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

Reflect, Renew and Explore

AFTD CONFERENCE 2016

MINNEAPOLIS, MN

DOUBLETREE BY HILTON HOTEL MINNEAPOLIS-PARK PLACE | MINNEAPOLIS, MN

1500 Park Place Blvd., Minneapolis, MN 55416

May 13, 2016, 9:30 a.m. to 5:30 p.m.

Dear Friends,

As Board Chair of the Association for Frontotemporal Degeneration, I am honored to welcome you to our 2016 Education Conference and Annual Meeting in Minneapolis.

I am very pleased to be back in Minnesota, which is where I was born and raised. Similarly to many of you who have joined us today, I am here because this disease has touched my family directly. Both my father and brother were taken by FTD but like all of you, I draw hope from the progress this organization is driving for our community.

While there are no treatments to slow or stop the progression of FTD at this time, research is advancing. Among the initiatives you will learn about today, several items stand out to me. First: a multi-year FTD Biomarkers Initiative has been made possible through a generous gift from the Samuel I. Newhouse Foundation. Identifying biomarkers for FTD will lead to quicker diagnosis and more effective treatments. Second: AFTD will announce the launching of the FTD Disorders Registry, created to understand the impact FTD has on persons diagnosed, caregivers and families, while empowering our community to be equal partners in future research. You will also learn today about AFTD's new affiliation process for support group leaders, which is already helping to improve support options in communities across the country.

Gain comfort from those whom you will meet here today. At the same time, I would challenge you to draw inspiration from what you learn at this conference to engage more deeply in AFTD's mission. Advocacy by caregivers, persons diagnosed and family members is so important to our community. If you are able to, I encourage you to join us in spreading awareness, building strong resources and supports, and fostering FTD research.

Our work together today demonstrates our commitment to building a better future—one that does not include the devastating impacts of this disease.

Warm Regards,

Jary Larsen

Jary Larsen, Ph.D.
AFTD Board Chair

Reflect, Renew and Explore

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MINNEAPOLIS, MN

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THE DAY'S PROGRAM

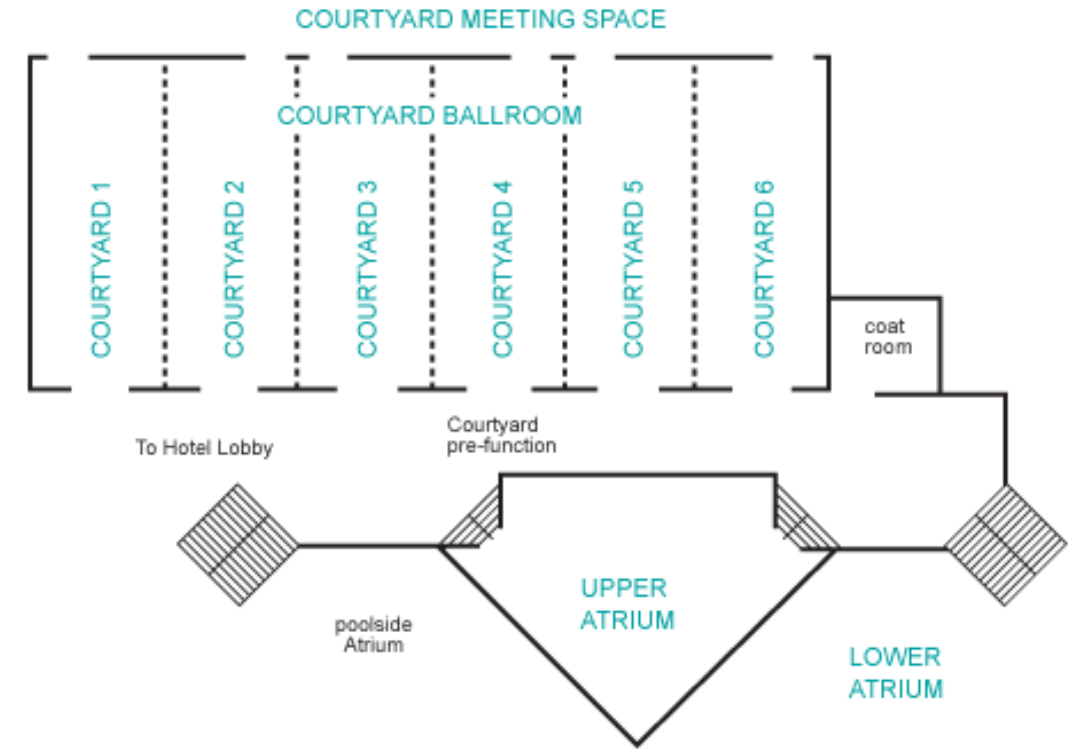
AFTD 2016 Education Conference

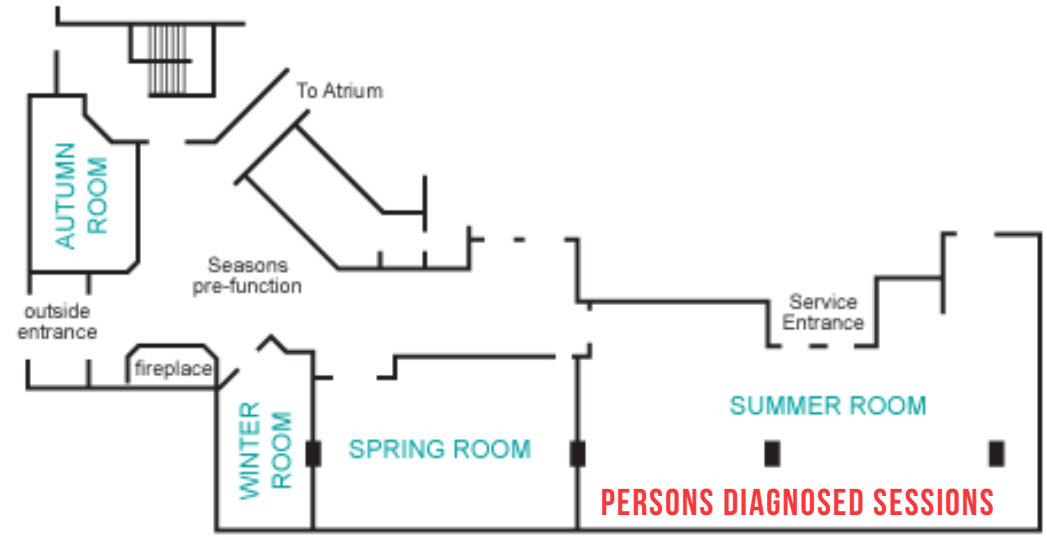
Minneapolis, MN | May 13, 2016

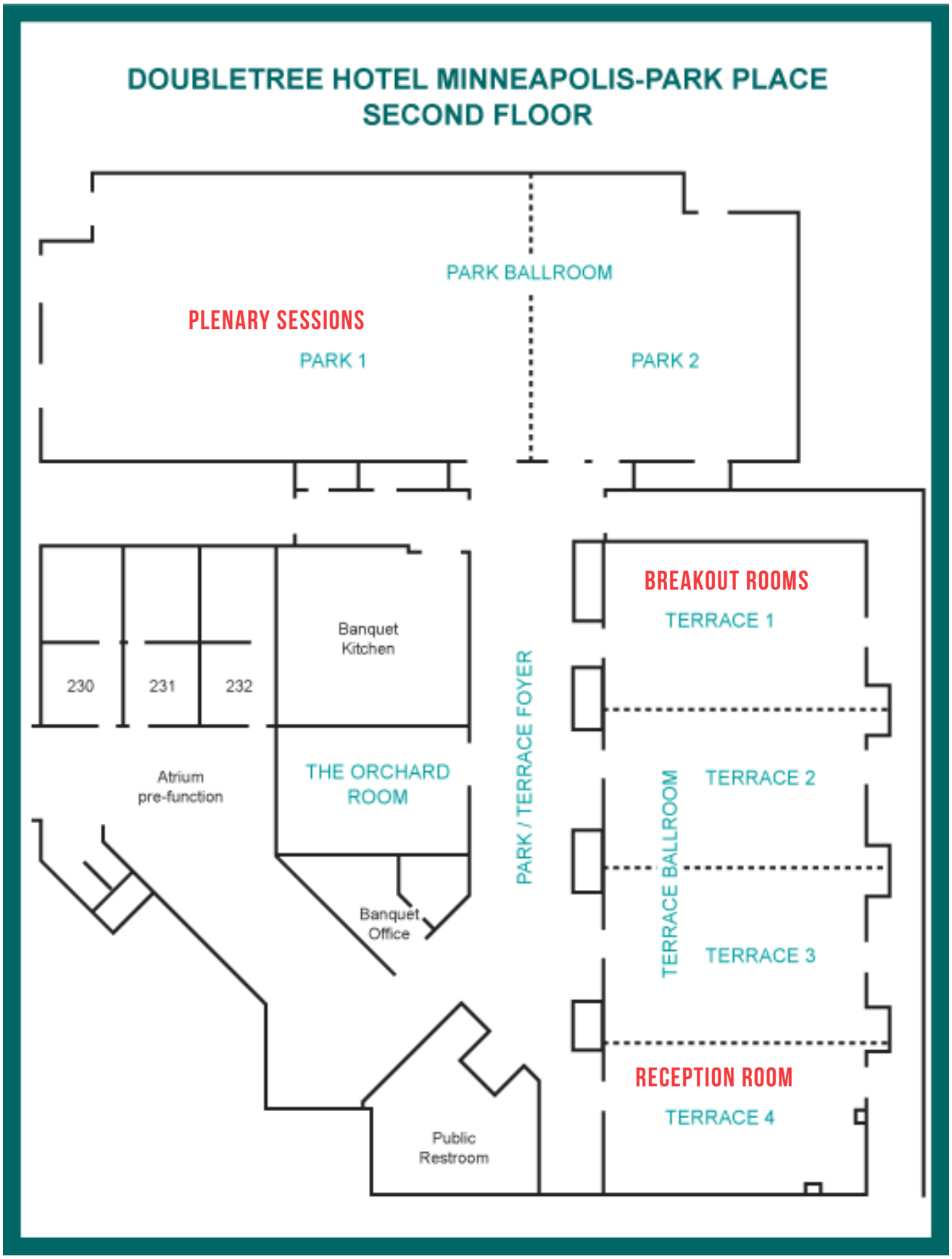
8:30 a.m.	**Registration**
9:30 a.m.	**Welcome Address** Jary Larsen, Ph.D., AFTD Board Chair
9:35 a.m.	**Welcome by Susan Suchan** Susan Suchan, living with PPA
9:45–10:15 a.m.	Summer Room: **Optional Morning Session for Persons with FTD:** Building Bridges, Teresa Webb Matt Sharp, M.S.S., AFTD Program Manager
9:45–10:15 a.m.	**Overview of FTD Disorders** Bradley F. Boeve, M.D., Chair, Behavioral Neurology, Mayo Clinic, Rochester, MN
10:15-10:45 a.m.	**Research Advances, ARTFL/LEFFTDS** David Knopman, M.D., Professor of Neurology, Mayo Clinic, Rochester, MN
10:45-11:15 a.m.	**FTD Disorders Registry** Dianna Wheaton, M.S., Ph.D., CHES, Director, FTD Disorders Registry
11:15–11:45 a.m.	**Q&A with Morning Speakers**
11:45 a.m.–12:45 p.m.	**Lunch**
1:00–1:25 p.m.	**AFTD Annual Report** Susan Dickinson, M.S., CGC, AFTD Executive Director
1:25–1:45 p.m.	**A Care Paradigm for People with FTD** Alvin Holm, M.D., FACP, Director, Cognitive and Behavioral Disorders Program, Bethesda Hospital
2:00–3:30 p.m.	**Breakout Sessions:** Applying Concepts of Wellness, Environment and Support
3:30-3:45 p.m.	**Break**
3:45-4:05 p.m.	**Impact on the Family** Darby Morhardt, Ph.D., LCSW Associate Professor, Director of Education, CNADC, Northwestern University Feinberg School of Medicine
4:05-4:45 p.m.	**Young Families Panel Discussion** Darby Morhardt, Gail Andersen, Matt Dineen, Sharon Denny
4:45-5:05 p.m.	**Practical Tools to Manage Your Stress** Charlene Martin-Lille, M.A., Resiliency Specialist, Mayo Clinic, Rochester, MN
5:05-5:30 p.m.	**Keynote Address:** **Dealing with FTD:** **A Creative Journey** Nancy Carlson, Author, Illustrator, Caregiver
5:30 p.m.	**Closing/Thank you** Susan Suchan Jary Larsen, Ph.D.
5:45–8:00 p.m.	**Social Reception–Hosted by AFTD's** Board of Directors

Stay for a buffet-style reception and conversation with today's speakers, AFTD Board and staff members, and most importantly, each other.

DOUBLETREE HOTEL MINNEAPOLIS-PARK PLACE
FIRST FLOOR



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THE DAY'S PROGRAM: BREAKOUT SESSIONS

**BREAKOUT SESSION OVERVIEW 2:00 P.M.–3:30 P.M.

BREAKOUT SESSIONS: APPLYING CONCEPTS OF WELLNESS, ENVIRONMENT AND SUPPORT

Conference attendees can attend the breakout session from the list below that best fits their interests and needs. Experts will provide guidance and practical ideas for care during informative and interactive 90-minute sessions.

FOR PERSONS DIAGNOSED: "SUPPORTING EACH OTHER"

Attendance at this afternoon breakout session is limited to people who have been diagnosed with an FTD Disorder.
Speaker: Teresa Webb
Facilitator: Matt Sharp, M.S.S.

MOVEMENT DISORDERS

For people interested in PSP, CBD or FTD/ALS
Speaker: Robin Riddle, M.B.A.
Facilitator: Nadine Tatton, Ph.D.

LANGUAGE DISORDERS

For people interested in primary progressive aphasia (PPA) or language and communication decline.
Speakers: Darby Morhardt, Ph.D., M.S.W., Becky Khayum, M.S., CCC-SLP and Robert and Linda Caughey
Facilitator: Bridget Moran, M.P.H.

BEHAVIOR DISORDERS

For people interested in positive approaches to behavior changes at home and in the community.
Speakers: Angela Lunde, M.A., CWC and Geri Hall, Ph.D., ARNP
Facilitator: Debra Niehoff, Ph.D.

RESIDENTIAL AND FACILITY CARE

For people considering residential care and how to promote a positive experience.
Speakers: Rebekah Wilson, M.S.W. and Lynn Erkkila M.S.W., LICSW
Facilitator: Sharon Denny, M.A.

COMFORT CARE AND END OF LIFE CONSIDERATIONS

For people interested in issues in advanced FTD, addressing end of life decisions and the value of hospice.
Speaker: Nancy Flowers, M.S.W., LCSW
Facilitator: Kerri Barthel, M.S.W.

ADDITIONAL PROGRAM DETAILS

FOR PERSONS DIAGNOSED

MORNING SESSION–BUILDING BRIDGES

The morning session will start with the game "Heads Up" as a fun way to break the ice and make introductions. Teresa and Matt will then lead a discussion about communicating effectively with care partners about FTD symptoms and challenges, despite differing experiences of life with FTD. Discussion topics will be introduced through role playing. Group members will have opportunities to enact conflict scenarios that can arise during routine activities such as "going to the market," and will be asked to share experiences with the group and discuss how to communicate their perspective on common challenges.

AFTERNOON BREAKOUT SESSION–SUPPORTING EACH OTHER

The afternoon session will offer time for networking and informal conversations about what people do for support, as well as what they do to connect with others. The session will include short presentations by people diagnosed with FTD about different ways they have found support or connected with peers locally or remotely. AFTD Program Manager Matt Sharp will host the session and collect ideas and suggestions to help AFTD develop more supports and resources for people with FTD.

REST, RELAX AND NETWORK

Following the afternoon breakout session, participants are welcome to attend the rest of the afternoon talks. Additionally, the room used for the afternoon session will remain available after 3:45 for anyone who wants to continue discussions or just relax in a quiet space.

ADDITIONAL RESOURCES

MEET YOUR REGIONAL COORDINATOR: Stop by the regional coordinator table and meet your regional coordinator volunteer. Learn about AFTD's volunteer program and opportunities in your area. AFTD's regional coordinator volunteers are ambassadors for AFTD and the principal coordinator of volunteer activities in their region. Come find out how you can get involved and make change happen.

THE AFTD-TEAM–GRASSROOTS EVENTS LUNCH: Hosting a grassroots event is a powerful way to raise awareness, and raise funds to Fight This Disease head on. Planning a fundraiser for AFTD is easy – and it's an excellent and fun way to meet and connect with others in your community! Join AFTD Grassroots Events Coordinator Bridget Graham and Development Manager Pamela E. McGonigle, M.A. for lunch at the conference. They'll share information about upcoming events, and about exciting ways in which you can raise awareness in your area in 2016, while supporting AFTD's mission! Room assignments will be clearly posted and announced at today's conference.

SUPPORT GROUP FACILITATORS LUNCH: Support Groups are one of the best resources available today for families facing FTD. Ever thought about starting a group in your area? If so, join Support Services Manager Bridget Moran to learn about AFTD's network of support, discuss your interest and hear from others who are currently leading groups. Grab your lunch and join us any time from 11:45am–12:45pm. Room assignments will be clearly posted and announced at today's conference. We look forward to meeting you! *Can't make it to lunch? Contact Bridget Moran any time at bmoran@theaftd.org or 267-758-8653 to learn more.

CERTIFICATES OF ATTENDANCE: Certificates of Attendance for healthcare professionals will be available after Nancy Carlson'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 from AFTD Program Manager Matt Sharp.

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SPEAKER BIOS

GAIL ANDERSEN, AFTD Recording Secretary, Mason, OH, is retired from Procter & Gamble after a 31-year career. After her retirement in December 2013, she joined the AFTD Board. Ms. Andersen has brought important experience in strategic planning and project management to the board. Prior to joining the board, she served on AFTD's Task Force for Families with Children, and she and her children have held several fundraisers for AFTD. Gail's husband died in 2012 at the age of 56 with bvFTD, with symptoms starting at the age of 43. Gail was raising young children at the time of Larry's onset of symptoms, diagnosis and admission to a long-term care facility. Their children are currently 29, 22 and 18 year-old triplets. Gail dealt with many challenges of bvFTD and found the support of AFTD critical in their FTD journey. She is also very interested in FTD research.

KERRI BARTHEL, M.S.W., AFTD Volunteer Manager, has over 15 years of experience advocating for and supporting the needs of individuals with life-threatening and debilitating diseases and their families. Her extensive 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.

BRADLEY F. BOEVE, M.D., is Chair, Behavioral Neurology at Mayo Clinic in Rochester, Minnesota. A member of AFTD's Medical Advisory Council, Dr. Boeve's clinical and research interests include normal aging, neurodegenerative disorders that cause cognitive impairment/dementia, neurogenetics, prion disorders, autoimmune/inflammatory encephalopathies, and the neurologically-based sleep disorders. Specific disorders of interest include mild cognitive impairment, Alzheimer's disease, Pick's disease, frontotemporal dementia, Lewy body dementia, corticobasal degeneration, posterior cortical atrophy, Creutzfeldt-Jakob disease, "Hashimoto's encephalopathy," nonvasculitic autoimmune meningoencephalopathies, REM sleep behavior disorder, narcolepsy and restless legs syndrome/periodic limb movement disorder.

NANCY CARLSON is an accomplished author and illustrator of over 60 children's books. In 2012, her husband Barry was diagnosed with FTD, making her the caregiver and breadwinner for the family. Despite numerous daily and financial challenges, Nancy continues to draw and post fun and inspirational doodles daily on her website and Facebook page. She also maintains a busy national speaking schedule on both her books and the FTD journey, visiting many schools, conferences and libraries each year.

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 five 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 25 years of experience in program development for disability organizations. She has been with AFTD since September 2008.

SUSAN DICKINSON, M.S., C.G.C., joined AFTD as Executive Director in February 2008. She is a certified genetic counselor who brings more than 20 years' 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 $2.8 million organization with 15 full-time staff members. 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 a multi-year, $5 million initiative to identify biomarkers for FTD. She holds an M.S. in genetic counseling from Arcadia University and B.A. in biology and psychology from Swarthmore College.

MATTHEW DINEEN has been teaching Religious Education in Ottawa since 1995. He is a proud husband and father to 3 children: Justin (15), Rebecca (14) and Peter (11). He thoroughly enjoys watching his children participate in the sports of hockey and baseball. After his wife of 18 years was diagnosed with FTD in January 2013 and subsequently placed in long-term care, he became a "Dementia Champion" through the Alzheimer Society. Despite family responsibilities, work duties and commitments, he continues to tirelessly and courageously campaign for a national dementia plan in Canada. In his spare time, he enjoys playing sports, reading, listening to music and volunteering with the Special Olympics.

LYNN ERKKILA, M.S.W, LICSW, is a Clinical Social Worker and Psychotherapist in Out-Patient Services at Bethesda Hospital (Healtheast Care System). She has 30+ years of healthcare experience with primary emphasis in the field of Dementia care, in addition to Brain Injury, Concussion and Attention Deficit Disorder. She holds her Master's Degree from the University of St. Thomas/ St. Catherine University.

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

BRIDGET GRAHAM joined AFTD in October 2015 as Grassroots Events Coordinator. With a B.S. in Speech Communication from Millersville University of Pennsylvania, Bridget brings experience in marketing and business administration to her role. With specific expertise in leveraging social media platforms, Bridget assists the AFTD-Team in their efforts to host and promote the volunteer-hosted events that are a crucial part of AFTD's fundraising and awareness building efforts.

GERI HALL, PH.D., ARNP, Clinical Nurse Specialist, Banner Alzheimer Institute, has worked extensively in developing programs of care strategies for people with Alzheimer's disease and related dementias. The Progressively Lowered Stress Threshold Model (PLST), developed in 1987 by Dr. Hall and a colleague at the University of Iowa, is a widely regarded and researched psycho-social educational approach to understanding behavior and planning care for people with dementia. She brings this extensive experience to a clinical practice in which she sees individuals with the most complex behavior needs, including many people with FTD. Dr. Hall currently serves on AFTD's Long-Term Care Education Committee, which spearheads education initiatives for community health providers; she also co-facilitates two Phoenix FTD support groups.

ALVIN HOLM, M.D., FACP, is the Founder and Director of the Cognitive and Behavioral Disorders Program at Bethesda Hospital in St. Paul, Minnesota. A graduate of the University of Iowa College of Medicine, Dr. Holm completed a residency in internal medicine at the University of Minnesota, as well as a fellowship in Geriatrics at the Veterans Administration Medical Center in Minneapolis under the direction of Dr. Gabe Maletta. With more than 25 years of experience in adult medicine and neuropsychiatry, Dr. Holm's clinical practice is entirely devoted to the evaluation and treatment of cognitive and behavioral disorders in late life. He has authored original research in the treatment of behavioral disturbances in the demented elderly and has served as an assistant clinical professor of medicine at the University of Minnesota, training resident physicians and fellows in the science and art of behavioral medicine.

BECKY KHAYUM, M.S., CCC-SLP, is a Speech-Language Pathologist (SLP) and Co-Founder of MemoryCare Corporation, a company that provides therapy, support and counseling for individuals with neurodegenerative disease in the Chicago and Indianapolis regions. She specializes in the non-pharmacological treatment of dementia syndromes, with a focus on person-centered care. Becky also participates in research targeting treatment approaches for Primary Progressive Aphasia, and is currently collaborating with the Northwestern Cognitive Neurology and Alzheimer's Disease Center on the Communication Bridge Study, an Internet-based speech-language therapy program for individuals with dementia. Becky holds a Master of Science degree in Speech-Language Pathology from the University of Arizona and a Bachelor of Science degree in Communication Disorders from Purdue University.

DAVID KNOPMAN, M.D., is a Professor of Neurology in the Mayo Clinic College of Medicine, a Consultant in Neurology at the Mayo Clinic, and co-investigator in the Mayo Alzheimer's Disease Research Center. His research and clinical interests are in dementing illnesses. David earned his Doctorate Degree in 1975 from the University of Minnesota Medical School. He did his internship at Hennepin County Medical Center, Minneapolis, Neurology residency at the University of Minnesota and a fellowship in Behavioral Neurology at Hennepin County Medical Center and the University of Minnesota. He is the author of over 400 articles on various topics in dementia including aspects of clinical trials, epidemiology, vascular dementia, frontotemporal dementia and Alzheimer's. He was the Deputy Editor of Neurology from 2009 to 2015. David was Co-Chair of the NIA-AA committee that drafted the revised criteria for Alzheimer's disease dementia. He is currently Vice Chair of the Medical and Scientific Advisory Council of the Alzheimer's Association, and Chair of the Medical Advisory Council for the Association for Frontotemporal Degeneration.

ANGELA LUNDE, M.A, CWC, is part of the Education and Outreach Core at the Mayo Clinic Alzheimer's Disease Research Center and is the Cognitive Health and Wellness Director at Mayo Clinic Charter House. She is a collaborator in Behavioral Neurology Family Seminars and HABIT® (Healthy Action to Benefit Independence & Thinking). She is involved in training professionals about methods and best practices in dementia and person-directed care. Currently, she authors the Alzheimer's expert blog and newsletter, and is a contributing writer and editor for the Mayo Clinic Guide to Alzheimer's and Related Dementia's. She was named Associate in the Department of Neurology in 2012.

CHARLENE MARTIN-LILLIE, M.A., is employed at Mayo Clinic in Rochester, Minnesota. She currently works at the Healthy Living Program where she teaches resiliency classes such as stress-management, mindfulness and positive psychology. Charlene spent much of her career working with caregivers and those affected with dementia, including FTD. She continues to be an advocate for those impacted by dementia through state wide Alzheimer's initiatives, as well as a volunteer for AFTD.

PAMELA E. MCGONIGLE, M.A., joined AFTD as Development Manager in April 2011. She has more than 16 years of significant experience and achievements in nonprofit organizations with a proven track record in developing and implementing fundraising strategies, plans and programs that yield enhanced visibility and increased revenue streams. Currently, Pam serves as the chair of the board of directors for NOAH, another rare disease organization. Pam is a Paralympic gold medalist, and for the past 20 years she has been an active spokesperson for persons with disabilities.

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.

DARBY MORHARDT, PH.D., LCSW, is Associate Professor, Director of Education and clinical social worker for the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University Feinberg School of Medicine. Dr. Morhardt has 30 years of clinical experience with cognitively impaired individuals and their families. Her publications and research interests are focused on the experience of families living with various forms of dementia. She organized and continues to facilitate one of the first support groups for families caring for persons with frontotemporal degeneration (FTD), and more specifically helped design and implement education and support for individuals with primary progressive aphasia (PPA) and their families. In addition to the development and evaluation of family support programs, she directs the planning of the Northwestern FTD/PPA caregiver conference which has a local and national reach.

DEBRA NIEHOFF, PH.D., joined the AFTD staff in October 2015 as Research Manager. A neuroscientist by training, she holds a Ph.D. from the Johns Hopkins University School of Medicine. The author of two popular science books, her experience includes teaching at the college level and scientific and medical writing, as well as service on the board of a drug and alcohol treatment facility in Bucks County, PA. Debra is responsible for the administration of AFTD grant funding programs as well as planning for the FTD Treatment Study Group.

ROBIN RIDDLE, M.B.A., is CEO of Brain Support Network (BSN), headquartered in Menlo Park, California. In 2004, after her father was diagnosed with progressive supranuclear palsy (PSP), Robin organized and led a support group for people in the San Francisco area caring for a loved one diagnosed with atypical parkinsonian disorders. Two of these, PSP and corticobasal degeneration (CBD), are classified as frontotemporal degeneration (FTD) disorders. When her father died in 2007, Robin donated his brain to the Mayo Clinic. This experience motivated her to found BSN, a non-profit dedicated to helping family members make this critical—but logistically challenging—contribution to the search for treatments and cures for neurodegenerative diseases. BSN has organized the donation of approximately 300 brains to research and was responsible for 16% of brains donated to the Mayo Clinic in 2015. See www.brainsupportnetwork.org for more information. Robin also works at Stanford University Medical Center.

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 Dept. 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.

SUSAN SUCHAN is a mother of two beautiful daughters and five fabulous grandchildren. She is currently 58-years-old and at the age of 48, was diagnosed with Early Onset Alzheimer's (EOA) after losing her ability to smell and taste. She lived not really being bothered too awfully much with the diagnosis and didn't tell many about it at all. She learned to compensate rather easily. Approximately 3+ years ago, she began falling and having much difficulty in multitasking, as well as forgetting how to complete a task. It was then that she was diagnosed with FTD. She has now also been diagnosed with PPA. She currently lives with her sister and husband. Susan is unable to work and now uses a walker, on bad days, to assist with walking. She has stated "I have a good life but one that is being drastically changed by an FTD diagnosis."

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 of 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.

REBEKAH WILSON, M.S.W, is the Director of Education and Community Relations for Choices in Senior Care. In this role, she provides staff and community education regarding dementia and dementia care standards, as well as ongoing consultation and support for Choices in Senior Care clients. Rebekah has devoted her career to the mission of improving quality of life for individuals with dementia and supporting their caregivers. Her work includes hospice and home health care, assisted living care, and geriatric care management. In these areas, she has used her specialties in teaching, community outreach, marketing and developing innovative strategies for providing comfort care for individuals with dementia and support for their care partners. She has presented at local, state and national conferences as a dementia care trainer in Alzheimer's disease, FTD, behavior management and other caregiving topics.

"BUILDING BRIDGES" & "SUPPORTING EACH OTHER"

Sessions for People with FTD

MATT SHARP & TERESA WEBB

In creating these sessions for people with FTD, our goals were to stimulate discussions: about working with care partners to confront challenges and minimize conflict; and about what individuals can do to find the support and help they need to manage and adapt to whatever changes may come after being diagnosed with an FTD disorder.

ADDRESS CHANGING RELATIONSHIPS

INTERPERSONAL RELATIONSHIPS ARE CHANGED BY FTD.

The adjustments are challenging for the person with FTD and their care-partner or family in different ways. Open communication and patience are needed by all, to adapt to changes and create new ways of connecting.

FAMILY AND FRIENDS CAN BE VERY SYMPATHETIC…

…But they can't be empathetic because they are not in our shoes. On the other hand, people with FTD can be empathetic (to varying degrees). Communicating your experience to care-partners and others will help them understand.

JUST BREATHE.

When you breathe, you expand and it helps you stay flexible. When you hold your breath you become rigid.

PICK YOUR BATTLES.

Not everyone will understand. Some people you think you can count on will disappoint you. Invest energy in those who listen and try to help.

CREATE THE SUPPORT YOU NEED (WITH ADVICE FROM PEOPLE WITH FTD)

CREATIVE SYSTEMS AND SUPPORTS ARE NEEDED.

Not all people with FTD have a spouse, partner or family to turn to. FTD affects many single people who manage the disease alone as long as they can.

FIND SOMETHING THAT YOU ARE PASSIONATE ABOUT AND GO DO IT.

"My answer may sound simple or trivial but here it is: I read my Bible, I pray constantly throughout the day and I spend time with my family. To remind myself to pray I wear a leather bracelet so when I see it...I pray. God gives me the strength I need to keep going. My life is in His hands and as long as He gives me life I'll focus attention on Him. For me, it's that simple!" —Joe Ware

SURROUND YOURSELF WITH POSITIVE, WELL-INFORMED PEOPLE.

"There is no way I could manage to make it through FTD without my four avenues of support. First is my husband, who is my primary caregiver. He is my rock. My daughter is the next one. She listens to me and my frustrations and keeps me calm no matter what I am dealing with. The third is the online support group that I am lucky enough to be part of. All the members are diagnosed with FTD and we understand and support each other through our challenges. Last is my psychologist. She knew about FTD, but actually researched more about it so she could benefit me best. With her, I can talk about anything. Sometimes, she gives me advice on how to better deal with issues. Always, she gives me affirmation that I can do this!"—Cindy O'Dell

EXPRESS YOURSELF. YOUR EXPERIENCE OF THE DISEASE IS UNIQUE.

Find ways to share thoughts, feelings and concerns through talking with people close to you, or through creative arts, hobbies or activities. Some people write blogs about their experiences.

INCREASE AWARENESS. TELL YOUR STORY. IT ALL STARTS WITH YOU.

- Participate in events to raise awareness of FTD.
- Tell your story to help people understand that not all dementia is Alzheimer's disease.
- We can and will improve many things for people with dementia.

FIND AND CONNECT WITH OTHER PEOPLE DIAGNOSED WITH FTD.

ORGANIZE A GATHERING.

Opportunities to meet others are scarce, so create your own gathering. Hold a dinner party or similar event for people you know and invite them to bring a friend. AFTD may be able to help you network. Write them at: info@theaftd.org.

ASK TO BE INCLUDED IN EVENTS FOR CAREGIVERS.

Increasingly, caregiver groups, service providers and individuals will include people with FTD in events for caregivers, and/or will be receptive to suggestions for events that are open to all.

TRY A YOUNGER-ONSET OR EARLY-STAGE DEMENTIA GROUP.

Local communities may have programs for people with young-onset or early-stage Alzheimer's disease. These education and support groups can be helpful for some people with FTD. Check with an Alzheimer's Association Chapter or memory care center for groups in your area.

EXPLORE ONLINE OR REMOTE GROUPS. OPTIONS INCLUDE:

- FTD Patient Support Group on Facebook. A private, diagnosed persons-only group. For more info contact: ftdsuportinfo@gmail.com.
- DAI Meeting of the Minds Webinars. A webinar series that is free for people with dementia and unemployed care partners, and offers opportunities to connect with a broad community of people living with dementia. See the link below for more details: http://www.dementiaallianceinternational.org/events/dai-webinars/
- To Whom I May Concern. An interactive theater program for people recently diagnosed with a progressive brain illness. People share their stories using their own words and scripting. 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.

KEYNOTE SPEAKER: NANCY CARLSON

Nancy Carlson has written and illustrated more than 60 children's books since 1979. Publishers Weekly said of Nancy's book *I Like Me!*: "The foundation of a healthy self-image, the cornerstone of a happy and successful life, is what Carlson's work is all about."

In late fall 2012, Nancy heard two words from a neurologist that would rock the happy life she had created with her husband Barry McCool: frontotemporal degeneration (FTD). So the journey with FTD began. What does an author and illustrator do when the family has no health insurance, is one rent check away from being homeless, has a husband swearing at her all day long and the IRS breathing down her back? She keeps creating!

Nancy continued to author and illustrate books, but she also created a blog, "Putting One Foot In Front of the Other," which is about her family's FTD journey. She also continues to draw and post a fun and inspirational doodle a day on her website and Facebook page. Nancy maintains a busy national speaking schedule on both her books and the FTD journey, visiting many schools, conferences and libraries each year. For more information on Nancy, visit: www.nancycarlson.com or you can follow her blog: http://puttingonefootinfrontoftheother.com/

PRESENTATION: OVERVIEW OF FTD DISORDERS

Frontotemporal Lobar Degeneration:
Clinical Features, Subtypes and Pathology




Brad Boeve MD
Department of Neurology
Mayo Clinic
Rochester, Minnesota
USA

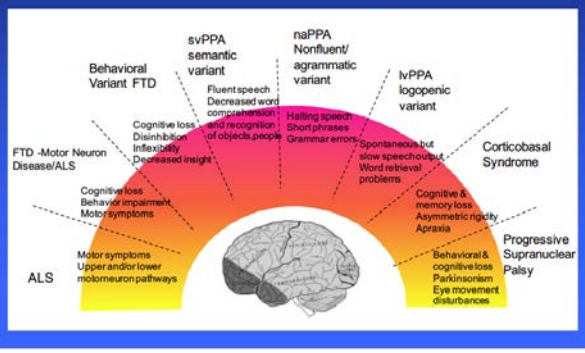
mayo

FTLD: Clinical Features, Subtypes and Pathology
Objectives

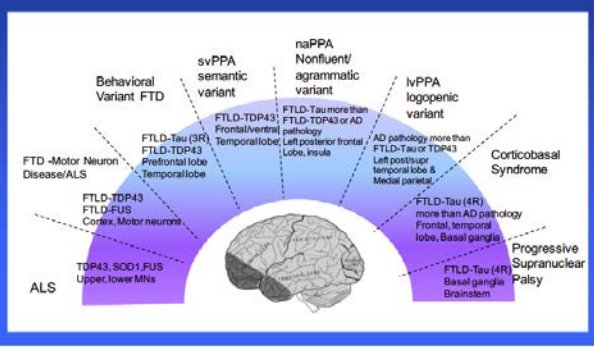
Review the key aspects of FTLD:

- Clinical features
- Subtypes
- Pathology

FTLD: Clinical Features, Subtypes and Pathology
Clinical Features of Each Syndrome



FTLD: Clinical Features, Subtypes and Pathology
Syndrome – Pathology Associations



FTLD: Clinical Features, Subtypes and Pathology
Syndrome – Pathology Associations

TAU	TDP	FUS	AD
tau protein	TAR DNA binding protein	Fused in sarcoma protein	Alzheimer's Disease pathology

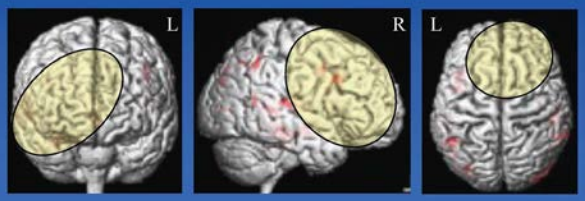
FTLD: Clinical Features, Subtypes and Pathology
Behavioral Variant Frontotemporal Dementia (bvFTD)

Clinical Features

- Apathy
- Loss of empathy
- Disinhibited behavior
- Mental rigidity
- Diminished insight
- Executive dysfunction

FTLD: Clinical Features, Subtypes and Pathology
Behavioral Variant Frontotemporal Dementia (bvFTD)

Brain-Behavioral Relationships



FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Semantic Variant

Clinical Features

- Prominent naming difficulties
- Loss of word meaning

FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Agnosia Variant

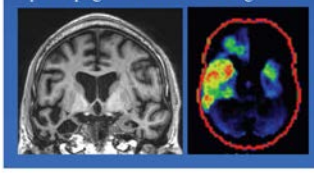
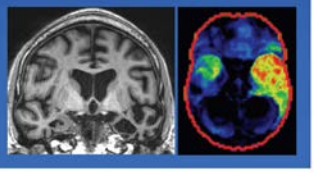
Clinical Features

- Prominent visual agnosia (loss of visual meaning of faces or objects)
- Later develop naming difficulties

FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Variant Comparison


prosopagnosia/associative agnosia

semantic variant PPA

FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Nonfluent Variant

Clinical Features

- Slow, halting speech
- Grammatical and articulatory errors
- Short phrases

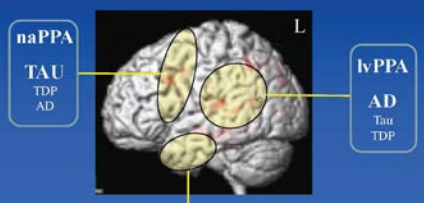
FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Logopenic Variant

Clinical Features

- Slower speech
- Word retrieval problems
- Difficulties with repeating statements/questions

Presentation: Overview of FTD Disorders

FTLD: Clinical Features, Subtypes and Pathology
Primary Progressive Aphasia – Summary



FTLD: Clinical Features, Subtypes and Pathology
ALS - Terminology

Terms all mean same disorder:

- Amyotrophic lateral sclerosis (ALS)
- Motor neuron disease (MND)
- Lou Gehrig's disease

FTLD: Clinical Features, Subtypes and Pathology
ALS

Clinical Features

- Altered speech
- Muscle weakness and atrophy
- Arm and/or gait difficulties
- Pseudobulbar affect

FTLD: Clinical Features, Subtypes and Pathology
ALS

Brain-Behavioral Relationships

FTLD: Clinical Features, Subtypes and Pathology
FTD-ALS

Clinical Features

FTD

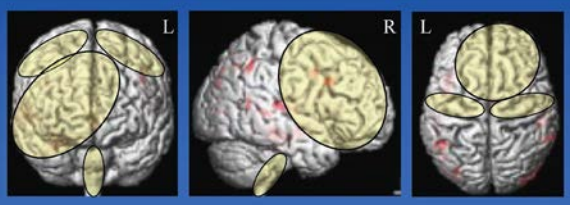
- Apathy
- Loss of empathy
- Disinhibited behavior
- Mental rigidity
- Diminished insight
- Executive dysfunction

ALS

- Altered speech
- Muscle weakness and atrophy
- Arm and/or gait difficulties
- Pseudobulbar affect

FTLD: Clinical Features, Subtypes and Pathology
FTD-ALS

Brain-Behavioral Relationships



FTLD: Clinical Features, Subtypes and Pathology
Corticobasal Syndrome (CBS)

Distinctive Clinical Features

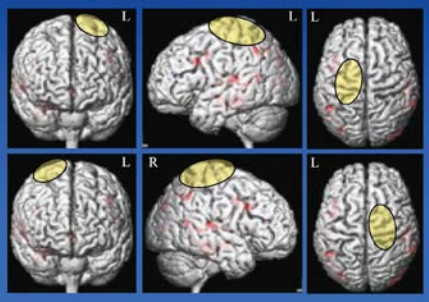
- Progressive
- Asymmetric
- Rigidity
- Apraxia

"Cortical"
- Apraxia
- Myoclonus
- Cortical sensory loss
- Alien limb phenomenon
- AOS/aphasia
- Visuospatial deficits

"Basal"
- Rigidity
- Dystonia
- Fisted hand

FTLD: Clinical Features, Subtypes and Pathology
Corticobasal Syndrome (CBS)

Topography of Degeneration



FTLD: Clinical Features, Subtypes and Pathology
Progressive Supranuclear Palsy Syndrome/Richardson's Syndrome

Distinctive Clinical Features

- Parkinsonism
- Vision problems
- Gait impairment and falls

Other Features
- Speech changes
- Swallowing changes
- Pseudobulbar palsy
- Executive dysfunction

FTLD: Clinical Features, Subtypes and Pathology
Progressive Supranuclear Palsy Syndrome/Richardson's Syndrome

Topography of Degeneration

FTLD: Clinical Features, Subtypes and Pathology
Conclusions

- The symptoms and behaviors reflect the disease and DO NOT define the person
- The symptoms match the location of degeneration in the brain far better than the underlying dysfunctional protein or genetic associations
- This variability of symptoms and dysfunctional protein will make future treatment decisions challenging

FTLD: Clinical Features, Subtypes and Pathology
Future Directions

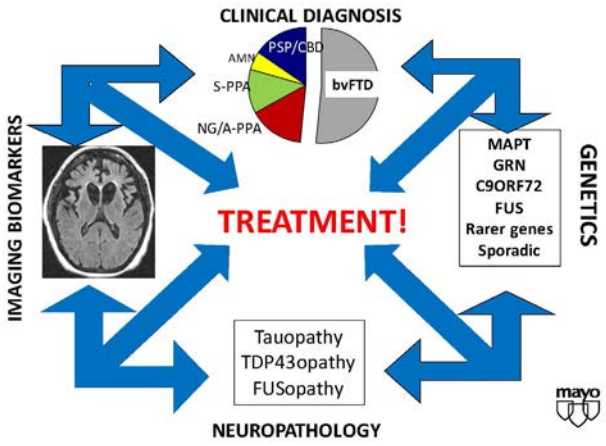
- Improve ability to accurately establish a diagnosis as early as possible
- Improve management and quality of life for patients and families
- Develop better biomarkers for tau vs TDP-43 vs Alzheimer's disease
- Plan for disease-modifying therapies

A·R·T·F·L
Advancing Research & Treatment for Frontotemporal Lobar Degeneration

Longitudinal Evaluation of Familial FrontoTemporal Dementia Subjects
LEFFTDS

AFTD Education Conference
Research Update: Focus on Two Large Federally Funded Projects: LEFFTDS and ARTFL

David Knopman MD
Neurology
Mayo Clinic
Rochester MN



A·R·T·F·L
Advancing Research & Treatment for Frontotemporal Lobar Degeneration

Longitudinal Evaluation of Familial FrontoTemporal Dementia Subjects
LEFFTDS

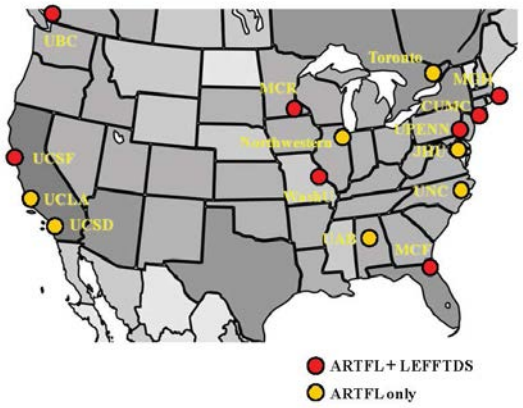
Leader: Adam Boxer MD, PhD, University of California, San Francisco

- **Any FTLD syndrome** without a known gene mutation

Co-Leaders: Brad Boeve MD, Mayo Clinic; and Howard Rosen MD, University of California San Francisco

- **Member of family with a known mutation** in one of the three major FTLD related genes: MAPT, PGRN, or C9ORF72.

ARTFL/LEFFTDS Consortium



LEFFTDS & ARTFL

- The first multicenter effort to pool resources across major research centers in North America
- Will use state-of-the-art imaging (MR and PET scanning), cerebrospinal fluid testing, blood testing
  - To learn more about biology of disease
  - To improve diagnosis
  - To facilitate efforts to develop treatment

Major Factors in Drug Discovery

- **Basic Science**
  - Understanding disease mechanisms
  - A valid animal model of disease
  - Better molecular tools to study cellular functions
- **Human testing**
  - Ability to diagnose persons with the specific disease (e.g., tauopathy)
  - Ability to determine whether the drug is doing what it's supposed to do ("target engagement")
  - Having a valid way of measuring meaningful outcomes

Approaches to Treatment of FTLD

- **Treat once people become symptomatic**
  - Advantage: it is obvious who to treat
  - Disadvantage: disease is sometimes quite advanced by the time people become symptomatic
- **Treat at-risk people while they are still asymptomatic**
  - Advantage: treat before irreversibility
  - Disadvantages:
    - How to identify at-risk people?
    - How to identify specific disease involved?
- ***Genetic FTLDs can minimize the disadvantages***

The major FTLD Genes

- *MAPT* gene chr 17 (6% familial cases)
  - Tauopathy causing bvFTD or nf/ag PPA
- *GRN* gene chr 17 (7% familial cases)
  - TDP-43 inclusions causing bvFTD or PPAs
- *C9orf72* gene chr 9 (11% familial cases)
  - Most common genetic cause of FTLD & ALS
- Rare mutations
  - *FUS, TAR-DP43, CHMP2B, VCP*

From DeJesus, Neuron 2011

Why study familial (genetic) FTD?

- Familial FTD makes up about a third of all FTD
- Up to 10% of apparently sporadic cases of FTD harbor a mutation in an FTD-related gene
- We know the specific disease of persons with familial FTD
- Clues about the mechanisms in familial disease come from knowledge of the genes involved
- Knowing about family history and genetic cause makes treatment while still asymptomatic possible

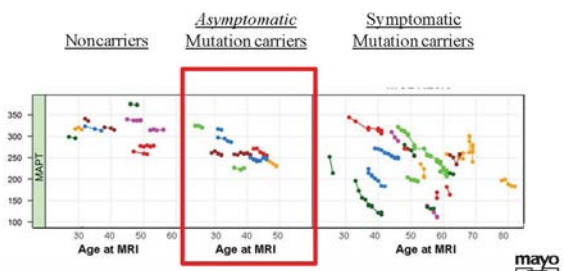
The numbers "game" in familial FTD: having enough people to do studies

8 LEFFTDS sites pooled their experience

- 45 families with **MAPT** (out of about 130+ known)
  - With mutation: 50 affected, 36 asymptomatic
- 81 families with **PGRN** (out of about 230+ known)
  - With mutation: 55 affected, 27 asymptomatic
- 180 families with **C9ORF72** (of about 330 known)
  - With mutation: 99 affected, 28 asymptomatic

Changes in brain volume using serial MR scans

Frontotemporal Volume
***MAPT* Mutation Carriers**



What LEFFTDS contributes to advancing therapeutic research

- Large groups of carriers of FTLD mutations including symptomatic and asymptomatic individuals
  - Ability to study prodromal phase of illness (before symptoms)
  - Ability to test imaging studies (brain scans), cerebrospinal fluid substances, or blood tests that might:
    - Tell who has what gene mutation
    - Tell who will become symptomatic within a year or two
    - Serve as source of participants for new clinical trials

What about sporadic (non-genetic) FTD?

- Sporadic FTLD patients being recruited for ARTFL
- Constitutes the majority of cases
- More challenging for early detection since knowledge of family history is absent
- Clues about disease might be different from familial FTD
- Challenges
  - Difficult to identify normal people who are at risk
  - In symptomatic persons, specific disease is usually uncertain

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Looking ahead over next 5 years

- LEFFTDS & ARTFL is the first-ever effort to pool participants and resources across North America for FTLD
- LEFFTDS hopes to test new "biomarkers" of FTLD subtypes over the next 5 years
- LEFFTDS & ARTFL participants will undoubtedly be the backbone of new clinical trials in next 5 years

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PRESENTATION: FTD DISORDERS REGISTRY

FTD DISORDERS REGISTRY

May 13, 2016
AFTD Education Conference
Minneapolis, MN

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

FTD Disorders Registry Overview

- What is a Registry?
  - A database of information from persons affected by a disease or condition
- Why is it important?
  - Provides a central community for persons affected
  - Resource for learning about 'natural history' – the typical changes caused by the disease
  - *Research- ready* patient community to accelerate clinical trials for drugs or treatments for the condition
  - Assist with design of patient-centered studies and care practices

FTD DISORDERS REGISTRY

FTD Disorders Registry Format

- Both a Contact & Research Registry
  - Contact
    - Participant mailing address/email list
    - Allows contact to send information updates
  - Research
    - Requires a 'consent to participate'
    - Allows health outcome research via surveys/questionnaires
    - Supports clinical trial or research study recruitment
- Self-report, participant entered data
- Curated, audited, & edited for errors/omissions

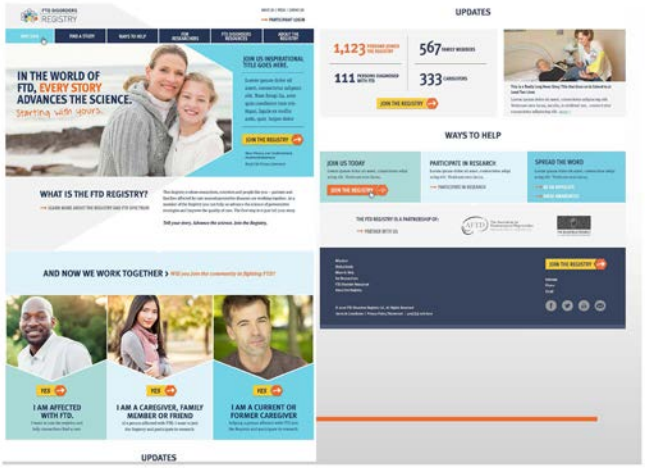
FTD DISORDERS REGISTRY

FTD Disorders Registry Target Population

FTD disorders spectrum: bvFTD, PPA, PSP, CBD, FTD-ALS, Richardson's Syndrome, or Pick's disease

- Individuals diagnosed with a FTD disorder
  - Individual enrolling for him/herself
  - Individual enrolling with the assistance of a care partner
- Family members of individual diagnosed with FTD
- Caregivers (current/former) of an individual diagnosed with FTD

FTD DISORDERS REGISTRY



The FTD Disorders Registry: why now?

- Provides a fully-independent resource
- Demonstrates a commitment to research
- Will provide information on the FTD community for patients, family members and researchers
- Provides a Registry for both ARTFL and LEFFTDS clinical networks
- Will provide a key resource for Pharma and Biotech companies in FTD drug development programs

FTD DISORDERS REGISTRY

Presentation: FTD Registry Disorders

FTD Disorders Registry Quality Assurance

- Experienced Registry Director
  - Research Scientist; biochemistry, genetics, population health
  - Genetic Counselor
  - >20 years clinical research in rare degenerative disease
- Intake surveys/questionnaires
  - FTD Disorders Registry
    - Demographic, disease impact, research ready
  - ARTFL
    - Lifestyle, autoimmune, clinical trials
  - Others (e.g., Non-profit, Researcher initiated, Industry)
- Focus group pilot testing
  - Caregivers, Social Workers, Support Group Leaders & ThinkTank (FTD diagnosed volunteers in varying stages)
  - Website content, marketing messages, consent forms & surveys

FTD DISORDERS REGISTRY

FTD Disorders Registry, LLC

- Independent entity with the patient/caregiver registry as sole non-profit mission
  - Delaware LLC formed by AFTD & Bluefield Project, March 2015
  - Structured so that other patient advocacy groups could join
  - Tax exempt 501(c)(3) status granted (awaiting documentation)
  - Funded by grants from founding organizations and Rainwater Charitable Foundation's Tau Consortium

THE BLUEFIELD PROJECT to cure frontotemporal dementia

AFTD The Association for Frontotemporal Degeneration

FTD DISORDERS REGISTRY

Key Personnel in the Registry

Dr. Dianna K. H. Wheaton, Registry Director	Former Director, Southwest Eye Registry and DNA Processing Laboratory	
Management Committee	All volunteer, acts as Board of Directors for LLC	
Emily Levy, AFTD Representative	AFTD Board member 2010-2016; founded Boston area FTD support group, biotech consultant	
Dr. Rodney Pearlman, Bluefield Representative	President, Bluefield Project to Cure FTD, experienced biotech executive	
Patrick Brannelly, Independent	Program Manager, Tau Consortium	
Dr. Suzanne Markel-Fox, Independent	Former Director, Global Clinical Safety & Pharmacovigilance, GlaxoSmithKline	
Scientific Advisory Board	Dr. Adam Boxer UCSF, Chair	
	Dr. Bradley Boeve, Mayo Dr. Daniel Kaufer, UNC Dr. Jessica Langbaum, Banner/API	Dr. Lawrence Golbe, RWJ/Rutgers Dr. David Knopman, Mayo Dr. Chiadi Onyike, Johns Hopkins
Key AFTD operational support		
Dr. Nadine Tatton	AFTD Scientific Director	

FTD DISORDERS REGISTRY

Registry Development Partners

ALZHEIMER'S PREVENTION REGISTRY

- Banner Health Alzheimer's Prevention Initiative
  - Leverage software design of APR
  - Reciprocity on IT developments & improvements

PROVOC

- Provoc sharing recruiting approaches and strategy from APR learnings
  - Provoc creating marketing campaign
    - Assisted APR reach >200,000 registrants

freeflowdigital

- Freeflow Digital developing software & integration

FTD DISORDERS REGISTRY

Research Marketing and Outreach

- Distribute FTD Disorders Registry-branded outreach via multiple venues and modalities
  - AFTD, Bluefield Project, CurePSP, ALS Association & other non-profit organizations
  - ARTFL & LEFFTDS
  - NIH
  - Scientific meetings & conferences
  - FTD family education conferences
  - Social media (e.g., Twitter, Facebook)

FTD DISORDERS REGISTRY

How to Join FTD Disorders Registry

1. Sign up today! Join the contact registry at AFTD Education Conference & Annual Meeting

2. Register for research - ***June 2016***

- http://www.ftdregistry.org
- Toll free: 888-840-9980

FTD DISORDERS REGISTRY

PRESENTATION: A CARE PARADIGM FOR PEOPLE WITH FTD

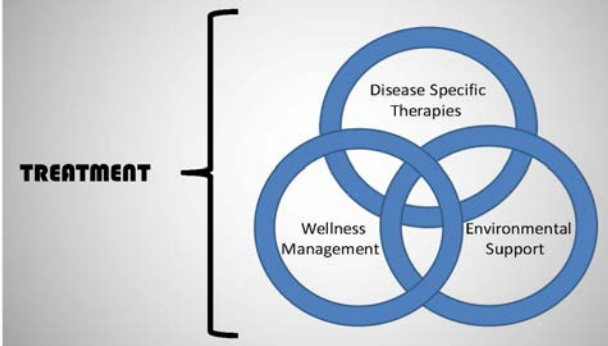
A Care Paradigm for Persons with Frontotemporal Degeneration

Alvin C. Holm, MD, FACP

Manifestations of Dementia

- Cognitive
- Functional
- Non-cognitive (behavioral/neuropsychiatric)
- Interface (medicine/psychiatry/neurology)

Care Paradigm



*Effective treatment programs are developed and adjusted **longitudinally** depending on the needs of the patient and caregiver/family*

Treatment

- Disease specific
  - preventative (primary, secondary)
  - symptomatic (pathobiologically targeted)

Treatment

- Wellness
  - thoughtful treatment of existing illnesses
  - identification and treatment of new illnesses
  - diet
  - physical activity
  - daily routine
  - ***caregiver wellness***

Treatment

- Environmental Support
  - physical environment
  - caregiver environment
  - expectational environment

Environmental support is to a patient with FTD what a prosthetic limb is to an amputee

BREAKOUT SESSION:

Movement Disorders: Tips, Resources & Gadgets

ROBIN RIDDLE, M.B.A., CEO, BRAIN SUPPORT NETWORK
ROBIN.RIDDLE@BRAINSUPPORTNETWORK.ORG
650-814-0848

FALL PREVENTION

- Not all falls can be prevented. We do the best we can.
- As soon as falls start happening or balance problems begin, learn new ways of walking (including turning), transferring, exercising, being safe in the bathroom, etc. Ask for an occupational therapy (OT) assessment. Acceptance and adaptation are important.
- "The rule"—If you find yourself reaching out to touch walls, furniture, friends or caregivers (or they are reaching to you) while walking, you are in need of an assistive device. Devices – canes, walkers, wheelchairs. Ask for a physical therapy (PT) assessment. Our family liked the UStep walker (www.ustep.com).
- Safe walking: slow down; concentrate (on one thing at a time); don't carry anything; avoid shuffling. Families and aides can learn how to use a gait belt to assist with walking and transferring.
- Making the environment (bedroom, bathroom, living room) as safe as possible. Remove rugs. Add grab bars where needed. Use sturdy seating. Place light switches, phones, toilets, heat sources, etc. in easily reachable spots. Consider footwear.
- Gadgets for getting in and out of bed—bed rail; SuperPole; trapeze; satin sheets.
- Gadgets for getting in and out of vehicle: plastic garbage bag on seat, Handy Bar allows a safe place to hold.
- Exercise is important, regardless of disease stage. Consider seated exercise or exercises while lying down. Caution with treadmills.
- Safety gear such as: helmets, HipSaver (shorts with hip and tailbone pads), bed alarms, chair alarm (Posey is a good brand), and geriatric recliner chairs.

SWALLOWING

- Coughing during meals is a sign that the timing and coordination of the swallow mechanism may be changing. Two concerns—choking and aspiration pneumonia. Know the Heimlich maneuver. Good oral hygiene is important to reduce chances of aspiration pneumonia. Consider Biotene mouthwash, Toothette Swabs, suction toothbrush.
- Beware of "silent aspiration," where there is no coughing or choking during meals.
- Consider a modified barium swallow study (aka, VFSS—Videofluoroscopic Swallowing Study).
- Thickening liquids and pureed food. Thickening options—commercial (gum-based or cornstarch-based) and non-commercial. Gum-based is ideal if diabetes is a concern. Our family liked SimplyThick-brand gum-based thickener. Non-commercial thickeners include oatmeal, gelatin, bananas, banana flakes, potato flakes, tofu, etc. There are pre-thickened, pre-packaged liquids available—water, milk, fruit juices.
- Cookbook suggestions: "The Dysphagia Cookbook," "Meals for Easy Swallowing," "Soft Foods for Easier Eating Cookbook."
- Products that might help: plate elevator, flexi-cut cup, spill-proof flo tumbler, OXO grip spoon, scooper plate, non-skid bowl. A good online medical supply store for these items is Bruce Medical, www.brucemedical.com.
- Consider the environment – quiet and focused on chewing and swallowing.
- Have feeding tube discussion early, when there's no crisis.

OTHER TIPS

- Exercise, exercise, exercise.
- Therapies: Physical Therapy, Occupational Therapy, and Speech Therapy.
- Importance of a care team.
- Support Group Options: in-person support groups (those with diagnosis; for caregivers only), online support groups and telephone-based support groups, counseling, friends, environments "away" from neurological decline.
- Social interaction.
- Be open to change.
- Please consider brain donation! Brain donation is still the only way to confirm a diagnosis. Donation enables medical research into the causes, treatments, and cures for FTD. See www.brainsupportnetwork.org for more info.

RESOURCE SHEETS

- Top Resources on PSP: www.brainsupportnetwork.org/BSN-PSP-resources-2016-02.pdf
- Top Resources on CBD: www.brainsupportnetwork.org/BSN-CBD-resources-2016-02.pdf
- "Falls and Dysphagia in PSP," Summer 2015 issue of "Partners in FTD Care" newsletter, published by AFTD: www.theaftd.org/wp-content/uploads/2015/07/PinFTDcare_Newsletter_summer_2015.pdf

BREAKOUT SESSION:

Adjusting to Language Changes: Strategies and Tips

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BECKY KHAYUM, M.S., CCC-SLP
BECKY.KHAYUM@MEMORYCARECORP.COM
BOB AND LINDA CAUGHEY

WHAT IS APHASIA?

- Aphasia is an acquired communication disorder that results from damage to portions of the brain that are responsible for language.
- In the vast majority of people, these areas are on the left side of the brain.
- The disorder impairs the expression and understanding of language as well as reading and writing.
- Aphasia does NOT affect intelligence.

PRIMARY PROGRESSIVE APHASIA (PPA)

The diagnosis is made in any patient in whom language impairment (aphasia) caused by a neurodegenerative disease (progressive) constitutes the most important aspect of the clinical picture (primary) (Mesulam, 2003).

- Varied language patterns in PPA
- These language disorders are heterogeneous
- Some are fluent, others not
- Some with comprehension deficits, others not

THREE CLINICAL SUBTYPES OF PPA

1. Agrammatic/Nonfluent—problem with word order and word production.
   Also known as Progressive Nonfluent Aphasia (PFNA)
   Speech is effortful and reduced in quantity. Sentences become gradually shorter and word-finding hesitations more frequent – almost stuttering. Word order may be abnormal or used in the reverse sense ("yes" for "no"). Word understanding is preserved, but comprehension, especially of lengthy or grammatically complex sentences, may become impaired.
2. Semantic—problem with understanding of words.
   The person seems to have forgotten the names of common objects. Main feature is loss of word meaning, even of common words. While speech remains fluent, it loses many nouns, or "content" words, and therefore can sound empty of meaning.
3. Logopenic—problem with word-finding.
   Interruptions of fluency due to frequent word-finding pauses but relatively intact syntax and word comprehension. The person is fluent when engaged in conversational "small talk," but markedly nonfluent when responding to directed questioning.

HETEROGENEOUS PROGRESSION OF PPA

As the disease progresses, PPA patients may develop memory disorders, associative agnosias, personality changes, motor neuron disease, or asymmetric extra-pyramidal deficits—emphasizing the lack of rigid boundaries in these neurodegenerative syndromes.

NEUROPATHOLOGY

- 60-70% of PPA patients demonstrate FTLD subtypes, and approximately 20% demonstrate the typical plaques and tangles of AD.
- The FTLD pathology may include focal neuronal loss, gliosis, tauopathy, ubiquinopathy with TDP-43 proteinopathy (known as FTLD-U), and superficial vacuolation.
- Unknown: In the PPA-AD cases, why does the plaque/tangle pathology, known to cause the greatest initial neuronal loss in entorhinal and hippocampal areas, seemingly affect other distinct brain regions, accounting for the "aphasia without amnesia" pattern?

GENETICS

- In non-familial cases, the agrammatic/ nonfluent variant (PNFA) seems more closely associated with tauopathy whereas the semantic variant may be more closely associated with TDP-43.
- The vast majority of cases of PPA are sporadic, but familial cases have also been linked to FTLD pathology and mutations in the progranulin gene.
- In contrast to the sporadic cases, the familial cases display an association with the agrammatic/nonfluent FTLD variant rather than the semantic variant of PPA.

TREATMENTS

- Transcranial magnetic stimulation presently being studied and results look hopeful.
- Small controlled trial with bromocriptine was negative.
- Memantine versus placebo trial reported no benefits.
- Anecdotal reports with cholinesterase inhibitors are mainly negative (one small study showed a marginal benefit with galantamine).

SPEECH/LANGUAGE PATHOLOGY EVALUATION IS AN ESSENTIAL COMPONENT OF CLINICAL DIAGNOSIS OF PPA. IT SHOULD INCLUDE:

- Assessment of different language modalities and components: speech, repetition, comprehension, reading, writing, phonology, syntax, semantics.
- Assessment of functional communication skills for different settings and needs, and for planning a treatment strategy.
- Client/family education and support.

NEED TO UNDERSTAND THE PROGRESSIVE NATURE OF THE SPEECH-LANGUAGE IMPAIRMENTS:

- Unlike stroke, in PPA, speech-language abilities gradually decline.
- Initially, communication difficulties are the only cause of limitation to activities of daily living.
- Ultimately, concomitant cognitive and motor difficulties develop.

THE GOAL OF SPEECH-LANGUAGE TREATMENT IS FUNCTIONAL COMMUNICATION:

- Maximize communication at each stage of the illness.
- Consider each individual in the context of their environment and communication demands.
- Tailor treatment approach to current level of functioning with understanding of likely progression.
- Address the symptoms—different for each individual.
- Staged treatment approach i.e. assess-treat-assess-treat.
- Determine appropriateness for high-tech augmentative and alternative communication devices (AAC).
- Implement communication strategies and tools before they are needed.
- Consider groups throughout the continuum.

IMPORTANT CONSIDERATIONS REGARDING SPEECH-LANGUAGE TREATMENT

- It is very important that a care partner, family member, or close friend be present at treatment sessions. Many of the strategies require a "team" approach.
- The goals and strategies for each individual and family will be different and will need to be adjusted as symptoms change over time.
- It is critical that the therapy focuses upon words and topics that are personally relevant to the individual with PPA. Workbooks and computer "brain games" have little research supporting their effectiveness in increasing communication skills for individuals with PPA.
- Communication Interventions and Strategies:
- Communication Supports: Using a combination of different communication strategies and tools, depending on the environment and context, is important in all stages:

UNAIDED (NATURAL APPROACHES)	AIDED (LOW-TECH AND HIGH-TECH OPTIONS)
Talking around the word	Paper and pencil/dry erase board—writing or drawing
Thinking of the first letter	Communication Books/ Wallets
Gestures	Communication Boards/Cards
Eye gaze	Speaking Computers
Body language	Mobile Technologies
Communication Partner Training	Speech Generating Devices

ADDITIONAL SPEECH-LANGUAGE INTERVENTIONS

- Rehearsal of personally relevant words: treatment may focus upon the oral and written rehearsal of words that are important in daily conversations.
- Word Pronunciation: treatment may target strategies to increase the ability to pronounce multi-syllabic personally relevant words.
- Script training: writing out and rehearsing conversations that may be used in daily conversations to increase fluency and production (e.g., telephone calls, explaining the condition, ordering food at a restaurant or drive-thru, prayers, jokes, explaining a recent trip).
- Personal Picture Description: Selecting personally relevant pictures and describing them as a home exercise, with a focus upon the retrieval/pronunciation of key content words.
- Auditory Comprehension Strategies: Communication partners are trained to modify the environment (eliminating distractions) and use positive communication strategies (e.g., repetition, speaking more slowly, using writing or pictures) to facilitate comprehension of daily conversations.
- Communication Wallets, Books, or Boards: Speech-Language Pathologist's (SLP's) can help individuals and families formulate personalized communication aids, word-based or picture-based, to help communication in daily conversations. These aids contain words and pictures, by category, which are frequently used in daily conversations. The aids are a "back-up" plan if the individual is having trouble communicating the message.
- Electronic Aids or Speech-Generating Devices: High-tech communication aids aren't for everyone! If they are used, they need to be SIMPLE and contain personal content and pictures. Individuals who are very familiar with the use of computers/smart phones and tablets and who have good sequencing and comprehension skills may be candidates for these devices. The use of the "photo stream" to facilitate daily conversations may be helpful for individuals who enjoy taking pictures. Electronic aids should always be accompanied by paper-based/low-tech aids.
- Writing strategies: The SLP may recommend different strategies to help with writing emails, texts, lists or checks. These include use of technology (spell-check and voice recognition), in addition to written templates for specific writing tasks (e.g., grocery list or "To Do" list templates).

- Reading strategies: The SLP may recommend different strategies to help with daily reading tasks, such as reading a hard copy of a novel while listening to the "book on tape" or use of technology to look up words to increase single word comprehension.
- Number strategies: The SLP may recommend different strategies to increase comprehension ability, by speaking or writing information containing numbers.

TIPS FOR THE SUPPORTIVE COMMUNICATION PARTNER

Is it ok to fill in the word for the individual with PPA?

- Ask the person with PPA what they prefer!
- Many people prefer for those who are close to them to help fill in the words. This is fine! It will allow the conversation to move forward and decrease anxiety. It will NOT make the condition progress more quickly.
- Many couples develop a "signal" for when the individual would like help during conversation.

When the individual can't think of a word:

- Don't play 20 questions!
- Usually saying, "Tell me about it…" is the best way to help the individual to talk around the word and communicate the message.

Come up with a plan for how to best tell family, friends, and strangers about the aphasia and what they can do to help. This often takes much of the anxiety away during conversations.

- Work with your SLP to make a "PPA card" that briefly describes what aphasia is and then suggests "What you can do to help." This card can help others to better understand the condition and positive communication strategies.

RESOURCES

www.theaftd.org/wp-content/uploads/2016/01/PinFTDcare_Newsletter_Winter2016.pdf
AFTD's Partners in FTD Care Winter 2016 Issue

www.aphasia.org
National Aphasia Association

www.brain.northwestern.edu
Cognitive Neurology and Alzheimer's Disease Center (CNADC) of the Northwestern University Feinberg School of Medicine

www.memory.ucsf.edu
UCSF Memory and Aging Center

www.reknewprojects.org
REKNEW: Reclaiming Expressive Knowledge in Elders with Communication Disorders – View -> Primary Progressive Aphasia -> Communication supports

www.aphasiasoftwarefinder.org
Aphasia Software Finder

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Mesulam MM, Rogalski EJ, Wieneke C, Hurley RS, Geula C, Bigio EH, et al. Primary progressive aphasia and the evolving neurology of the language network. Nat Rev Neurol. 2014;10(10):554-69. PMCID: PMC4201050.

BREAKOUT SESSION:

Behavior Changes

For people concerned with behavior changes at home and in the community

GERI HALL, PH.D., ARNP, CNS, FAAN, AND ANGELA LUNDE, M.A., CWC

Behavioral change is a hallmark of FTD and a primary source of challenges for people with FTD and their caregivers. When confronted with a new, troublesome behavior, you may find it helpful to begin by describing it in detail, including the circumstances under which it occurs. Responding compassionately and effectively to your own feelings is as important as how you respond to the behavior itself.

For recommendations on responding to specific behaviors from Geri Hall, Ph.D., ARNP, CNS, FAAN, see the chart below.

WHAT TYPES OF BEHAVIOR ARE MOST LIKELY TO BE AFFECTED IN FTD?

THE NEW NORMAL

- Allow time to feel hurt, anger, grief.
- Accept your feelings as normal.
- Believe that a pivotal shift occurs when acceptance makes its way in.
- Accept that a diagnosis, with all its implications, will have a profound impact on your marriage, relationship or friendship.
- Accept that you will not be perfect and you will get angry.
- Accept that you can only do your best and your best is good enough.
- Act from your own empathy, empowered by feeling good about what you can do.
- Practice Self-Compassion every day.

> "I didn't cause it. I can't change it, and I can't control it. But I do have choices about how to live each moment. . . I will make life as enjoyable, dignified, and meaningful as possible for as long as I can." —Eleanor, caregiver for her husband

QUESTIONS TO GUIDE A RESPONSE OR ACTION (OR NOT):

- Is there a new medical problem or condition?
- Is there a trigger in the environment or situation?
- Is it something that I did?
- Is it really a problem? What would happen if I did nothing?
- Can I change anything?
- How am I feeling?
- Can I offer myself the compassion I need in this moment?

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Behavioral Changes in Frontotemporal Degeneration

GERI HALL, PH.D., ARNP, CNS, FAAN

The chart below lists common behavioral changes and approaches for managing them.

Early FTD Type of Behavior	Approaches
• Routinized behavior	• Keep a consistent daily routine to minimize anxiety due to executive losses. Allow for 2 or more quiet periods per day. • Confirm diagnosis and apply for disability. Avoid reassignment to lower level job to maximize disability compensation.
• *Decreased attention (changes activities frequently) • *Decreased concentration (poor job performance)	• Carry a card asking bystanders for patience. **Avoid circumstances and substances that might trigger rude behavior - e.g. alcohol and loud parties.
• *Loss of inhibitions and social "filter" (rude talk)	• Establish clear limits and enforce them - e.g. give a specific amount of money to spend at the casino and leave after pre-set length of time; or use gift cards instead of credit cards. • Disconnect internet and supervise financial transactions.
• *Increased impulsive behavior (sex, gambling) • *Poor judgment (bad financial moves)	• Meet with elder-law attorney to discuss decision-making tools to protect savings—e.g. durable power of attorney or conservatorship.
• *Increasing self-absorption ("ME first/ I want it NOW!") • *Loss of empathy toward others ("Mom died? When's lunch?")	• Recognize that self-absorption and loss of empathy have nothing to do with you. Treat yourself as you would like to be treated. Use the "please excuse" cards** whenever possible. Avoid situations with potential for negative interactions and leave if they are developing.
• Decreased executive function, inability to organize self and execute steps to accomplish goals • *Compulsions/obsessions (repetitive acts, eating constantly)	• Break activities down into small steps and provide instructions accordingly. • Use written or visual cuing. • Engage in activity if safe. Stopping these behaviors may cause resistance. If unsafe, try to find a substitute - e.g. riding a stationary bike at the gym instead of outside on the streets.
• *Confabulation (telling false stories)	• This is not lying, but something the brain "makes up" when it doesn't know an answer. Do not try to correct unless it poses a danger to the patient or others.

***Behavior is a symptom that cannot be changed**

****available from AFTD**

Early FTD Type of Behavior	Approaches
• *Lack of insight • Loss of sense of risk and danger	• Do not try to convince the person they have a disease. If you need to do something, let someone else be the villain —i.e. blame the doctor, police etc. • Monitor driving, using power tools, etc...Stop if unsafe • Monitor time around vulnerable people— e.g. young children.
• Anger and "hair-trigger emotions" • Aggression, delusions, paranoia	• Look for triggers. Minimize TV, especially constant news, salacious talk shows, and violent programs etc.… • Do not try to explain or reason. Avoid confrontational truth-telling that can trigger anger. • Placate the behavior and try to distract. Use "therapeutic fiblets," apologize, agree, play dumb or vow to help. • Ask family members for help and try to find much-needed respite. • Seek medical treatment for frequent anger (more than once a week) aggression, paranoia or delusions (fixed false beliefs). This may include a brief hospitalization.
• *Apathy—Loss of interest in activities. Sitting and doing nothing	• Try to interest in short-term activities, hire companion, treat for depression. • Redirect person, try day programming and other activities; try to find an activity that attracts safe compulsion.
• *Disinhibition (spontaneous affection, cursing, sexual gestures, spontaneous undressing, urinating in inappropriate places)	• Redirect behavior and distract. • Use complicated clothing that is difficult to remove. • Direct to use the toilet every two hours. • Try adult day program. • Turn off the TV except family shows. Avoid murder mysteries, aggressive talk shows and continual news feeds —"never watch anyone on TV who you wouldn't invite to dinner!"
• Psychosis (paranoia, delusions [fixed false beliefs]) • Hallucinations • Physical aggression	• Seek medical attention and antipsychotic medications. • Make sure you are safe. Have a charged cell phone on you at all times to summon help and/or a "safe place" you can retreat to. • Consider a psychiatric stay for the individual with FTD.
• Gorging on food	• Put out bowls of acceptable food (and candy) and have a safe locked place to hide extra. Put a lock on the fridge. Don't worry so much about food balance and weight gain as the person will begin to lose weight spontaneously.

Early FTD Type of Behavior	Approaches
• Compulsions (playing solitaire, find-the-word puzzles, blocks, Legos, particular movies)	• Compulsions are self-soothing behaviors. Use these compulsions as activities as long as they are safe and don't drive you crazy. Explain their importance to respite workers, day program and residential care staff. They can help fill time and allow some brief periods of respite.
• *Sleep disorders	• Sleep disorders need to be assessed and treated by a physician. Have spouse move into second bedroom, especially if the person with FTD is aggressive or very active.
• *Refusing, unreasonable behavior	• Never try to reason with someone with FTD. • Remember that communication is more about body language and tone of voice - especially if speech is lost. • If the caregiver angrily approaches, the person with FTD may respond with anger.
• *Falls	• Use padded clothing and provide assistance while walking. • Place yoga mat by bed and put mattress on a low frame to minimize impact of falling out of bed.
• *Incontinence	• Use a bedside commode. • Get help when lifting individual out of bed or from chair. • Assess for injuries after any fall, even minor ones. • Use incontinence garments and change them several times a day to prevent skin breakdown and avoid urinary tract infections (UTI). • Have a physician check for a UTI if mental status suddenly worsens. • Avoid caffeine. • Push fluids, not just water. Try sweet beverages, shakes and nectars. • Monitor for choking. • Initiate bowel regimen to minimize defecating to once daily.

***Behavior is a symptom that cannot be changed**

****available from AFTD**

BREAKOUT SESSION:
Residential and Facility Care

LYNN ERKKILA, LICSW AND REBEKAH WILSON, M.S.W.

WHEN IS THE RIGHT TIME TO MAKE THE TRANSITION?

RECOGNIZING THE SIGNS THAT INDICATE IT MAY BE TIME TO CONSIDER ALTERNATIVE PLACEMENT.

- When the caregiver is experiencing signs of burnout.
- Difficulty sleeping, depressed mood, anxiousness, decreased social activities, worry and irritability.
- When there is a change in the physical statuzs.
- Have there been changes to physical health? Is there increased risk for falling?
- When there are signs of aggression that are difficult to manage in the home setting.
- Hitting, scratching, difficult to redirect and refusing to bathe are examples.
- When the individual is sundowning.
- Sundowning is the increased anxiety and agitation that some people with dementia (and occasionally some without dementia) often display in the later afternoon and evening hours. Sundowning behaviors include restlessness, falls, calling out, crying, pacing, wandering, fearfulness, mood swings, paranoia, hallucinations and shadowing.
- When there are home safety concerns.
- Are they able to safely use a stove? Be at home alone? Safely drive? Is there a risk of wandering outside of the home?

HOW TO EVALUATE CARE NEEDS.

STEPS TO TAKE FOR A COMPREHENSIVE EVALUATION:

- Physical examination.
- It is important to have a thorough examination to make sure that all aspects of care are identified.
- Cognitive evaluation.
- The Allen Cognitive Level Screen (ACLS) determines functional level.
- Neuropsychological testing.
- Functional status evaluation.
- Bathing, dressing, grooming, ambulation and ability to feed self are identified
- (This will help determine the cost of care).
- Brain imaging.
- Head CT, MRI, PET scan are types of imaging that can assist in the diagnostic process.

WHAT TO LOOK FOR IN FACILITIES.

CONSIDERATIONS WHEN EXPLORING CARE OPTIONS:

- Size
- Memory care assisted living facilities typically range from 14 to 60 beds whereas, residential care facilities can range from 3 to 10.
- Costs
- This is important to check to see if there is a base rate with services in addition, or all inclusive.
- Services offered

- Is there on-site Physical Therapy, occupational therapy, adult day programming, special diets, transportation, physician visits?
- Location
- Is the community near family members?
- Secured or non-secured
- Does the individual need a locked unit or a wander guard system to ensure safety?
- Hours of licensed staff onsite
- Are there LPNs and/or RNs on staff during the day, evening and night shift?

QUESTIONS TO ASK WHEN SEARCHING FOR FACILITIES.

HOW IMPORTANT IS IT TO HAVE VARIOUS OPTIONS ON ONE CAMPUS?

- Is there a continuum of care model?
- Senior Living Apartments, Assisted Living, Memory Care Assisted Living, Residential
- Group-Home.
- What are the true costs?
- It is important to address the specifics. For example, each time the individual needs assistance with the bathroom, bathing or medication management, ask if there are additional costs for those services, or are they built in to the daily care charge?
- What happens if I run out of money?
- What potential funding sources will cover care when private pay is exhausted? If any, is there a waiting period before that funding becomes available?
- What does the lease agreement say?
- It is important to read the fine print and also encouraged to seek medical consultation for the lease review, specifically in regards to the eviction policy.
- 5. What does the home care agreement say?

WHERE—THE SPECTRUM OF COMMUNITY LIVING.

1. Independent Living Centers.
2. Assisted Living Centers.
3. Skilled Nursing Facilities (nursing homes, LTC Facility).
4. Memory Care Communities.
5. Residential Care Homes.
6. Continuing Care Retirement Communities.

RESOURCES

THESE AREA RESOURCES CAN BE HELPFUL.

The state or local Area Agency on Aging.

- Long-Term Care Ombudsman's office.
- The state licensing agency.
- Friends and neighbors.
- Certified senior advisors.
- Retirement counselors/Elder-law attorneys.
- The caregiving checklist offered through www.AARP.org

Particular Considerations in FTD Residential Care

PLAN AHEAD: It may take time to find a facility that meets your needs. Explore options early as a well-planned transition can reduce stress and contribute to the effectiveness of the placement.

FIND THE RIGHT LEVEL OF CARE: Be honest about why you are seeking residential care. Identify the person's current abilities, limitations and challenging behaviors to ensure effective assessment and the best match to the care needed. Consider the physical environment, skill and experience level of staff.

LOCATION: Facilities near busy streets or intersections may pose danger to individuals with FTD who may get out of the building and roam. The facility closest to family may not be the best overall fit.

PARTNER WITH STAFF: It is very important as a caregiver or family member to be a part of the care team, because your insight is priceless to staff and their ability to care effectively for the person with FTD. Use AFTD's Daily Care Snapshot tool (see link below) to share the person's background, interests and needs. As much as possible, be a part of the care conference meetings to encourage individualized approaches to FTD symptoms and behaviors. Provide AFTD as a resource for facility staff.

MANAGEMENT OF BEHAVIORS: Redirection techniques and engaging individuals with FTD should be the first approach to behaviors; and only after these things don't work should staff resort to medication. When assessing for management of behaviors, give specific scenarios to staff members and ask them how they would handle the behavior. Look for their understanding of behaviors that are common in individuals with FTD. FTD care is less about changing behaviors than minimizing their intrusiveness and ensuring safety and well-being.

LOW STIMULATION ENVIRONMENT: People with FTD do best in an environment that is not overly stimulating in terms of noise, lights and activity. It is important to have different common areas in addition to a person's room that can provide quiet.

ROUTINE & ENGAGEMENT IN ACTIVITIES: People with FTD do well with a routine but may not be able to follow an established structure of group activities. Ask how staff would develop and implement an individual routine as needed. Have the staff give examples of how they accommodate this.

INDOOR AND OUTDOOR WALKING SPACES: Pay attention as you are touring a facility to the walking paths and areas. Often individuals with FTD like to walk; the more areas available for them to walk the better.

NUTRITION OPTIONS INCLUDING FINGER FOODS: It is important that staff offer nutritious finger foods because people with FTD may have difficulty sitting down to eat a whole meal. Also, inquire about specific diet options if needed.

MEDICATION MANAGEMENT: Many physicians and facilities are unfamiliar with FTD. Careful coordination around medications is especially important. The goal should be the least amount of medications with the highest level of functioning.

STAFF KNOWLEDGE OF DEMENTIA AND FTD: Is staff trained on the different types of dementia, including FTD? Encourage family to gauge commitment to continued learning about the disease and creative interventions.

THERAPY/RESTORATIVE/EXERCISE PROGRAMS: What programs are available to keep residents physically active or support communication needs? Look for facilities that offer therapy or restorative programs to keep residents as physically and functionally independent as possible for as long as possible.

STAFFING RATIO: What is the resident to staff ratio? Does this change during different shifts? People with FTD do better in smaller facilities or units with more staff available.

STAFFING PATTERNS: Do the same caregivers and nurse work with the same residents on a daily basis? Or, does the resident have a different caregiver daily? The ability to develop consistent routine with staff is helpful in FTD. Shared shifts can be important for staff quality/morale when behavior issues require particular 1:1 time.

SUPPORT SERVICES FOR FAMILY: Receiving support from others who are going through a similar experience is helpful for caregivers of individuals with FTD. What resources are available at or through the facility?

MEDICAID/MEDICAID WAIVER PROGRAMS/PRIVATE PAY/LONG TERM CARE INSURANCE: Have an understanding of your finances as you look at long-term placement. FTD tends to be diagnosed in individuals at a young age and care may deplete resources quickly. Consult an elder law attorney in your state for assistance with planning.

RN ON STAFF: Having an RN on staff can be very helpful in managing the medical oversight. Especially, with an individual with FTD, a nurse can be trained to notice specific changes in behaviors and can talk to the doctor about performing labs or tests to see what may be taking place with the resident.

COST: Depending on if the facility costs are all inclusive or more of an a la carte style—meaning there is a base rate that is offered, but the cost goes up with the more assistance or care an individual needs. This is important to be aware of so you don't find yourself paying more money than you anticipated.

AVAILABLE ACCOMMODATIONS: Are respite care, day stays and other accommodations available? Especially, early on when you are looking at transitioning an FTD individual into a facility, utilizing respite care and day stays can give you a good picture of whether or not the facility is a good fit.

TRANSITION PLANNING: People with FTD most often have several transitions in care (AL, NH) understand how the facility approaches planning for a transition, how they involve family and coordinate with other providers.
Use of In-Patient Care: Ask about and understand how the facility approaches coordination with family and hospital in event in-patient care is needed.

CHECK OUT THE FOLLOWING RESOURCES FROM AFTD FOR MORE INFORMATION AND CHECKLISTS ON HOW TO NAVIGATE RESIDENTIAL AND FACILITY CARE.

AFTD'S DAILY CARE SNAPSHOT TOOL

download here: http://www.theaftd.org/wp-content/uploads/2009/03/Packet-Daily-care-snapshot.pdf

INFORMATION ON FACILITY CARE OPTIONS:

http://www.theaftd.org/life-with-ftd/managing-health-care/residential-care-options

EASING THE TRANSITION: RESIDENTIAL LONG-TERM CARE AND FTD.

Partners in FTD Care, Fall 2015: http://www.theaftd.org/wp-content/uploads/2015/05/PinFTDcare_Newsletter_Fall2015.pdf

BREAKOUT SESSION:
Comfort Care and End of Life Considerations

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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.

PALLIATIVE 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 respond to 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 plans 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 our families will receive the necessary support to allow us 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 will 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 hospice is the most appropriate option for future care. Indications that it may be time to consider hospice include a person's inability to walk, dress or bathe without assistance, inability to communicate and incontinence. In addition, the person with FTD will have experienced one or more signs of dementia-related decline, including aspiration pneumonia, infection or weight loss.

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 appear to be more robust, which can complicate hospice admission. It is good to become familiar with the eligibility criteria for hospice and other health care 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 can live longer, and in the absence of signs of decline or symptoms that require treatment, the hospice re-certification process can be difficult.

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 change as well.

In addition to the services of the interdisciplinary team, the costs of medications needed for pain and symptom management, and the costs for durable medical equipment and supplies, are also a hospice benefit – covered by Medicare, Medicaid and private insurances.

While Music and Massage therapists are not core members of the hospice team, the availability of Music and Massage therapy, along with dementia training for all staff, increases the quality of the care available to patients with dementia. Best practices include Music and Massage therapy referrals for all dementia patients and the availability of consultation to staff and families, on topics such as dementia behaviors and guidance with decision-making.

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 that allows for up to five days of respite in a long term-care facility, for caregivers in need of a "break" from care.

Hospices are required to provide bereavement support to families for 13 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 play an important support role at end of life. Staff serve 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 explore caregiver goals of care and assist with identifying and arranging any additional services needed to support end of life care. Hospice staff facilitate 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 ways to creatively respond to them.

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 these individuals. When selecting a hospice, caregivers may wish to ask hospice staff about the organization's experience caring for persons with dementia.

QUESTIONS SHOULD INCLUDE:

- What is your organization's experience working with persons with dementia? With persons with FTD?
- What training does your staff receive to provide advanced dementia care at end of life? On caring for persons with FTD?
- Who provides your training? Staff internal/external to the organization?
- If the organization has little-to-no experience with FTD, are they willing to learn?
- Describe the organization's ability to provide consultation to staff and caregivers on dementia behaviors, advance directives and end of life decision making.
- 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

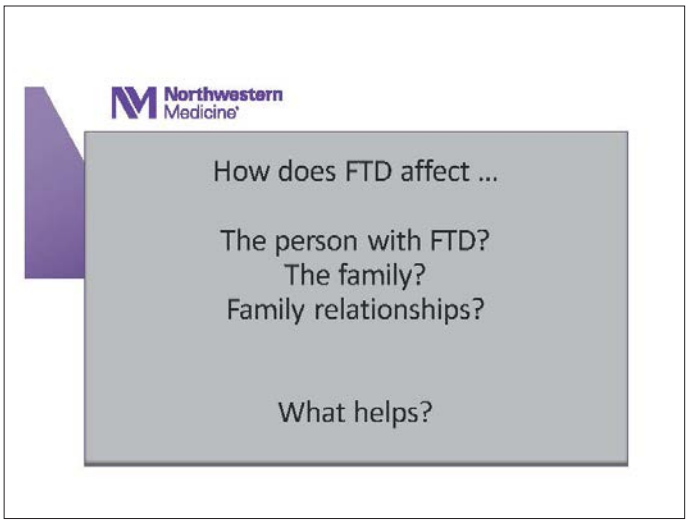
NATIONAL INSTITUTE ON AGING: booklet on hospice and palliative care and end of life dementia care, "End of Life: Helping with Comfort and Care." https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction
Alzheimer's Association: booklets on end of life dementia care, "End of Life Decision Making," "Ethical Issues in Alzheimer's disease: End of Life Issues." www.alz.org

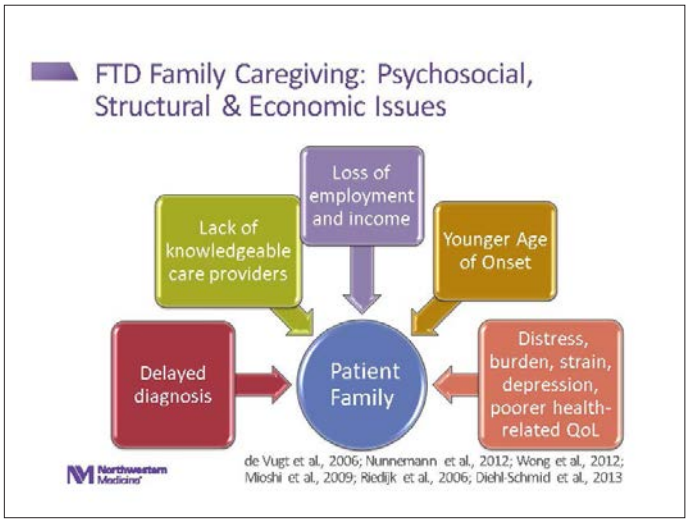
ALZHEIMER'S ASSOCIATION, GREATER ILLINOIS CHAPTER:
"Encouraging Comfort Care: A Guide for Families of People Living in Care Facilities."
http://www.alzheimers-illinois.org/pti/comfort_care_guide.asp

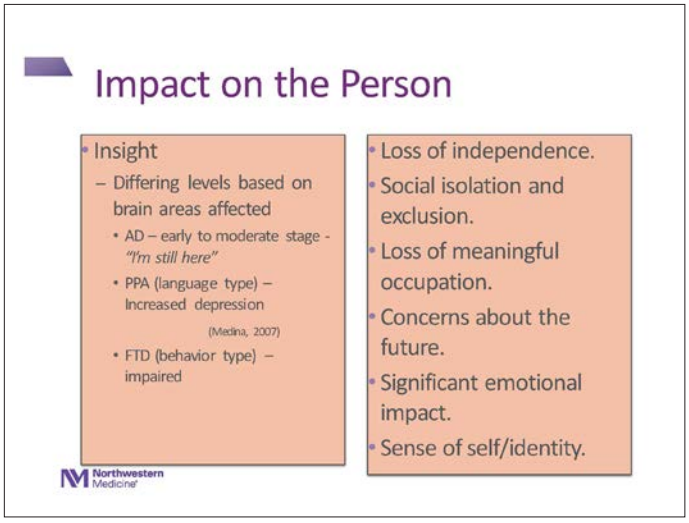
MAYO CLINIC: information on end of life care, "Alzheimer's disease: Anticipating End of Life Needs." http://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20044065

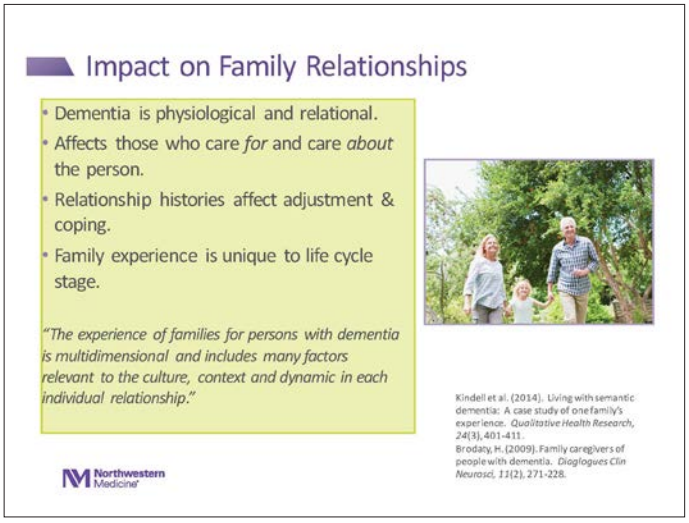
AFTD: FTD-specific information on hospice, end of life symptoms and advocating for care.
http://www.theaftd.org/life-with-ftd/managing-health-care/hospice-end-of-life

PRESENTATION: IMPACT ON THE FAMILY

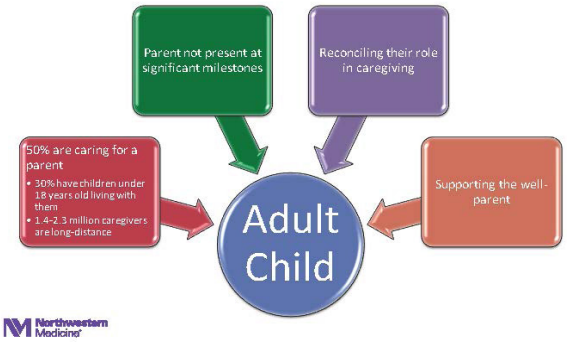








Impact on Adult Child



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Longing for Emotional Connection

"I miss my mom a lot – yea, I miss her – I have to come to terms with that, but I miss her – it is definitely a loss I can't talk to her about. She is taking care of Dad and she used to take care of me. She is not there in the same way and I don't expect her to be. Her partner is dying, she lost her home and quality of living. She doesn't need to hear how things have changed between us. She needs support – love – she doesn't need to hear me say 'why don't you pay attention to me any more?'"

~adult daughter

Northwestern Medicine

Continuity & Discontinuity:

This is not 'Still Alice'

- My parent is a different person, ...doesn't know me, ... isn't very nice,...is aggressive, ...is suspicious, ...can't talk to me

Sikes & Hall (2016)

– *"It's like there's two Moms and in your head, you never quite let go of...but you're constantly grieving for the old Mom because she's sort of there but not ...it sounds awful, but people who have a parent who dies when they are in their teens or twenties, it's like quick, and it's awful but then you're allowed to grieve ...whereas people don't see that with this, they just think actually you should be grateful that your Mom is still here and she's not dead and it's like well, it's really not that simple but I think admitting that to anyone is really hard because people don't expect you to think that, I don't think."* (Elizabeth, 28)

Northwestern Medicine

Impact on Partner/Spouse

- Loss of a companion
  - Feeling "robbed of the future."
  - Role changes in the relationship.
  - Reciprocity in relationship diminishes "Am I still married?"
  - Loss of a couple identity and parenting partner.
  - Apathy has been shown to have the most impact on the marital relationship (du Vugt et al., 2003).

- Balancing care with maintaining own life.
- Managing expectations of others.
- Coping with emotions.

"...our relationship has changed...We were partners and we are not now... I miss him. He feels like my child; it's difficult to ...respond to him the way I have in the past on everything. It's the dependence. I feel like his mom."

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Shift in Role as a Parent

- Increasing dependence on spouse / partner and children.
  – *"Yes, there are changes – I don't feel like a mom anymore. I've not been emotionally available and that was a big part of being a mother for me. I have to ask them for help instead of they can always ask me for help. I don't like to be a burden, but I think I am."*

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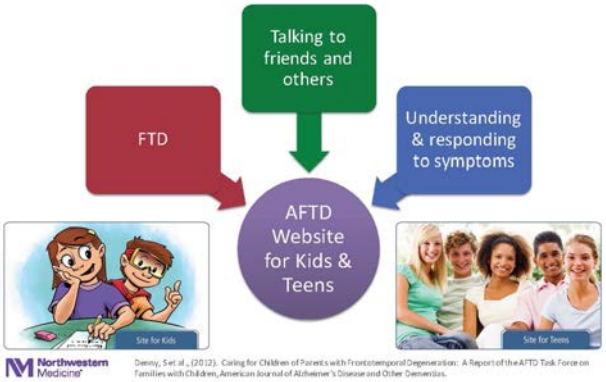
Key Issues and Concerns for Children & Teens

Need for Education



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Denny, S et al., (2012). Caring for Children of Parents with Frontotemporal Degeneration: A Report of the AFTD Task Force on Families with Children, American Journal of Alzheimer's Disease and Other Dementias.

Key Issues and Concerns for Children & Teens
How to handle emotional concerns

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Denny, S et al., (2012). Caring for Children of Parents with Frontotemporal Degeneration: A Report of the AFTD Task Force on Families with Children, American Journal of Alzheimer's Disease and Other Dementias.

Key Issues and Concerns for Children & Teens
Managing Daily Living Needs

- Answering questions from friends
- Knowing what to do when friends can't come over
- Problem solving logistics of school demands
- Finding support
- Adjusting to financial changes
- Adapting to changes at home
- Providing personal care

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Impact on Family Unit

- Constant re-evaluation of the balance between the needs of the person with FTD and the families' needs and limitations.
- Ambiguity and uncertainty about the future.
- Future planning discussions and financial matters.
- Suggestions/criticism from other family/friends.
- Social isolation of family.

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Complicated Dynamics

- Providing care to someone who did not care for you.
  - Doing the "right thing."
  - Cultural scripts and expectations.
- Caregiver misconceptions that increase stress and prevent good self care.
  - "If I do it, I will get the love, attention and respect I deserve."
  - "If I don't do it, no one will."
- Older parent taking care of a middle-aged child.
- Different ideas about care needs.
- How do you respond to family members who do not get involved?
- Tensions of previous conflict/dynamics may erupt as person needs more care.

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Family Conflict

- Different ideas about care needs.
- Tensions of previous conflict/dynamics may erupt as person needs more care.
  - Separate yesterday's battles from today's decisions.
- Who is leading the family care team?
  - Power of attorney for health care and finances.
- Mediation/family meeting facilitation/care manager.

"Others lose the right to criticize you when they fail to respond, or fail to follow through on their promises."

- Cheryl Woodson, MD

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As a Family – "Staying Connected While Letting Go"

- Normal grief reaction.
- One grieves what is, what will not be, what was.
- Talk about what is happening - withholding feelings diminishes relationships.

- Spend time together – Spend time apart.
- Try to find balance.
- Practice relentless self-care and forgiveness.

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Braff, S. & Olenik, M.R. (2005). *Staying Connected While Letting Go: The Paradox of Alzheimer's Caregiving*, Lanham, MD: Rowman & Littlefield.

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What Helps?

Find a Skilled and Responsive Care Team

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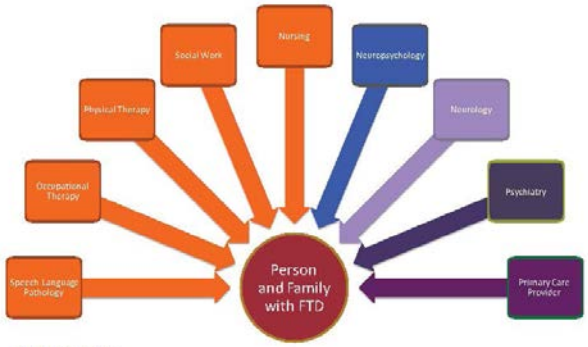
Expand Your Care Team



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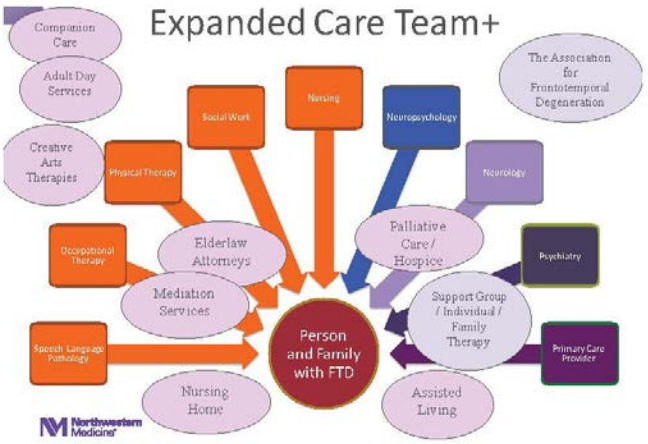
Expanded Care Team+



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Family Resilience

- Throughout losses, there is often an expression of hope and strength within the structure of relationships.
- A family's ability for resiliency will influence how they adapt over time.
- The strength of the relationships and person to person commitment has the capacity to override the challenges.
- With help and support, patients and families can live meaningful lives.

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No two people with FTD are alike.
No two families are alike in their needs for care and support.

"Maintaining or enhancing quality of life is the ultimate objective."

2013 World Alzheimer's Report

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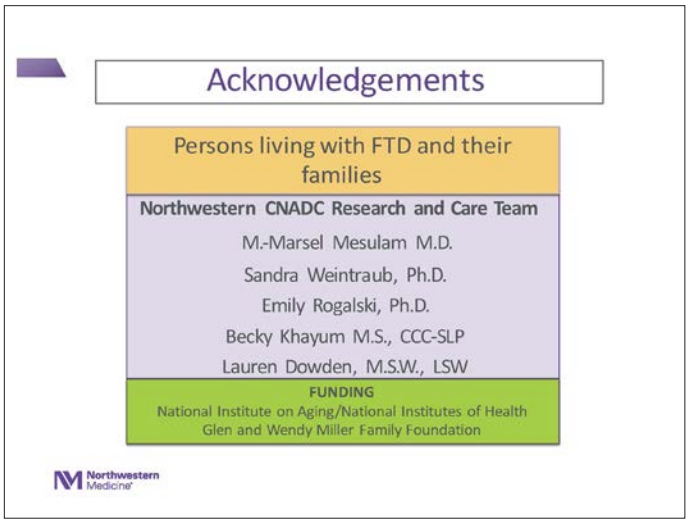
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Northwestern Medicine


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Northwestern University Feinberg School of Medicine
www.brain.northwestern.edu
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NOTES

AFTD RESOURCES

AFTD WEBSITE—WWW.THEAFTD.ORG

The place for information, resources and support related to FTD. Includes recently expanded sections on Research and I Have FTD, and a link to Get Involved.

AFTD KIDS AND TEENS WEBSITE—WWW.AFTDKIDSANDTEENS.ORG

Explore. Learn. Connect. This website with separate sections for young children and teens provides reliable information and empowering coping strategies for children who have a parent or other close relative affected by FTD.

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 staffed Monday through Friday, during AFTD office hours.

CONNECTING WITH SUPPORT

AFTD connects people with FTD and caregivers with support that fits their needs. Visit the AFTD 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 a new group for men caring for a spouse.

For persons with FTD: http://www.theaftd.org/life-with-ftd/i-have-ftd/support
For caregivers: http://www.theaftd.org/life-with-ftd/support-for-caregivers

INFORMATION ON RESEARCH PARTICIPATION

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.

Visit AFTD's website for more information on these listed resources, and to access additional information available for people with FTD, families and professionals.

MANAGING A NEW DIAGNOSIS

Checking Things off the List

LEARN	
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.	
Visit AFTD's website and register for the newsletter (www.theaftd.org).	
Contact AFTD's HelpLine with questions: 866-507-7222 or info@theaftd.org.	
Learning is ongoing. Continue to read and ask questions.	
START IMPORTANT CONVERSATIONS	
The person diagnosed and care partner should talk about what each of them sees changing and its impact. Acknowledge without judging the different perspectives and experiences.	
Identify ways you can adjust to keep doing things that are most important to each person and to close family or friends.	
Help the person diagnosed to identify factors important to them in how they would like to receive care as their needs change over time.	
Share information about the disease and your needs with key family and friends.	
If you have children or teens, get AFTD's booklet "What About the Kids?"	
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 list of what you need. Ask family, friends and neighbors to help.	
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 or the person with the disease. Visit 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.	

Managing a New Diagnosis Checking Things off the List (continued...)

ADDRESS LEGAL AND FINANCIAL ISSUES	
Consult an Elder Law attorney.	
Plan transition from employment, if still working.	
Complete legal documents (Power of Attorney, living will, will, etc.).	
Review financial and health care programs.	
Apply for Social Security Disability (Compassionate Allowances Program).	
Determine eligibility for Veterans Administration benefits.	
DEVELOP 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 respite grant for family caregivers.	
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. State that the person has a neurological disorder.	
Keep the 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 a similar device if there is any risk the person may get lost in the community.	
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.	
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.	

COMING MAY 2016

HTTP://WWW.FTDREGISTRY.ORG

The FTD Disorders Registry is a secure electronic database that collects information from people diagnosed with any one of the FTD disorders, their caregivers and family members. Completing registry research surveys will help us understand the impact of the disease on families. Future research may include studies by scientists who want to learn more about FTD biology by following participants over time, or use the data to develop new therapeutics. All research participant information in the registry is 'de-identified' (made anonymous) by removing your name or other personal identifiers and replacing with an ID code to protect your identity.

JOIN THE REGISTRY.
TELL YOUR STORY.
ADVANCE THE SCIENCE.

Partners in FTD Care is an education initiative of AFTD that brings together clinical experts, health professionals and families to promote understanding of frontotemporal degeneration (FTD) and develop best practices in community care. Partners in FTD Care helps primary care providers as well as home health, day program, facility care and rehabilitation therapy providers gain the knowledge and confidence to serve people with FTD and their families.

FREE QUARTERLY E-NEWSLETTERS

Case-based studies describe common FTD care issues from clinical care practice.
Questions, interventions and side bar articles serve as in-service training tools.
"What to Do About..." one pager offers succinct, hands-on interventions for common care management challenges.
Examples of success to inspire person- and family-centered care practices.

RECENT TOPICS INCLUDE:

- Maximizing Communication in Primary Progressive Aphasia.
- Easing the Transition to Residential Long-Term Care.
- Falls and Dysphagia in Progressive Supranuclear Palsy.
- Changes in Eating and Managing Related Compulsive Behaviors.

ORDER TRAINING MATERIALS FOR YOUR STAFF. INTRODUCTORY MATERIALS INCLUDE:

AFTD's powerful film, It Is *What It Is* on DVD—a brief documentary that introduces FTD and the challenges patients and families face. The film includes a companion booklet, and offers discussion questions for trainers to use with staff.
Clinical case studies—developed by experts to highlight different presentations of FTD and interventions; these include discussion questions for participants and leader's version.
Tools and resources—to facilitate placement, understand symptoms and plan effective care.

PARTNERS IN FTD CARE ADVISORS

Sandi Grow, RN
Lisa Gwyther, LCSW
Geri Hall, Ph.D., A.R.N.P.
Barbara Harty, R.N., M.S.N., G.N.P.
Susan Hirsch, M.S.
Jill Shapira, Ph.D., R.N.
Rebekah Wilson, M.S.W.

Visit the Healthcare Professionals Section of AFTD's website for FTD clinical criteria and information on treatment, interventions and the Partners in FTD Care initiative.

Order your training packet and register for FREE Partners in FTD Care e-newsletters at:
http://www.theaftd.org/understandingftd/healthcare-professionals or email: PartnersinFTDcare@theaftd.org

IT'S TIME TO TAKE ACTION AND VOLUNTEER!

HAS FRONTOTEMPORAL DEGENERATION (FTD) AFFECTED YOUR LIFE?
DO YOU WANT TO HELP MAKE A DIFFERENCE FOR FAMILIES FACING FTD NOW, AND IN THE FUTURE?

AFTD VOLUNTEERS & STAFF

You can get involved today by joining a national network of volunteers making a positive impact in the lives of those impacted by this disease. AFTD needs the time and talents of volunteers everywhere to help create a world where FTD is understood, effectively diagnosed, treated, cured and ultimately prevented.

Opportunities vary from leadership roles and residential facility outreach, to hosting fundraisers. We will explore projects together that best suit your skills and preferences.

You will be provided with guidance and support to ensure that you have a satisfying and rewarding experience that will meet your individual goals.

ARE YOU READY TO TAKE ACTION?

TO LEARN MORE:
http://www.theaftd.org/getinvolved/volunteer
or
Contact Kerri Barthel
Volunteer Manager
267-758-8652 / kbarthel@theaftd.org

SUPPORT GROUPS ARE ONE OF THE BEST RESOURCES AVAILABLE TODAY FOR FAMILIES FACING FTD.

AFTD has formalized relationships with—and begun an affiliation process for—individuals leading FTD-caregiver support groups. Since we began this initiative in August 2015, more than 40 facilitators have completed initial training, and the numbers continue to grow. Our hope is to achieve a network of volunteer support group leaders who are well informed about FTD, and learn about meaningful application of best practices for FTD support groups. In these roles, individuals have support and backing from each other, as well as the information hub of the community: AFTD.

As part of this initiative, we offer training and opportunities for support group leaders to network, process their role as leaders and learn from the experts. AFTD is building a network of volunteers that embody the essence of knowledge, compassion, respect and dignity.

Think this sounds like a natural fit for you? If so, please join Support Services Manager, Bridget Moran for lunch at today's conference to learn about AFTD's network of support, discuss your interest and hear from others who are currently leading groups. Grab your lunch and join us any time from 11:45 a.m.–12:45 p.m. Look for the room assignment, which will be clearly indicated at today's conference. We look forward to meeting you!

CAN'T MAKE IT TO LUNCH?

Contact Bridget Moran at bmoran@theaftd.org or 267-758-8653 to learn more.

FOOD FOR THOUGHT® 2016…

Recipe: AFTD's Food for Thought® Campaign 2016_____

Serving: All 50 States_____

Prep Time: Now_____

Cook Time: September 25–October 9, 2016_____

Ingredients: Food, Drink & Education _____

DIRECTIONS:

1. It's time to start thinking about AFTD's 4th Annual Food for Thought Campaign. Team up with friends and family, or plan something yourself. Any event—big or small—as long as it involves food and a little FTD education

2. Your event can take place any day during the two-week period September 25th through October 9th, 2016.

3. Planning an event is easy. AFTD staff and volunteers are here to help! Share your story, raise awareness, and raise vital funds to support AFTD's mission in your community!

4. Put your state on the map, to show nationwide resolve against this disease. Email Bridget Graham at bgraham@theaftd.org, or fill out this form to get started: http://tinyurl.com/FFT2016

FIGHT FTD WHEREVER FOOD IS SERVED… JOIN FFT 2016 TODAY.

AFTD's Food for Thought

THANK YOU FOR COMING!

SEE YOU NEXT YEAR IN BALTIMORE!
SAVE THE DATE: MAY 5,2017!