisa is a past president of the Gerontological Society of America and was the first recipient of the John Heinz Congressional Fellowship in Aging and Health. She has published more than 150 articles, chapters and books on dementia and family care. Ms. Gwyther co-chaired the NC Dementia Capable state plan task force in 2015–2016, and was a National Academies of Science, Engineering and Medicine consensus panelist for two major recent reports on cognitive aging and family caregiving. She received her graduate training in social work at Case Western Reserve University. She is an advisor to AFTD's Partners in FTD Care educational series.

Rod Hall spent his career in printing industry management. His current AFTD independent fundraising campaign—developing a 2018 FTD calendar—leverages his 45 years of printing experience. His mother had Pick's disease, and his advocacy for the FTD community began when he was diagnosed in early 2016.

Sharon Hall: After a long career in the corporate world, Sharon Hall retired in 2014 to care for her mother full time, and has been caregiver to her husband Rod since his FTD diagnosis. An advocate for FTD awareness and support, she facilitates an AFTD affiliated support group, and hosts weekly FTD chats and a podcast on Caregiving.com.

David Irwin, M.D. is an Assistant Professor of Neurology at the University of Pennsylvania Perelman School of Medicine. Dr. Irwin is a former post-doctoral fellow at the Penn Center for Neurodegenerative Disease Research and Frontotemporal Degeneration Center. Dr. Irwin's research is focused on improving comparative clinicopathological studies in neurodegenerative disease through development of novel digital image analysis methods for use on human autopsy histology samples. The overarching goal of this approach is to improve the ante mortem diagnosis of underlying neuropathology for improved clinical trials targeting specific pathogenic proteins (e.g. Tau, TDP-43, alpha-synuclein) that characterize these disorders.

Kerri Keane, M.S.W., AFTD Volunteer Manager, has more than 16 years of experience advocating for and supporting the needs of individuals with life-threatening and debilitating diseases and their families. Her background includes developing and implementing effective programs, and a passion for volunteering. Her past work has included spearheading and managing a grassroots advocacy coalition in Pennsylvania for four years, and completing two international missions through Doctors Without Borders. Kerri now uses her skills and experience to strengthen and expand AFTD's volunteer network.

Sarah Lawrence, M.S., is a Research Program Manager in the department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine. In this position, she leads a team that carries out clinical trials in Alzheimer's disease and FTD under the direction of Johns Hopkins faculty members. Mrs. Lawrence has 5+ years of clinical and community research experience in aging and chronic disease prevention. She holds her Master's degree in Genetic Counseling from the University of Pittsburgh, and a Bachelor of Arts degree in Biology from the University of Delaware.

Maya Lichtenstein, **M.D., M.H.S.** works as a behavioral neurologist with Geisinger Health System in Pennsylvania as part of a multidisciplinary team diagnosing and caring for patients with dementia and their families. Dr. Lichtenstein studied medicine at the Sackler School of Medicine in Tel Aviv, trained as a resident of neurology at Penn State Hershey Medical Center, and was a fellow in behavioral neurology for two years at the University of British Columbia's Clinic for Alzheimer Disease and Related Disorders in Vancouver. From UBC, she also received a master of health science degree in clinical epidemiology and began a project funded by AFTD that she continues to recruit for at Geisinger. This project looks at the differences in social cognition in patients with behavioral-variant frontotemporal dementia (bvFTD) and depression with the goal of making a screening tool for earlier diagnosis of bvFTD.

Lauren Massimo, **Ph.D., C.R.N.P.** is a Research Associate at The Pennsylvania State University College of Nursing and the University of Pennsylvania Frontotemporal Degeneration Center. Dr. Massimo's research focuses on identifying the cognitive and neural basis for neuropsychiatric symptoms in neurodegenerative disease. Over her decade-long career as a nurse practitioner in cognitive neurology, she has enjoyed the opportunity to work with and support many patients with neurodegenerative disease and their families. She has received numerous grants and awards including The John A. Hartford Foundation Building Academic Geriatric Nursing Capacity Award and two National Research Service Awards. She is currently funded by the National Institute on Aging for her work on the biologic basis underlying longitudinal decline in frontotemporal degeneration. Dr. Massimo holds a bachelor's degree in Nursing from The Pennsylvania State University, a master's degree as an Adult and Gerontology Nurse Practitioner and a Ph.D. in Nursing from the University of Pennsylvania.

Bridget Moran, **M.P.H.** joined AFTD in May 2015 as Support Services Manager. She now works collaboratively with AFTD staff and volunteers to foster resilience in and engage our growing community. A key part of Bridget's role is to create and manage a national network of support groups across the U.S. She holds a Master's in Public Health from Drexel University. Bridget joined AFTD from the University of Pennsylvania, where she coordinated clinical and research projects in the fields of mental and community health.

Weiyi Mu, **Sc.M., C.G.C.** is a genetic counselor at the Johns Hopkins University School of Medicine. She received her Master of Science in Genetic Counseling from the Johns Hopkins Bloomberg School of Public Health and is certified by the American Board of Genetic Counseling. She has a special interest in adult neurogenetic populations, including familial dementias and ALS. She provides to patients and their families evaluation of whether a genetic cause for dementia is likely, genetics education, coordination and interpretation of genetic testing, and counseling to facilitate decision-making and adaptation to living with a chronic condition.

Shana Nissen shares her time and talents as an AFTD volunteer in many ways. Based in Texas, she is an AFTD-affiliated support group facilitator who co-leads a San Antonio support group. Shana and her daughter Athena have hosted several AFTD grassroots events, and their family's story was recently profiled in WAG Magazine. Shana's husband Andy, a veteran diagnosed with FTD in his mid-30s, passed away in 2016.

Chiadi Onyike, **M.D.**, a neuropsychiatrist, is an Associate Professor of Psychiatry and Behavioral Sciences at Johns Hopkins University and Director of the Johns Hopkins Frontotemporal Dementia and Young-Onset Dementias Program. His work focuses on the epidemiology, neuropsychiatry and treatment of the frontotemporal dementias, young-onset Alzheimer's disease and related disorders. Dr. Onyike serves on AFTD's Medical Advisory Council, the Executive Committee of the International Society for Frontotemporal Dementias, the FTD Disorders Registry's Scientific Advisory Board, the FDA Advisory Committee for Peripheral and Central Nervous System Drugs, and Maryland's Virginia I. Jones Alzheimer's Disease and Related Disorders Council. He has also served on the Board of the Alzheimer's Association of Greater Maryland. After receiving a Medical Degree from the University of Nigeria, Dr. Onyike completed his internships at the University of Nigeria Teaching Hospital and St. Elizabeth's/CMHS in Washington D.C., a research fellowship in Neurochemistry/Cell Signaling at the University of Maryland at Baltimore, and a residency in Psychiatry and fellowships in Clinical Psychiatry and Psychiatric Epidemiology at Johns Hopkins. He holds a graduate degree in Clinical Epidemiology.

Rebecca Rye, M.S.N. is a Psychiatric Nurse Practitioner currently working in the Johns Hopkins Frontotemporal and Young-Onset Dementia Clinic. She provides ongoing care, including management of neuropsychiatric symptoms and care coordination with other medical providers. She supports and assists caregivers to connect with community resources.

Matthew Sharp, M.S.S., 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. During Matt's last semester of graduate school his father-in-law was diagnosed with behavioral variant FTD. 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 and the development of the organization's growing advocacy efforts.

Maura English Silverman, M.S., C.C.C./S.L.P. is the Founder and Executive Director of the Triangle Aphasia Project (TAP), Unlimited. She serves as director and manager to a staff of 17 Speech Pathologists who provide group therapy programs across the Triangle area of North Carolina. Maura is a North Carolina-licensed Speech Language Pathologist, a nationally certified member of the American Speech-Language-Hearing Association and an Aphasia Hope Foundation Professional Panel Expert, as well as being founder and an active Governance Committee member for Aphasia Access. She has taught as an adjunct professor/guest lecturer for the Department of Speech-Language-Hearing Sciences at Hofstra University, UNC–Chapel Hill, Shaw University and North Carolina Central University. She received her Bachelor of Science in Communication Disorders from Marywood University and her Master of Science degree in Speech Language Pathology from Ithaca University.

Peter V. Stewart, Ph.D. is an early-career neuropsychologist at the Geisinger Health System in Pennsylvania. He completed his graduate training in Clinical Psychology at Indiana University of Pennsylvania and his postdoctoral residency at Geisinger Medical Center. Dr. Stewart practices as a generalist adult neuropsychologist and has a special interest in neurodegenerative conditions and dementia. As a member of Geisinger's Aging Brain and Behavioral Neurology Center and in his general practice, Dr. Stewart provides direct clinical services to individuals affected by dementia and their family members, with an emphasis on diagnostic evaluation. Dr. Stewart is actively engaged in research focused on designing algorithms to predict functional status in individuals with dementia using neuropsychological test data.

Nadine Tatton, Ph.D., 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. She has a personal connection to ALS, having been a family caregiver and is deeply committed to the translation of scientific discoveries into treatment opportunities that will benefit patients and caregivers alike in FTD and other neurodegenerative disorders.

Kyrana Tsapkini, Ph.D., is Assistant Professor at the Department of Neurology at Johns Hopkins School of Medicine. Her research examines the interactions between language and cognitive systems in post-stroke and primary progressive aphasia (PPA). In her investigations she is using behavioral, structural and functional imaging, and brain stimulation methodologies. Her recent research interests involve finding ways to augment the effects of speech and language interventions in PPA by using transcranical direct current stimulation (tDCS). She also investigates the brain mechanisms of tDCS interventions using multimodal imaging to unravel structural and functional connectivity and neurometabolite changes in the brains of participants with PPA. Her research has been supported by grants from Johns Hopkins University, the National Institutes of Health (NIH) and philanthropy.

Catherine Verrier Piersol, Ph.D., OTR/L, FAOTA, is associate professor in the Department of Occupational Therapy and Director of Jefferson Elder Care at Thomas Jefferson University. Jefferson seeks to bridge the gap between research and practice by providing evidence-based services to people with dementia and their caregivers with the goal of optimizing participation, and promoting quality of life and well-being. Dr. Piersol is a licensed occupational therapist, researcher and educator with more than 34 years of experience. In addition to current research projects that are evaluating community-based dementia interventions, she receives funding from the Pew Charitable Trust to implement a program for elders with dementia and their caregivers living at home. Dr. Piersol provides consultation to agencies and has presented extensively on best practice in dementia care. Her publications include a home health manual for occupational therapists and, most recently, a caregiver's guide to dementia that targets strategies for activity engagement.

Teresa Webb worked as a registered nurse and clinical case manager for 20 years. She retired from managed care in 2010, the same year she was diagnosed with PPA/FTD. Teresa advocates for FTD awareness and strives to find ways to promote healthy and positive living that enhance independence and quality of life.

Dianna Wheaton, M.S., Ph.D. 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.

Diana Winoker, M.B.A., retired from a 36-year career in the financial services industry that included work in estate and retirement planning as well as investment and asset management after being diagnosed with FTD in 2012. Diana currently lives on her own in Tampa, FL, and is a passionate advocate for greater awareness and respect for people diagnosed with FTD.

Kati Woodford is a North Carolina-based AFTD volunteer. Currently a mental health technician for a behavioral health hospital focused on acute psychiatric and substance use complications, she has a history of working with vulnerable youth populations in in-home, community based and psychiatric residential treatment programs. A graduate student working toward a Master's in Social Work, she helps to administer AFTD's Young Adult Facebook group. Her father was diagnosed with FTD in 2016.

Mary Anne Wylie, M.S., R.N., A.P.N. is an Advanced Practice Psychiatric Nurse in the Johns Hopkins Frontotemporal Dementia and Young-Onset Dementias Clinic. She works with patients and families to provide illness education and assist with caregiver issues, accessing community resources and end-of-life care.

AFTD Education Conference 2017
Baltimore, Maryland

Clinical Update and Overview of FTD Disorders

Chiadi U. Onyike, MD, MHS
Associate Professor, Neuropsychiatry
FTD and Young-Onset Dementias Program
Johns Hopkins SOM

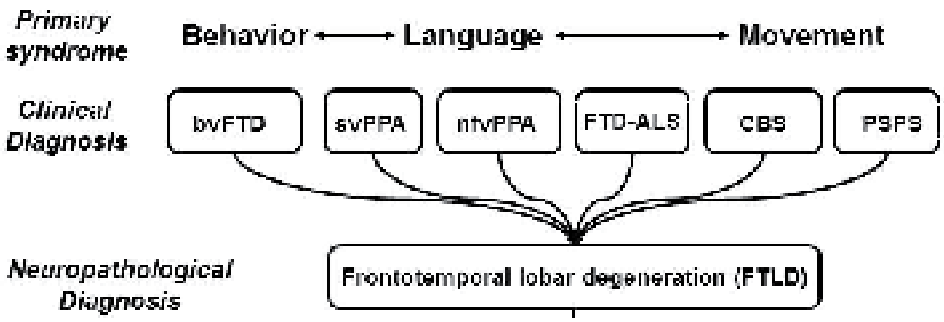
Classical definition of frontotemporal dementia (FTD)

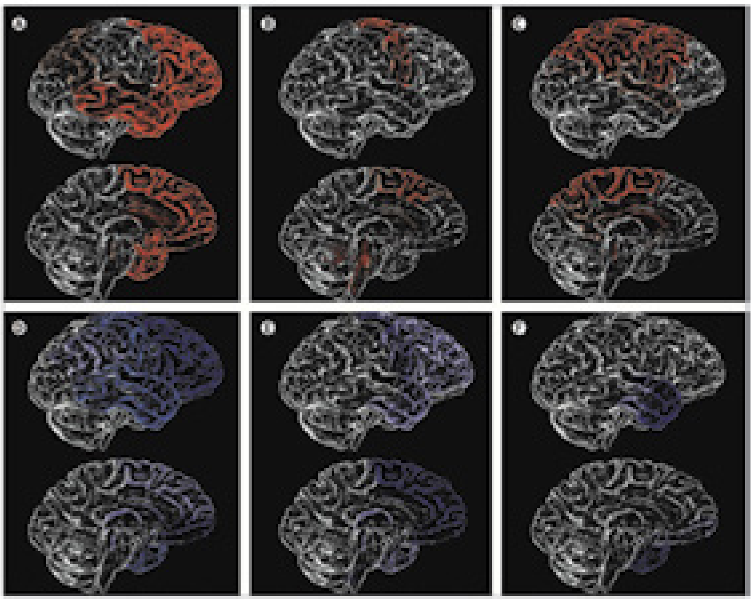
Onyike et al., 2011; Onyike & Diehl-Schmid, 2013

"…hallmarks are progressive decline in [conduct]: coarsening of temperament, dispositions, judgment, and comportment; dysregulation of emotions, drives and self-control; and disintegration of language and communication…"

*"Thus results a **behavioral phenotype** beginning with combinations of indifference, impatience, carelessness, jocularity, insensitivity, distractibility, impulsiveness, stereotyped behaviors, compulsions and rigid routines; **or language phenotypes** featuring either effortful, dysfluent, agrammatical speech, plus impaired comprehension of sentences, **or** fluent, vacuous speech, with anomia and word (and object) agnosia".*

Spectrum of FTD syndromes





Patterns of atrophy in FTD

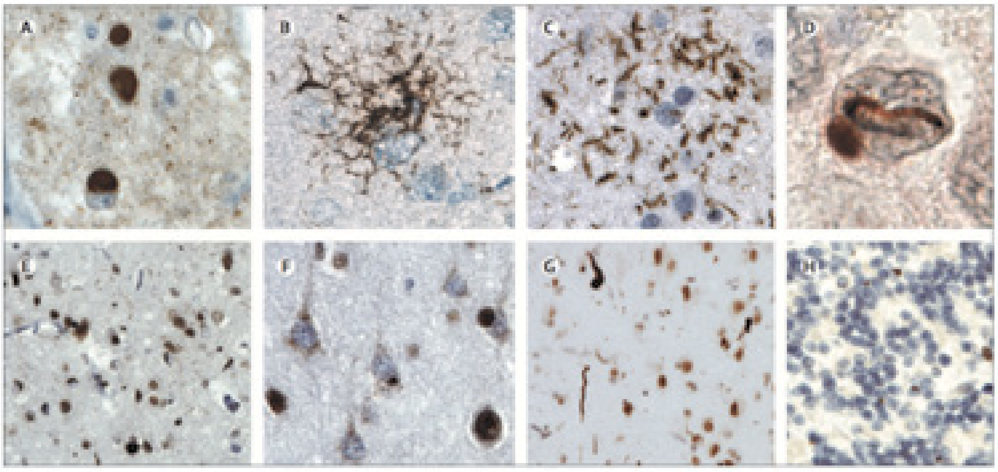
Bang et al., 2015

(**A**) Pick's disease
(**B**) PSP
(**C**) CBD
(**D**) FTLD-TDP type A
(**E**) FTLD-TDP type B
(**F**) FTLD-TDP type C.

FTLD-TDP type A shows an asymmetrical dorsal pattern of atrophy that involves the frontal lobe and temporal lobe (anterior, medial, and posterior regions), orbitofrontal cortex, anterior cingulate gyrus, inferior parietal lobe, striatum, and thalamus.

FTLD-TDP type B shows a more medial pattern mainly involving the medial and polar temporal lobe, anterior insular, cingulate and medial prefrontal cortices, and the orbitofrontal cortex. The frontal lobe is more severely affected in the posterior areas.

FTLD-TDP type C shows right-predominant or left-predominant anterior temporal lobe atrophy, plus involvement of the amygdala, hippocampus, orbitofrontal cortex, and insular cortex.



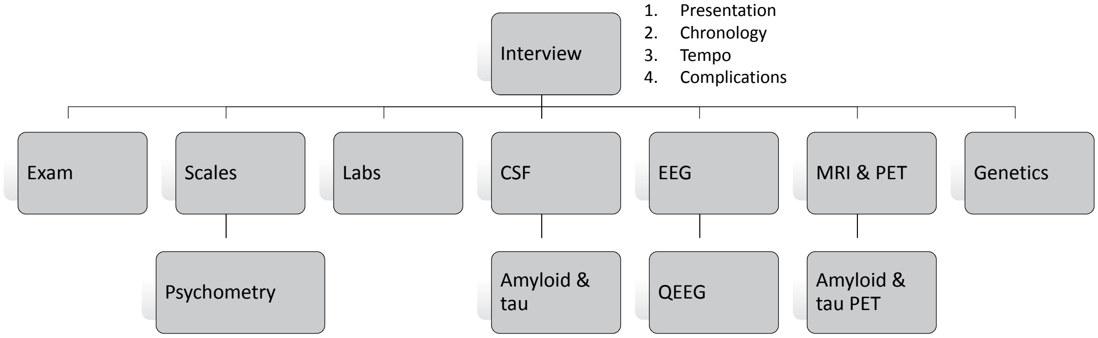
Histopathology in FTD *Bang et al., 2015*

FTLD-tau: (**A**) Pick bodies in Pick's disease; (**B**) a tufted astrocyte in PSP; (**C**) an astrocytic plaque in CBD.
FTLD-TDP: (**E**) small compact or crescentic cytoplasmic inclusions and short neuropil threads in FTLD-TDP type A; (**F**) diffuse or granular cytoplasmic inclusions in FTLD-TDP type B; and (**G**) long, tortuous dystrophic neurites in FTLD-TDP type C. TDP is seen in the nucleus in neurons lacking inclusions and localized to the cytoplasm as inclusion bodies in FTLD-TDP.
Other FTLD types are characterized by FUS-immunoreactive inclusions that stain negatively for tau and TDP-43; a vermiform neuronal nuclear inclusion in a dentate gyrus granule cell is shown (**D**); this neuron contains an ovoid cytoplasmic inclusion.
Small juxtanuclear ubiquitin-positive, TDP-negative inclusions (**H**) are pathognomonic of *C9orf72* FTLD and contain dipeptide repeat proteins.
Methods: Immunostains are 3-repeat tau (A), phospho-tau (B and C), FUS (D), TDP-43 (E–G) and ubiquitin (H). Sections are counterstained with haematoxylin.

Genetic diversity in hereditary FTD

Gene	Locus	%	Pathologic type	Clinical type
MAPT	17q21	20-25	Tau +	FTD ± parkinsonism; PNFA; CBD; PSP
PGRN	17q21	20-30	TDP43 +	FTD; SD
C9ORF72	9p21	25-40	TDP43 +	FTD; FTD-ALS; ALS; amnesic; psychiatric
CHMP2B	3p11.2	<1	Ubiquitin +, Tau –, TDP43 –	FTD
VCP	9p13	<1	TDP43 +	IBMPFD
TBK1	12q14.1	<1	TDP43 +	FTD; FTD-ALS; ALS

Evaluation schema

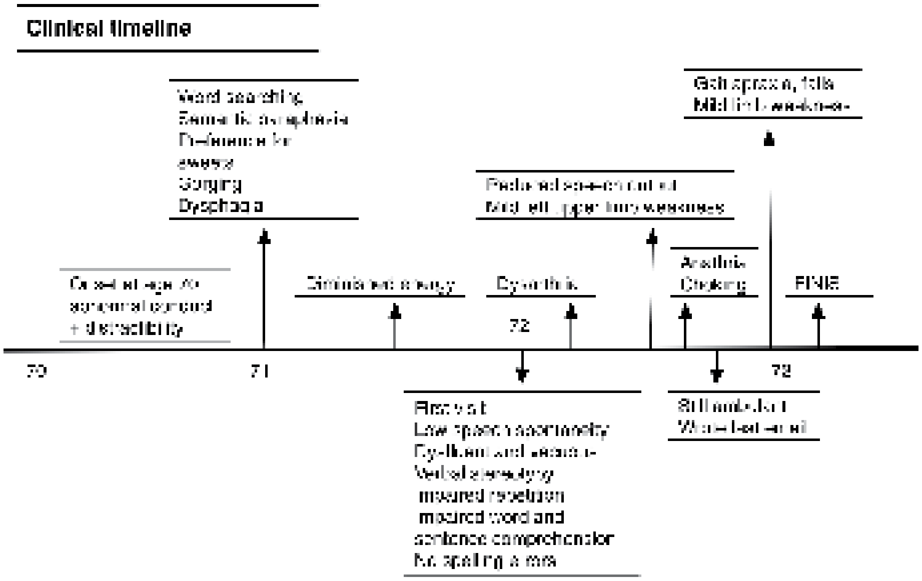


Interview

1. Presentation
2. Chronology
3. Tempo
4. Complications

- Exam
- Scales
  - Psychometry
- Labs
- CSF
  - Amyloid & tau
- EEG
  - QEEG
- MRI & PET
  - Amyloid & tau PET
- Genetics

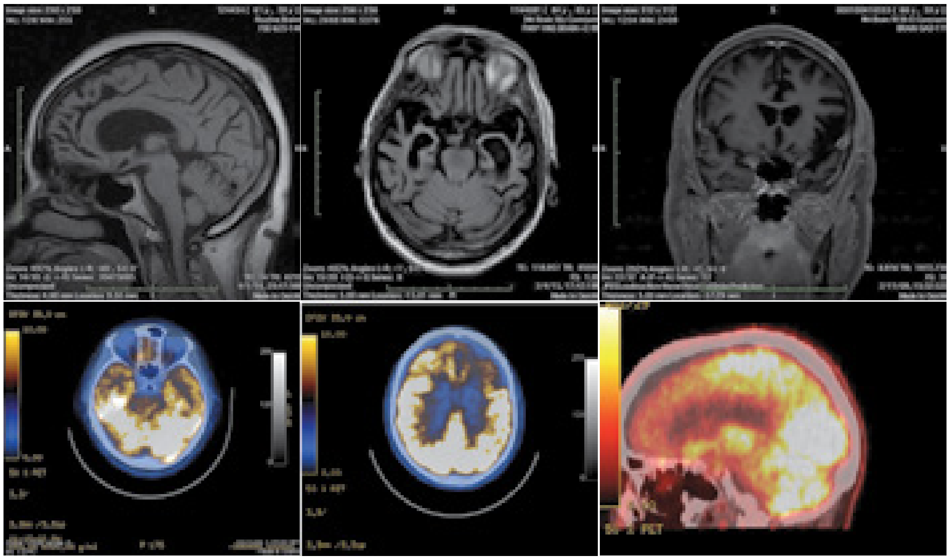
Illustration of historical data in FTD-ALS



Commonly used psychometric measures

Test	Domain	Comments
MMSE	Cognition	Widely known and takes 5-10 minutes to administer.
MoCA	Cognition	Widely available; takes ~10 minutes. Very sensitive in the early stages
ACE	Cognition	Better known in Europe and Asia; Takes 15-20 minutes
FRS	Illness severity	Used in studies to measure severity; takes >20 minutes
NPI; NPI-Q	Behavior	Widely used; measures many behaviors – but not that define FTD
FAB	Behavior	Developed for FTD; may help distinguish FTD from AD in the clinic
CDR; CDR7	Illness staging	Widely used; in-person and online training available; Modified version for FTD

Brain MRI and FDG-PET in FTD *Onyike CU, images from the JH FTD-YOD Clinic archives*

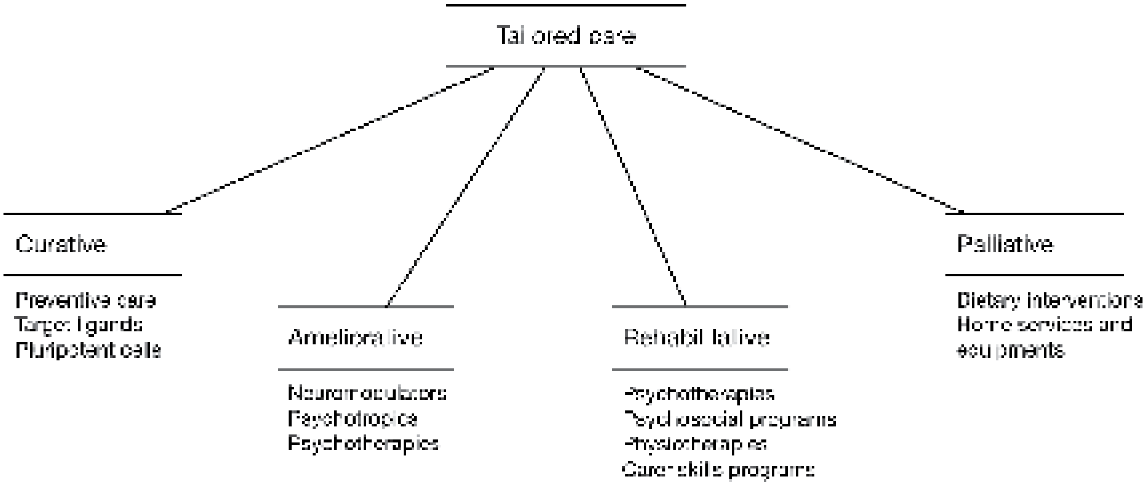


Basis of dementia care

Onyike & Huey 2013; Wylie et al., 2013

Problem	Role	Intervention
Disease/disorder	Diagnose	Provide evaluation, direct investigation, make referrals
Disability, crisis	Solve problems	Crisis interventions and psychosocial/rehabilitative care
Distress	Provide relief	Make prescriptions
Demoralization, stress	Guidance	Provide clarification, support and direction

The modes of dementia care



Tailored care

Curative

Preventive care
Target ligands
Pluripotent cells

Ameliorative

Neuromodulators
Psychotropics
Psychotherapies

Rehabilitative

Psychotherapies
Psychosocial programs
Physiotherapies
Carer skills programs

Palliative

Dietary interventions
Home services and
equipments

Behavioral interventions for FTD

Belle et al., 2006; Gitlin et al., 2010; Nichols et al., 2011; McKinnon et al., 2013; Mioshi et al., 2013; Wylie et al., 2013; O'Connor et al., 2014; Samus et al., 2014; Bier et al., 2015; Morhardt et al., 2015; Onyike, 2016

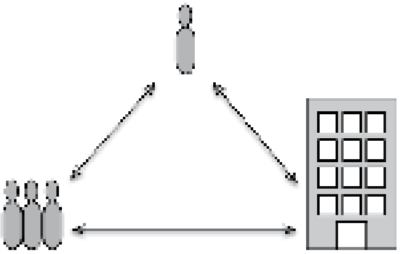
- Psychotherapeutic methods
  - Social engagement, structured and unstructured activities, use of distractors
  - Behavior remodeling
  - **TAP**: Tailored Activities Program
  - **DICE: Describe, Investigate, Create, Evaluate**
  - Problem-Solving Therapy approaches

- Care support programs
  - Clinic-based **case management**
  - **ACT**: Advancing Caregiver Training
  - **REACH**: Resources for Enhancing Alzheimer's Caregiver Health
  - **COPE**: Care of Persons with Dementia in their Environment

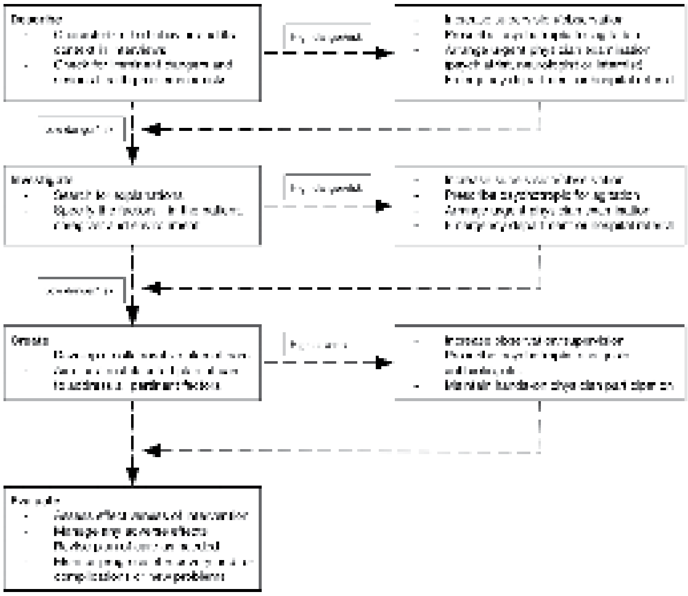
- Rehabilitative devices and programs
  - Alarms, trackers, and smartphone and tablet apps
  - **MIND@Home**: Maximizing Independence in the Home
  - **CARE-D**: Care Pathway Model for Dementia

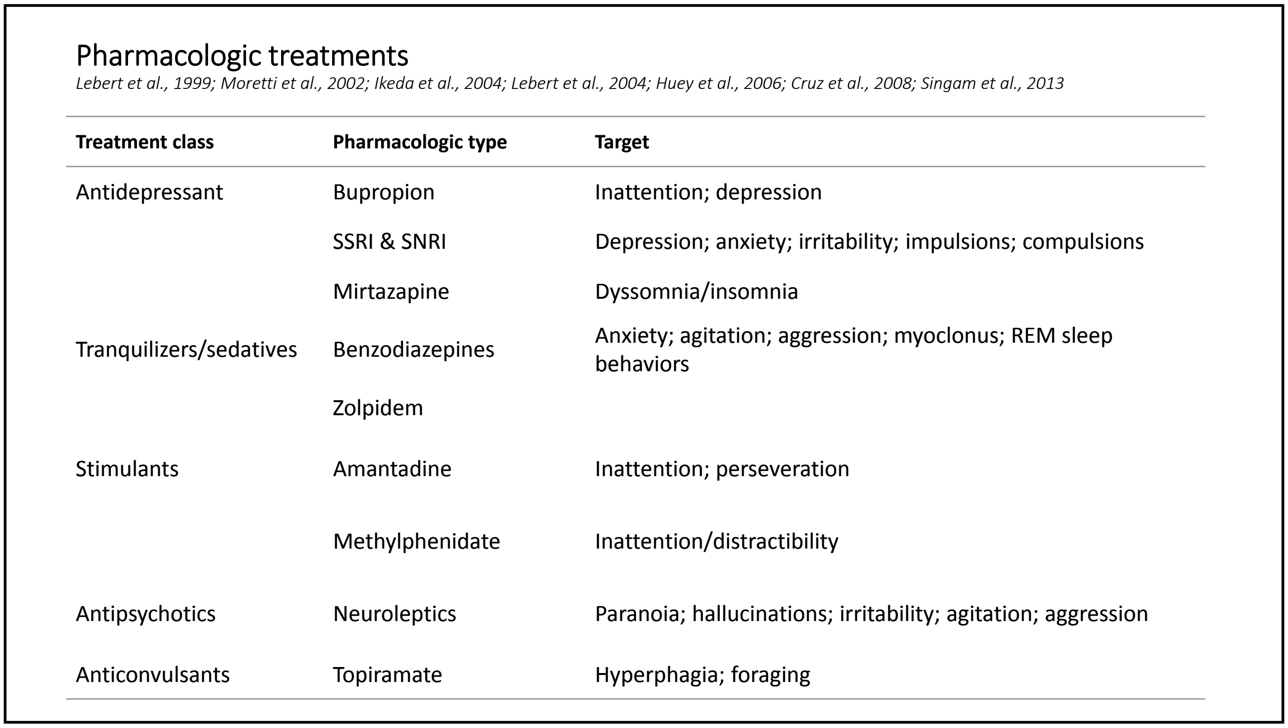
The DICE (Describe, Investigate, Create, Evaluate) Method

Onyike 2016, adapted from Kales et al., 2015



The care triad:
- Person
- Carers
- Environment

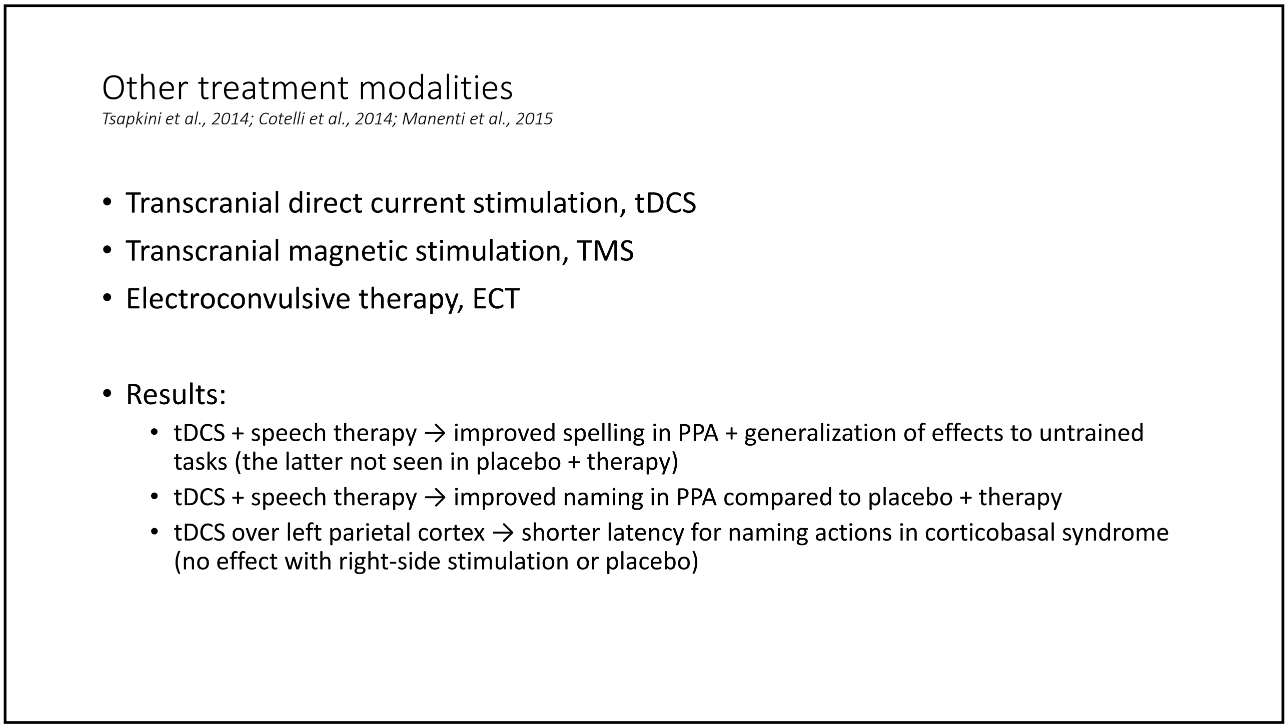




Pharmacologic treatments

Lebert et al., 1999; Moretti et al., 2002; Ikeda et al., 2004; Lebert et al., 2004; Huey et al., 2006; Cruz et al., 2008; Singam et al., 2013

Treatment class	Pharmacologic type	Target
Antidepressant	Bupropion	Inattention; depression
	SSRI & SNRI	Depression; anxiety; irritability; impulsions; compulsions
	Mirtazapine	Dyssomnia/insomnia
Tranquilizers/sedatives	Benzodiazepines	Anxiety; agitation; aggression; myoclonus; REM sleep behaviors
	Zolpidem	
Stimulants	Amantadine	Inattention; perseveration
	Methylphenidate	Inattention/distractibility
Antipsychotics	Neuroleptics	Paranoia; hallucinations; irritability; agitation; aggression
Anticonvulsants	Topiramate	Hyperphagia; foraging



Other treatment modalities

Tsapkini et al., 2014; Cotelli et al., 2014; Manenti et al., 2015

- Transcranial direct current stimulation, tDCS
- Transcranial magnetic stimulation, TMS
- Electroconvulsive therapy, ECT

- Results:
  - tDCS + speech therapy → improved spelling in PPA + generalization of effects to untrained tasks (the latter not seen in placebo + therapy)
  - tDCS + speech therapy → improved naming in PPA compared to placebo + therapy
  - tDCS over left parietal cortex → shorter latency for naming actions in corticobasal syndrome (no effect with right-side stimulation or placebo)

Clinical trials on the horizon

Low-dose lithium

ClinicalTrials.gov ID#: NCT02862210
https://clinicaltrials.gov/ct2/show/NCT02862210

- Design:
  - RCT for agitation, aggression and disinhibited/compulsive behaviors
  - N = 60; 12 week Phase II trial
  - NPI ≥6; MMSE 5–26
  - Titration: 150, 300, 450 and 600 mg/day
  - Serum [Li] 0.2–0.6 mmol/L, sampling 12–14 h after last dose, blinded
  - Goals: change in agitation, aggression and restlessness scores

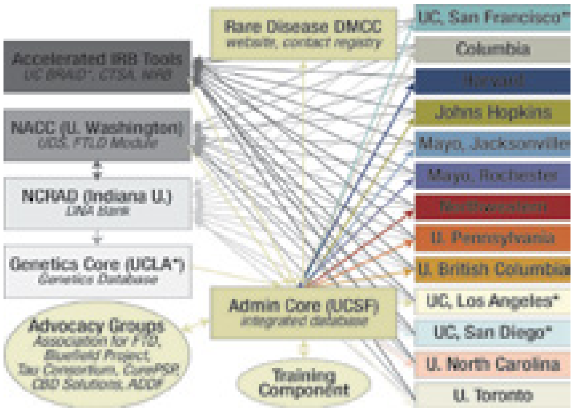
Intranasal oxytocin (FOXY)

ClinicalTrials.gov ID#: NCT01937013
https://clinicaltrials.gov/ct2/show/NCT01937013

- Design:
  - RCT for apathy/asocial states
  - N = TBD; 16 week Phase II trial
  - Entry based on diagnosis,
  - Dose finding phase (stage 1, weeks 1–6): placebo v. 24, 48 and 72 U
  - Stage 2 (weeks 11–16): placebo v. selected dose
  - Exclusion criteria relate to mimics of diagnosis or behaviors, and to compliance and safety
  - Goals: change in NPI apathy and IRI empathy scores.

How you can participate

- ARTFL/LEFFTDS centers
  - Observational studies
  - Genetics
- **Clinical trials:** http://www.theaftd.org/life-with-ftd/participate-in-research/clinical-trials-laypersons
- FTD Registry: https://ftdregistry.org
- Neuropathology: FTD centers, ADRCs
- At Johns Hopkins:
  - Clinic: +1-410-502-2981
  - ARTFL: +1-410-502-5816
  - Trials: +1-410-550-9020
- Support groups: http://www.theaftd.org/get-involved/regions



Washington U.
UAB,
Birmingham

Presentation: FTD Disorders Registry

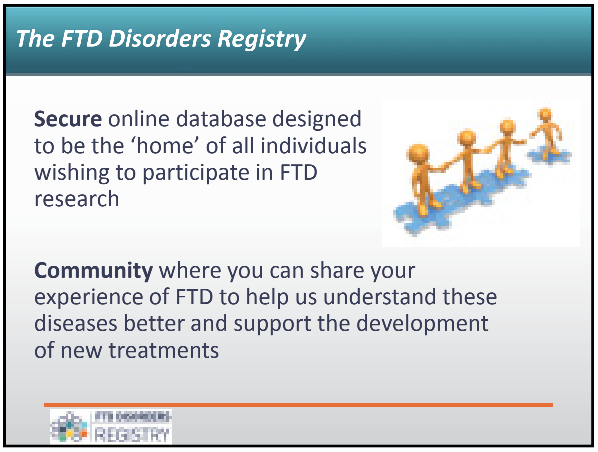
FTD DISORDERS
REGISTRY

2017 AFTD Annual Education Conference

Baltimore, MD

May 5th, 2017

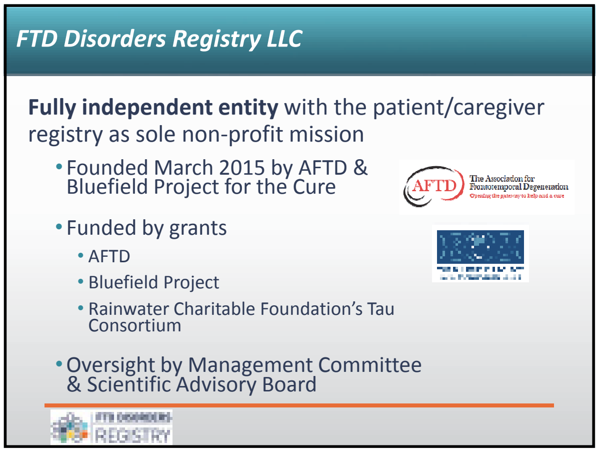
FTD Disorders Registry LLC
Dianna K.H. Wheaton, MS, PhD, CHES



The FTD Disorders Registry

Secure online database designed to be the 'home' of all individuals wishing to participate in FTD research

Community where you can share your experience of FTD to help us understand these diseases better and support the development of new treatments



FTD Disorders Registry LLC

Fully independent entity with the patient/caregiver registry as sole non-profit mission

- Founded March 2015 by AFTD & Bluefield Project for the Cure
- Funded by grants
  - AFTD
  - Bluefield Project
  - Rainwater Charitable Foundation's Tau Consortium
- Oversight by Management Committee & Scientific Advisory Board

FTD Disorders Registry Format

- **Contact** & **Research** registry
  - Health outcomes research
  - Support clinical trial & research study recruitment
- Self-report, participant-entered data via online survey tool
- Curated, audited, & error checked
- IRB-approved & HIPAA-compliant platform

FTD Disorders Registry Research Tools

Surveys/questionnaires

- FTD Disorders Registry intake surveys
  - Demographics
  - Disease impact
  - Research ready
- ARTFL
  - Lifestyle questionnaire
  - Autoimmune history
  - Clinical trials
- Additional surveys to be added

FTD Registry Homepage

Why Join?

- Your experience can improve our knowledge of FTD, impact care, and help others
- Participating in research surveys will provide data to advance the science
- The Registry will be the go-to site to recruit for FTD clinical trials

FTD Disorders Registry, cont'd.

FTD Registry Target Population

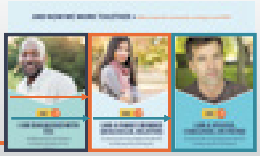
Who can Join?

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

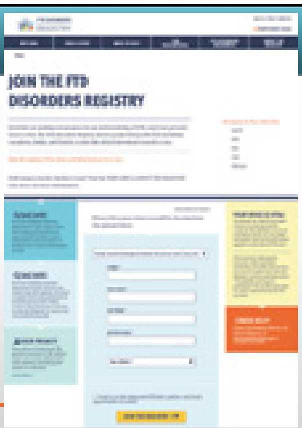
FTD diagnosed person
Self-enroll or with helper →

Biological family member →

Spouse/Caregiver/Friend →



Join the Registry



Contact Registry

- Share name & email
- email updates

Research Participation

Research Registry

- Login account with password
- Informed Consent

FTD Disorders Registry Data & Privacy

- Registrant's personally identifiable information (PII) masked with GUID
- Registry Director is ***sole person with access to PII***
- Aggregate, de-identified data shared with the public via website, newsletters, publications
- Third-party access to de-identified data
  - Reviewed by Scientific Advisory Board & approved by Management Committee

FTD Disorders Registry Timing

- **Join the FTD Disorders Registry.**
- **Tell your story.**
- **Advance the science.**

www.ftdregistry.org
www.facebook.com/EndFTDregistry
@EndFTDregistry

10:45 a.m. Breakout Session: Demystifying Diagnosis

Demystifying Diagnosis of Frontotemporal Degeneration

Neuropsychological and Behavioral Neurologic Perspectives

Peter Stewart, Psy.D.
Maya Lichtenstein, M.D.

Caring

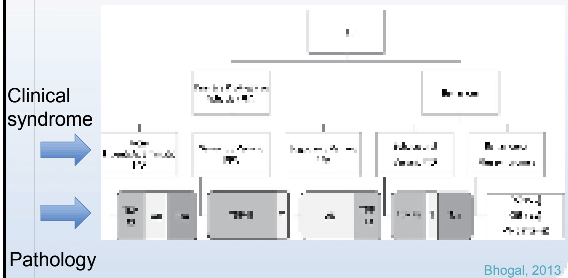
The Importance of Diagnosis

- Explanatory value
- Prognosis and knowing what to expect
- Treatment and care planning
- Possibility of being involved in research
- Better understanding of and care for individuals down the road (i.e., Scientific Progress)

What is FTD?

- Progressive disease
  - Can be sporadic or familial
- Caused by abnormal accumulation of proteins in the brain
  - Tau or TDP-43
- Leads to brain cell death
  - Which we see on imaging (CT/MRI) as “atrophy” or shrinkage
- Preferentially affects the frontal and/or temporal lobes
  - Most common first symptoms are changes in behavior or changes in language

Frontotemporal Lobar Degeneration



Bhogal, 2013

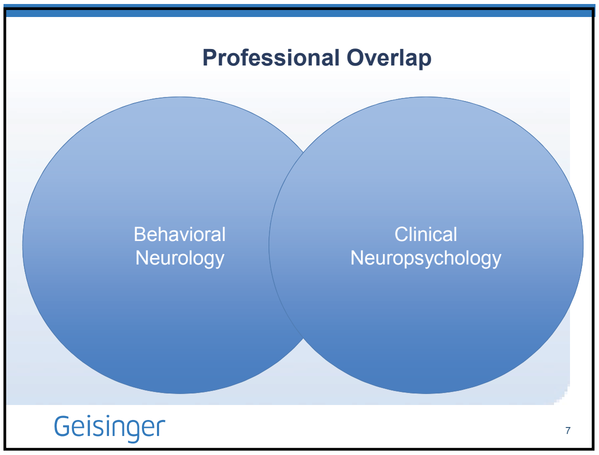
What is Neuropsychology?

- Psychology is the study of behavior
- Clinical Neuropsychology is the study of brain behavior relationships
  - Diagnosis and treatment of conditions affecting the brain
  - Emphasis on cognitive and behavioral testing
  - Investigation of strengths and weaknesses

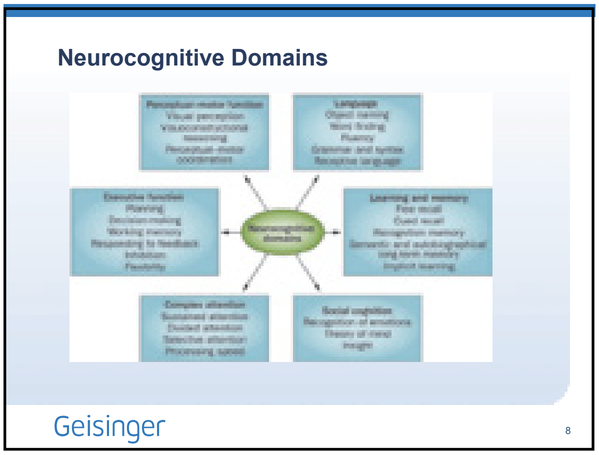
What is Behavioral Neurology?

- Subspecialty of neurology for the evaluation and treatment of brain disorders that affect cognition (how we think) and behavior (how we act)
- Behavioral neurologists see people who come with changes in their cognition or behavior
- We work with neuropsychologists, radiologists and others to help identify what specifically has changed and by how much, and to identify the underlying cause of these changes

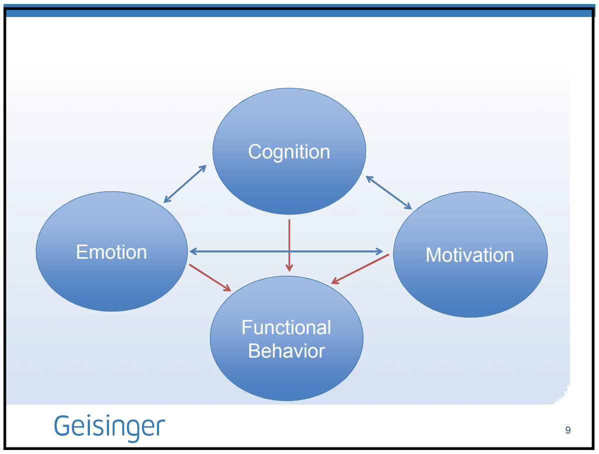
Demystifying Diagnosis, cont’d.

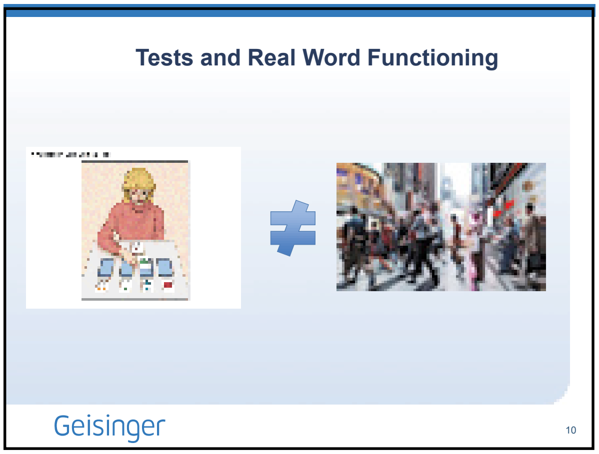


Professional Overlap

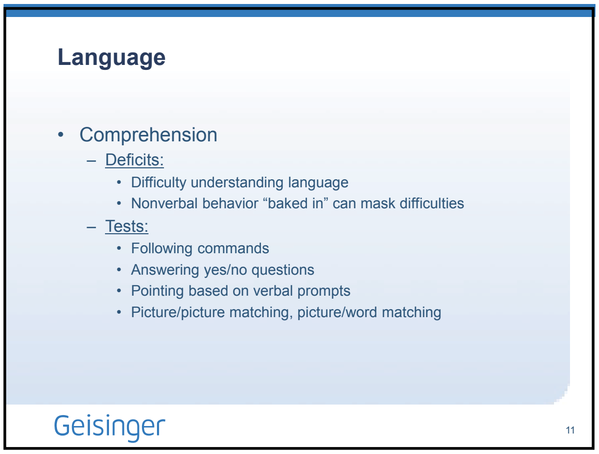


Neurocognitive Domains



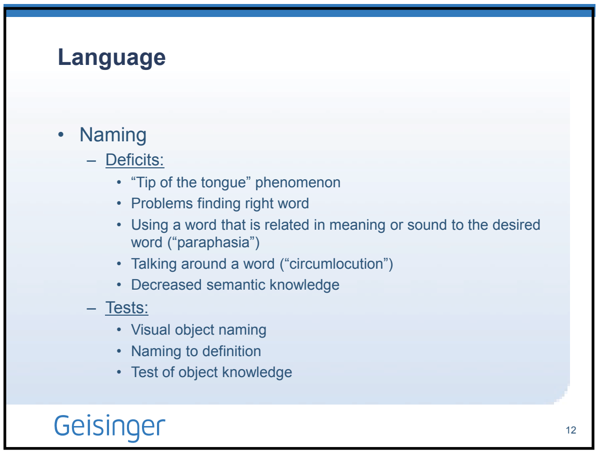


Tests and Real Word Functioning



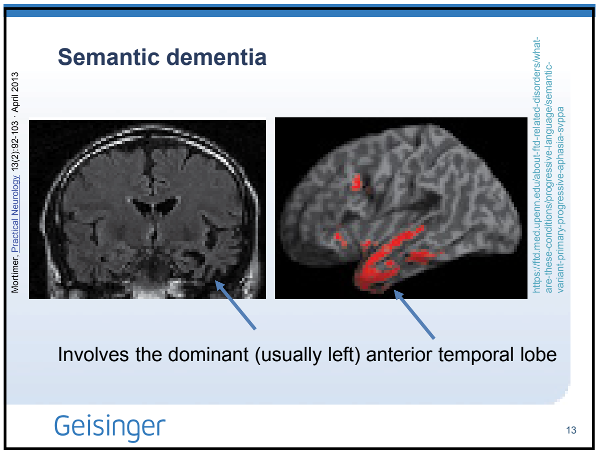
Language

- Comprehension
  - Deficits:
    - Difficulty understanding language
    - Nonverbal behavior “baked in” can mask difficulties
  - Tests:
    - Following commands
    - Answering yes/no questions
    - Pointing based on verbal prompts
    - Picture/picture matching, picture/word matching



Language

- Naming
  - Deficits:
    - “Tip of the tongue” phenomenon
    - Problems finding right word
    - Using a word that is related in meaning or sound to the desired word (“paraphasia”)
    - Talking around a word (“circumlocution”)
    - Decreased semantic knowledge
  - Tests:
    - Visual object naming
    - Naming to definition
    - Test of object knowledge



Semantic dementia

Mortimer, Practical Neurology 13(2):92-103 · April 2013

https://ftd.med.upenn.edu/about-ftd-related-disorders/what-are-these-conditions/progressive-language/semantic-variant-primary-progressive-aphasia-svppa

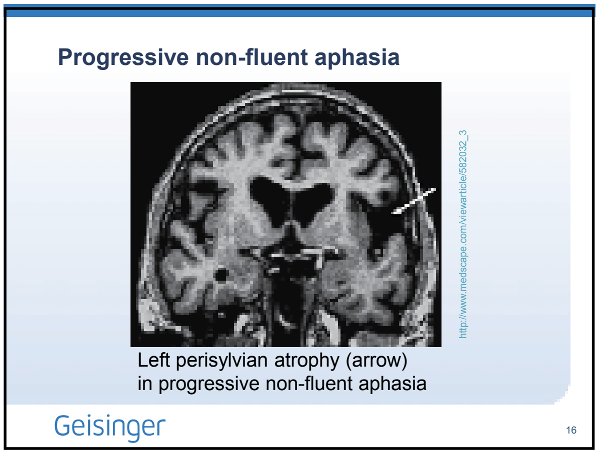
Involves the dominant (usually left) anterior temporal lobe

Semantic Dementia: Progressive loss of the *meanings* of things

- Difficulty finding the right word
  - Substitutions of words within categories, e.g. cow for horse
- Loss of knowledge of what words mean or what objects are for.
  - “What is a can opener?” and not knowing what its use is
- Difficulty understanding what other people are saying
  - “What is a mafia?”
- Problems with reading and writing
  - E.g. Surface dyslexia/dysgraphia (YACHT)
- May develop changes in behavior

Language

- Fluency
  - Deficits:
    - Difficulty “getting words out”
    - Simplified sentence structure
    - Loss of grammar
    - Problems with making speech sounds
  - Tests:
    - Picture description
    - Automatic speech
    - Verbal fluency procedures



Progressive non-fluent aphasia

http://www.medscape.com/viewarticle/582032_3

Left perisylvian atrophy (arrow)
in progressive non-fluent aphasia

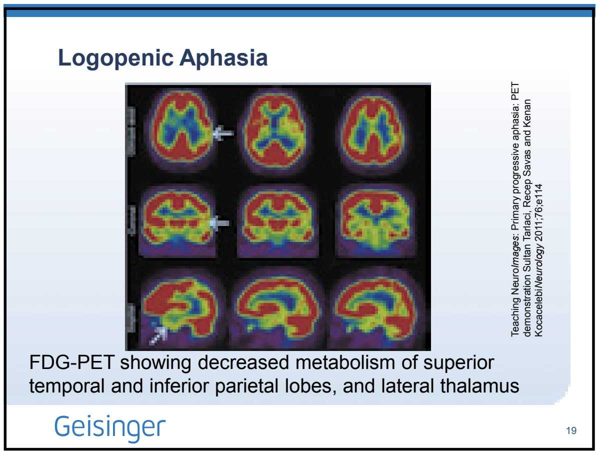
Progressive non-fluent aphasia

- Effortful and halting speech
- Sound substitutions
  - “bebble” for “pebble”
- Sentences lack proper grammar
  - May not use articles (“the”), adjectives or prepositions
- May have trouble understanding complex sentences
  - “I burned dinner but not the cake”
- May have trouble in producing sounds
  - “Apraxia of speech”
- May develop problems similar to Parkinson’s disease
  - Tremor, body rigidity, falls

Language

- Repetition
  - Deficits:
    - Difficulty repeating words/sentences
  - Tests:
    - Word repetition
    - Sentence Repetition

Demystifying Diagnosis, cont'd.



Logopenic Aphasia

FDG-PET showing decreased metabolism of superior temporal and inferior parietal lobes, and lateral thalamus

Teaching Neuro*Images*: Primary progressive aphasia: PET demonstration Sultan Tarlaci, Recep Savas and Kenan Kocacelebi*Neurology* 2011;76;e114

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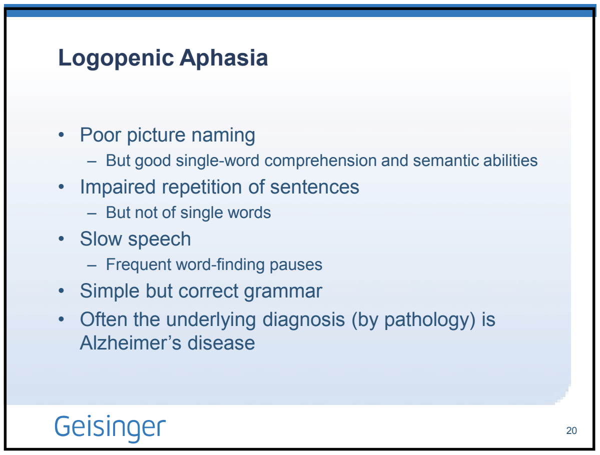
19



Logopenic Aphasia

- Poor picture naming
  - But good single-word comprehension and semantic abilities
- Impaired repetition of sentences
  - But not of single words
- Slow speech
  - Frequent word-finding pauses
- Simple but correct grammar
- Often the underlying diagnosis (by pathology) is Alzheimer's disease

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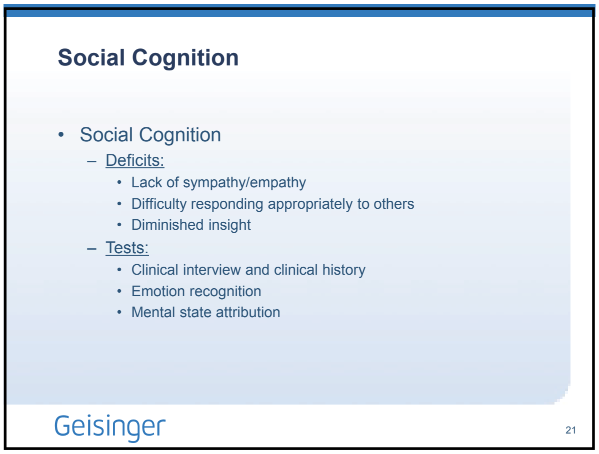
20



Social Cognition

- Social Cognition
  - Deficits:
    - Lack of sympathy/empathy
    - Difficulty responding appropriately to others
    - Diminished insight
  - Tests:
    - Clinical interview and clinical history
    - Emotion recognition
    - Mental state attribution

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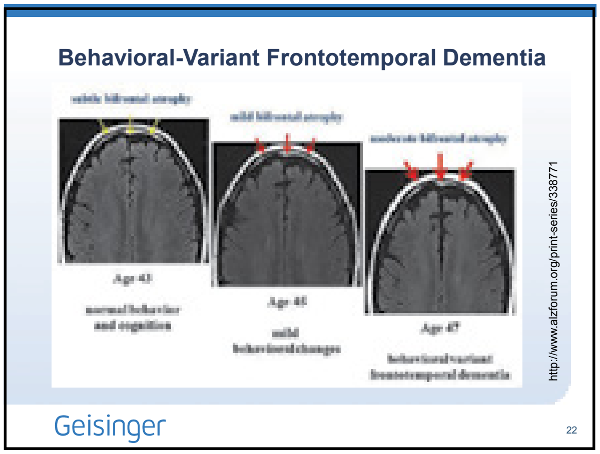
21



Behavioral-Variant Frontotemporal Dementia

http://www.alzforum.org/print-series/338771

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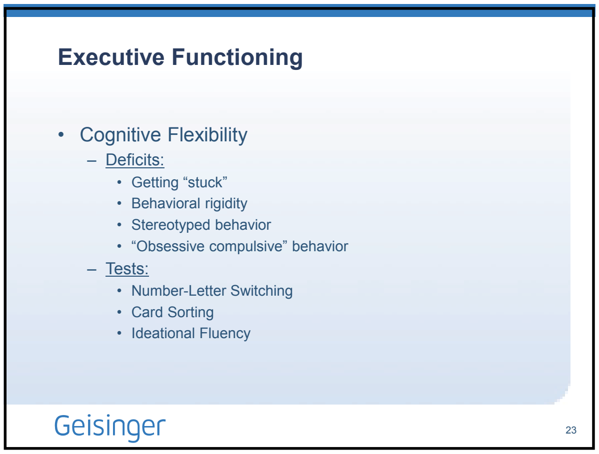
22



Executive Functioning

- Cognitive Flexibility
  - Deficits:
    - Getting "stuck"
    - Behavioral rigidity
    - Stereotyped behavior
    - "Obsessive compulsive" behavior
  - Tests:
    - Number-Letter Switching
    - Card Sorting
    - Ideational Fluency

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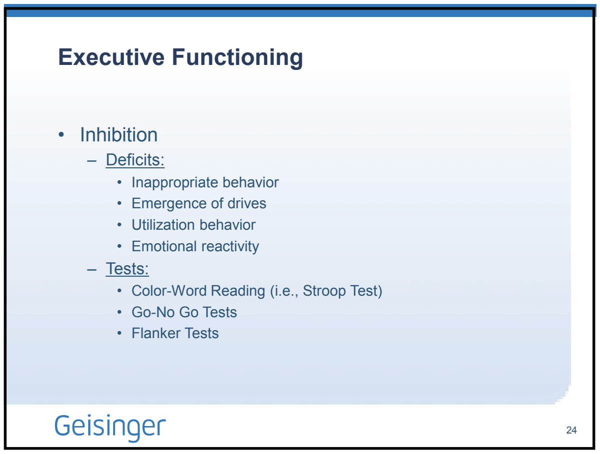
23



Executive Functioning

- Inhibition
  - Deficits:
    - Inappropriate behavior
    - Emergence of drives
    - Utilization behavior
    - Emotional reactivity
  - Tests:
    - Color-Word Reading (i.e., Stroop Test)
    - Go-No Go Tests
    - Flanker Tests

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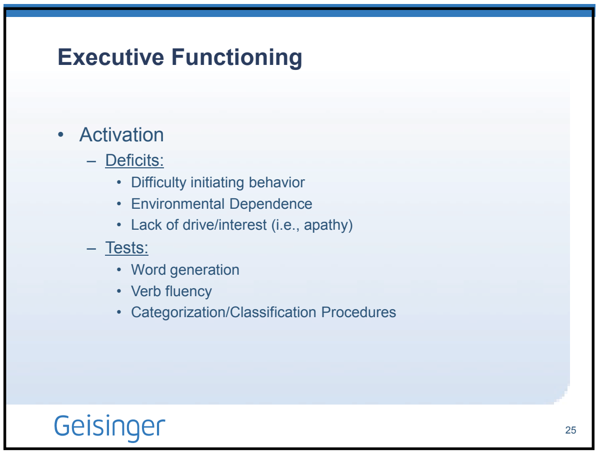
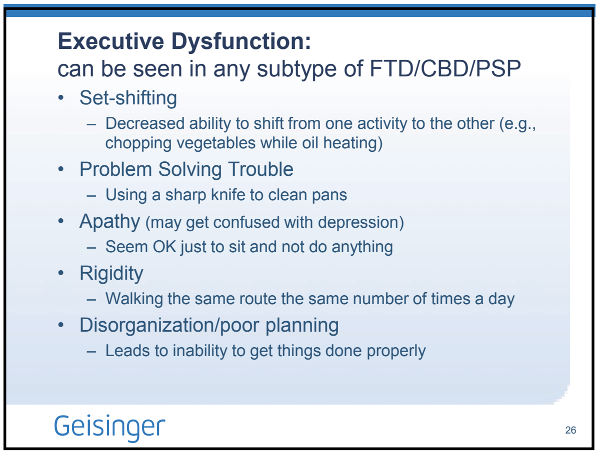
24

Demystifying Diagnosis, cont'd.



Executive Functioning

- Activation
  - Deficits:
    - Difficulty initiating behavior
    - Environmental Dependence
    - Lack of drive/interest (i.e., apathy)
  - Tests:
    - Word generation
    - Verb fluency
    - Categorization/Classification Procedures



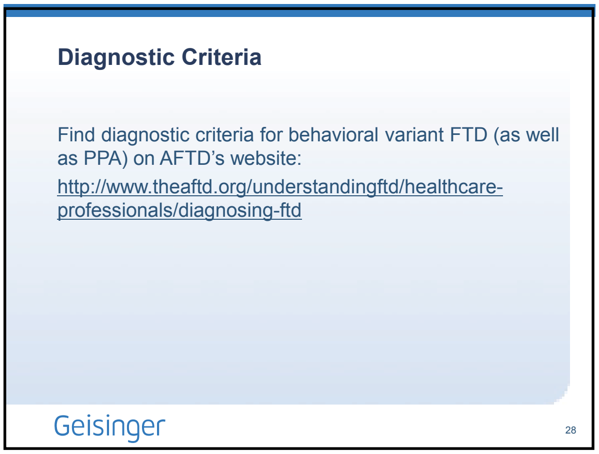
Executive Dysfunction:

can be seen in any subtype of FTD/CBD/PSP

- Set-shifting
  - Decreased ability to shift from one activity to the other (e.g., chopping vegetables while oil heating)
- Problem Solving Trouble
  - Using a sharp knife to clean pans
- Apathy (may get confused with depression)
  - Seem OK just to sit and not do anything
- Rigidity
  - Walking the same route the same number of times a day
- Disorganization/poor planning
  - Leads to inability to get things done properly

Improving Functioning

- YOU are the most important intervention!
  - Be aware of strengths and weaknesses
  - Provide assistance and help
  - Structure the environment
  - Suggest the word the person is looking for
  - Eliminate tasks that are difficult frustrating
  - Use strengths to overcome weaknesses
  - Advocate for your loved one for the best:
    - Diagnosis
    - Treatment
    - Support services



Diagnostic Criteria

Find diagnostic criteria for behavioral variant FTD (as well as PPA) on AFTD's website:

http://www.theaftd.org/understandingftd/healthcare-professionals/diagnosing-ftd

Notes

10:45 a.m. Breakout Session:
Brain-Behavior Relationships: Why Does He Act That Way?

Understanding Brain-Behavior Relationships in Frontotemporal Degeneration

Lauren Massimo, PhD, CRNP

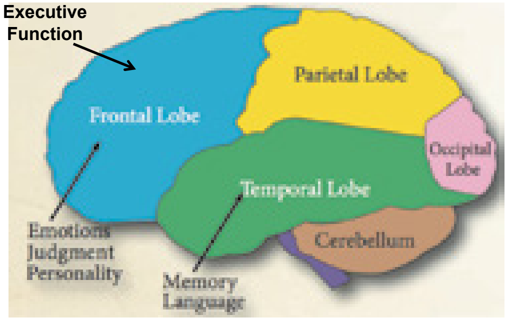
Penn
Frontotemporal
Degeneration Center

Criteria for bvFTD

Possible bvFTD (3 of 6 must be present)

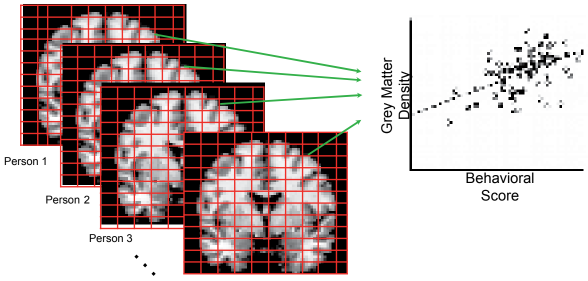
- ☑ Behavioral disinhibition
- ☑ Apathy
- ☑ Loss of sympathy or empathy
- ☑ Perseveration, stereotyped, or compulsive/ritualistic behavior
- ☑ Hyperorality or dietary changes
- ☑ Executive deficits, relative sparing of memory

Rascovsky, et al., 2011



Neuroimaging Methods

Standard approach for studying brain-behavior relationships:



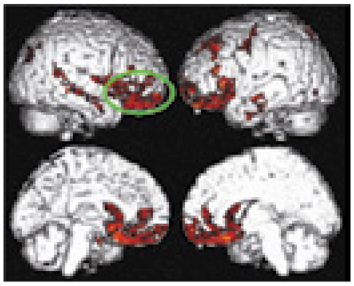
Courtesy of Corey McMillan

Disinhibition

- Socially inappropriate behavior
- Loss of manners
- Impulsive behavior

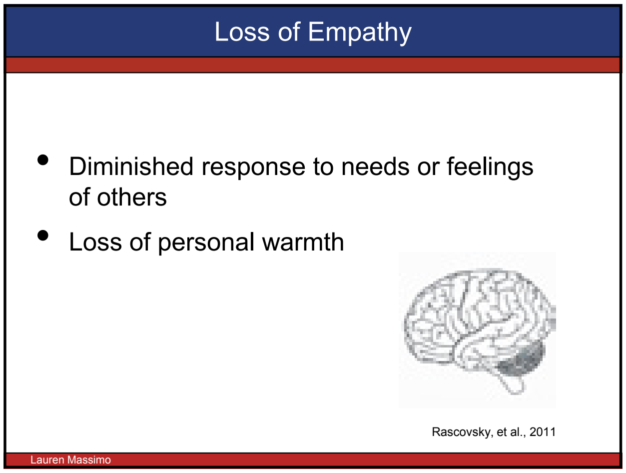
Rascovsky, et al., 2011

Neuroimaging Correlates of Disinhibition



Massimo et al., 2009

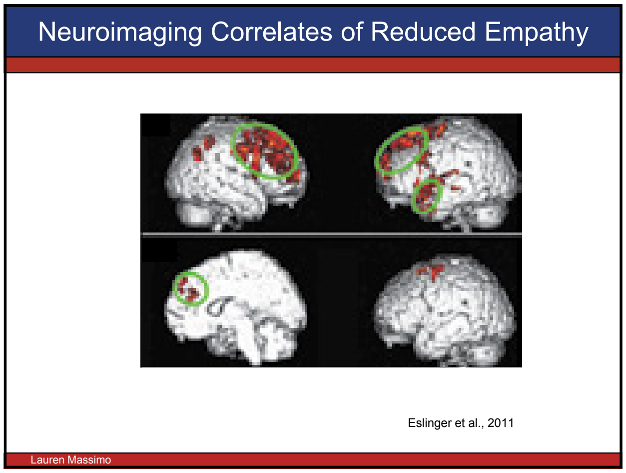
Brain-Behavior Relationships: Why Does He Act That Way?, cont'd.



Loss of Empathy

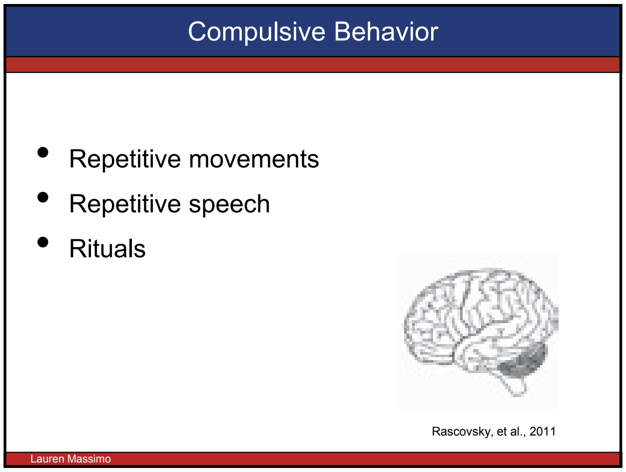
- Diminished response to needs or feelings of others
- Loss of personal warmth

Rascovsky, et al., 2011



Neuroimaging Correlates of Reduced Empathy

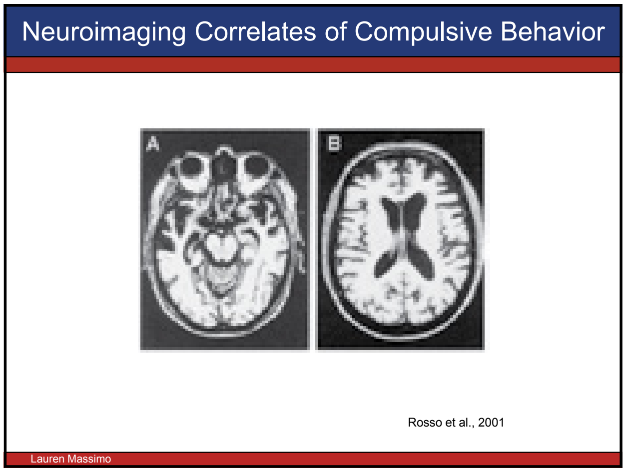
Eslinger et al., 2011



Compulsive Behavior

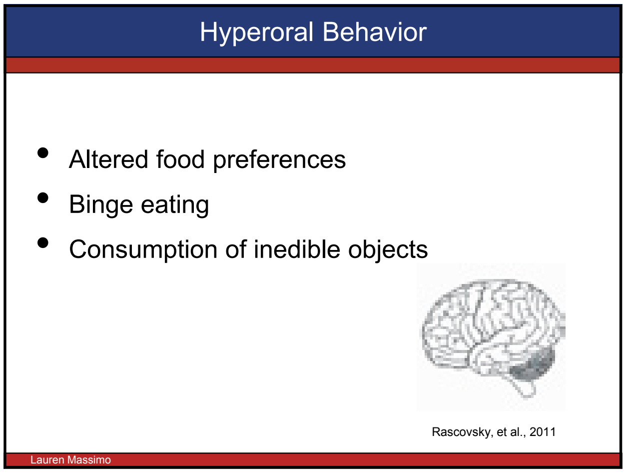
- Repetitive movements
- Repetitive speech
- Rituals

Rascovsky, et al., 2011



Neuroimaging Correlates of Compulsive Behavior

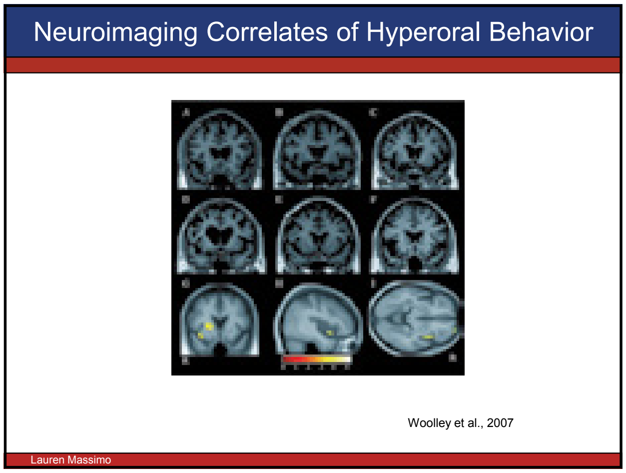
Rosso et al., 2001



Hyperoral Behavior

- Altered food preferences
- Binge eating
- Consumption of inedible objects

Rascovsky, et al., 2011



Neuroimaging Correlates of Hyperoral Behavior

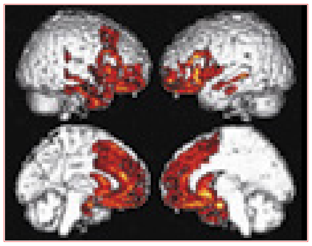
Woolley et al., 2007

Brain-Behavior Relationships: Why Does He Act That Way?, cont'd.

Apathy

- Passivity
- Loss of interest
- Loss of spontaneity
- Lack of motivation

Neuroimaging Correlates of Apathy



Massimo et al., 2009

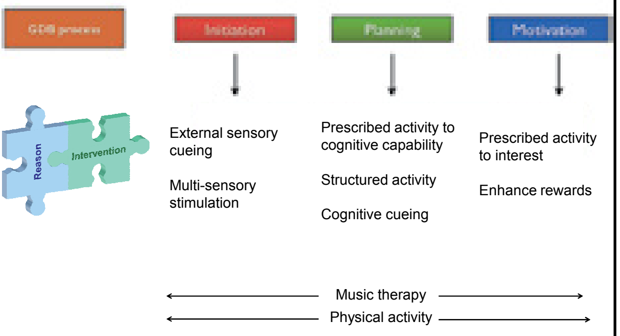
Neuroimaging Correlates of Apathy Subtypes

Subtypes of Apathy in FTD

Subtype	N (%)
SINGLE-COMPONENT	12 (60%)
Initiation	2 (10%)
Planning	8 (40%)
Motivation	2 (10%)
MULTI-COMPONENT	8 (40%)
Initiation and Planning	3 (15%)
Initiation and Motivation	1 (5%)
Initiation, Planning and Motivation	4 (20%)

Massimo, Evans & Grossman, 2014

Potential Interventions for Apathy by Subtype



External sensory cueing

Multi-sensory stimulation

Prescribed activity to cognitive capability

Structured activity

Cognitive cueing

Prescribed activity to interest

Enhance rewards

Music therapy

Physical activity

Conclusions

- Behavioral symptoms emerge when there is damage to frontal and temporal lobes of the brain.
- Individualized treatments for behavioral symptoms can best be developed in a context where anatomic substrates are understood.

10:45 a.m. Breakout Session:

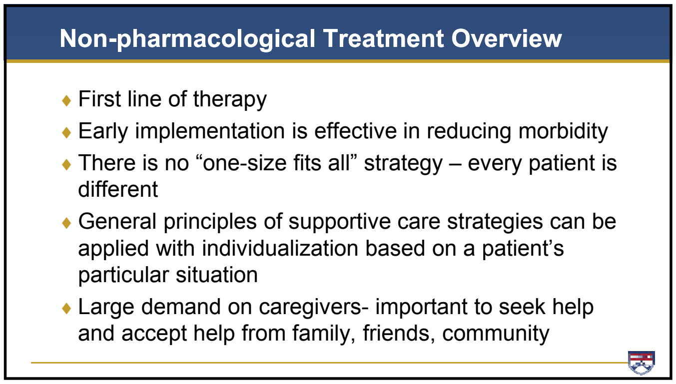
Medications and Non-Pharma Approaches to Treatment

David Irwin, MD Penn FTD Center

Medications and Non-Pharma Approaches to Treatment

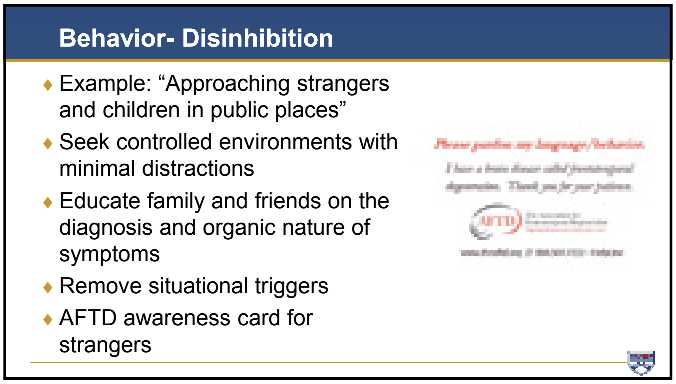
David J. Irwin, MD

Penn Frontotemporal Degeneration Center



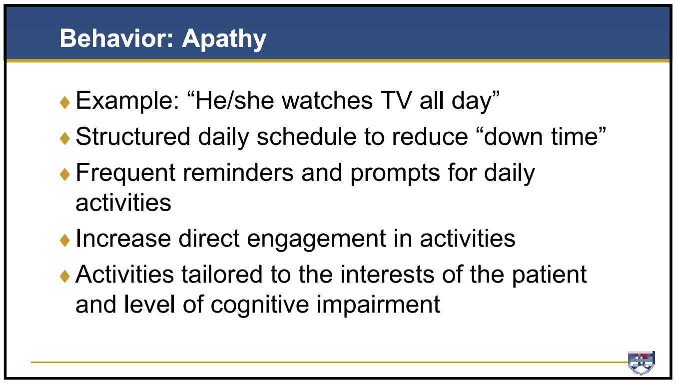
Non-pharmacological Treatment Overview

- First line of therapy
- Early implementation is effective in reducing morbidity
- There is no “one-size fits all” strategy – every patient is different
- General principles of supportive care strategies can be applied with individualization based on a patient’s particular situation
- Large demand on caregivers- important to seek help and accept help from family, friends, community



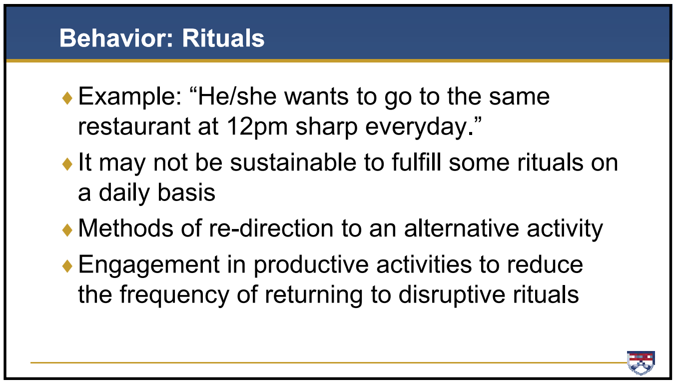
Behavior- Disinhibition

- Example: “Approaching strangers and children in public places”
- Seek controlled environments with minimal distractions
- Educate family and friends on the diagnosis and organic nature of symptoms
- Remove situational triggers
- AFTD awareness card for strangers



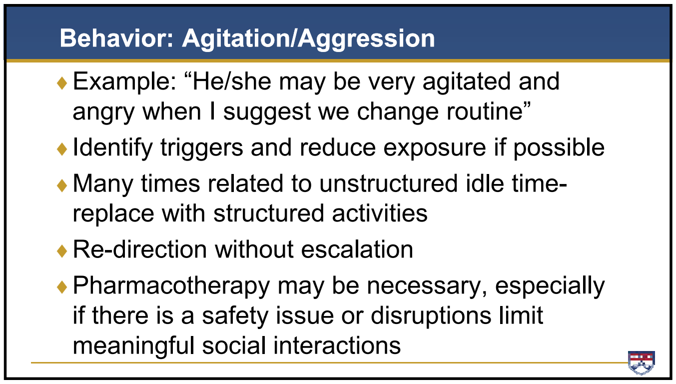
Behavior: Apathy

- Example: “He/she watches TV all day”
- Structured daily schedule to reduce “down time”
- Frequent reminders and prompts for daily activities
- Increase direct engagement in activities
- Activities tailored to the interests of the patient and level of cognitive impairment



Behavior: Rituals

- Example: “He/she wants to go to the same restaurant at 12pm sharp everyday.”
- It may not be sustainable to fulfill some rituals on a daily basis
- Methods of re-direction to an alternative activity
- Engagement in productive activities to reduce the frequency of returning to disruptive rituals



Behavior: Agitation/Aggression

- Example: “He/she may be very agitated and angry when I suggest we change routine”
- Identify triggers and reduce exposure if possible
- Many times related to unstructured idle time- replace with structured activities
- Re-direction without escalation
- Pharmacotherapy may be necessary, especially if there is a safety issue or disruptions limit meaningful social interactions

Medications and Non-Pharma Approaches to Treatment, cont'd.

Language: Slow hesitant speech (naPPA)

- Speak slowly, loudly and clearly
- Allow the patient time to interject into conversation to avoid isolation
- Do not help the patient find the word unless they ask
- Avoid large group socializing and instead use small groups in quiet locations with minimal distractions
- Educate family and close friends
- Speech assist devices and speech recognition software for typing are available

Motor difficulties

- Physical therapy for gait safety training and home assessments to reduce risks of falls
- Occupational therapy for help with buttoning clothing, using utensils (helpful for apraxia-CBS).
- Assist devices to improve ability to grasp utensils
- Range of motion exercises to prevent contractures.

Supportive Care Checkpoints

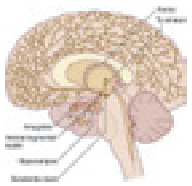
- It is important to anticipate functional decline and safety issues prior to the need to implement them so there is sufficient time to gather resources necessary
- Common transition periods of supportive care to anticipate include:
  - When to stop working
  - When to stop driving
  - When to limit access to finances
  - When to supervise medication administration
  - When to limit or change travel plans
  - When to have full time supervision (day centers, visiting companions)
  - When to consider long term care options

Outline

- Non-Pharmacological Treatment Strategies
  - Behavior
  - Language
  - Motor
  - Supportive Care "Check-points"
- **Pharmacological Treatments**
  - **Acetylcholinesterase inhibitors and memantine (Alzheimer's drugs)**
  - **Selective serotonin reuptake inhibitors (anti-depressants)**
  - **Dopamine antagonists (neuroleptics)**
  - **Benzodiazepines and mood stabilizers**
  - **Treatments for associated symptoms (motor, sleep)**

Pharmacological Treatment Overview

- Neurotransmitter systems regulate brain function
- Small populations of brain cells deep in the brain (i.e. nuclei) distribute neurotransmitters widespread throughout the brain to affect mood and behavior
- These populations of neurons are differentially affected by Alzheimer's disease (AD) and different forms of Frontotemporal degeneration
- Pharmacological treatments are based on augmenting these neurotransmitters to target specific behavioral symptoms
- Limited clinical trial data to guide decision making

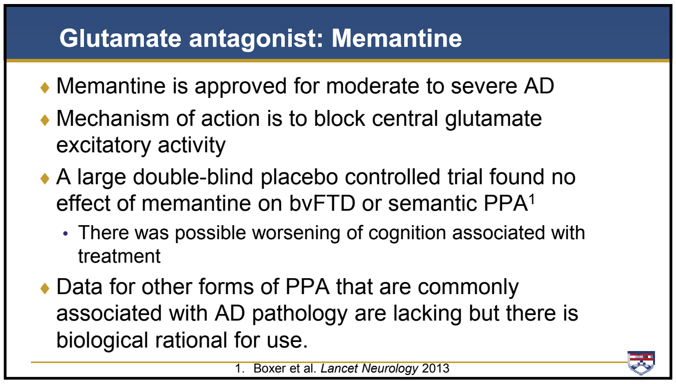


Acetylcholinesterase inhibitors

- Examples: donepezil, rivastigmine, galantamine
- These agents increase brain levels of acetylcholine which are deficient in AD and forms of Lewy body disease
- Acetylcholine is not deficient in FTLD[1]
- These agents may worsen behavior in FTLD[2]
- Patients with PPA likely to have AD pathology (i.e. logopenic variant) there is biological rationale for these therapies

1. Huey et al. *Neurology* 2006
2. Irwin et al. *Am J Alz Dis Rel Disord* 2010.

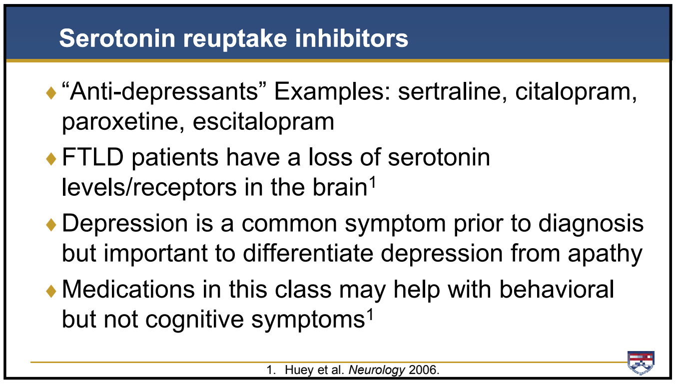
Medications and Non-Pharma Approaches to Treatment, cont'd.



Glutamate antagonist: Memantine

- Memantine is approved for moderate to severe AD
- Mechanism of action is to block central glutamate excitatory activity
- A large double-blind placebo controlled trial found no effect of memantine on bvFTD or semantic PPA[1]
  - There was possible worsening of cognition associated with treatment
- Data for other forms of PPA that are commonly associated with AD pathology are lacking but there is biological rational for use.

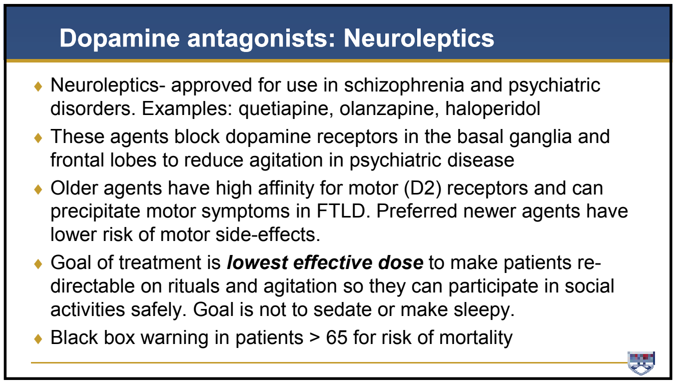
1. Boxer et al. *Lancet Neurology* 2013



Serotonin reuptake inhibitors

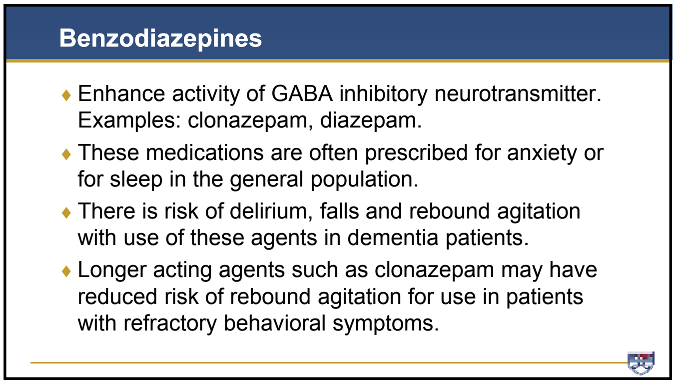
- "Anti-depressants" Examples: sertraline, citalopram, paroxetine, escitalopram
- FTLD patients have a loss of serotonin levels/receptors in the brain[1]
- Depression is a common symptom prior to diagnosis but important to differentiate depression from apathy
- Medications in this class may help with behavioral but not cognitive symptoms[1]

1. Huey et al. *Neurology* 2006.



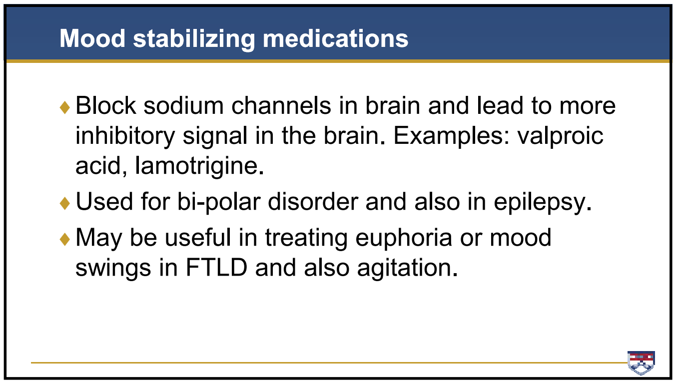
Dopamine antagonists: Neuroleptics

- Neuroleptics- approved for use in schizophrenia and psychiatric disorders. Examples: quetiapine, olanzapine, haloperidol
- These agents block dopamine receptors in the basal ganglia and frontal lobes to reduce agitation in psychiatric disease
- Older agents have high affinity for motor (D2) receptors and can precipitate motor symptoms in FTLD. Preferred newer agents have lower risk of motor side-effects.
- Goal of treatment is ***lowest effective dose*** to make patients re-directable on rituals and agitation so they can participate in social activities safely. Goal is not to sedate or make sleepy.
- Black box warning in patients > 65 for risk of mortality



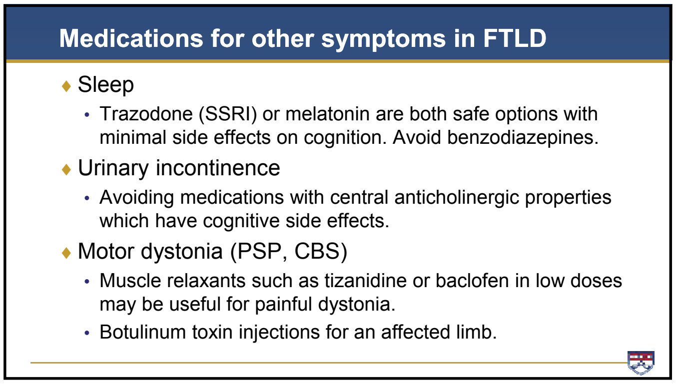
Benzodiazepines

- Enhance activity of GABA inhibitory neurotransmitter. Examples: clonazepam, diazepam.
- These medications are often prescribed for anxiety or for sleep in the general population.
- There is risk of delirium, falls and rebound agitation with use of these agents in dementia patients.
- Longer acting agents such as clonazepam may have reduced risk of rebound agitation for use in patients with refractory behavioral symptoms.



Mood stabilizing medications

- Block sodium channels in brain and lead to more inhibitory signal in the brain. Examples: valproic acid, lamotrigine.
- Used for bi-polar disorder and also in epilepsy.
- May be useful in treating euphoria or mood swings in FTLD and also agitation.



Medications for other symptoms in FTLD

- Sleep
  - Trazodone (SSRI) or melatonin are both safe options with minimal side effects on cognition. Avoid benzodiazepines.
- Urinary incontinence
  - Avoiding medications with central anticholinergic properties which have cognitive side effects.
- Motor dystonia (PSP, CBS)
  - Muscle relaxants such as tizanidine or baclofen in low doses may be useful for painful dystonia.
  - Botulinum toxin injections for an affected limb.

10:45 a.m. Breakout Session:
FTD Research: The Value of Studies and Opportunities for Involvement

FTD RESEARCH:
The Value of Studies and Opportunities for Involvement

Sarah Lawrence, MS - Research Program Manager
Ann Fishman, MBA - Sr. Research Coordinator
Weiyi Mu, ScM - Genetic Counselor
Suzanne Dana - Spouse/Caregiver

Johns Hopkins University School of Medicine

Ways to Get Involved in FTD Research

- FTD Disorders Registry
- Research Studies
  - Interviews/Qualitative Studies
  - Observational Studies (ARTFL and LEFFTDS)
  - Clinical Trials
- Brain and Tissue Donation

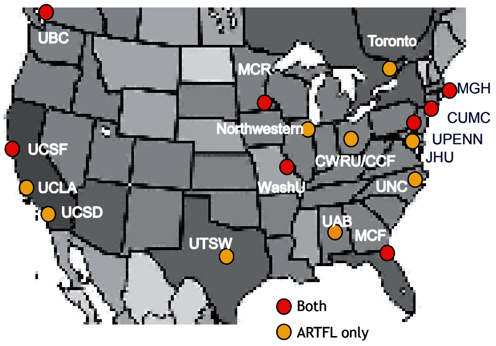
FTD Disorders Registry
https://ftdregistry.org/

Qualitative studies and surveys

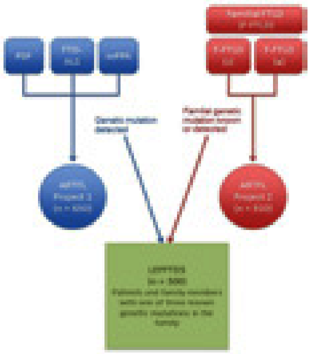
Interviews -
talking about your
experience about FTD

Surveys -
medical and/or
psychological impact of FTD

ARTFL and LEFFTDS Sites



Observational Studies: ARTFL and LEFFTDS



FTD Research: The Value of Studies and Opportunities for Involvement, cont'd.

Observational Studies:

ARTFL

- To build a reliable FTD clinical research network to support treatment and clinical trials that focus on the prevention of FTD.
- To determine the clinical characteristics of sporadic FTD syndromes and the barriers to clinical trial participation.
- To develop a familial FTD cohort for clinical trials and biomarker studies.

- Information available at https://www.rarediseasesnetwork.org/cms/artfl/About-Us

Observational Studies:

ARTFL

- Men and women aged 18-85
- Able to walk with assistance
- Have a study partner
- Project 1: Diagnosis of PSPS, svPPA, CBS, bvFTD, nfvPPA, FTD/ALS
- Project 2: Symptomatic or asymptomatic member of family with known genetic mutation or family history

Observational Studies: LEFFTDS

Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects

- **Primary goal:** identify the most robust methods to track disease progression in familial FTD so that clinical trials of disease-modifying therapies can be designed appropriately
- **Study population:** Have a mutation, or be a relative of an individual with a mutation
  - microtubule associated protein tau (MAPT)
  - progranulin (PGRN; also known as granulin or GRN), or
  - chromosome 9 open reading frame 72 (C9ORF72)

Clinical Trials

- The goal of clinical research is to advance treatment, prevention, diagnosis and understanding of disease.
- There are many types:
  - **Prevention trials** look for better ways to prevent a disease in people who have never had the disease or to prevent the disease from returning. Better approaches may include medicines, vaccines, or lifestyle changes, among other things.
  - **Treatment trials** test new treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.

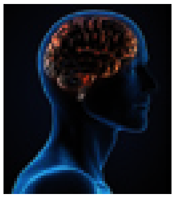
Ref: NIH Clinical Trials and You: The Basics

Clinical Trials

- **Low-dose lithium for behavioral symptoms in bvFTD**
  - Men and women aged 40-85
  - Must have a diagnosis of bvFTD, sv-PPA, nfv-PPA
  - Must have a study partner or caregiver to attend study visits
  - Must have evidence of behavioral symptoms (agitation, aggression, disinhibition, repetitive behaviors)

- There may be others coming down the pipeline…

Brain and Tissue Donation



- Obtain a definitive diagnosis
- Some research can only be done on brain tissue
- Identify genetic mutations
- Important to plan ahead

NIH NEUROBIOBANK

https://neurobiobank.nih.gov/

UCSF Memory and Aging Center

http://memory.ucsf.edu/resources/brainbank

Misconceptions about Research Participation

- MYTH: Research is the same as clinical treatment
  - **FACT: Clinical treatment is patient-focused, research has a broader outlook**
- MYTH: Observational studies can replace clinical care
  - **FACT: You still need to see your regular care team for treatment management**
- MYTH: Being seen at an academic medical center is the same as being enrolled in research
  - **FACT: Joining a research study involves consent and is separate from clinical visits**

Misconceptions about Research Participation

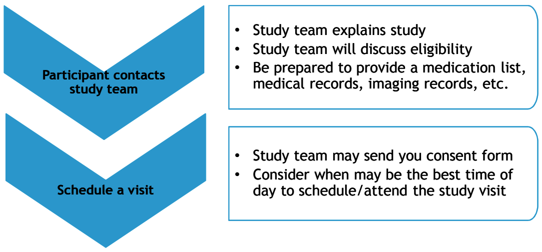
- MYTH: Anyone interested in a research study is eligible
  - **FACT: Studies often have a specific population in mind**
- MYTH: Everyone enrolled in a clinical trial will receive treatment
  - **FACT: You may receive a placebo**
- MYTH: Research participants are treated like guinea pigs
  - **FACT: Research is bound by ethical guidelines**

Genetic testing: research versus clinical testing

An example of the boundaries between clinical and research

	CLINIC	RESEARCH
CLIA Certified?	Yes	No
Will results be disclosed?	Yes	Not Always
When can I expect results?	1-2 Months	Years
Who pays for testing?	Patient/Insurance	Study
What is the purpose?	For Patient/Family	Research

The Research Experience: What Happens When You Call?



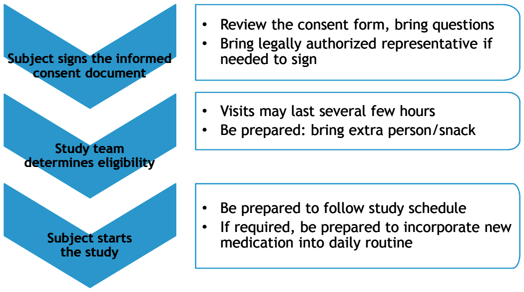
Participant contacts study team

- Study team explains study
- Study team will discuss eligibility
- Be prepared to provide a medication list, medical records, imaging records, etc.

Schedule a visit

- Study team may send you consent form
- Consider when may be the best time of day to schedule/attend the study visit

The Research Experience: Advice for a Research Day



Subject signs the informed consent document

- Review the consent form, bring questions
- Bring legally authorized representative if needed to sign

Study team determines eligibility

- Visits may last several few hours
- Be prepared: bring extra person/snack

Subject starts the study

- Be prepared to follow study schedule
- If required, be prepared to incorporate new medication into daily routine

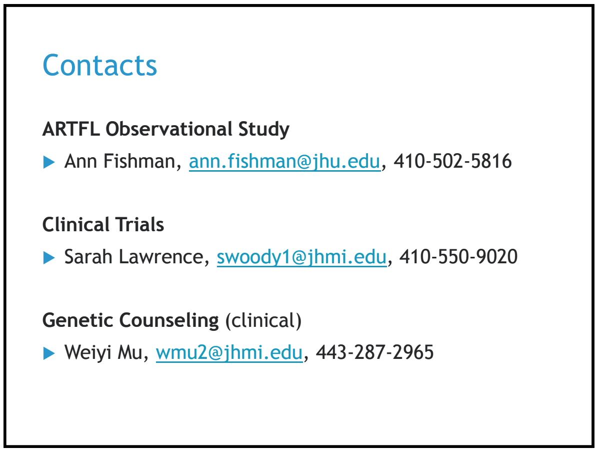
(What should be) Frequently Asked Questions

- Do I have to pay for any of the study procedures?
- Can transportation be provided for study visits?
- Is there reimbursement for travel expenses?
- Can I keep any of the study information?
- Who will oversee my care during the study?
- Will I have access to the study medication after I finish the study?
- Can I continue to see the study doctor after I've finished the study?
- Does participation in one study automatically exclude me from other studies?
- Where can I go to find out about other studies if I'm not eligible for any here?

FTD Research: The Value of Studies and Opportunities for Involvement, cont'd.

Why People Participate

- Access to new treatments
- Contribute to the greater good
- Explore more resources
- Provides a positive course of action
- Help the next generation



Contacts

ARTFL Observational Study

- Ann Fishman, ann.fishman@jhu.edu, 410-502-5816

Clinical Trials

- Sarah Lawrence, swoody1@jhmi.edu, 410-550-9020

Genetic Counseling (clinical)

- Weiyi Mu, wmu2@jhmi.edu, 443-287-2965

Thanks for joining us!

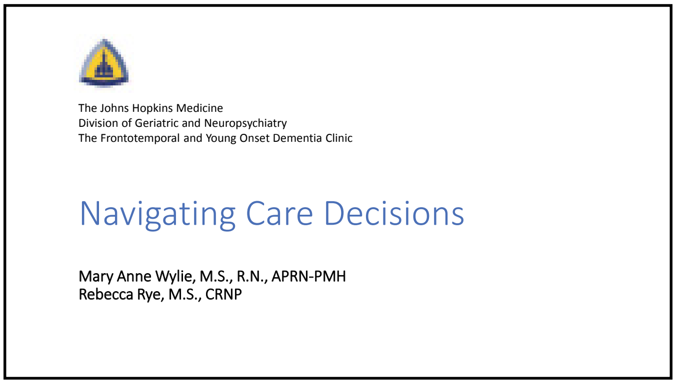
Resources:

- AFTD
- NIH
- Clinicaltrials.gov

Thanks to research participants
for your contributions!

Notes

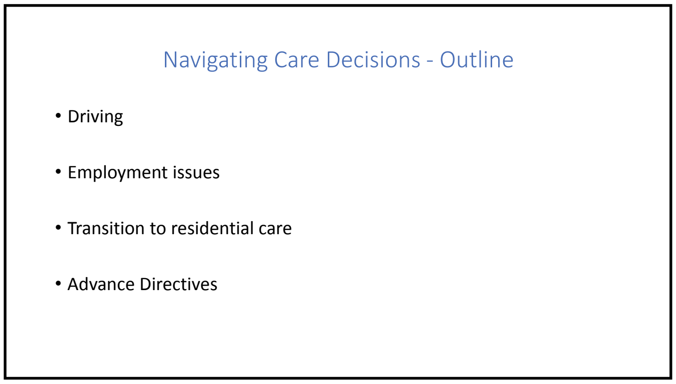
2:00 p.m. Breakout Session:
Navigating Key Care Decisions in FTD



The Johns Hopkins Medicine
Division of Geriatric and Neuropsychiatry
The Frontotemporal and Young Onset Dementia Clinic

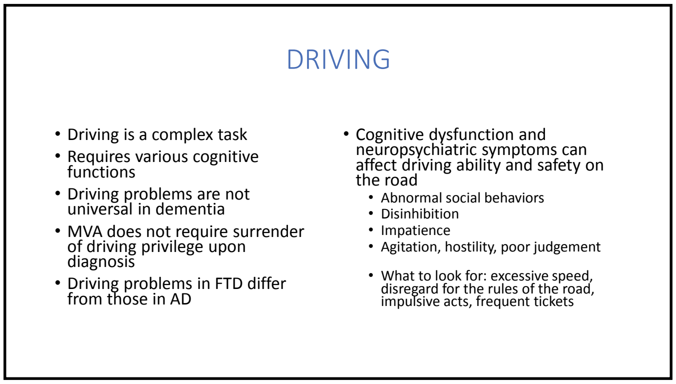
Navigating Care Decisions

Mary Anne Wylie, M.S., R.N., APRN-PMH
Rebecca Rye, M.S., CRNP



Navigating Care Decisions - Outline

- Driving
- Employment issues
- Transition to residential care
- Advance Directives



DRIVING

- Driving is a complex task
- Requires various cognitive functions
- Driving problems are not universal in dementia
- MVA does not require surrender of driving privilege upon diagnosis
- Driving problems in FTD differ from those in AD
- Cognitive dysfunction and neuropsychiatric symptoms can affect driving ability and safety on the road
  - Abnormal social behaviors
  - Disinhibition
  - Impatience
  - Agitation, hostility, poor judgement

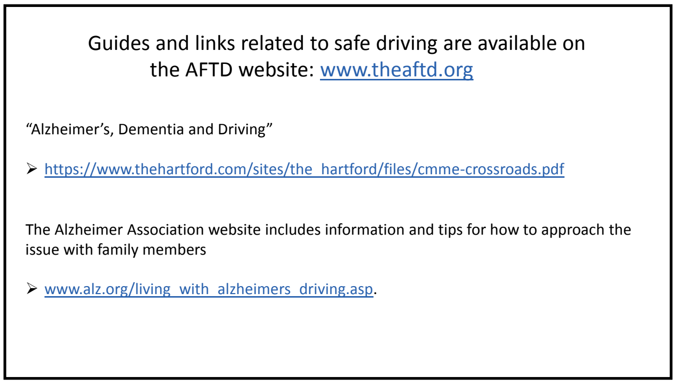
  - What to look for: excessive speed, disregard for the rules of the road, impulsive acts, frequent tickets

DRIVING – what you need

- Know your local MVA rules
  - Reporting mechanisms: physician, family, concerned citizen
  - Standards for physician reporting vary by state

- Formal driving assessments: OTR; local MVA
  - Typically not covered by insurance
  - May need to be retested as disease progresses

- Be mindful of impacts:
  - For the person: loss of independence; loss of purpose
  - For the family: more responsibility/burden



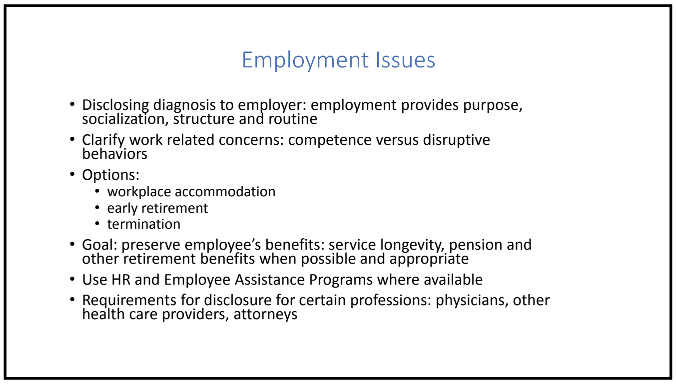
Guides and links related to safe driving are available on the AFTD website: www.theaftd.org

"Alzheimer's, Dementia and Driving"

➢ https://www.thehartford.com/sites/the_hartford/files/cmme-crossroads.pdf

The Alzheimer Association website includes information and tips for how to approach the issue with family members

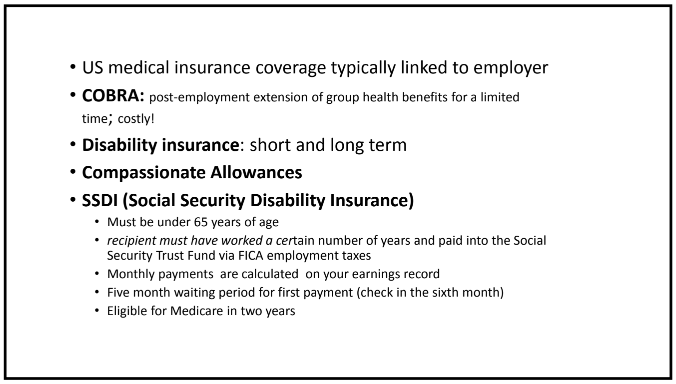
➢ www.alz.org/living_with_alzheimers_driving.asp.



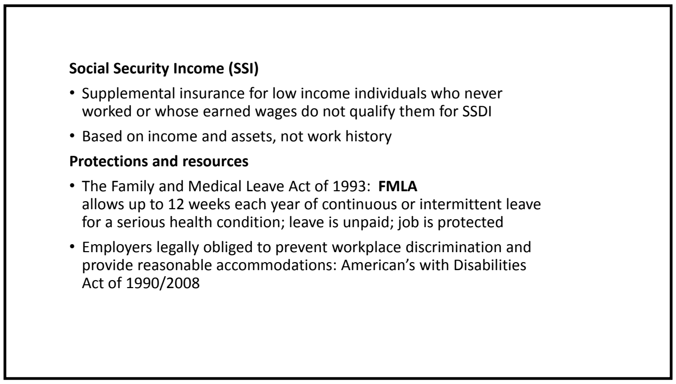
Employment Issues

- Disclosing diagnosis to employer: employment provides purpose, socialization, structure and routine
- Clarify work related concerns: competence versus disruptive behaviors
- Options:
  - workplace accommodation
  - early retirement
  - termination
- Goal: preserve employee's benefits: service longevity, pension and other retirement benefits when possible and appropriate
- Use HR and Employee Assistance Programs where available
- Requirements for disclosure for certain professions: physicians, other health care providers, attorneys

Navigating Key Care Decisions in FTD, cont'd.



- US medical insurance coverage typically linked to employer
- **COBRA:** post-employment extension of group health benefits for a limited time; costly!
- **Disability insurance**: short and long term
- **Compassionate Allowances**
- **SSDI (Social Security Disability Insurance)**
  - Must be under 65 years of age
  - *recipient must have worked a cer*tain number of years and paid into the Social Security Trust Fund via FICA employment taxes
  - Monthly payments are calculated on your earnings record
  - Five month waiting period for first payment (check in the sixth month)
  - Eligible for Medicare in two years

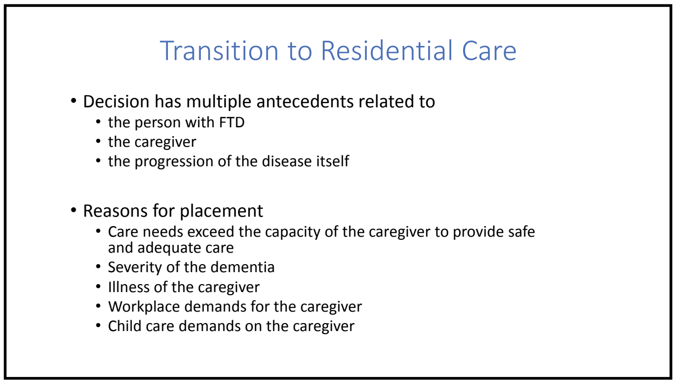


Social Security Income (SSI)

- Supplemental insurance for low income individuals who never worked or whose earned wages do not qualify them for SSDI
- Based on income and assets, not work history

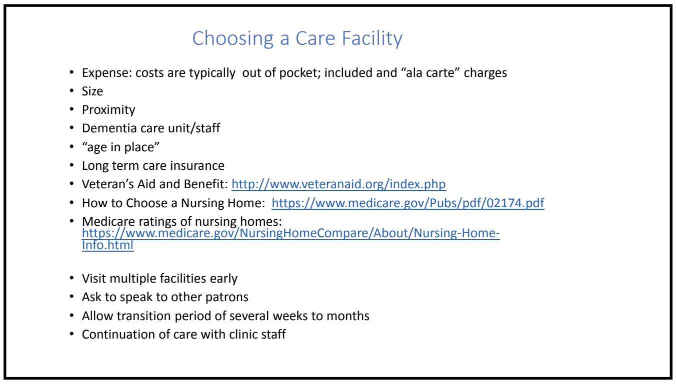
Protections and resources

- The Family and Medical Leave Act of 1993: **FMLA** allows up to 12 weeks each year of continuous or intermittent leave for a serious health condition; leave is unpaid; job is protected
- Employers legally obliged to prevent workplace discrimination and provide reasonable accommodations: American's with Disabilities Act of 1990/2008



Transition to Residential Care

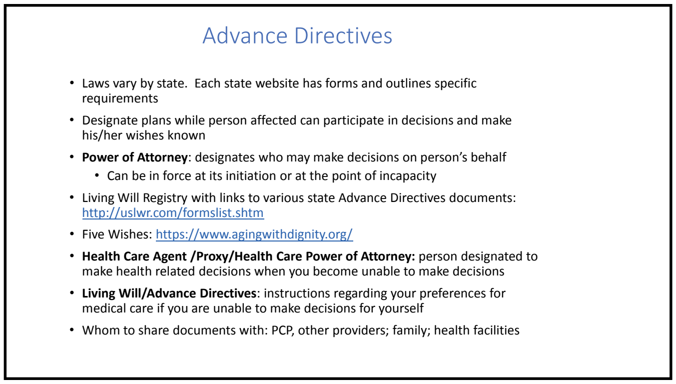
- Decision has multiple antecedents related to
  - the person with FTD
  - the caregiver
  - the progression of the disease itself
- Reasons for placement
  - Care needs exceed the capacity of the caregiver to provide safe and adequate care
  - Severity of the dementia
  - Illness of the caregiver
  - Workplace demands for the caregiver
  - Child care demands on the caregiver



Choosing a Care Facility

- Expense: costs are typically out of pocket; included and "ala carte" charges
- Size
- Proximity
- Dementia care unit/staff
- "age in place"
- Long term care insurance
- Veteran's Aid and Benefit: http://www.veteranaid.org/index.php
- How to Choose a Nursing Home: https://www.medicare.gov/Pubs/pdf/02174.pdf
- Medicare ratings of nursing homes: https://www.medicare.gov/NursingHomeCompare/About/Nursing-Home-Info.html

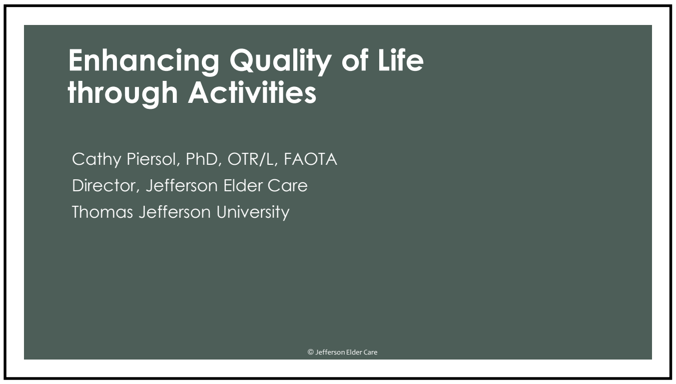
- Visit multiple facilities early
- Ask to speak to other patrons
- Allow transition period of several weeks to months
- Continuation of care with clinic staff



Advance Directives

- Laws vary by state. Each state website has forms and outlines specific requirements
- Designate plans while person affected can participate in decisions and make his/her wishes known
- **Power of Attorney**: designates who may make decisions on person's behalf
  - Can be in force at its initiation or at the point of incapacity
- Living Will Registry with links to various state Advance Directives documents: http://uslwr.com/formslist.shtm
- Five Wishes: https://www.agingwithdignity.org/
- **Health Care Agent /Proxy/Health Care Power of Attorney:** person designated to make health related decisions when you become unable to make decisions
- **Living Will/Advance Directives**: instructions regarding your preferences for medical care if you are unable to make decisions for yourself
- Whom to share documents with: PCP, other providers; family; health facilities

2:00 p.m. Breakout Session:
Enhancing Quality of Life Through Activities



Enhancing Quality of Life through Activities

Cathy Piersol, PhD, OTR/L, FAOTA
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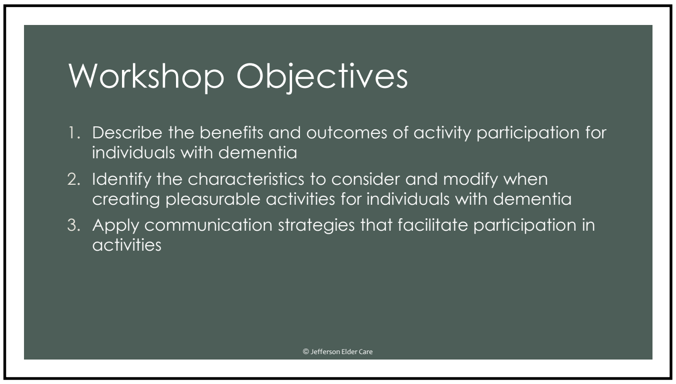

Workshop Objectives

1. Describe the benefits and outcomes of activity participation for individuals with dementia
2. Identify the characteristics to consider and modify when creating pleasurable activities for individuals with dementia
3. Apply communication strategies that facilitate participation in activities

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- The home is the predominant setting for care
- Families are the principal source of support and care
- Caregivers experience greatest distress and upset about behavioral symptoms
  - Apathy
  - Impulsiveness
  - Disinhibition
  - Compulsive or repetitive actions
  - Aggression (hitting, grabbing, inappropriate touching)

Activities can help

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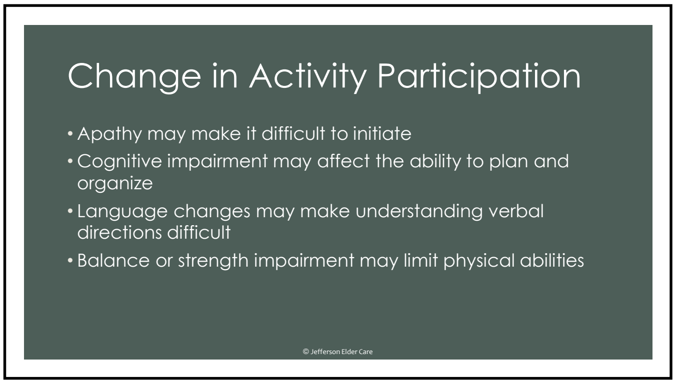

Change in Activity Participation

- Apathy may make it difficult to initiate
- Cognitive impairment may affect the ability to plan and organize
- Language changes may make understanding verbal directions difficult
- Balance or strength impairment may limit physical abilities

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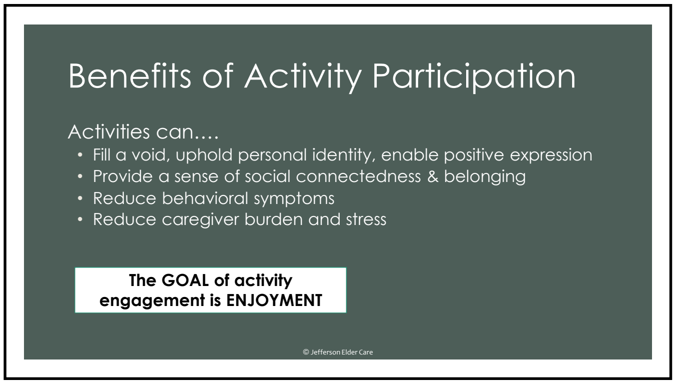

Benefits of Activity Participation

Activities can….

- Fill a void, uphold personal identity, enable positive expression
- Provide a sense of social connectedness & belonging
- Reduce behavioral symptoms
- Reduce caregiver burden and stress

The GOAL of activity engagement is ENJOYMENT

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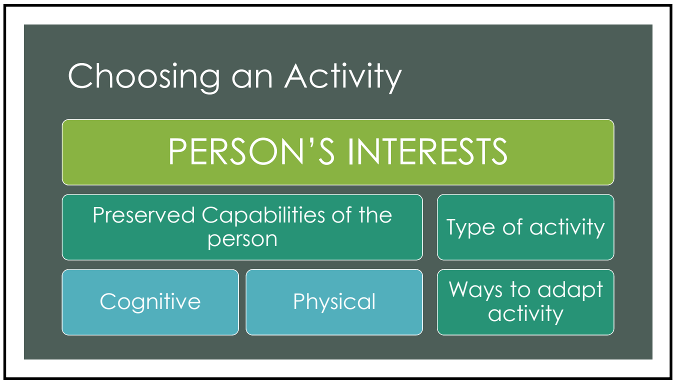


Choosing an Activity

PERSON'S INTERESTS

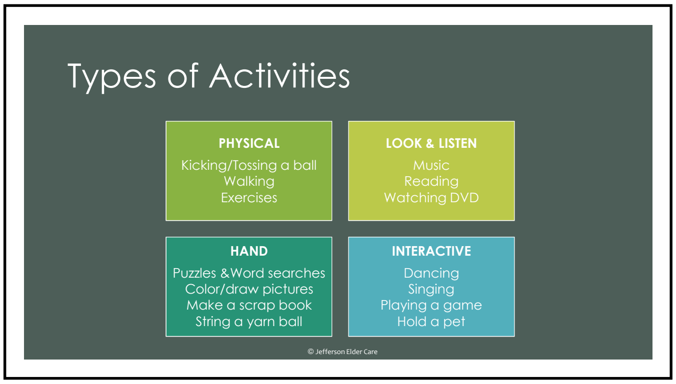
Preserved Capabilities of the person

Type of activity

Cognitive

Physical

Ways to adapt activity



Types of Activities

PHYSICAL
Kicking/Tossing a ball
Walking
Exercises

LOOK & LISTEN
Music
Reading
Watching DVD

HAND
Puzzles &Word searches
Color/draw pictures
Make a scrap book
String a yarn ball

INTERACTIVE
Dancing
Singing
Playing a game
Hold a pet

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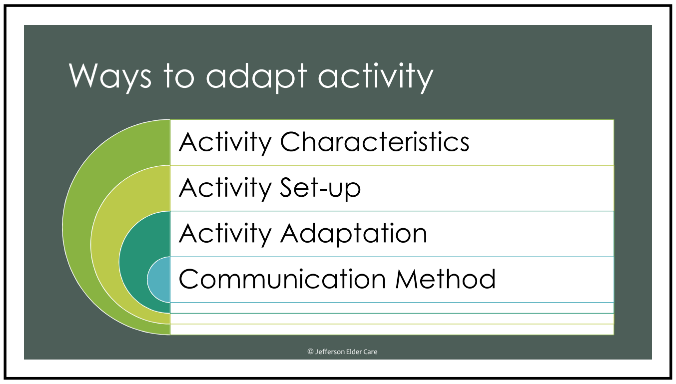

Ways to adapt activity

- Activity Characteristics
- Activity Set-up
- Activity Adaptation
- Communication Method

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Activity Characteristics

- Interest
- Familiarity
- Repetitive
- 1-2 steps
- Enjoyment and pleasure is the goal

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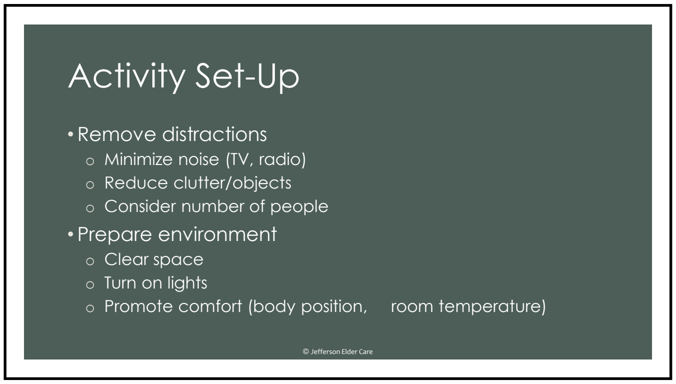

Activity Set-Up

- Remove distractions
  - Minimize noise (TV, radio)
  - Reduce clutter/objects
  - Consider number of people
- Prepare environment
  - Clear space
  - Turn on lights
  - Promote comfort (body position, room temperature)

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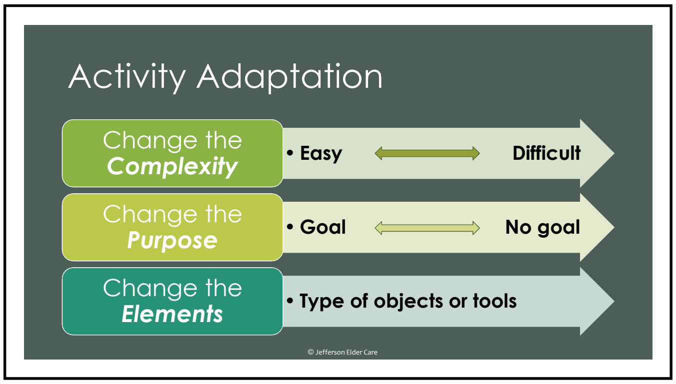

Activity Adaptation

Change the ***Complexity*** — • Easy ⟷ Difficult

Change the ***Purpose*** — • Goal ⟷ No goal

Change the ***Elements*** — • Type of objects or tools

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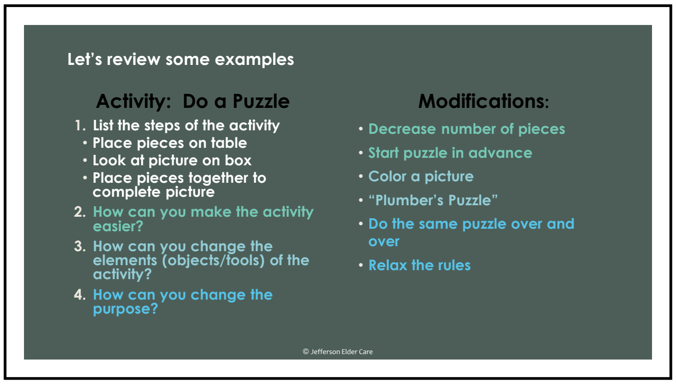

Let's review some examples

Activity: Do a Puzzle

1. List the steps of the activity
   - Place pieces on table
   - Look at picture on box
   - Place pieces together to complete picture
2. How can you make the activity easier?
3. How can you change the elements (objects/tools) of the activity?
4. How can you change the purpose?

Modifications:

- Decrease number of pieces
- Start puzzle in advance
- Color a picture
- "Plumber's Puzzle"
- Do the same puzzle over and over
- Relax the rules

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Another example

Activity: Sort Clothes

1. List the steps of the activity
   - Place basket of laundry on table
   - Sort the shirts, pants, socks, etc. in piles
   - Sort the darks, lights in piles
2. How can you make the activity easier?
3. How can you change the elements (objects/tools) of the activity?
4. How can you change the purpose?

Modifications:

- Sort two items
- Sort the same item by color
- Move cloths from one basket to another
- Sort coins, utensils or playing cards
- Sort clothes when wandering in house
- Have a basket of towels always ready
- Relax the rules

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One more example

Activity: Make a Salad

1. List the steps of the activity
   - Get ingredients
   - Prepare vegetables
   - Put in bowl and mix together
   - Pour the dressing
2. How can you make the activity easier?
3. How can you change the elements (objects/tools) of the activity?
4. How can you change the purpose?

Modifications:

- Chop vegetables in advance
- Only do one or two steps (tear lettuce, pour dressing)
- Provide a written list of steps
- Make a muffin or cake mix, fruit salad or strawberry short cake
- Tear lettuce while in kitchen
- Put veggies/fruit in & out of a bowl
- Relax the rules

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Final Consideration: Communication Method

- Acknowledge what person is saying to reassure and provide security.
- Use words of encouragement.
- Allow sufficient time for the person to understand and respond.
- Be prepared to distract or redirect if person gets agitated.
- Go along with the person's belief of what is true and avoid trying to explain or rationalize

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Communication Method

- Speak slowly and look at the person directly
- Avoid abstract questions; rather use direct statements
- Avoid open-ended questions; rather offer no more then 2 choices at a time
- Provide only 1or 2 simple directions
- Use a cuing strategy

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Cuing Strategies

VERBAL	VISUAL	DEMONSTRATION	TACTILE
Say "Stand up" "Let's go" "Hold this" "Put down"	Display Check lists Pictures Symbols	Show Start first step Do the action Do the activity	Touch Hand over hand Physical support

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Small Group Activity: Use the Worksheet in your Handout

Activity: ________________

1. Describe the activity.
2. How can you make the activity easier?
3. How can you change the elements (objects/tools) of the activity?
4. How can you change the purpose?
5. What ways will you use to communicate?

Modifications:

- ____________________
- ____________________
- ____________________
- ____________________
- ____________________
- ____________________
- ____________________
- ____________________

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Additional Resources

- Exploring Activity Options
  - Pleasant Events Schedule (Teri & Logsdon, 1991)
- AFTD Partners in FTD Care Issue #19: Summer 2016
- Finding Activities & Materials

Mind-Start	http://www.mind-start.com/ 612-868-5831
Alzheimer's Store	www.alzstore.com 800-752-3238
Nasco Senior Activities	www.enasco.com/senioractivities 800-558-9595
S & S Worldwide	www.ssww.com 800-288-9941

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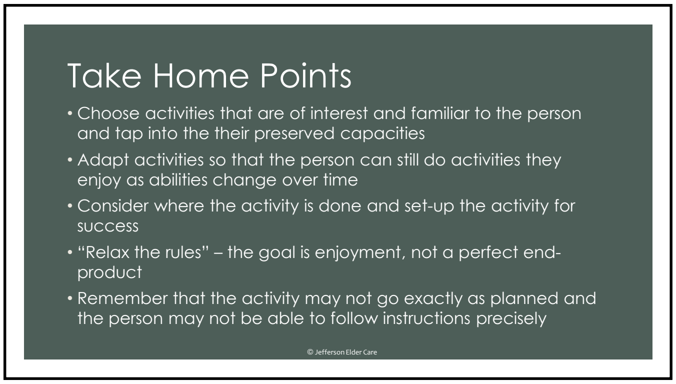

Take Home Points

- Choose activities that are of interest and familiar to the person and tap into the their preserved capacities
- Adapt activities so that the person can still do activities they enjoy as abilities change over time
- Consider where the activity is done and set-up the activity for success
- "Relax the rules" – the goal is enjoyment, not a perfect end-product
- Remember that the activity may not go exactly as planned and the person may not be able to follow instructions precisely

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Thank You!

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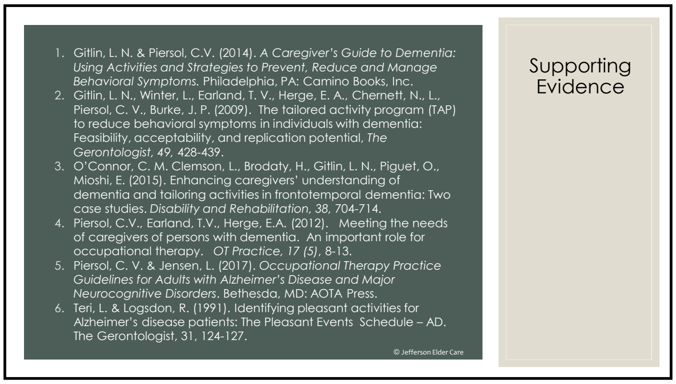

Supporting Evidence

1. Gitlin, L. N. & Piersol, C.V. (2014). *A Caregiver's Guide to Dementia: Using Activities and Strategies to Prevent, Reduce and Manage Behavioral Symptoms*. Philadelphia, PA: Camino Books, Inc.
2. Gitlin, L. N., Winter, L., Earland, T. V., Herge, E. A., Chernett, N., L., Piersol, C. V., Burke, J. P. (2009). The tailored activity program (TAP) to reduce behavioral symptoms in individuals with dementia: Feasibility, acceptability, and replication potential, *The Gerontologist, 49,* 428-439.
3. O'Connor, C. M. Clemson, L., Brodaty, H., Gitlin, L. N., Piguet, O., Mioshi, E. (2015). Enhancing caregivers' understanding of dementia and tailoring activities in frontotemporal dementia: Two case studies. *Disability and Rehabilitation, 38,* 704-714.
4. Piersol, C.V., Earland, T.V., Herge, E.A. (2012). Meeting the needs of caregivers of persons with dementia. An important role for occupational therapy. *OT Practice, 17 (5)*, 8-13.
5. Piersol, C. V. & Jensen, L. (2017). *Occupational Therapy Practice Guidelines for Adults with Alzheimer's Disease and Major Neurocognitive Disorders*. Bethesda, MD: AOTA Press.
6. Teri, L. & Logsdon, R. (1991). Identifying pleasant activities for Alzheimer's disease patients: The Pleasant Events Schedule – AD. The Gerontologist, 31, 124-127.

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Notes

2:00 p.m. Breakout Session:
Communication Strategies and Emerging Research in PPA

Kyrana Tsapkini, PhD, Johns Hopkins School of Medicine
Stephanie Grasso, M.A., CCC-SLP, The Aphasia Research and Treatment Lab,
The University of Texas at Austin

I. Research on language interventions in primary progressive aphasia (PPA): Why participation matters

Top 10 reasons why participating in research matters:

1. There is no proven medication(s) that would either slow the progression of the degenerative disease or that would alleviate its symptoms.
2. The only studies that have shown improvement in language symptoms or delays in deterioration are experimental studies of speech-language interventions.
3. Participating in research engages the person with PPA and the caregiver in the most updated methods available.
4. It is taking action, i.e., better than sitting idle at home or being depressed about the current condition.
5. It ignites interest, effort, engagement and hope for both participants and partners.
6. In many cases it involves meeting more people with PPA and finding support groups and other resources available.
7. Techniques shown may be learned and applied at home or with the regular speech language pathologist.
8. It strengthens awareness and interest to the scientific community for more targeted and engaging approaches.
9. It shows courage to face life difficulties and find solutions.
10. Even if it may not help the participant, it may help others and it is wonderful to be a contributor in the battle with PPA.

Top 10 facts about transcranial direct current stimulation (tDCS) research in PPA

1. There is actually very little research on tDCS in PPA, so results should be taken cautiously. More research is needed with more participants.
2. What we know so far about tDCS parameters in language interventions is that it is not a panacea and it does not alleviate language symptoms only by itself.
3. TDCS should be coupled with a language task to have any effect. It is not recommended as a do-it-yourself (DIY) method. A speech-language pathologist is best suited to perform it with the patient.
4. The language task to be coupled with tDCS is important and has to be associated with the area of the brain stimulated.
5. The area of stimulation matters as does the location of current flow, the duration, and the current intensity. We do not know the most effective parameters for each PPA variant yet. This is another reason not to assume it can easily be done at home.
6. Other parameters of people's lifestyles should be taken into account as they may affect tDCS: other drugs taken together (such as antiepileptic drugs), exercise, or food.
7. The same tDCS parameters do not help each variant in the same way. For example, different PPA variants may need different areas of stimulation and different tasks.
8. There are some people who respond to tDCS and some who do not. We do not yet know why.
9. The effect of improvement for responders is about 20% more than with speech language therapy alone. TDCS is an augmentative technique, not a replacement for speech language therapy. In responders, other non-practiced language and cognitive functions do not automatically improve.

10. TDCS still remains an investigational technique whose mechanism is not yet well understood. It is exciting, however, to see even small improvements. More research is needed to figure out how it may slow down the progression of the underlying disease, how it affects the brain, how it can be more effective. Participating in investigational research generates hope in everyone: participants, caregivers and researchers.

Resources:

Use the link: **www.clinicaltrials.gov** and look up PPA or primary progressive aphasia, speech-language pathology research or tDCS.

II. Primary Progressive Aphasia: A Staged Approach to Care

General Guidelines for Treatment Provided by a Speech-Language Pathologist (SLP)

- The goal of treatment is to maximize functional (not perfect) communication at each stage
- SLPs should consider each individual's communication contexts to promote communication in all environments
- The treatment approach that is used should be tailored to the person's current speech and language profile, while planning for the inevitable progression of symptoms
- Treatment is ideally provided in 'doses,' where the SLP will assess then provide treatment, will assess again, and is followed by more treatment
- The SLP should introduce the concept of alternative and augmentative communication, and provide options that may be appropriate
- The SLP should anticipate the progression of each person and introduce communication strategies and tools before they are required
- It is critical that the focus of treatment is on words and topics that are personally relevant to the individual with PPA
- Pre-packaged materials such as workbooks and cognitive games are not evidence-based for improving communication in this population

In the Mild Stage of PPA: Working with a SLP

- Obtain an evaluation with a SLP to evaluate communication abilities
- Discuss treatment options and begin treatment
  - A plan should be discussed with the individual with PPA and their family members
- Once treatment begins, communication partners should be included in these sessions so that practice can continue in the home
- Evaluate augmentative and alternative communication (AAC) options (communication book or devices) with the SLP, although the individual with PPA may not be interested in relying primarily on AAC at this stage
- The progressive nature of the disease should be discussed and it is recommended that the individual with PPA and their caregivers attend support groups
- The SLP can provide a card for the person with PPA that identifies and explains their diagnosis

Relevant Communication Strategies

- Eliminate background noise and distractions so that the person with PPA is better able to understand the intended message (e.g. face the person, and turn off the television)
- If a response is incomplete or unclear- ask for clarification; do not pretend to understand
- It is common for individuals at this stage to have difficulty with word finding, and often communication partners are uncertain as to whether they should "fill in" the word for the person with PPA
  - Discuss this with the individual with PPA and come up with a plan that both parties are comfortable with

- Individuals with the nonfluent/agrammatic variant of PPA may begin practicing articulation of difficult and frequently used words
- Participation in a communication support group can encourage practice with and social use of language

Restitutive Approaches: "Rebuilding" Speech and Language Skills

- Treatment for word-finding: This approach is evidence-based and most research suggests that using approaches that contain cueing hierarchies promote robust gains
  - Evidence is emerging that caregivers can be trained to administer this treatment at home with the training and support of a SLP
  - General strategies:
    - Have a picture present of the item that the person is trying to name
    - Semantic circumlocution: Have them talk around the word/give a description of the item (e.g. it looks like a horse, but it has black and white stripes…)
    - Sound-based or written cues: Have the individual attempt to come up with the written form of the word, or the initial sound. This may help them retrieve the rest of the word.
    - Have them say and write the word repeatedly
- Script Training: This approach is also evidence-based and is most suitable for individuals with the nonfluent/agrammatic variant of PPA
  - This approach is primarily homework-based
  - Topics are functional and should be selected by the individual with aphasia and their caregivers/communication partners
  - Videos are created and the individual with PPA should speak in unison with that video until they have mastered the script
  - E.g. Introduction Script: My name is Stephanie Grasso. I live in Austin, Texas. I am a SLP and enjoy my work. What do you do?

Multimodality Communication:

*Note: Multimodality communication can be, and should be used at all stages

- Use of word-retrieval strategies: 1) talking around the word (e.g. describing the item they are unable to retrieve) 2) attempting to come up with the first sound of the words, or to write the intended message
- Gestures to convey meanings
- Drawing to convey information

Progression to Moderate PPA: Working with a SLP

- Continue to see a SLP for ongoing evaluation and treatment
- Use scripts for topics the person would like to discuss in everyday communication (e.g., information about their diagnosis, family, hobbies, etc.)
- The individual with PPA should continue to practice word-finding strategies for items that are important for their everyday communication
- With an SLP, evaluate an augmentative and alternative communication device or book and begin to use this system
  - This may include developing a personalized communication notebook or communication wallet (e.g. note cards on keyring). This provides a visual vocabulary of key words, people, and activities that can be used by the person with PPA and their communication partners

Relevant Communication Strategies in Moderate PPA

- Use shorter sentences with simpler grammatical structures to facilitate improved comprehension
  - If the person with PPA does not understand your message, simplify rather than add information to the message
- Rather than providing a list of directions or complicated questions, give one direction or ask one question at a time
- Use questions that offer a choice, rather than open-

ended questions ("Do you want a hamburger or a hotdog?" rather than "What do you want to eat?")

- Use all modalities to support communication (e.g. gestures, pictures, visual aids)
- Use affirming statements (e.g., "Take your time.")

Types of Augmentative and Alternative Communication (AAC) and Suggestions

*Note: AAC can be used at any stage, but is used more frequently beginning in the moderate stages

- AAC systems can range from low tech to high tech devices
  - Low tech devices typically come in the form of individualized communication books and boards
  - High tech devices can include speech generating devices and iPads
- These systems usually include places and people the person knows and may want to talk about
- Other items include a calendar to discuss time, and a local map to discuss location
- Implementing AAC without training provided by a SLP is not recommended
- Training usually occurs over several sessions with communication partners present, and in the community to facilitate the use of the device outside of the therapy location
- Individuals with PPA may be resistant to using AAC initially

Moderate-to-Severe PPA: Working with a SLP

- The SLP may train home health, adult day and residential care staff to use communication tools (AAC) and strategies to facilitate successful communication
- If scripts were previously used in treatment, videos of the individual with PPA speaking phrases from their scripts may be added to a 'voice bank' on a communication system (e.g. iPad)
- The SLP will also conduct an evaluation of swallowing and dysphagia as needed

Relevant Communication Strategies in Moderate-to-Severe PPA

- Communication at this stage will be largely nonverbal
- Continue to use multiple modalities (gestures, writing single words, drawing) as verbal communication becomes increasingly challenging
- It is important to check for comprehension often
- Encourage regular use of a communication book, wallet and/or other augmentative and alternative communication device
- When communicating with the person with PPA, referring to items on their AAC system may increase their comprehension of the intended message

Resources:

Finding an SLP: http://www.asha.org/profind
Search for a SLP that has experience in aphasia and dementia. A skilled clinician will be able to treat PPA based on this experience. However, if a clinician is not the right fit, seek another.

Video Making Service for Scripts:
http://www.speakinmotion.com
Speak in Motion: VAST
Communication partners or SLPs can order personalized videos from VAST. They provide a close-up video of a healthy speaker's mouth that the individual with PPA can practice with.

AFTD Partners in FTD Care: Maximizing Communication Success in Primary Progressive Aphasia (Issue #17: Winter 2016) **http://www.theaftd.org/newsroom/newsletters/partners-in-ftd-care-newsletters**. This issue provides an overview of PPA and its subtypes, offers practical tips for facilitating communication at each stage of the disease, and provides a listing of online resources to aid individuals living with PPA and their caregivers.

2:00 p.m. Breakout Session:
Comfort Care and End of Life Considerations

Nancy Flowers, M.S.W., LCSW
Community Education Program Manager/Dementia Project Manager
Rainbow Hospice and Palliative Care • NFlowers@RainbowHospice.org, 847-653-3134

This session focuses on the ways that palliative and hospice care support the emotional, spiritual and physical care needs of persons with FTD and their families, and improves quality of life at end of life.

Benefits of palliative and hospice care

Palliative care is specialized medical care that improves quality of life by easing pain, symptoms and stress during the course of a serious illness. In addition to FTD and other dementias, conditions such as cancer, heart disease, respiratory disease, kidney failure, AIDS, Amyotrophic Lateral Sclerosis (ALS) and other neurological diseases may benefit from palliative care intervention.

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

Palliative care consultation can be provided in conjunction with medical treatments, and is available to persons with FTD at any time during the care process. Palliative care physicians and nurse practitioners provide consultation on pain and symptom management, and include the education and support needed to help patients and families decide on future directions for care. This approach to care provides relief of suffering through the early identification and treatment of pain. Palliative care also addresses physical care needs and emotional, spiritual and caregiver concerns. As end of life approaches, palliative care practitioners help guide medical caregivers and families to identify the care that is most appropriate for the person with FTD and help identify the right time to transition to hospice.

Hospice care

Hospice care is an interdisciplinary model of care that provides compassionate care for people facing a life-limiting illness or injury. Hospice care utilizes a team oriented, holistic approach to end of life care. This approach provides expert medical care, pain management and emotional and spiritual support tailored to patient and family needs and preferences. As defined by the National Hospice and Palliative Care Organization (NHPCO), hospice care is premised on the belief that each of us has the right to die pain-free and with dignity, and that families will receive the necessary support to allow their family members to do so.

At some point in the care of a person with advanced dementia, the physician may tell the family that further treatment interventions will not be helpful and recommend hospice care. Hospice care can be initiated when a person with FTD has been determined to have a life expectancy of less than six months and the family is in agreement with medical recommendations that curative treatments are no longer helpful and 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 in the past year one or more signs of dementia-related decline 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.

Medicare, Medicaid and most private insurances pay for palliative and hospice care but the eligibility criteria can be a challenge. The young age of many people with FTD means their overall health may be more robust, which can complicate approval for hospice admission. It is useful to become familiar with the hospice eligibility criteria for dementia and for other services that you may need to advocate for over the course of the disease's progression.

Once admitted to hospice, a person can remain on hospice for as long as they qualify which will, for most persons, be until death. However, in some instances, persons diagnosed with FTD may experience a slower decline and the hospice re-certification process may prove to be difficult. If the hospice team makes the determination that the person with FTD no longer meets hospice criteria, the person or their family may appeal this decision. In some instances this appeal will result in the person remaining under hospice services. Persons who are discharged from hospice due to failure to meet criteria may be re-evaluated and re-admitted as their condition changes.

An interdisciplinary team provides hospice care wherever a hospice patient resides or needs care: in homes, long term care facilities, hospice in-patient units and hospital settings. Regardless of the location of care, the team includes a physician, nurse, social worker, chaplain, nurse's aide and specially trained volunteers. The team may also include music and massage therapists. A customized plan of care is developed by the interdisciplinary team, in conjunction with the person with FTD (as able) and the family. The frequency of staff visits is based on the needs and preferences of the hospice patient and their family. As a person's care needs change the visit frequency of team members will also change, and generally increases as end of life approaches.

Hospice offers several levels of care: Routine, General In-Patient, Continuous, and Respite, each with specific eligibility requirements. Most patients spend their entire time in hospice at the Routine level of care, receiving care in either a home setting or a long term care facility. General In-Patient level of care provides symptom management for medically unstable patients in hospitals, skilled facilities or hospice in-patient units. Continuous Care is offered when a hospice patient who would otherwise require hospitalization for symptom management is cared for in a home or long term care facility setting. Respite Care is a benefit which allows for up to five days of respite in a long term care facility for caregivers in need of a "break" from care.

In addition to palliative care, the services of the hospice interdisciplinary team and the care levels described, Medicare, Medicaid and most private insurances cover the cost of medications needed for pain and symptom management, and durable medical equipment and supplies.

Hospices are required to provide bereavement support to families for thirteen months following the death of the hospice patient. Bereavement services vary from hospice to hospice, but include some type of outreach to the newly bereaved, either by phone or through mailings, and may also include individual and group counseling and family focused activities.

Hospice staff plays an important support role at end of life. Staff serves as a primary source of support and education, providing information about medical conditions, recognizing changes in condition and caring for a person at end of life. Staff explores caregiver goals of care and assists with identifying and arranging any additional services needed to support end of life care. Hospice staff facilitates discussions about the benefits of advance planning documents (Powers of Attorney, Five Wishes, POLST, DNR) and provides the information and guidance needed to enable caregivers to make care decisions. This education and support can help to increase caregiver confidence about end of life care giving and better prepare the caregiver for the person's death.

Some hospices are beginning to train their staff to care for persons with dementia. It is my experience that dementia specific training helps staff provide a higher quality of care to persons with dementia and their families. Training should include information on FTD and other types of dementia, the impact of brain changes on function, the meaning of behaviors and creative responses to behavior.

Dementia Care at End of Life

While most hospices care for persons with dementia, very few have trained their staff to meet the physical, emotional and spiritual care needs of persons with dementia. When selecting a hospice, caregivers may wish to ask hospice staff about the organization's experience caring for persons with dementia. Questions should include:

1. What is your organization's experience working with persons with dementia? With persons with FTD?
2. What training does your staff receive to provide advanced dementia care at end of life? On caring for persons with FTD?
3. Who provides your training? Are the educators internal or external to the organization?
4. If the organization has little to no experience with FTD, are they willing to learn?
5. Describe the organization's ability to provide consultation to staff and caregivers on dementia behaviors, advance directives, and end of life decision making.
6. What experience does your organization have working with area dementia care providers? Providers that work with persons with FTD?

Resources

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.nhpco.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

AFTD: FTD-specific information on hospice, end of life symptoms and advocating for care.
http://www.theaftd.org/life-with-ftd/managing-health-care/hospice-end-of-life

AFTD Partners in FTD Care: Comfort Care and Hospice in Advanced FTD (Issue #20: Fall 2016)
http://www.theaftd.org/newsroom/newsletters/partners-in-ftd-care-newsletters

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

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

2:00 p.m. Breakout Session:
Moving Forward with an FTD Diagnosis

Guide for Living with FTD

A three legged stool:
Finances, healthcare and daily living

This guide was created in 2017 by Rod Hall and Diana Winoker to help others with FTD to find resources, adapt to changes and live with the diagnosis. The document is meant to be updated with new information, as needed.

Finances

- **Elder Law Attorney**
  Elder Law is a specialty within the law that covers a wide range of issues related to retirement and aging that may also impact people with FTD who are under 65. It is not practiced by a general attorney. To find an elder law attorney in your area go to **www.naela.org**.
- **SSDI (Social Security Disability)**
  People with FTD qualify for expedited medical review under Social Security's Compassionate Allowances – see URL below:
  https://www.ssa.gov/compassionateallowances

  After you are on SSDI for 24 months, you qualify for Medicare, no matter what age you are at the time.

- **Short term and long term disability**
  Short-term and long-term disability insurance is often acquired through employment, but you can usually convert employer-provided policies to private pay when you stop working.
- **Health Insurance**
  You can pay for health insurance by using COBRA for 18 months after you leave employment, and you can get an extension, in some cases, to cover you until you are eligible for Medicare.
- **Unions**
  Unions often offer benefits to members, like health insurance and life insurance as well as retirement or pensions.
- **401K/IRA – Savings plans**
  These can be withdrawn as early as 55, in the case of retirement. The age of no-penalty withdrawals is 59½. Rules apply, check with your plan.
- **Long-Term Care Insurance**
  This pays for care in a facility, such as assisted living. It usually pays a set amount per day, and then you pay the remainder. Some employers offer this insurance. If you had this it is worth keeping. If you are already diagnosed, you will not be able to obtain this.
- **Life Insurance**
  Life insurance acquired through employment can often be transferred to a policy you pay for yourself. You may be able to convert a life insurance policy to cash to pay for long-term care. Check with your insurance agent for details.

Healthcare

- **Confirm the diagnosis**
  See the "In Your Region" Section of AFTD website for medical centers with expertise diagnosing FTD
- **Learn about disease symptoms and what you might expect.**

  Start a file of key articles and resources on FTD that will help educate others.

  Find good information online from websites you can trust including videos discussing a wide range of FTD related topics.

  - **www.theaftd.org** and AFTD's YouTube Channel
  - Mayo Clinic FTD information and Mayo clinic's FTD video
  - UCSF Memory and Aging Center and UCSF YouTube videos
- **Do doctors understand FTD?**

  Express your concerns about Anesthesia and medications. Prepare yourself for visits to Emergency rooms and other healthcare providers and realize you may know more about FTD than the professionals. Whatever you can do to teach them will benefit you.
- **Medicine**

  Nobody can treat you or give you medication without your permission. Do your own research. Good info on symptomatic treatments for FTD is available at the sites below:

  - **http://www.theaftd.org/understandingftd/healthcare-professionals/treatment**
  - **http://www.memory.ucsf.edu/ftd/overview/ftd/treatment/multiple**
- **Integrated healthcare**

  It is wise to get all doctors on the same page. Have the neurologist communicate with primary care and any other specialists you see.
- **Preventive testing (colonoscopy, prostate, etc.)**

  Do you really need these procedures? What will you do with the results? If you would not treat something they find (i.e. cancer), why do the test?

Daily Living

- **A guide on living with FTD, by Cindy O'Dell.**
  https://www.theaftd.org/wp-content/uploads/2016/12/Coping-With-FTD.pdf
- **Personal Hygiene**

  Caring for your hygiene is important to your basic health. If showers bother you, try waterless soaps and shampoos. Try mouthwash instead of a brush and eat ¼ apple after each meal.
- **Parenting with FTD**

  - AFTD's booklet "What About the Kids?"
  - Additional resources available on AFTD's Children and Teens webpage
  - AFTD Kids and Teens Website
- **Food**

  Many have carb and sweet cravings. Try to replace some sweets with fruits. Limit alcohol intake. Try to vary your food choices.
- **Local transportation**

  Check with your local Agency on Aging for options of low cost transportation. Many local transit authorities offer discounted or free service to persons with disabilities.
- **Travel by planes, trains and automobile**

  - For general information: **https://wwwnc.cdc.gov/travel/page/disability**
  - For air travel: **https://www.tsa.gov/travel/passenger-support** - call 72 hours (or more) in advance. They will take you through security and all the way to your gate.
  - For train travel: **https://www.amtrak.com/accessible-travel-services**

Moving Forward with an FTD Diagnosis, cont'd.

Money for daily living

Set spending limits. Prepaid debit or credit cards are good options to consider if you tend to overspend or buy things impulsively.

Activities, interests, socializing

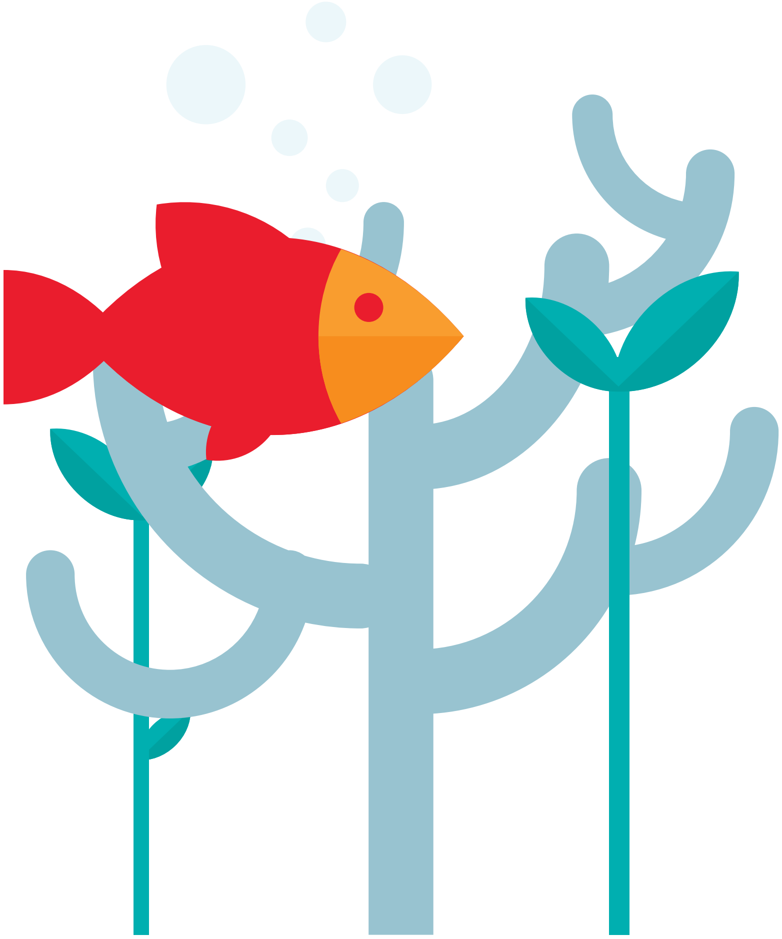
Find and connect with other people diagnosed with FTD.

- Organize a gathering - Opportunities to meet others are scarce so create your own.
- Ask to be included in events for caregivers.
- Try a younger-onset or Early-stage dementia group – Check with an Alzheimer's Association Chapter or memory care center for groups in your area.

Join an on-Line or remote groups. Options include:

- FTD Patient Support Group - a private, diagnosed persons-only Facebook group. For more info contact: **ftdsuportinfo@gmail.com**
- DAI Meeting of the Minds Webinars - see below for more details: **https://www.dementiaallianceinternational.org/events/dai-webinars**
- To Whom I May Concern. An interactive theater program for people recently diagnosed with a progressive brain illness to share their stories in their own words: **http://towhomimayconcern.org**
- Dementia Mentors provides mentoring, motivation, social engagement and more for those living with dementia. **https://www.dementiamentors.org/home.html**
- AFTD Telephone Support Group for People with FTD. Contact **info@theaftd.org** or **(866) 507-7222** for details.

When traveling to AFTD Conference, or attending a day program use AFTD Comstock Respite and Travel Program. For more details, call **866-507-7222** or email **info@theaftd.org**.



Keynote Speaker: Halima Amjad

Halima Amjad, MD, MPH is an Assistant Professor of Medicine in the Division of Geriatric Medicine at Johns Hopkins University.

Halima's father, a dentist who came to the U.S. from Pakistan in the 1970s to build a successful practice in Philadelphia, was diagnosed with the primary progressive aphasia form of FTD at age 60.

She shared her family's journey in an essay, "*Caring for Dementia: Returning to the Village*," which won the John A. Hartford Foundation's 2014–15 Better Caregiving Better Lives story contest.

To read her essay, visit **http://www.johnahartford.org/blog/view/dementia-caregiving-returning-to-the-village**

Dr. Amjad currently sees patients at the Johns Hopkins Memory and Alzheimer's Treatment Center and engages in research focused on improving care and health services for people with dementia. Ongoing experience with his illness has had a strong influence on her work.

In her keynote address, she will reflect on her family's FTD journey, and offer her vision of an effective system of FTD care and support.

> **"Only families juggling dementia understand the pain of losing a loved one twice, once in mind and later in body. And only these friends understand the emotionally and physically exhausting experience of caring for someone who cannot appreciate you or love you back in the same way."**

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AFTD Resources

Whether you are a person diagnosed, a caregiver, or a child with a diagnosed parent, AFTD offers information designed to be useful throughout a family's journey with FTD. We offer vital information, links to local support resources, information on coping strategies, materials to raise awareness and educate professionals, opportunities to get involved and ways to connect with others.

AFTD's Website - www.theaftd.org

AFTD's website is the place for FTD information, resources and support. Offers essential information for people and families facing a new diagnosis, information and strategies for managing FTD, opportunities to participate in research, ways to volunteer, fundraise, support AFTD with a donation, or otherwise get involved, and the latest FTD-related news. The website is also a hub for getting in contact with us.

AFTD HelpLine - 866.507.7222 toll-free or info@theaftd.org

AFTD's most important direct service to people with FTD, caregivers and professionals, the HelpLine is reachable by phone or email, and staffed Monday through Friday during AFTD office hours.

AFTD Kids and Teens Website - www.AFTDkidsandteens.org

Explore. Learn. Connect. This website offers separate sections for young children and teens, providing reliable information and empowering coping strategies for all who have a parent or another close relative affected by FTD.

Connecting with Support:

AFTD connects people with FTD and caregivers with support that fits their needs. Visit our website for listings of AFTD-affiliated groups and other local groups by region. Contact us for information on specialized telephone and web-based groups for persons diagnosed, caregivers of people with FTD/ALS, caregivers with children/teens at home and for men caring for a spouse.

Finding Support for Persons with FTD:

Access **www.theaftd.org**, then choose Life with FTD -> I Have FTD -> Support. You can also access the following link directly: **http://www.theaftd.org/life-with-ftd/i-have-ftd/support**

Finding Support for Caregivers:

Access **www.theaftd.org,** then choose Life with FTD -> Support for Caregivers. You can also access the following link directly: **http://www.theaftd.org/life-with-ftd/support-for-caregivers**

Information on Ways to Participate in Research:

Visit AFTD's website to learn about ways you can participate in research, including the FTD Disorders Registry, ARTFL/LEFFTDS research studies and emerging clinical trials.

Publications, Videos and Newsletters:

Refer to AFTD materials for information on awareness, support, care and advocacy efforts aimed to improve quality of life for those living with FTD and their families.

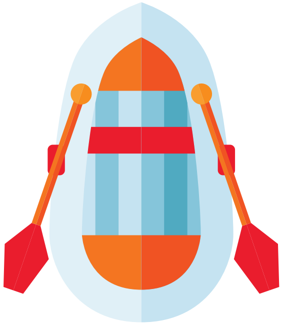
Comstock Respite and Travel Grants:

Comstock Respite Grants help full-time, unpaid caregivers arrange short-term daytime or overnight care for loved ones diagnosed with FTD. Caregivers decide how to best use the funds based on their situation and needs. Comstock Travel Grants provide modest financial assistance to make it possible to attend an FTD education conference. The maximum annual award for these programs is $500.

For People with FTD:

People diagnosed with FTD will find increasing resources at AFTD. Facilitated by AFTD staff, a mutual support group meets monthly online via Zoom, an easy to use computer web-camera platform. We continue to offer new volunteer opportunities, and we are now piloting small Quality of Life grants for persons diagnosed. Find out more about these opportunities by contacting **info@theaftd.org** or calling **866-507-7222**.

AFTD's website offers more information on all of the resources listed above. Visit us at **www.theaftd.org**.



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. When FTD is diagnosed, consider how you will approach living with the disease.	
Engage with people who understand FTD as early 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**.	
The person with FTD and care partners start important conversations regarding care and support over time. Acknowledge where perspectives are similar and different.	
Identify ways you can adjust to keep doing things that are most important to each person and to close family or friends.	
Share information about the disease and about your needs with key family and friends.	
If you have children or teens, get AFTD's booklet, *What About the Kids?* and visit **www.AFTDKidsandTeens.org**.	
Learn about the disease.	
Confirm the diagnosis.	
Learn about the disease symptoms and what you might expect.	
Start a file of key articles and resources on FTD that will help 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 establish coordination.	
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 support options for caregivers and the person with the disease. Visit **http://www.theaftd.org** and ask about phone 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, will.).	
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 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 caregiver 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.	

The first step is simple: Tell your story.

FTD DISORDERS REGISTRY

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.

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 18 years of age (19 in those states and provinces where the age of majority is 19; Alberta, Saskatchewan, Newfoundland and Labrador currently excluded).

We hope you will consider **becoming part of the Registry**. Visit the Registry website, **http://www.ftdregistry.org for more information**

Advance the science: Tell your story.

AFTD Education Conference 2017
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Essential Guidance for Managing 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 clinical experts and health care professionals, each edition focuses on a specific FTD care issue and suggests intervention strategies to help readers cope with the unique challenges presented by FTD.

Each issue includes discussion questions, sidebar articles and the one-page handout "What to Do About…" that offers succinct, hands-on interventions specific to the given topic.

Recent topics addressed include:

- Using occupational therapy to help persons diagnosed to remain active in their lives.
- Providing FTD care when there are children in the home.
- Securing end-of-life comfort care in advanced FTD cases.

Partners in FTD Care materials can 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.

Partners in FTD Care

a quarterly newsletter for healthcare professionals
Fall 2016

Comfort Care and Hospice in Advanced FTD

Introduction

Frontotemporal degeneration is the most common cause of dementia in people under the age of 60. It typically strikes when individuals are fully engaged in their family, career and social lives, long before giving much thought to advance care planning or end-of-life decision-making. While the clinical presentation and progression may vary, FTD is ultimately a terminal condition. For people living with FTD and their families, learning about comfort care and discussing advance planning are central to ensuring the highest possible quality of life and making informed decisions at end-of-life.

The Case of Mark H.

EARLY ILLNESS

Mark H. was diagnosed with FTD when he was 60 years old, but he had begun exhibiting symptoms about three years prior. His wife Terry, her 30-year-old son Jeff and Mark's long-time co-workers had started noticing unusual changes in Mark's behavior. Mark had had a long and successful career in sales, being twice recognized as his company's top performer, but his job performance was becoming inconsistent. He started ignoring clients' phone calls and missing appointments, and failed to make his sales goals two years running. Terry felt Mark was emotionally withdrawing from the family and was concerned he was depressed. She insisted that he see his doctor, who referred him for a psychiatric consultation. Mark was treated for depression and anxiety for nearly two years without improvement.

Mark's increasingly self-centered decision-making and unusual behavior frustrated Terry. He followed the same routine every day after work: He arrived home at exactly 5:00 p.m., hardly speaking a word, then watched five consecutive game shows and insisted on eating dinner of a cheeseburger, French fries and two bananas. At Terry's insistence, Mark's psychiatrist referred him to a cognitive-behavioral neurologist. After a comprehensive evaluation, the neurologist concluded Mark had behavioral variant FTD (bvFTD) and advised Mark, Terry and Jeff to get Mark's legal affairs in order while he could still participate in the planning.

Mark and Terry had never heard of FTD, nor had they ever discussed a living will or advance health care decisions, thinking that they would have plenty of time to do so when they were older. Terry and Jeff tried to encourage Mark to talk about his care wishes, but Mark showed little interest. There was no reason to plan, he insisted; he was fine. The family learned that Mark's apathy was a sign of bvFTD, and that it would worsen over time. Terry persuaded Mark to meet with their attorney, who helped them complete their wills and durable Power of Attorney (POA) documents. Mark agreed, indifferently, to having Terry as his POA.

(continued on next page)

Young-Onset Dementia and Comfort Care

Professional dementia literature shows that most people would not choose aggressive medical interventions to prolong life if they enter an advanced stage of dementia, but would rather opt for measures to keep them comfortable. Unfortunately, people with terminal dementia often instead receive aggressive medical treatment that does not meaningfully improve quality of life.

Studies of advanced dementia are usually based on elderly people with Alzheimer's disease. People with FTD, however, face an even more difficult road to receiving the comfort care they may prefer. Typically a young-onset dementia, FTD occurs long before many people consider advance care directives. Additionally, FTD poses an acute threat to family stability. Its high emotional, social and financial toll leaves many dedicated family caregivers isolated, exhausted and overwhelmed. The behavioral changes that FTD causes can tear families apart, leaving the person diagnosed without loved ones to advocate health care providers on their behalf.

Departing from customary medical interventions may appear to outsiders as a form of neglect or giving up, especially when the person is younger. But current research suggests that aggressive medical interventions—for infections, fractures, swallowing problems, etc.—may pose more distress and discomfort to those living in the advanced stages of dementia, without improving the quality of their remaining days. Collaboration with quality hospice care presents an opportunity: to empower persons with FTD and their families: to arrange for comfort in a disease that has relentlessly taken it away.

AFTD The Association for Frontotemporal Degeneration
Opening the gateway to help and a cure

Partners in FTD Care
1 • Fall 2016

www.theaftd.org // 267.514.7221

To subscribe to the Partners in FTD Care newsletter, email **PartnersinFTDcare@theaftd.org**.

Past issues can be accessed on AFTD's **www.theaftd.org** website under News & Events -> AFTD Newsletters / Partners in FTD Care. Or access a direct link at: **http://www.theaftd.org/newsroom/newsletters/partners-in-ftd-care-newsletters**.

Additional training materials, including the powerful AFTD documentary film It Is What It Is, are available for healthcare professionals via AFTD's website under *Understanding FTD/For Healthcare Professionals*. Or access a direct link at: **http://www.theaftd.org/understandingftd/healthcare-professionals**.

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

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

Get Connected, Get Involved: AFTD on Social Platforms

The isolation of FTD lessens when you find others who understand what you're going through. AFTD's social networks can help you to make new connections, find information, gain support and get involved in the fight to **#endFTD** – locally, across the country and around the world.

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. Medical questions should still be directed to AFTD's HelpLine at info@theaftd.org or 866-507-7222.

AFTD's Closed Young Adult Facebook Group:

To join, write: youngadults@theaftd.org

AFTD's young adult Facebook group is for people in their 20s and 30s who have a loved one with FTD. This group serves as a supportive space for young adults to gather and share their experiences online. To become a member of this group, 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.

The 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.

Twitter:

https://twitter.com/aftdcure, @AFTDCure

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

Classy:

https://www.classy.org/charity/the-association-for-frontotemporal-degeneration/c39607

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 Facebook Page:

https://www.facebook.com/worldFTDunited

Not a resource from AFTD, but a Facebook page where AFTD, other international organizations, and advocates around the world unite to raise FTD awareness and fight this disease!

Care.
Connection.
Discovery.

Ready to Take Action and Volunteer?

You can make a difference for families facing FTD, now and in the future.

Conduct facility outreach.

Organize a Meet and Greet in your area.

Lead a support group.

Tell your FTD story.

Host a fundraiser.

Represent AFTD at a community event.

We'll explore projects together that suit your skills and interests and find the right volunteer opportunity for you.

Volunteer with AFTD today!

To learn more:
Visit
www.theaftd.org/get-involved/volunteer
OR
Contact AFTD Volunteer Manager, Kerri Keane:
267-758-8652, **kkeane@theaftd.org**

Care.
Connection.
Discovery.

Support Groups Help Families Facing FTD

One of the best resources available today for people facing FTD are others who understand the disease. With more than 100 FTD-focused support groups across the United States, we hope you take advantage of this growing network of support. Today, more than half of these groups are led by an AFTD-affiliated volunteer. For details on groups in your area, **visit with volunteers at our regional tables today**.

Don't see a face-to-face group near you? **Join the "Making a Difference…" afternoon breakout** to learn more about becoming a volunteer with AFTD's newest initiative, which offers training and assistance for those wanting to start and lead a support group in their own area.

AFTD also offers online and phone-based support groups.
Contact AFTD's HelpLine for more information:

866-507-7222, **info@theaftd.org**

Support groups can help.
Connect with people who understand.

Care.
Connection.
Discovery.

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**

Notes

AFTD
The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

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