

COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER

of the Northwestern University Feinberg School of Medicine presents the

**FRONTOTEMPORAL DEGENERATION
and PRIMARY PROGRESSIVE APHASIA
ANNUAL CONFERENCE**

MONDAY, NOVEMBER 4, 2013

THE CNADC WOULD LIKE TO THANK THE
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FRONTOTEMPORAL DEGENERATION *and* PRIMARY PROGRESSIVE APHASIA

ANNUAL CONFERENCE

MONDAY, NOVEMBER 4, 2013

AGENDA

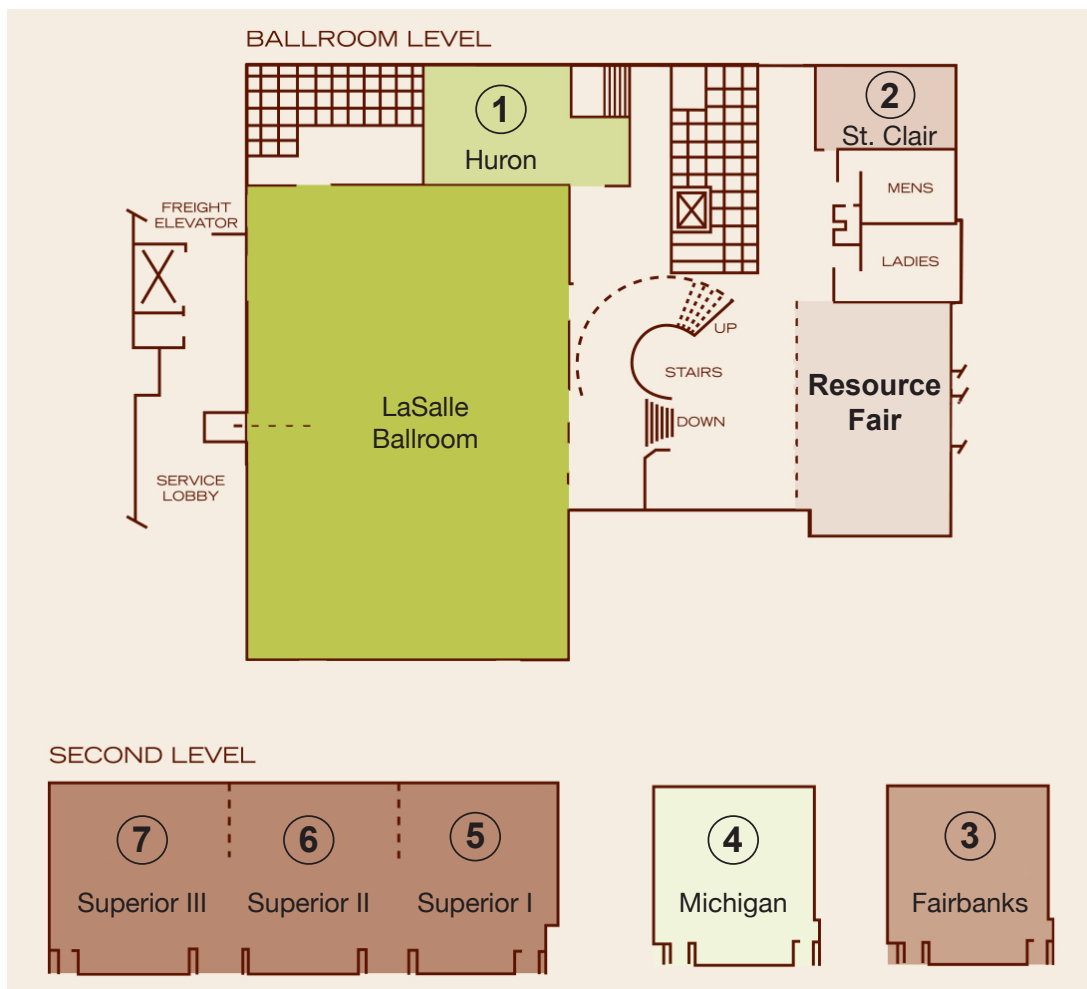
8:00-9:00 AM	Registration and Resource Fair
9:00-9:15 AM	Welcome
9:15-9:45 AM	Introduction to PPA and FTD Marsel Mesulam, MD
9:45-10:45 AM	Interventions for Language Changes Becky Khayum, MS, CCC-SLP Coping with Relationship and Behavior Changes Darby Morhardt, MSW, LCSW
10:45-11:00 AM	Break and Resource Fair
11:00 AM-noon	Question-and-Answer Session with Marsel Mesulam, Darby Morhardt, Becky Khayum, and families living with PPA and FTD
noon-1:00 PM	Lunch and Resource Fair
1:00-2:30 PM	Breakout Session 1 <i>Please see page 3 for breakout session locations</i>
2:30-3:00 PM	Break and Resource Fair
3:00-4:30 PM	Breakout Session 2 <i>Please see page 3 for breakout session locations</i>

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MAP OF CONFERENCE

Breakout Sessions		
Map #	Session Topic	Room Name
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2	Support Group for Family Caregivers	St. Clair Boardroom
3	Support Group for Family Caregivers	Fairbanks
4	Navigating Family Conflict	Michigan
5	Approaches to Behaviors	Superior I
6	Expanding Your Care Team As Needs Change (Early to Middle Stage)	Superior II
7	Expanding Your Care Team As Needs Change (Middle to Later Stage)	Superior III



THANK YOU!

The Cognitive Neurology and Alzheimer's Disease Center (CNADC) of the Northwestern University Feinberg School of Medicine thanks the Association for Frontotemporal Degeneration and the National Aphasia Association for their collaboration and support of this special event.



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



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Thank you to the families living with FTD and PPA who provided support for this conference:

Bill Floyd

Lorene Schlie

Ron Kinnamon

Sally Kinnamon

2013 Planning Committee Members:

Kevin Connolly

Joshua Kaplan-Lyman

Jennifer Medina

Darby Morhardt

Mary O'Hara

Emily Rogalski

Sandra Weintraub

Christina Wieneke

Kristine Zachrich

and all the volunteers who have made this day a success!

The CNADC appreciates your dedication
and commitment to making this day possible.

PROGRAM HIGHLIGHTS

Marsel Mesulam, MD

**Director, Cognitive Neurology and Alzheimer's Disease Center (CNADC)
Feinberg School of Medicine**

Marsel Mesulam is the Ruth Dunbar Davee Professor of Neuroscience and the Director of the multi-departmental Cognitive Neurology and Alzheimer's Disease Center at Northwestern University's Feinberg School of Medicine in Chicago.

His research has addressed the neural connectivity of the monkey brain, the organization of human cholinergic pathways, the representation of cognitive functions by large-scale neurocognitive networks, and the neurobiology of dementias. He introduced a new method for tracing neural pathways by axonal transport, identified the source of cortical cholinergic pathways in the primate brain, and characterized a unique form of language-based dementia known as primary progressive aphasia.

He received the Javits Award from the National Institute of Neurological Disease and Stroke, the Director's Award from the McKnight Foundation, the Wartenberg Lectureship Award from the American Academy of Neurology, Lifetime Achievement Awards from the Alzheimer's Association and the Society for Behavioral and Cognitive Neurology, and the Lishman Award from the International Neuropsychiatry Association. He has been included in multiple lists of "America's Top Doctors" and "Chicago's Best Doctors."

His students and trainees hold leadership positions in the US and abroad. He has published more than 400 research papers and edited a popular textbook of Behavioral and Cognitive Neurology. He is Chair of the Medical Council of the Association for Frontotemporal Degeneration, a past Vice President of the American Association of Neurology and a past President of the Organization of Human Brain Mapping. His current research focuses on the functional imaging of neurocognitive networks and on the pathophysiology of focal dementias.

Becky Khayum, MS, CCC-SLP

Becky Khayum is a speech-language pathologist who specializes in the treatment of memory and cognitive-communication disorders. She is the co-founder and president of MemoryCare Corporation, a company dedicated to providing individualized therapy services to those suffering from Alzheimer's and other memory disorders. Prior to her work with MemoryCare, Becky served as therapy coordinator for a Brookdale Senior Living facility for several years and has also worked in multiple skilled nursing facilities in the Chicago region. Becky has developed a passion for educating professionals and caregivers on strategies that facilitate communication and memory 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.

PROGRAM HIGHLIGHTS

Darby Morhardt, MSW, LCSW

Darby Morhardt, MSW, LCSW, is Research Associate Professor and the Director of the Education and Information Transfer Core for the Cognitive Neurology and Alzheimer's Disease Center (CNADC) at Northwestern University Feinberg School of Medicine. Ms. Morhardt holds a master's degree in social work from Jane Addams College of Social Work at the University of Illinois at Chicago. She completed postgraduate work in family therapy at the Institute for Juvenile Research at University of Illinois at Chicago and is a PhD candidate at Loyola University Chicago School of Social Work.

Ms. Morhardt has 29 years of clinical experience with cognitively impaired individuals and their families. This work led to the development of quality of life enrichment programs and interventions for persons and families living with younger onset and early stage dementia, particularly those with frontotemporal degeneration (FTD) and primary progressive aphasia (PPA).

Ms. Morhardt is also responsible for organizing the CNADC's community education and outreach programs. She is one of nine faculty on the Steering Committee for the Alliance for Research in Chicagoland Communities (ARCC), Center for Community Health within Northwestern's Institute for Public Health and Medicine. ARCC's mission is to grow equitable and collaborative partnerships between Chicago area communities and Northwestern University for research that leads to measurable improvement in community health.

PROGRAM HIGHLIGHTS

Breakout Sessions

Expanding Your Care Team As Needs Change (Early to Middle Stage)

Sandra Weintraub, PhD, Mary O'Hara, AM, LCSW, Janna Dutton, JD

A “care team” is a circle of professionals, families, and friends involved in a patient’s care that is assembled at diagnosis and provides guidance, care, and support throughout the progression of the disease. This session will discuss how to create a care team and the important next steps after receiving a diagnosis including legal and financial planning, finding meaningful activity for the diagnosed person, and support for the family.

Expanding Your Care Team As Needs Change (Middle to Later Stage)

Joshua Hauser, MD, Darby Morhardt, MSW, LCSW

As care needs increase, the care team must expand as well. This session will discuss how to recognize when more care is needed, options for additional care, approaches to implementing and evaluating this care, and support for the family during this time.

Approaches to Behaviors

Deborah Reed, MD

People with FTD/PPA can experience a range of behavioral symptoms that can be difficult to manage. This session will review non-medical interventions, as well as medications that can help alleviate behavioral symptoms, promote quality of life, and help families cope with difficult behaviors.

Strategies for Communication

Becky Khayum, MS, CCC-SLP, Smita Mahajan, MA, CCC-SLP

This session will review communication challenges in FTD/PPA and the benefits of speech therapy throughout the progression of the disease. Attendees will learn strategies for supporting language abilities and resources available to maximize communication among family members.

Support Groups for Family Caregivers

Mary Popelar, MSW, LCSW, Julia Rao, PhD, Jennifer Medina, PhD, Derin Cobia, PhD

These professionally facilitated support group sessions will offer a safe and confidential space for family caregivers to share with others who understand the experience of having a loved one diagnosed with FTD/PPA. Attendees will share their experiences, learn new ways to cope with challenges, and connect with others in a similar situation.

Navigating Family Conflict

Marcia Spira, PhD

Dealing with family dynamics when a loved one has dementia can be difficult, complex, and emotional. This session will discuss the experience of families in conflict, resources available to resolve conflict, and strategies for continuing to provide the best care for the diagnosed individual.

PROGRAM HIGHLIGHTS

Speaker Biographies

Derin Cobia, PhD is an Assistant Professor of Psychiatry and Behavioral Sciences at Northwestern University's Feinberg School of Medicine, a staff neuropsychologist with the Northwestern Medical Group, and Associate Director of the Clinical Psychology Doctoral Program in the Division of Psychology. Dr. Cobia is interested in using working memory and approach motivation paradigms to explore how theories of reward influence disease expression and may target treatments. He also studies the neurodegenerative processes in primary progressive aphasia, a language-based dementia, and is interested in how the dissolution of language varies as a function of disease burden and location in the perisylvian networks of the brain.

Sharon Denny, MA is Program Director for The Association for Frontotemporal Degeneration (AFTD), where she leads support and education efforts for people with FTD, their families and professionals. She has introduced new initiatives to address the needs of children and teens, and support for people with the disease. A committee of clinicians and family caregivers created Partners in FTD Care as an on-going effort to educate community healthcare providers and promote best practices in FTD care. Ms. Denny has a Master's in Clinical Psychology and more than twenty-five years' experience in program development for disability organizations. She has been with AFTD since 2008.

Janna Dutton, JD has been practicing in the area of elder law for more than 30 years. As a result, Janna has the knowledge and depth of experience to skillfully navigate through a diverse range of elder law matters, including guardianship and financial exploitation matters, trusts and estate planning, Medicaid planning and applications and probate and estate administration. She is certified by the National Elder Law Foundation as an elder law attorney and has held this certification since 1995.

Ellayne Ganzfried, MS, CCC-SLP is a speech-language pathologist and the Executive Director of the National Aphasia Association. She is the Past President of the NYS Speech-Language-Hearing Association (NYSSLHA), Long Island Speech-Language-Hearing Association (LISHA) and the Council of State Association Presidents for Speech Language Pathology and Audiology (CSAP) and remains active in these associations. Ellayne is a Fellow of the American Speech-Language-Hearing Association (ASHA). Ellayne has written articles and presented regionally and nationally on a variety of topics including aphasia, rehabilitation and leadership skills.

Joshua Hauser, MD is Assistant Professor of Medicine (Palliative Medicine) at Northwestern's Feinberg School of Medicine, where he also serves as Fellowship Director in Palliative Medicine and director of palliative care at the Jesse Brown VA Medical Center. At Northwestern, he currently chairs the Professional Development Committee, one of four committees responsible for the medical school curriculum renewal. For the past three years, he has also directed the Education on Palliative and End of Life Care (EPEC) Project. Dr. Hauser graduated from Harvard Medical School. He completed his residency in primary care internal medicine at the Brigham and Women's Hospital, the Robert Wood Johnson Clinical Scholars Program and fellowship in Clinical Medical Ethics at the University of Chicago and palliative care fellowship at Northwestern.

Smita Mahajan, MA, CCC-SLP earned her Master of Arts Degree in Speech-Language Pathology from Northwestern University. She has a passion for working with adult neurogenic disorders and has worked in a variety of settings including acute care, skilled nursing, outpatient rehabilitation and home health. Smita is bilingual and fluently speaks Hindi and Punjabi.

PROGRAM HIGHLIGHTS

Speaker Biographies

Jennifer Medina, PhD is an Instructor in the Department of Psychiatry and Behavioral Sciences at Northwestern University Feinberg School of Medicine. Dr. Medina received her PhD in Clinical Psychology with an emphasis in clinical neuropsychology from Northwestern University. She completed an internship in Clinical Psychology at Rush University Medical Center and a two-year Post-doctoral Fellowship in Clinical Neuropsychology at the University of Illinois at Chicago. Her current clinical and research interests include the co-morbidity of mood disorder and neurological conditions.

Mary O'Hara, AM, LCSW is a social worker and the Assistant Director of Education at Northwestern's Cognitive Neurology and Alzheimer's Disease Center (CNADC). In addition to helping facilitate the CNADC's Quality of Life Enrichment Programs, Mary also provides education and support to diagnosed persons and their families in the Neurobehavior and Memory Clinic.

Mary Popelar, MSW, LSW, is a social worker and graduate of Loyola University Chicago where her concentration was in health and gerontology. Mary was formerly a graduate intern at the CNADC where she assisted in quality of life programs and education. Mary currently works at the 24-hour helpline of the Alzheimer's Association to support individuals and families experiencing memory loss. Mary also works as the Manager of Prevention Programs at the Illinois Chapter, American Academy of Pediatrics.

Julia Rao, PhD, graduated from Northwestern University in June 2013 with a degree in clinical neuropsychology. There she worked with Drs. Sandra Weintraub and Emily Rogalski at the Cognitive Neurology and Alzheimer's Disease Center examining naming deficits in those with primary progressive aphasia as well as neuroanatomical features of SuperAging, or those over 80 years of age who do not show any signs of normal aging memory loss. After completing her clinical internship at the Alpert Medical School at Brown University, she started her neuropsychology postdoctoral fellowship at the University of Illinois at Chicago in July 2013. She is interested in functional brain abnormalities in depression and how these changes interact with normal brain functional changes due to aging.

Deborah Reed, MD is Assistant Professor of Clinical Psychiatry and Behavioral Science, a college mentor, and the former Division Director of Geriatric Psychiatry at Northwestern University Feinberg School of Medicine. She is also the Consulting Psychiatrist at the Cognitive Neurology and Alzheimer's Disease Center (CNADC). Dr. Reed received her Doctor of Medicine degree from the Medical College of Pennsylvania. Her interests include the pharmacologic management of cognitive and behavioral syndromes in patients with dementia, attention deficit disorder and other neurologic conditions.

Marcia Spira, PhD, LCSW is professor of social work in the School of Social Work at Loyola University Chicago. She teaches courses in practice with older adults and their families as well as directs the Institute on Aging, Intergenerational Study and Practice. Her current scholarship includes several projects and publications on the impact of cognitive decline on families and communities. Professor Spira is also a clinical social worker and trained in elder mediation.

Sandra Weintraub, PhD is Professor of Psychiatry, Neurology, and Psychology at Northwestern University Feinberg School of Medicine and is the Clinical Core Director of Northwestern's Cognitive Neurology and Alzheimer's Disease Center. Her research focuses on the neuropsychology of primary progressive aphasia and frontotemporal degeneration.

ABOUT THE CNADC

Cognitive Neurology and Alzheimer's Disease Center Northwestern University Feinberg School of Medicine

Patient Care

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Research and Education

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Chicago, IL 60611
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Mission:

The Cognitive Neurology and Alzheimer's Disease Center (CNADC) is a multidisciplinary organization dedicated to the following pursuits:

1. Conducting research to discover how the brain coordinates cognitive functions such as memory, language, attention, and emotion.
2. Discovering causes and treatments for diseases that disrupt these functions, such as Alzheimer's disease, frontotemporal degeneration and primary progressive aphasia.
3. Transferring the benefits of this research to patients and their families.
4. Training researchers and clinicians who want to work in this field.

Neurobehavior and Memory Clinic

The Neurobehavior and Memory Clinic is staffed by physicians from the Northwestern Medical Faculty Foundation, a multispecialty group practice of the full-time faculty at Northwestern's Feinberg School of Medicine. Offering a comprehensive array of diagnostic, therapeutic, and innovative care, the clinic has a multidisciplinary staff that includes behavioral neurologists, neuropsychologists, neuropsychiatrists, geriatricians, and licensed clinical social workers.

Medical Services

- Evaluation of memory and other thinking abilities by a clinical neuropsychologist using specialized tests
- Evaluation and follow-up care by behavioral neurologists and geriatric specialists in dementia
- Psychiatric evaluation and treatment for associated mood and behavior disorders
- Management of medication for memory disorders
- Referral to our center's research studies and clinical trials

Supportive & Educational Services

- Disease education, counseling, and referrals to community support by licensed clinical social workers
- Symptom-specific coping strategies, interventions, and resources from clinic specialists
- Support for patients, caregivers, and family members

Life Enrichment Programs

- The Buddy Program matches first year medical students with persons living with early stage dementia. This program provides companionship for persons with dementia and gives medical students the unique opportunity of spending time with diagnosed individuals at an early stage.
- The Memory Ensemble is a program of improvisational theater and intervention for persons with early-moderate dementia which offers a unique and enriching experience. Participants learn to use their instincts, creativity and spontaneity as they explore and create together.
- iLUMAnations, a program for persons with memory loss and their care partners, helps spark creative dialogue and nurture positive interactions as participants tour the art galleries of LUMA.

CURRENT FTD/PPA RESEARCH AT NORTHWESTERN CNADC

Language in Primary Progressive Aphasia

The purpose of the study is to gain a better understanding of the diagnosis, progression, and characterization of primary progressive aphasia (PPA). To do this, we look at many different aspects of the disease: neurological, defined by a clinical exam and MRI; neuropsychological, defined by a large battery of tests examining memory, attention, naming, and others; and linguistic, measured through picture, word and sentence comprehension tests.

The study lasts three days total, about 7 hours each day, including breaks. The individual diagnosed with PPA and their study partner are compensated for travel, meals, and accommodations. Participants also receive a daily stipend for their time.

To participate, one must have a diagnosis of PPA, be a native English speaker, have the ability to read large print, have adequate hearing to follow conversation, have no significant medical illness that would interfere with future participation, pass a safety screen for an MRI, and not have claustrophobia. For more information, contact Christina Wieneke: 312-908-9681 or c-wieneke@northwestern.edu.

Memory Disorders Research Core

The purpose of the research core is to better understand various dementia syndromes, including Alzheimer's disease, behavioral-variant frontotemporal degeneration, primary progressive aphasia, and other related disorders. This registry supports many different research studies on aging and dementia and identifies the needs of diagnosed individuals and families to provide improved counseling, education, and referrals to community services.

Tasks include an interview with the diagnosed individual and family members, a series of paper and pencil tests to evaluate memory and thinking skills, and a meeting with a social worker. Each research visit is approximately 1.5 hours in length. There is no cost for participation. For more information about eligibility, contact Mallory Swift: 312-926-1851 or memory-research@northwestern.edu.

Other Research Directions

- Clinically testing new drug therapies for Alzheimer's disease (AD)
- Identification of pre-Alzheimer conditions and disease prevention studies
- Studying the effect of sleep deficits on memory and cognitive function
- Causes and treatments of PPA, FTD, and other younger onset dementias
- Identifying brain factors associated with "SuperAging"
- Treatment and prevention of dementia
- Nature of cognitive and behavioral changes in dementia
- The impact of non-medication interventions on quality of life

THE IMPORTANCE OF BRAIN DONATION

Brain donation is one of the most important contributions to research.

As researchers work to better understand disorders that affect mental function with aging, brain donations are essential to their progress.

By studying the anatomy, pathology, and chemistry of the brains of people with memory problems or cognitive disorders, we are able to expand our knowledge of diseases such as Alzheimer's and Frontotemporal Lobar Degeneration and take steps toward prevention and treatment.

While major advances have already been made possible through the generosity of brain donation, there is still much more to be learned and a need for continued support.

Brain donation provides a valuable service to families.

A comprehensive brain autopsy is performed on each person who is in our Alzheimer's Disease Core Center study and makes a brain donation to our Center. The family of the donor receives a full report detailing the neuropathologist's findings. At present, neurodegenerative diseases can only be diagnosed with 100% certainty through a brain autopsy, so families are provided with a definitive diagnosis.

Such information is useful if other family members develop a problem with memory or thinking in the future or if there is a known family history.

Making this generous donation provides the family with a way to potentially help others, which can create a sense of hope and power over the illness that affected their loved one.

Make the decision to be a brain donor with your family.

The decision to become a brain donor requires careful thought and planning. As you and your family consider making this important contribution, please keep in mind that the bereavement period is not the optimal time to begin planning for a brain autopsy. It is best to make arrangements as far in advance as possible, even though death may be years away. There are several things that you and your family can do to prepare in advance.

Begin talking about brain donation with your family now. Early discussion can reduce stress at the time of death.

Brain donation is a private matter. Northwestern's Alzheimer's Disease Center respects the decisions of each individual and his or her family. Our Autopsy Coordinator is available to assist you and your family during the decision-making process. Our staff can be reached Monday through Friday, from 8am to 5pm.

312-926-1851 or memory-research@northwestern.edu

RUN4PAPA

An Average Person Doing Extraordinary Things



From left: Jason with his grandfather, Dr. Louis Heyman, after The Big 5 Marathon; Jason during the Great Wall of China Marathon in 2012; Jason at the Entabeni animal reserve in South Africa.

The Run4Papa campaign was started in July of 2011 as a partnership between Jason Boschan and the Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC) with the goal of raising research funds and awareness for Primary Progressive Aphasia (PPA). Jason's grandfather, Dr. Louis Heyman, was diagnosed with PPA which inspired Jason to act. After a little over 2 years, Jason has run marathons on three continents, raced in 13 states, logged over 1,000 miles, and raised over \$95,000 for PPA research and education at CNADC.

This past year Jason ran the Boston Marathon where he was pulled off the course at the 25th mile. He also ran and finished the Big 5 Marathon on an animal reserve in South Africa in June. Jason was devastated by what happened in Boston, but it inspired him to finish what he called the toughest race of his lifetime in South Africa.

Boschan's fundraising efforts this past year were focused on funding the first ever national speech therapy trial for PPA patients. The pilot funding raised by Boschan helped get the speech therapy trial off the ground and the Alzheimer's Association and the Association for Frontotemporal Degeneration have awarded grants to continue and expand the trial.

Sadly, Dr. Heyman, the inspiration for the Run4Papa campaign passed away in September. Jason is determined to continue the campaign to honor his grandfather's legacy and support everyone suffering from PPA. Jason is now a CNADC Advisory Board member and more committed than ever in helping fight dementia.

To read Jason's stories about the Boston Marathon, Big 5 Marathon, and his touching eulogy to his grandfather, please visit www.run4papa.com. If you would like Jason to run a race in your state, contact him at Jason@run4papa.com

EDUCATIONAL HANDOUTS

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HELPFUL DEFINITIONS AND ACRONYMS

Augmentative and Alternative Communication (AAC) – Strategies used to assist or replace communication for individuals with communication disorders. There are both high- and low-tech types of AAC.

Alzheimer's Dementia or Dementia of the Alzheimer Type (DAT) - A form of brain degeneration where memory is the primary symptom; however the disease progressively affects other cognitive abilities including language, behavior/personality, visuospatial, and motor abilities. This is the most common form of dementia in persons over age 65. Ninety percent of the time it is caused by Alzheimer brain disease.

Alzheimer's Disease – The term used for the final brain diagnosis at post mortem autopsy showing neurofibrillary tangles and plaques.

Agnosia – Loss of the ability to recognize objects visually.

Agrammatic PPA (PPA-G) – A subtype of PPA usually presenting with word-order problems (agrammatism), but preserved single word comprehension. Sometimes called progressive nonfluent aphasia (PNFA).

Agrammatism – A symptom of aphasia characterized by difficulty putting words into the correct order, resulting in grammatically incorrect production.

Apathy – A behavioral condition characterized by the lack of interest in or concern for the activities of others, or self.

Aphasia – Loss of language (any form of language production – speech, writing – or comprehension – reading).

Apraxia of Speech – Difficulty performing purposeful movements of the mouth. Also known as oral-motor apraxia or verbal dyspraxia.

Brain Atrophy – Degeneration of areas of the brain due to disease. In PPA, degeneration occurs in the areas of the brain that control language processing. In bvFTD, degeneration occurs in the areas of the brain that control behavior, personality, and emotion.

Behavioral-Variant Frontotemporal Degeneration (bvFTD) - A condition characterized by gradual changes in behavior, personality, reasoning, and problem solving that progress over time.

Corticobasal Degeneration (CBD) – A type of frontotemporal lobar degeneration pathology that includes symptoms of poor coordination, rigidity, and impaired balance eventually resulting in the inability to walk. Cognitive and visuospatial impairments, hesitant and halting speech, muscular jerks and difficulty swallowing may also occur.

Clinical Diagnosis – A diagnosis made by the doctor's impression based on initial and presenting symptoms (also known as a syndrome).

Cognition – High-level mental function and processes, including: learning and remembering information; focusing, maintaining and shifting attention; understanding and using language; accurately perceiving the environment and performing calculations.

HELPFUL DEFINITIONS AND ACRONYMS

Dementia – A general term for a gradual loss of thinking abilities over a year or more, eventually so severe that they interfere with one's ability to complete daily activities.

Depression – A behavioral condition characterized by sadness and emotional withdrawal, sometimes with symptoms of loss of appetite and insomnia.

Disinhibition – A behavioral condition characterized by unrestrained behavior, such as talking to strangers.

Dysarthria – Difficulty in articulating words.

Dysgraphia – Deficiency in the ability to write.

Dysphagia – Difficulty swallowing.

Dysphasia – An impairment of speech and verbal comprehension.

Executive Function – The cognitive system that controls and manages planning, mental flexibility, abstract thinking, suppressing inappropriate actions and rule acquisition.

Frontal Lobe – The part of the brain that controls executive functioning, planning and executing movements, and personality.

Frontotemporal Degeneration (FTD)* – FTD causes a group of disorders that are identified according to distinct clinical signs and symptoms, or specific pathology. Subtypes of FTD are identified clinically according to the symptoms that appear first and most prominently. Clinical diagnoses include behavioral variant FTD (bvFTD), primary progressive aphasia (PPA), and the movement disorders progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD).

Frontotemporal Lobar Degeneration – A diagnosis made on the brain tissue after death that refers to protein and molecule abnormalities; common in individuals who during their lifetime are given a clinical diagnosis of PPA, bvFTD, PSP, and CBD.

Logopenic PPA (PPA-L) – A type of PPA characterized by problems with word-finding but preserved single word comprehension and grammar production.

Mixed PPA (PPA-M) – A type of PPA that has characteristics of PPA-G (word-order problems) and PPA-S (word-comprehension problems).

MRI - Magnetic resonance imaging. A type of imaging scan using powerful magnets to visualize deep structures of the brain.

Behavioral Neurology – A subspecialty of neurology that focuses on brain conditions that cause changes in behavior and cognition. Behavioral neurologists are specialists trained in the diagnosis and treatment of dementia syndromes.

Pathological Diagnosis – The diagnosis made by examining tissue under a microscope after the person's death to determine the underlying cause for the dementia.

Pick's Disease – A pathological diagnosis that is a type of frontotemporal lobar degeneration. Pick's disease is based on an abnormality in brain cells of the tau protein.

HELPFUL DEFINITIONS AND ACRONYMS

Primary Progressive Aphasia (PPA) – A clinical syndrome defined by the progressive loss of language over time.

Progressive Supranuclear Palsy (PSP) – This term is used both as a clinical syndrome (a *Parkinson's-plus syndrome*, meaning that it is a disease that has some of the symptoms of Parkinson Disease such as slowing of movements, stiffness, tremors, falls, and shuffling of the feet) and a pathological diagnosis which is another type of frontotemporal lobar degeneration (FTLD).

Semantic PPA (PPA-S) – A type of PPA characterized by problems with word-comprehension but relatively preserved grammar production and fluency. This is sometimes referred to as **Semantic Dementia**.

Temporal Lobe – The part of the brain, some parts of which control language, some which control auditory processing, and others which control retentive memory.

** Reprinted from the Association for Frontotemporal Degeneration, www.theaftd.org*

FREQUENTLY ASKED QUESTIONS ABOUT BEHAVIORAL VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

What is behavioral variant Frontotemporal Dementia (bvFTD)?

- bvFTD is a condition characterized by gradual changes in behavior, personality, reasoning, and emotion.
- Most people with bvFTD are in their 50s and 60s at onset, but it has been seen in ages as early as 21 and late as 80.

What are some features of bvFTD?

- Impairments in social skills and inappropriate or bizarre social behavior
- Lack of awareness (insight) about changes in behavior
- Change in activity level; apathy, withdrawal, loss of interest, lack of motivation
- Decreased judgment in financial decisions, impulsive spending
- Changes in personal habits; lack of concern over personal appearance
- Alterations in personality and mood
- Changes in one's customary emotional responsiveness
- A lack of sympathy or compassion in someone who was typically responsive to others

What causes bvFTD?

- bvFTD arises when parts of the brain that control behavior and personality malfunction. The underlying diseases are called “degenerative” because they involve loss of brain cells.
- Specifically in bvFTD, cells in the frontal lobe (the area of the brain which controls behavior, judgment, personality and emotion) begin to malfunction or die.
- Researchers are currently learning more about the proteins that cause brain cell destruction in bvFTD

Is bvFTD hereditary?

- The majority (50-70%) of bvFTD cases are sporadic, meaning the disorder develops in that person by chance rather than being inherited, and the risk to family members is the same as that of any individual in the general population.
- According to AFTD, a very small percentage (5-10%) of bvFTD patients have a family history suggestive of a hereditary condition with an autosomal dominant pattern of inheritance. This means there is a clear pattern of a bvFTD-type diagnosis passed from parent to child; that is, virtually every patient has an affected parent and each child of an affected person has a 50% chance to inherit the disorder.
- In about 20-40% of bvFTD cases the disorder appears to be “familial”, meaning that it is not directly inherited but members of the family are at an elevated, though undetermined, risk for developing the disorder.

Why have I never heard of bvFTD?

- bvFTD is a rare form of dementia that affects fewer people than the most common type of dementia, Alzheimer's disease. However, frontotemporal degeneration is one of the most common dementia diagnoses of people under the age of 65.

FREQUENTLY ASKED QUESTIONS ABOUT BEHAVIORAL VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

- Because bvFTD affects individuals at a younger age, doctors may not recognize the features and often misdiagnose the individual with a psychiatric disorder. Increasing awareness about bvFTD in the medical community will facilitate more efficient and accurate diagnoses.

How does bvFTD progress?

- The progression of bvFTD is variable from person to person and can unfold over many years, ranging from 2 to 20 years with a mean course of 8 years from the onset of symptoms.
- While behavior and personality changes are typically the first symptoms, memory and language abilities can change as the disease progresses and spreads to other areas of the brain which control these functions.
- Eventually, as the illness progresses, a person becomes dependent upon others for all aspects of their care.

How is bvFTD different from Alzheimer Disease (AD)?

- Alzheimer Disease is caused by a different kind of brain cell malfunction. Unlike bvFTD, Alzheimer Disease usually begins by affecting the parts of the brain that control short-term memory; therefore, the symptoms consist of forgetting events and conversations instead of behavior changes.
- In Alzheimer Disease, there is a specific type of change in the brain involving collections of two proteins called tau and amyloid. In bvFTD, the changes in the brain are different, and are more variable. We know of at least three different abnormal proteins that can accumulate in malfunctioning brain cells in bvFTD: tau, TDP-43 and FUS. Researchers are still working to understand these proteins.
- In the early stages of bvFTD, there is usually no true memory loss of the type that is seen in Alzheimer's dementia. Instead, there are changes in personality, emotion, ability to concentrate, social skills, motivation and reasoning. However, many patients with bvFTD may seem forgetful because they have more difficulty with concentration and attention; therefore, making it difficult to encode information or lay down new memories.

How is bvFTD different than cognitive impairment caused by a stroke or brain injury?

- Dementia due to stroke or brain injury develops suddenly. People with bvFTD develop changes slowly over time.
- People with stroke or brain injury can improve with therapy. People with bvFTD continue to worsen.
- According to the Association for Frontotemporal Degeneration (AFTD), there has been no evidence to date investigating the connection between traumatic brain injury and bvFTD. Frontal dysfunction is common in traumatic brain injury and can result in symptoms similar to bvFTD.

Is there treatment for bvFTD?

- There is no approved medical treatment for bvFTD.
- Studies have shown that most Alzheimer Disease medications, such as Exelon (rivastigmine), Razadyne (galantamine), Namenda (memantine) or Aricept (donepezil), are not effective in bvFTD.

FREQUENTLY ASKED QUESTIONS ABOUT BEHAVIORAL VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

- Quality of life enrichment and support programs offer individuals and families ways of coping with a diagnosis of bvFTD. These include support groups, individual and family counseling, educational materials, occupational therapy, physical therapy, speech therapy, behavioral home health, and other services.
- Medications may be helpful with certain features of the disorder, e.g. some types of antidepressants may reduce the behaviors associated with bvFTD.
- The Northwestern CNADC actively conducts research and clinical trials to improve the diagnosis and treatment of bvFTD. Your participation helps us reach these goals. Please go to the CNADC website (www.brain.northwestern.edu) to learn more about current research opportunities.

Does the diagnosis of bvFTD mean the end of an active life?

- People with bvFTD usually have to make adjustments or leave their jobs, since all professionals are heavily dependent on interpersonal communication, appropriate behaviors and sound judgment.
- Many people with bvFTD remain active for many years. While they may need additional supervision, many can continue to participate in social and civic activities.

Where can I go for more information?

- The Association for Frontotemporal Degeneration: www.theaftd.org
- Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC): www.brain.northwestern.edu

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

What is Primary Progressive Aphasia (PPA)?

PPA is a progressive impairment of language function.

Language is a uniquely human faculty that allows us to communicate with each other through the use of words. A language impairment caused by a brain disease is known as an “**aphasia**.” Progressive language difficulties in word-finding, word usage, word order, word comprehension or word spelling lead to a diagnosis of PPA. Each individual with PPA has a different pattern of impairment, leading to the classification of PPA into subtypes. Memory for recent events and the location of personal objects, spatial orientation, recognizing faces and the essential features of personality are initially preserved. In the beginning, all limitations of professional, social and recreational activities can largely be blamed on the language impairment. Aphasias caused by head trauma, stroke or brain tumor do not qualify for a PPA diagnosis. PPA is diagnosed only if the underlying cause is a “neurodegenerative” disease that progresses over many years.

What are some initial features of PPA?

This varies from one person to another.

In many instances, the patient may be the first to note that something is wrong and the complaints may initially be attributed to stress or anxiety. One or more of the following can emerge as the initial symptom:

- Slowed or halting speech
- Word-finding hesitations
- Sentences with abnormal word order in speech or e-mails
- Substitution of words (e.g., “table” instead of “chair”)
- Using words that are mispronounced or incomprehensible
- Difficulty understanding conversation despite normal hearing
- Sudden lapse in understanding simple words
- Forgetting the names of familiar objects
- Inability to think of names of people, even though the person is recognized
- New impairments in spelling

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

What are the subtypes of PPA?

*Researchers currently recognize three subtypes of PPA:
agrammatic, logopenic and semantic.*

PPA-G (Agrammatic/Nonfluent Subtype):

A problem with *word-order* and *word-production*

Speech is effortful and reduced in quantity. Sentences become gradually shorter and word-finding hesitations become more frequent, occasionally giving the impression of stammering or stuttering. Pronouns, conjunctions and articles are lost first. Word order may be abnormal, especially in writing or e-mails. Words may be mispronounced or used in the reverse sense (e.g., “he” for “she” or “yes” for “no”). Word understanding is preserved but sentence comprehension may suffer if the sentences are long and grammatically complex.

PPA-S (Semantic Subtype):

A problem with *word-understanding*

The principal feature is a loss of word meaning, even of common words. When asked to bring an orange, for example, the person may appear puzzled and may ask what an “orange” means. Speech has very few nouns and is therefore somewhat empty of meaning. However, it sounds perfectly fluent because of the liberal use of fillers. The person may seem to have forgotten the names of familiar objects. This is the one subtype where changes of personality and behavior are frequent. There may be agitation, display of excessive friendliness to strangers, change of dietary habits, etc.

PPA-L (Logopenic Subtype):

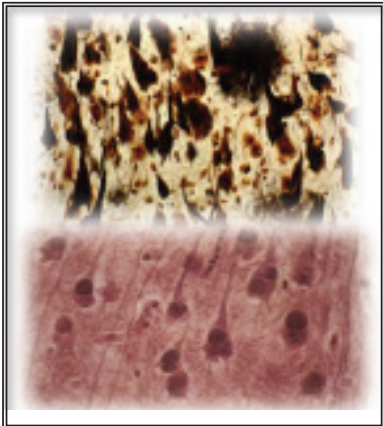
A problem with *word-finding*

In contrast to PPA-G, speech is fluent during casual small talk but breaks into mispronunciations and word-finding pauses when a more difficult or precise word needs to be used. Some people with PPA-L are very good at going around the word they cannot find. They learn to use a less apt or simpler word as well as to insert fillers such as “the thing that you use for it,” “you know what I mean,” or “whatchamacallit.” Spelling errors are common. The naming of objects becomes impaired. Understanding long and complex sentences can become challenging but the comprehension of single words is preserved.

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

What causes PPA?

PPA can be caused by Alzheimer's disease (AD) or Frontotemporal Lobar Degeneration (FTLD).



Microscopic examination of the brain after death determines the underlying pathological disease in PPA.

PPA arises when nerve cells in language-related parts of the brain malfunction. The underlying diseases are called “degenerative” because they cause gradually progressive nerve cell death that cannot be attributed to other causes such as head trauma, infection, stroke or cancer. There are several types of neurodegeneration that can cause PPA. The two most commonly encountered types are frontotemporal lobar degeneration (FTLD) and Alzheimer's disease (AD). Both FTLD and AD can lead to many different patterns of clinical impairments, depending on the region of the brain that bears the brunt of the nerve cell loss. When AD or FTLD attacks the language areas (usually on the left side of the brain), PPA results. PPA is caused by AD in approximately 30-40% of cases and by FTLD in approximately 60-70% of cases. In contrast, PPA is a very rare manifestation of AD.

In the vast majority of patients with AD, the most prominent clinical symptom is a memory loss for recent events (amnesia) rather than an impairment of language (aphasia). PPA is therefore said to be an “atypical” consequence of AD. The logopenic type of PPA has a particularly high probability of being caused by AD. Specialized positron emission tomography (PET) scans and examination of the spinal fluid may help to resolve the distinction between the two underlying diseases. Whether or not PPA is caused by AD or FTLD can be determined definitively only at autopsy through examination of brain tissue with a microscope.

Is it PPA or is it Alzheimer's?

It can be both.



For reasons outlined in the previous paragraph, the word “Alzheimer's” can be used in two different ways. The term **Alzheimer's dementia** (or Dementia of the Alzheimer-Type) is used to designate a progressive loss of memory leading to a more generalized loss of all cognitive functions. The term **Alzheimer's disease** (as opposed to Alzheimer's *dementia*) is used in a different way to designate a precise pattern of microscopic abnormalities in the brain. Sometimes these abnormalities become concentrated in language areas (instead of memory areas) of the brain and become the cause of PPA. So, while PPA patients don't have **Alzheimer's dementia**, 30-40% may have an atypical form of **Alzheimer's disease**. This dual use of the word “Alzheimer's” is confusing, even for the specialist, but is a feature of medical nomenclature that is here to stay.

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

How is PPA different than behavioral-variant frontotemporal dementia (bvFTD)?

bvFTD is a change in personality and behavior while PPA is an impairment in language function.

Behavioral-variant frontotemporal disease (bvFTD) is a diagnosis given when changes in personality and behavior (rather than memory or language) are the most prominent symptoms during the initial few years of a neurodegenerative condition. It is most often caused by FTLT, and on rare occasion by “atypical” Alzheimer’s disease. Often, people with bvFTD develop language problems as their illness progresses but this does not change the diagnosis to PPA since language is not the initial and most prominent problem. Conversely, PPA patients, especially those with PPA-S, may develop features characteristic of bvFTD as the disease progresses.

What is the relationship of PPA to Corticobasal Degeneration (CBD) and Progressive Supranuclear Palsy (PSP)?

CBD and PSP are two additional disorders caused by FTLT. They are characterized by impairments of hand movements, eye movements and gait. Some patients with PPA, especially those with PPA-G, may experience these additional impairments of movement and mobility as the disease progresses. So, in some patients, PPA may blend into CBD and PSP.

Why have I never heard of PPA? Why has my doctor not heard of PPA?

Because PPA is relatively rare.

There are many thousands of patients with PPA. Nonetheless, compared to the millions of patients with Alzheimer-type amnesic dementias, PPA is rare. Furthermore, it can start in a person’s 40s and 50s, an age range that physicians do not usually associate with neurodegenerative diseases.

How does PPA progress?

PPA progresses with different rates and trajectories.

The progression is variable and unfolds over many years. Word finding and word understanding become more impaired over time. Additional problems eventually arise in behavior, problem solving, memory and dexterity. Disinhibited, inappropriate behaviors (also seen in bvFTD) are more common with PPA-S while impairments in problem solving, multi-tasking movement and mobility (of the type seen in CBD and PSP) are more common in PPA-G.

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

Is PPA automatically diagnosed in every person with a progressive language impairment?

No. Aphasia can be a symptom in other forms of dementia.

PPA is diagnosed only if the language disorder arises in isolation and becomes the most prominent impairment during an initial period of approximately two years. There are many patients with typical amnesic Alzheimer-type dementias or with bvFTD who eventually also develop problems with word usage and comprehension. These individuals do not qualify for the PPA diagnosis because the language impairment is secondary in importance or late in appearance.

Is there treatment for PPA?

There are no pills yet for PPA. However, there are life-enriching interventions and speech therapies that help.

- Because of the 30-40% probability of AD, some physicians will prescribe AD drugs such as Exelon (rivastigmine), Razadyne (galantamine), Aricept (donepezil) or Namenda (memantine). None have been shown to improve PPA.
- Speech therapy may offer benefits in the early stages by teaching more effective communication strategies and ways to compensate for language difficulties.
- Quality of life enrichment and caregiver support programs offer individuals and families ways of coping with a diagnosis of PPA. Education and training can lead to interventions to maximize strengths and circumvent weaknesses for as long as possible. The effectiveness of such life enrichment programs is demonstrated by the growing interest in caregiver conferences held at specialized medical centers.
- Patients may be understandably depressed and frustrated. The depression may not be expressed verbally because of the aphasia. An appointment with a psychiatrist familiar with PPA and dementia may be necessary. Treatment with antidepressants may be indicated where appropriate.

Does the diagnosis of PPA mean the end of an active life?

Absolutely not.

People with PPA usually have to make major adjustments at work since almost all professions are heavily dependent on verbal communication. However, many people with PPA remain independent for many years, participate in social and civic activities, travel widely and take up novel hobbies ranging from gardening to square dancing, painting, carpentry, photography, etc. We encourage people with PPA to remain as physically and mentally active as possible.

FREQUENTLY ASKED QUESTIONS ABOUT PRIMARY PROGRESSIVE APHASIA (PPA): Diagnosis, causes, genetics, and treatments

Is PPA hereditary?

PPA is hereditary in a small number of patients.

In some families, there is an increased incidence of dyslexia and this may be a risk factor. In the vast majority of diagnosed individuals, PPA is not genetic. In a small number of people, PPA can be caused by hereditary forms of FTLN. The most common gene implicated in these families is the progranulin gene (GRN). Even in families with GRN mutations, one family member may have PPA while others may have bvFTD or movement disorders, including corticobasal degeneration (CBD). In the presence of GRN mutations, up to 50% of all family members will have FTLN. We therefore do not usually recommend genetic testing unless several family members have clinical patterns characteristic of PPA, bvFTD or CBD. Before proceeding with genetic testing, it's necessary to meet with a genetic counselor to review the implications of the results. The immediate purpose of genetic testing is to determine whether the person has a mutation that is responsible for the disease. However, the results have profound implications for family members who are healthy, especially those of child-bearing age. Do family members want to know the presence of a genetic disease for which there is no treatment? Do they realize that a negative result does not rule out the presence of a mutation in another gene not covered by the testing? Genetic testing for clinical purposes is a serious step that should not be initiated lightly.

Why should I participate in research?

It may sound trite to say that research is the only hope for finding answers to PPA, but, it is true. Patients, families and health-care professionals are all on the same team, working towards the same goal. Participation in brain-imaging studies, clinical trials, longitudinal cognitive testing, contributing blood and spinal fluid and agreeing to brain donation are key elements of a comprehensive research program. An individual with PPA may agree to participate in some aspects of the research program but not in all. All participation is obviously entirely voluntary and consent to participate may be withdrawn at any point. The information obtained through research will allow us to understand the genetic and molecular causes of PPA, to find more accurate ways to predict whether the underlying disease in an individual is AD or FTLN, and to develop effective treatment programs.

FREQUENTLY ASKED QUESTIONS ABOUT PROGRESSIVE SUPRANUCLEAR PALSY (PSP) AND CORTICOBASAL DEGENERATION (CBD)

What is PSP? What are some initial features of PSP?

Progressive supranuclear palsy (PSP) is a *Parkinson's-plus syndrome*, meaning that it is a disease that has some of the symptoms of Parkinson's Disease such as slowing of movements, stiffness, tremors, falls, and shuffling of the feet. In addition to these symptoms, people with PSP also develop problems moving their eyes, especially in vertical directions, resulting in a wide-eyed appearance. They may also develop difficulty swallowing. Unlike Parkinson's disease, people often fall backward instead of forward. They may also develop severe stiffness in the neck.

What is CBD? What are some initial features of CBD?

Corticobasal degeneration (CBD) is also a *Parkinson's-plus syndrome*. There are many variations on its name, such as corticobasal syndrome or disease, and corticobasal ganglionic degeneration. It is named after the parts of the brain that are damaged. These are a) the cortex, which is the outer part of the brain, and b) the basal ganglia, which are deep within the brain. Like Parkinson's disease, slowing of movements, stiffness, tremors, falls, and shuffling of the feet can be seen. Movement problems occur on one side of the body, such as stiffness, shaking, or loss of control. People with CBD may be unable to get their arm to do what they want even if they know how, which is called apraxia. Sometimes, the arm on that side might move on its own, called alien limb syndrome.

I looked PSP/CBD up on the internet, and it did not mention FTD or PPA. Why is that?

Not all people with PSP and CBD develop problems with memory, thinking, behavior or language. However, in some people, these problems do arise. In fact, sometimes these problems are the first symptoms, and the more classic symptoms listed above develop later.

People with PSP can develop a loss of motivation. They may lose interest in their everyday activities. Problems may arise with attention and concentration. They may lose the ability to control their mouth when speaking (speech apraxia), or progressive slurring of speech (dysarthria).

People with CBD can develop loss of inhibition. They may act or speak rudely or crudely, or lose empathy for others. They may develop difficulty with attention and concentration and may experience a type of language difficulty such as problems speaking in full sentences and understanding grammar. In fact, the language difficulty may be the first symptom.

My loved one was diagnosed with FTD/PPA, and now the doctor says they have CBD/PSP. Which one is right?

They are both right. People with dementia are diagnosed based on their initial or most severe symptoms. If their initial symptoms include behavior, attention, concentration, or language, they may be diagnosed with FTD or PPA. Some individuals develop classic symptoms of CBD or PSP later, at which point the new diagnosis may be added.

Some patients also have dementia types that do not “follow the rules,” and may have a mix of features from FTD, PPA, CBD, and PSP, or other dementias. In these cases, it is usually best to focus on managing the symptoms than focus on what label best fits them.

FREQUENTLY ASKED QUESTIONS ABOUT PROGRESSIVE SUPRANUCLEAR PALSY (PSP) AND CORTICOBASAL DEGENERATION (CBD)

Who gets PSP/CBD?

PSP and CBD afflict adults, typically between the ages of 45 and 70 years of age. Men are slightly more likely to get PSP than women. Men and women get CBD equally.

What happens as PSP/CBD progresses?

All the symptoms of PSP and CBD get worse as the diseases progress. Eventually, people become unable to safely walk. Swallowing problems may lead to choking on food or getting food in the lungs, leading to pneumonia. On average, people with these diseases die within 5 years of diagnosis. Death is usually from complications of falls or swallowing problems.

Is there any treatment for PSP/CBD?

There are currently no drugs that reverse the damage in either PSP or CBD. However, there are many treatments available. Supportive treatment for problems with behavior, swallowing, speech and communication, falls and mobility are available. Many people with PSP or CBD benefit immensely from occupational therapy, physical therapy, and speech therapy.

Some medications are helpful for symptom control in these conditions. Some people have improvement of their movements with Parkinson's Disease medication, such as carbidopa-levodopa, but in general, these medications are less effective in PSP or CBD than in Parkinson's Disease. For people with severe stiffness, muscle relaxants and Botox may be useful. Depression and motivation problems may be helped by antidepressants. In severe disease, antipsychotic medications can help treat agitation, but should not be used except when absolutely needed.

Currently, a clinical trial is underway to see if a new medication called davunetide will be useful in the treatment of PSP. We do not yet know what the results will be.

What causes PSP/CBD, and why do people get it?

Both PSP and CBD are caused by dying cells in the brain. These dying cells have collections of a protein called tau. This protein is normally found in the brain and helps brain cells with normal functioning. However, abnormal accumulations of tau are seen in PSP, CBD and many other dementias. One of the goals of current research on dementia treatment is developing agents targeting tau protein related pathology.

We do not know why most people get PSP or CBD, or how to predict who will. There is likely a combination of genetic factors that we do not currently understand.

Is PSP/CBD hereditary?

PSP and CBD are very rarely genetic. A small minority of cases is hereditary. These cases are inherited in an autosomal dominant pattern, meaning that on average, 50% of each generation is affected, and it does not skip generations.

A mutation in the microtubule-associated protein tau (MAPT) gene has been linked to PSP and CBD.

FREQUENTLY ASKED QUESTIONS ABOUT PROGRESSIVE SUPRANUCLEAR PALSY (PSP) AND CORTICOBASAL DEGENERATION (CBD)

In families with this gene, affected people may develop PSP, CBD, FTD, or PPA. Different family members may develop different diseases, and develop them at different ages. There is a genetic test available for MAPT, but it should only be done in cases where it runs in the family, and only after speaking with a genetic counselor.

Why have I never heard of PSP/CBD?

They are both very rare. They are also both likely underdiagnosed. If movement problems develop first, they may be misdiagnosed as Parkinson's Disease. If cognitive problems develop first, they may be misdiagnosed as Alzheimer Disease. If behavioral problems develop first, they may be misdiagnosed as depression.

Where can I go for more information?

www.psp.org (Foundation for PSP, CBD and related brain disease)

www.theaftd.org (Association for Frontotemporal Degeneration)

www.memory.ucsf.edu/education/diseases/ (UCSF Memory and Aging Center Disease Education)

www.wemove.org (Worldwide Education and Awareness of Movement Disorders)

THE FTD/PPA MEDICAL CARE TEAM

A care team is a group of professionals caring for patients and families. Together, your team can help you navigate the various questions, concerns and uncertainties that can affect well-being and quality of life. Below is a list of possible Medical Care Team members. Note that all of the professionals listed below may not be available in your area, covered by your health insurance, or familiar with FTD or PPA.

Primary Care Team

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

Neurologist

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

Neuropsychologist

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

Psychiatrist

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

Social Worker

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

THE FTD/PPA MEDICAL CARE TEAM

Speech and Language Pathologist (SLP)

- **What:** This clinician sees individuals with language and other cognitive changes. They evaluate different aspects of cognition and language in detail and can make recommendations and offer compensatory strategies.
- **Why:** SLPs help the patient and family members maintain essential communication for as long as possible. Family members should be included in the treatment sessions so they can receive education on how to facilitate communication.

Occupational Therapist (OT)

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

Physical Therapist (PT)

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

Individual Counselor/Therapist

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

Professional Care Manager

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

Palliative Care Team

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

RESPONDING TO CHANGES IN BEHAVIOR

Significant changes in behavior and personality are the main symptoms of behavioral variant frontotemporal degeneration (bvFTD) and sometimes occur in primary progressive aphasia (PPA) as the disease progresses. Not all people will express all symptoms. Symptoms don't occur in "stages" but rather existing symptoms will worsen and new symptoms may appear in an unpredictable manner. These are not the intentional behaviors of the person you love—**these behaviors are the result of an illness.**

BEHAVIOR	SUGGESTED INTERVENTIONS
<p><u>APATHY/LACK OF MOTIVATION</u></p> <p>Lack of interest, drive and/or inability to initiate activity. Often confused with depression.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> Unable to initiate going on a bike ride on their own, but if guided to a stationary bike, they will engage in riding. Unable to follow the steps to make a bowl of cereal. However, if the objects involved are laid out for them and they are cued appropriately, they can execute the numerous steps involved. 	<ul style="list-style-type: none"> Don't rely on the person to initiate activities. While they might be having trouble starting an activity, they may be able to participate if others do the planning/divide the task into small successive steps and provide assistance when needed. Limit and offer specific choices; e.g. "Do you want to walk to the park or to Jim's house?" instead of a more open-ended "What do you want to do today?" <ul style="list-style-type: none"> If they resist, do not force the activity. Try again later or have someone else suggest the activity.
<p><u>PERSEVERATION</u></p> <p>Repeating the same activity over and over when it no longer makes sense to do so.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> Repeatedly doing the laundry even if there is only one item to wash. Continuously talking about the same topic over and over. 	<ul style="list-style-type: none"> If the activity is not dangerous or costly, let it continue. Distract by getting their attention focused on something else that is important to them. Do not feel you need to explain why.
<p><u>POOR JUDGEMENT</u></p> <p>Doing an activity that is harmful to self or others with no understanding of consequences.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> Communicating with solicitors/scammers. Giving away large sums of money. 	<ul style="list-style-type: none"> Do not attempt to reason. You will never be able to convince them it is a bad idea or not to trust these people. Establish a structured schedule that does not allow for much alone time where calls can be made. Limit person's ability to call out/take calls. Limit their access to finances. Provide a debit card for small amounts of cash.
<p><u>DISINHIBITION</u></p> <p>Acting impulsively without considering the social effects of inappropriate behavior, or lacking insight that the behavior can offend others or cause harm.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> Making offensive comments to others or to strangers. Speaking about personal issues with strangers. Approaching other people's children as if they were acquainted, or hugging and kissing children. Shoplifting or other forms of theft 	<ul style="list-style-type: none"> Let friends and neighbors know about the diagnosis so they understand the behavior is not intentional. Go to places where the person is known well. Distract by getting their immediate attention onto another activity. It's okay to be firm by ending the conversation with, "Thank you, we have to go now," even though it may seem abrupt. Use "My companion has FTD" cards. Alert the local police of your loved one's condition.

RESPONDING TO CHANGES IN BEHAVIOR

BEHAVIOR	SUGGESTED INTERVENTIONS
<p><u>LACK OF EMPATHY/EMOTIONAL CHANGES</u> Showing no emotions (seeming flat and disinterested) or showing exaggerated, jocular or improper emotions. A lack of sympathy or compassion for others' distress.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Seems to withdraw in familiar company. • Displays inappropriate emotions, e.g., laughing at a funeral. • Seems to "not care" about another's distress by acting indifferent to spouse's diagnosis of cancer 	<ul style="list-style-type: none"> • Although it is very difficult, do not take this personally. • Find emotional support and companionship from other friends, family or support group. • Seek professional counseling surrounding your feelings around this change. • Let others know about the diagnosis so they are not offended. • Carry "My companion has FTD" cards.
<p><u>UTILIZATION BEHAVIOR</u> Difficulty resisting impulses to operate or manipulate objects that are within reach; "automatic" behavior, the kind of action we all have experienced when an elevator door opens and you automatically exit despite the fact that it is the wrong floor.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Picks up objects on a physician's desk. • Imitates others' behaviors. • Picks up the phone when walking by it even if it is not ringing or there is no intention of making a call. 	<ul style="list-style-type: none"> • If it is safe, determine if it can continue with understanding from others. • Determine if the behavior is putting the person or others at risk. If so, distract with other objects that get the person's attention immediately, such as calling them on a cell phone to interrupt an activity—the person is likely to answer it because it is an automatic behavior. • Note that calling their name may not work to get their immediate attention.
<p><u>HYPERORALITY</u> Compulsive eating; craving carbohydrates and sweets; no ability to regulate intake or "feel full." Sometimes dangerous due to possible aspiration and choking.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Taking food from someone else's plate at a dinner table. • Gorging on food to the point of vomiting. Eating anything in sight with no consideration for how much has been eaten. • Eating non-food items. • Eating uncooked meat from the refrigerator. • Eating only a certain type of food or sweet. 	<ul style="list-style-type: none"> • Set out portions, provide supervision. • If necessary, lock up food, keep raw foods out of sight. • Avoid "all you can eat" social events. ⁽¹⁾ • Use distraction to redirect from the table. • Provide alternatives, "We are out of ice cream, but we have Jell-O." ⁽¹⁾ • Provide a safe alternative of something to chew. • Discuss options for medications that may address this. <p>(1) Grow, Sandi, RN. Discussion: Problem solving template for FTD: Hyperoral behaviors. AFTD Committee on LTC Education. December 12, 2011</p>
<p><u>RITUALISTIC/COMPULSIVE BEHAVIORS</u> Acts that are completed over and over again, without purpose and unrelated to the circumstances in which they occur.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Person needs to continuously walk the same route each day. • Continuous whistling, drumming fingers in certain patterns. • Rigidity and inflexibility, and insistence on having his/her own way, increasing difficulty adapting to new or changing circumstances. 	<ul style="list-style-type: none"> • If it is safe, accept the behavior and arrange for necessary supervision. • If unsafe (e.g., scratching at a sore until it bleeds), attempt to use distraction and if unsuccessful consult with a physician to consider medications that can minimize compulsive behaviors. • Find additional activity that will keep the person occupied.

RESPONDING TO CHANGES IN BEHAVIOR

BEHAVIOR	SUGGESTED INTERVENTIONS
<p><u>AGGRESSION</u></p> <p>Because many individuals with FTD are not aware of their illness, they may become frustrated at limitations and constraints that they do not understand and consider to be unfair and punitive. As a result, the person may occasionally strike out at the caregiver or resist assistance. These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Shouting or name-calling. • Physical abuse (hitting, pushing). 	<ul style="list-style-type: none"> • Stay out of the person's way if they are combative. • In cases when you feel unsafe, call police but explain the person's condition. • Never point out the problem to the person. • Never try to reason about their behavior, or argue about the "logical" solution. • Consult with a psychiatrist for medications that may help.
<p><u>REASONING</u></p> <p>Unable to categorize information or think in the abstract; very literal interpretations. Lacks flexibility in thinking and unable to pursue an alternative solution if the first one doesn't work. May increase safety risk since they have difficulty recognizing consequences of behavior.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Cannot understand explanations about their own illness and is resistant to continued attempts to help keep them safe. • Behaves as if the caregiver is "bossy," unreasonable or trying to control them. • Cannot reason logically about the solutions to simple problems (e.g., how to respond in the event of a fire). 	<ul style="list-style-type: none"> • Do not argue. No amount of reasoning will make the person able to grasp the ideas. Instead, distract. • Firmly report what is going to happen and repeat the information from time to time, without explanation. E.g., "We are going to see a lawyer to make sure that we have the proper documents to sell the house." If asked for an explanation, say, "We will both have time to talk." • Make sure that all legal steps have been taken to protect the person and obtain power of attorney so that decision-making is not left to the person with significant reasoning deficits.
<p><u>SEXUAL DISINHIBITION⁽²⁾</u></p> <p>Increased interest in sexual behaviors and loss of appreciation for what is socially appropriate. Unable to control sexual desires due to impulsivity and disinhibition. Not only can this be embarrassing and devastating for families, if not monitored and managed closely, there can be legal implications.</p> <p><i>Examples:</i></p> <ul style="list-style-type: none"> • Makes inappropriate sexual comments. • Seeks out other relationships, online dating, public masturbation, interest in internet pornography. • Inappropriate sexual advances toward children. • More aggressive sexual behaviors with partner. 	<ul style="list-style-type: none"> • Seek a medical and psychiatric evaluation and discuss benefits and risks to any medications. • Assess when, who and what triggers the behavior. • If sexual demands are uncomfortable, sleep in separate rooms. • Keep the person physically active. • Use "The person I am with has FTD" card. • You may not be able to stop the behavior. Efforts should focus on modifying it, keeping the person safe, or allowing the person to engage in it privately. • Families and partners should seek out counseling to help cope. <p>(2) Discussion by Hall, Geri R. PhD; Bird, Thomas D. MD; Nichols, K. Frontotemporal Dementia: Issues of Sexuality. November 23, 2009</p>

RESPONDING TO CHANGES IN BEHAVIOR

Presentation of New Behavioral Symptoms

When the individual with behavioral changes shows new symptoms, don't assume that it is the disease. Because people with bvFTD find it increasingly difficult to articulate such things as pain or discomfort, they may manifest such things as agitation or irritability. It could be the disease or it could be something else that could be addressed with a visit to the primary care doctor. With all new behaviors that you observe, go through the following checklist to determine what is causing the change and find the most appropriate intervention:

- Could a separate **medical problem** be causing the change in behavior? For example, the person may have a toothache but be unable to articulate the precise problem. Another example is an imbalance of thyroid function or other chemical imbalance in the body that temporarily makes the bvFTD symptoms look a lot worse.
- Identify triggers of certain behaviors; is the **environment** triggering the behavior? Although many behaviors are erratic and have no explanation or precedent, some may be reactions to certain types of situations. For example, the person becomes agitated when there are more than three people talking. If so, what in the environment can be changed? In this example, the solution might be to reduce the number of people the person interacts with at one time. Invite one adult child and the grandchildren to dinner instead of the whole family. Try to identify if there are triggers and what they might be.
- Is this behavior **safe for them**? Is this **safe for me and others**? Some behaviors are very annoying but are not injurious to the person or others. On the other hand, if the person does not recognize that an infant cannot be left on the living room floor with the front door open and a flight of stairs not far away, precautions need to be taken to make sure that the person is not put in a situation where they cannot exercise appropriate judgment. Even though the person may be able to play with the child in an appropriate way, they are unable to be left alone with the child in this instance.

When to Consider Medications

Trying the above strategies is always the first step in responding to changing behaviors; however, sometimes medications can also help. Some serotonin reuptake inhibitors are often prescribed for carbohydrate craving, disinhibition and impulsivity. Persons who experience uncontrollable aggression or delusions are sometimes prescribed low doses of antipsychotic medications. It is important to consult with a specialist in this area, such as a psychiatrist with expertise in dementia and pharmacology.

BEHAVIORAL VARIANT FRONTOTEMPORAL DEMENTIA (bvFTD) FAMILY TIPS

- Educate yourself about the diagnosis. Become knowledgeable, but don't obsess over it.
- Acknowledge that your life will be very different.
- Do not take the person's behavior personally. Acknowledge that the person cannot control their symptoms or behavior. They are not intending to hurt you. They are no longer able to have normal reactions and feelings.
- Avoid confrontation. Do not argue or try to reason.
- Consider carrying "This person has FTD" wallet cards.
- When a behavior is disruptive, redirect. Provide materials to distract the person. For example, make a phone call, go for a walk, work on a puzzle, fold laundry.
- Be watchful of day-to-day activities (checkbook, paying bills, going out alone, driving, hygiene) and regularly evaluate the safety of leaving the person alone.
- Be aware that decision-making and judgment are impaired in the early stages.
- Consider asking the physician to require a driving evaluation.
- Be prepared to take on increased responsibilities that the other person used to handle.
- Keep a list of observations and questions that you can ask the doctor at each visit.
- Take time for yourself and ask others to help you commit to this promise.
- Minimize noise, overstimulation, and the number of people in a conversation.
- It is helpful to keep decision making to a minimum. Do not put the person in a situation that stresses failing reasoning capacity.
- Approach the person with a calm, reassuring tone and smile. Individuals with bvFTD are better at understanding positive emotional expressions than negative ones.
- As the person becomes less able to provide companionship, reciprocity, and emotional support to you, seek this out from others.

NEWLY DIAGNOSED CHECKLIST

FRONTOTEMPORAL DEGENERATION DISORDERS

Support

- ☐ *Tell someone.* Share this life-changing event with others who can support you.
- ☐ Visit a support group or seek out individual counseling.
- ☐ Ask your medical team to recommend a social worker or care manager to be your advocate.

Legal and Financial

- ☐ Meet with an Elder Law Attorney to discuss:
 - Durable Power of Attorney for Health Care and Property
 - Legal and financial planning including Social Security Disability
- ☐ Investigate potential eligibility for additional benefits through the Veteran's Administration, if applicable.
- ☐ Discuss future care plans with doctors and the diagnosed person, if possible.

Safety

- ☐ Obtain a Medical Alert Safe Return ID bracelet for you and the person with FTD/PPA.
- ☐ Contact your local Police to see if they have a safety program for dementia residents.

Medical Care

- ☐ Document changes in behavior and communication to share with health care providers.
- ☐ Continue to follow treatment plans from doctors regarding other medical conditions.
- ☐ Inquire about research opportunities.

Coping

- ☐ Maintain a daily routine of structured activity for the diagnosed person.
- ☐ Maintain your activities.

Communication

- ☐ Speak face-to-face and clearly to the person.
- ☐ Continue to include the person in conversations.

Quality of Life

- ☐ Take a lot of pictures with family and friends.
- ☐ Help them continue to enjoy their favorite activities as long as they can.
- ☐ Help them maintain their independence and dignity.
- ☐ Exercise together and stay as active as possible.

LEGAL & FINANCIAL PLANNING FOR THE FUTURE

Preparing Advanced Directives

Advanced directives outline a person's future wishes and instruct others how to carry out their wishes after they can no longer make decisions. In cases of Frontotemporal Degeneration (FTD) and Primary Progressive Aphasia (PPA), it is important these documents are completed as soon as possible because the disease progression will affect the person's ability to participate in decision-making. The documents *MUST* be prepared while the person is legally able to execute and understand them, so it is encouraged that you make these arrangements early on.

Guidance from an Expert

An elder law attorney is an expert in the field of legal planning and is knowledgeable in the areas of disability and guardianship. Speaking with an elder law attorney to begin legal planning and make arrangements for future care can reduce anxiety about the future for you and your loved one. You can locate an elder law attorney local by visiting the National Academy of Elder Law Attorneys at www.naela.org.

Terms to Know

- **Power of Attorney (POA) for Health Care:** A document that allows the diagnosed person (principal) to designate another person (agent) to make health care decisions on their behalf in the event the doctor determines they are unable to do so. The POA for health care speaks for the diagnosed person and is legally authorized to act, including withholding or withdrawing life support and making other health care decisions.
- **POA for Property:** A document that allows the principal to designate an agent to act for them in financial matters and property transactions in the event a doctor determines they are unable to do so. The POA for property is legally authorized to speak and make decisions on the diagnosed person's behalf.
- **Living Will:** This records the diagnosed person's wishes for medical treatment near the end of life. It expresses preferences to forgo life support, in the event it would only prolong the dying process. It does *not* authorize another person to make health care decisions, but communicates preferences to a health care provider.
- **Will:** This indicates how the diagnosed person's assets and estate will be distributed. It can also include funeral arrangements.
- **Living Trust:** This allows for properties of the diagnosed person to be owned in trust while the person is living. It appoints a designated trustee to control the assets and requires that the trustee manage the property according to the terms of the trust.
- **Guardianship:** Guardianship essentially takes away a person's rights, which is necessary in some cases to protect the person and family. A guardian is a surrogate decision-maker, appointed by the court to make either personal and/or financial decisions in the best interest of the person.
- **Medicare:** Health insurance program for persons 65+ or those receiving Social Security Disability Insurance for 2 years.
- **Medicaid:** Health insurance program for low-income individuals.

LEGAL & FINANCIAL PLANNING FOR THE FUTURE

Medicare vs. Medicaid

As you and your family plan for future care you may have some questions regarding the availability of assistance programs when paying for medical and long-term care. As FTD/PPA progresses, a person's care needs will increase and more assistance is necessary to meet the person's needs. The chart below provides details about two governmental programs, Medicare and Medicaid.

	Medicare	Medicaid
<i>Controlled by</i>	Federal Government	Individual State Government
<i>Pays for</i>	Primary hospital care, related medically necessary services, some medications.	All medications, health care costs if provider accepts Medicaid as payment.
<i>Long-term care</i>	Does not cover long-term care costs. Pays for first 20 days of nursing home care after 3-day inpatient hospital stay as long as the person requires skilled care from a nurse, physical, occupational, and/or speech therapist. For days 20-100, a co-pay is required.	Pays long-term care, home-health, and skilled nursing, physical, occupational, and speech therapies if the providers accept Medicaid as payment.
<i>Requirements</i>	Must have contributed to the federal Medicare financing system to be eligible.	Must meet state income and asset limits to be eligible.

CREATING OPPORTUNITIES FOR BRAIN HEALTH AND WELLNESS

In many ways, the brain is like a muscle and the term “use it or lose it” very much applies to optimizing brain health, especially as we age. The following wellness suggestions are intended to stimulate cognitive health and help individuals be their best selves in everyday life.

Live a Healthy Life.

What’s good for your heart is good for your brain! If quality of life is high, then people are feeling better and functioning better, so, it’s important to work on having a healthy and positive lifestyle.

Physical Activity

Research has shown that regular aerobic exercise can assist with maintaining cognitive health and preventing decline with age. Check with your doctor about appropriate physical activity that takes into account an individual’s medical history. There are many enjoyable low impact activities including yoga, tai chi, walking groups, etc. that can be found in your local community.

Nutrition and Diet

Talk to your doctor about diet and nutrition options that are best for you. Generally, a Mediterranean diet consisting of fruits, vegetables, fish, and whole grains, and limiting unhealthy fats has been associated with lowering risk for diseases such as high cholesterol, high blood pressure, obesity, and diabetes that increase the risk for cognitive decline with age.

Get your Zzzzzzz

Sleep well! Getting a good night of sleep each night is important for clear cognitive functioning during the day. Establish a regular sleep schedule and avoid “dozing” during the day. Increasing daytime activity can help promote better sleep during the night.

Meaningful Mentally Stimulating Activity

Meaningful activities are real things that an individual enjoys that make their heart sing, puts them in “the zone,” and helps them feel great! This can include things like “brain games.” While there is no strong evidence that crossword puzzles or Sudoku are scientifically beneficial, if a person likes them, then they should do them! Try something new, or revisit an old hobby. If you feel challenged by finding meaningful activities, then consult with a clinician, such as a psychologist, social worker, physician, or just talk to friends or family to get ideas. Some suggestions include:

- Participating in the creative arts, such as a dance movement group or dance class, a painting class, or singing in a chorus
- Joining a gardening club or group at a local garden
- Reading or joining a book club
- Attending learning groups or programs at local museums or community centers
- Volunteering

CREATING OPPORTUNITIES FOR BRAIN HEALTH AND WELLNESS

Social Engagement

Meaningful social relationships and social support has been shown in some studies to enhance neural functioning. This may include things like scheduling weekly lunch dates with friends or family and attending activity groups in the community. Regular social activity is recommended!

Emotional Support

Keep mood up and minimize stress. There are many negative impacts of stress on the brain, mood, and cognition. Spirituality and a sense of feeling grounded and connected to something important can also help maintain a sense of wellness. Talk to your doctor or care provider about professional support for emotions and coping with stress.

INDICATORS FOR ADDITIONAL CARE

Because the disease progression is different for each person, we are unable to predict when new symptoms will require a change in care. Despite this uncertainty, it is never too early to begin planning for the next level of care. Below are points that indicate when families should consider additional care.

Family Needs

- Family feels that the person's care needs exceed their ability to provide care.
- Family feels increasingly stressed, anxious, upset, frustrated, or depressed.
- Behavior changes are affecting the person and family's safety.

Safety

- Cannot manage finances; odd or excessive purchases.
- Inability to understand/obey traffic laws, has become more timid or aggressive on the road.
- Making poor decisions that jeopardize individual safety at home or in public.
- Unable to prepare food safely independently. Problems judging what is safe to eat.
- At risk of becoming lost.
- Verbal abilities hinder communication with others, especially in a crisis.
- Family expresses concern about leaving person alone for any amount of time.

Well-Being

- Lack of structure that includes physical, mental, and social engagement.
- Unable to initiate activities without assistance.
- Unable to participate in hobbies or regular household tasks without assistance.

Health

- Unable to manage medications properly.
- Physically dependent, difficulty walking without falling.
- Change in weight; losing weight or gaining excess weight.
- Trouble swallowing.
- Incontinence.

Activities of Daily Living

- Unable to bathe or manage personal hygiene.
- Difficulty toileting; is not cleaning self or using toilet appropriately.
- Difficulty dressing, choices are not appropriate for weather.

See page 44 for information on available care options

WHAT TYPES OF CARE ARE AVAILABLE?

Service	Description of care	How is it paid for?
Informal Respite www.eldercare.gov	Family, friends or volunteers (from local agencies or faith groups) offer to spend time with your loved one or assist you in other ways (shopping, cooking, etc.)	Volunteer Based
Private Duty Home Care www.homecareaoa.org www.eldercare.gov	Private duty home care staff are paid professionals who provide a range of services from companion services to skilled nursing care. Licensed agencies should meet criteria for the highest ethical standards and staff training.	Private Pay Long Term Care Insurance Some Disability Services Some Veteran's Benefits *Comstock Caregiver Grant
Care Management www.caremanager.org	Professional care managers provide assistance managing, organizing and overseeing care. They facilitate transitions in care and are especially helpful for long distance caregivers and families in conflict.	Private Pay Long Term Care Insurance
Home Health Care In-Home or Outpatient www.medicare.gov/homehealthcompare	Home health care includes physical, speech, and occupational therapies, skilled and behavioral health nursing, and social work. Services are temporary, short-term and provided in the home, outpatient setting or a facility. One must be "homebound" to be eligible for home health care.	Private Insurance Medicare Medicaid Some Veteran's Benefits
Adult Day Services www.nadsa.org www.alz.org (contact your local chapter) www.eldercare.gov	A structured day program that provides meals, supervision, stimulating and structured activity and social engagement. Some offer assistance with personal and medical care. Some adult day services offer transportation.	Private Pay Long Term Care Insurance Some Veteran's Benefits Ask about Sliding Scale Fee/Financial Assistance *Comstock Caregiver Grant

WHAT TYPES OF CARE ARE AVAILABLE?

Service	Description of care	How is it paid for?
Assisted Living and Nursing Home Care www.medicare.gov/nhcompare/ www.seniorhousingfinder.org/ www.alz.org (contact your local chapter)	<p>Assisted living facilities provide assistance with basic activities of daily living such as bathing, grooming and dressing. Most offer structured social activity and some provide medication assistance. Assisted living facilities do not offer complex medical services.</p> <p>A nursing home is normally the highest level of care outside of a hospital. Nursing homes provide what is called custodial care, including getting in and out of bed, and assistance with feeding, bathing and dressing. Nursing homes also provide skilled nursing and a high level of medical care. Some provide security to prevent wandering. A licensed physician supervises each patient's care and a nurse or other medical professional is almost always on the premises. For those able to participate, structured activities are provided.</p>	<p><i>Assisted Living</i> Private Pay Long Term Care Insurance Some Veteran's Benefits</p> <p><i>Nursing Home Care</i> Long Term Care Insurance Some Veteran's Benefits Private Pay Medicare (limited benefits) Medicaid</p>
Hospice and Palliative Care www.nhpco.org www.eldercare.gov	<p>Care that promotes dignity and comfort at the end of life. Provides therapies and support for diagnosed individual and family and focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.</p>	Private Insurance Medicare Medicaid

*The Comstock Caregiver Grant provides \$500 a year to help families living with FTD pay for respite services. Visit www.theaftd.org for more information.

Services and definitions can vary by state. The descriptions and websites listed are not exhaustive. Contact your local Area Agency on Aging (www.eldercare.gov) for more information on specific referrals.

IMPLEMENTING CHANGES IN CARE

Families living with FTD and PPA are in a state of constant transition throughout the course of the disease. Introducing any kind of change in care requires an adjustment for all. While sometimes difficult to implement, these changes can result in better support for the person and relief to families.

Whether in the early, middle or late stages of the disease, changes in care should occur when:

1. There are concerns about the person's safety.
2. There are concerns about the person's health and well-being.
3. There are concerns about the health, well-being and safety of the family member(s) providing care.

Coping with Change

People with dementia often have difficulty with change. Ideally, we try to introduce a change in care gradually, however, this is not always possible and sometimes things must happen urgently due to safety. In either case, our efforts should focus on:

- Helping the person adjust.
 - ❖ Introduce small modifications first, and only one at a time, if possible.
- In cases where something is taken away, do our best to replace it with an alternative. For example:
 - ❖ Checks and credit cards can be replaced with gift cards or a small amount of cash.
 - ❖ When a person must stop driving, find ways for them to continue to remain mobile.
 - ❖ Consider the strategy of “replacing” before “taking away.”
- Finding opportunities for the person to express their feelings about the change such as validating their feelings about their loss of independence, or having someone new in the home. For those with difficulty communicating, art, music or movement therapy can offer meaningful expression without words.

When the Person Does Not Agree

Sometimes, due to the disease, a person does not understand or agree that they need additional help/assistance. Due to impaired judgment, there comes a time when the person cannot make this decision in the interest of safety for themselves and others. This is especially difficult for families. In this situation:

- Avoid trying to reason with the person. THIS WILL SELDOM WORK.
- Consider alternative ways of presenting the change. Identify something meaningful to the person and think creatively about how this can be used to help implement the change. For example:
 - ❖ A “personal trainer” or “personal assistant” or “mentee” instead of a “companion/caregiver.”
 - ❖ When considering a day program, the person can be a “volunteer” or “consultant” instead of a participant.
- Look to your family, friends and care team as people who can suggest and carry out the change. Sometimes a former colleague, or an authority figure like a physician, has more influence than close family. For example:
 - ❖ A former NFL player who was refusing to shower was given special “NFL soap” from his former coach. He followed the specific instructions from his coach to use NFL soap and agreed to bathe again.
- Reframe the idea of additional help. Describe it as a support for YOU.
 - ❖ Suggest that you need an assistant or that you need additional help around the home.

IMPLEMENTING CHANGES IN CARE

Ask the Experts - Other Families

Some families worry about trying to introduce help to the person too early, believing the person is not ready or may react in an unpleasant way. As much as you can, speak with other families about their experience with these transitions. Ask when they made changes in care, and use this as a guide to identify turning points when a change will be needed for your loved one. This way you are planning in advance, rather than reacting in an already stressful situation.

In some cases, introducing a change “a little too early” is better than “a moment too late” for both the person and family.

THE WHYS, WHENS, AND HOWS OF RESPITE

1. Your Well-Being

Respite provides short-term breaks that relieve stress, restore energy, and promote balance in your life. Recognizing your own state of well-being is the first step in understanding why you might benefit from respite or assistance. Review the list below for signs that the stress of caring for your loved one may be affecting your health.

- Feel you have no time to yourself
- Unable to see friends/family
- Change in appetite
- Feel lonely
- Lack of interest in things once enjoyed
- Experience changes in mood
- Poor or disrupted sleep
- Putting off own medical visits
- Low energy
- Trouble focusing or concentrating
- Physical pain

2. Where Respite Could Help

Recognizing everything you are doing is the next step in understanding how you might benefit from respite (a break). Review the list below to assess when/where additional assistance could be helpful.

Activity	Currently Do	Have Assistance	Need Assistance
Social			
Provide/coordinate transportation			
Manage social calendar			
Ensure daily structure and activity			
Provide supervision and companionship			
Home			
Shopping			
Meal preparation			
Housekeeping/chores			
Pay bills/manage finances			
Medical			
Manage medical appointments			
Manage medications			
Communicate updates to family members			
Research care options			
Manage paid caregiver services			
Assist with personal care			

THE WHYS, WHENs, AND HOWs OF RESPITE

Recognize that assistance is available when, or even before, managing aspects of caring for a loved one becomes more difficult. This assistance can come in the form of family or friends who offer help, a volunteer or a hired service. See page 44 (types of care available) for care and respite options that might be best for your family.

3. Deciding How to Spend Your Respite Time

After you have identified the reasons for respite and what type of assistance works best for you and your family, recognize what you can do that rejuvenates you and keeps you healthy. For some this is gardening, and for others going to a movie or taking a class gives them a sense of renewal.

It is common for families to become so focused on their loved one that they lose sight of their own needs. Your mental and physical health is *JUST AS IMPORTANT* as your loved one's. Your health is critical to their well-being. As much as you can, make this commitment to yourself and ask others to help you do this.

4. Emotional Support

In addition to respite, ongoing emotional support for families can come in many forms. Some possibilities include:

- Support groups
- On-line forums
- Telephone support groups
- One-on-one connection with another family
- Individual counseling or therapy

See the Association for Frontotemporal Degeneration <http://www.theaftd.org> or the National Aphasia Association <http://www.aphasia.org> for more information on obtaining the emotional support options listed here.

5. Putting Respite Care Into Place

Creating an online calendar can allow others to see where there are opportunities to help your family. The website below offers this type of online calendar.

Lotsa Helping Hands:
<http://www.lotsahelpinghands.com>

LATE STAGE CARE IN bvFTD AND PPA

Late Stage Symptoms

Just as the progression of each person with Frontotemporal Dementia (FTD) and Primary Progressive Aphasia (PPA) is different, the symptoms at the end of life can differ as well. Below are some common late stage symptoms:

- Immobility, difficulty walking
- Chewing, swallowing difficulties
- Unable to sit up without support
- Muscle weakness, abnormal reflexes, rigidity, falls
- Limited verbal ability
- Weight loss
- Incontinence and infections
- Dependent for personal care, dressing, bathing, eating
- Increased sleep or changes in sleep behaviors

Although pneumonia due to complications of late stage symptoms (aspiration, choking, infection and/or respiratory weakness) may commonly cause death for a person with bvFTD and PPA, the neurodegenerative disease process is the official cause of death in many cases.⁽¹⁾

Palliative Medical Care

- Palliative care focuses on treating and managing the symptoms of a terminal illness as well as providing quality of life support for patients and families at any stage in the illness.
- The goal is not to cure the illness.

Hospice⁽²⁾

- Hospice is a philosophy of care that believes in a patient's right to be treated with respect and dignity towards the end of life.
- Hospice uses palliative medical care to provide comfort as life nears its end, rather than heroic lifesaving measures when they no longer offer promising outcomes.⁽¹⁾
- The goal is to maintain the patient's quality of life and to relieve pain and suffering as much as possible.

What Does Hospice Provide?⁽²⁾

- Hospice care attends to the emotional, spiritual, psychological, and physical needs of the patient and recognizes the important role family and friends play as caregivers.
- Hospice can be provided where the person lives (in the home, hospital, or a long term care facility).
- Hospice offers a range of compassionate care for both the patient and family, such as:
 - Physical, speech-language therapy
 - Nutrition/diet planning
 - Routine personal care and hygiene
 - Equipment, such as a hospital bed
 - Massage, art/music therapy
 - Supportive counseling
 - Case management
 - Respite care

Hospice is paid for by private insurance or Medicare. Some hospice agencies provide care, regardless of ability to pay.⁽¹⁾

Thinking About the Future

- While hospice is associated with the end of life, it is important for families to not view hospice as "giving up". On the contrary, it offers more care and support.

LATE STAGE CARE IN bvFTD AND PPA

- It is never too early to learn about hospice and investigate hospice agencies as part of planning for care.
- The advanced stages of FTD and PPA present families with emotionally difficult decisions. Seek support for yourself as you provide care to your loved one.
- Take comfort in knowing you have provided the best care and support possible to your loved one.

End of Life Considerations in FTD and PPA^(1,2)

- Late stage symptoms may look different for people with various forms of frontotemporal lobar degeneration (FTLD), which may lead clinicians to believe a person is not yet eligible (some forms of FTLD include behavioral variant frontotemporal dementia (bvFTD), primary progressive aphasia (PPA), progressive supranuclear palsy (PSP), and corticobasal degeneration (CBD)).
- We must advocate and educate physicians about the symptoms associated with end-of-life in persons with all forms of frontotemporal degeneration disorders and the benefits of hospice to the entire family.
- Persons with frontotemporal degeneration disorders are generally younger, stronger, healthier, and typically do not have the same co-existing chronic illnesses as an older adult.⁽¹⁾
- Hospice criteria for dementia are created based upon the Alzheimer's model of disease progression.

Ongoing Support for Families⁽³⁾

- Throughout the illness, families face ongoing loss and a range of emotions:
 - Loss of companionship
 - Loss of control
 - Loss of reciprocity in relationship
 - Fears about life without loved one
 - Uncertainty, fear
 - Social isolation
 - Feeling "robbed" of the future
 - Grief, guilt, depression, anxiety
- Each family member has unique ways of coping and different needs for support. Seek out the support that is best for you.

Finding Moments to Connect⁽⁴⁾

- Towards the end of life, finding moments that illicit positive emotions and responses can decrease caregiver distress, guilt and hopelessness.
- Sensory stimulation uses smell, taste, touch, vision and hearing to communicate, connect, stimulate and provide comfort with someone in the late stages.

Sources:

- (1) Maribeth Gallagher, DNP, Amy McLean, ANP, Rebekah Wilson, MSW. Discussion of Hospice and End-of-Life Symptoms in FTD. Hospice of the Valley, Phoenix, Arizona
- (2) The Association for Frontotemporal Degeneration (AFTD) (www.theaftd.org) c 2011.
- (3) Knott JE, Wild E: Anticipatory grief and reinvestment. In: Rando TA, ed.: Loss and Anticipatory Grief. Lexington, Mass: Lexington Books, 1986.
- (4) Simard, J. (2007); The end of life Namaste care program for people with dementia. Baltimore, MD: Health Professions Press.

IDENTIFYING COMMUNICATION STRATEGIES FOR PPA

Loss of language is the main presenting symptom of PPA. This means that an active reader, writer and conversationalist could lose their grammar and vocabulary, in addition to reading and writing abilities. Alternatively, a usually quiet individual may become more vocal but their speech may not be understood by others. Many individuals also experience difficulty with comprehending words or conversation. Every individual diagnosed with PPA is unique, and no one will experience the disease progression identically. Symptoms don't occur in "stages" but rather existing symptoms worsen and new symptoms appear in an unpredictable manner. It is important to remember that every individual with PPA has a unique set of communication strengths and preferences. Identifying and supporting these strengths and preferences can help them communicate most successfully and effectively.

Accepting PPA and Adapting to New Forms of Communication

When symptoms first appear, families are forced to let go of previous patterns of communication and implement new strategies and tools. *Communication Strategies* are alternative ways of communicating that the individual and family can begin to use to help them compensate for the loss. *Communication Tools* refer to high tech or low tech devices that assist the individual in communicating with others. A speech-language pathologist can help you learn these new strategies and tools.

Educate Yourself

- A Speech and Language Pathologist (SLP) can help teach new ways of compensating for losses and identify the most appropriate strategies/tools at each stage of the diagnosis.
- Become familiar with communication tools for all modes of communication. Using multiple modes of communication (speaking, writing, drawing, gesturing) can make communication more effective.
- It is best to implement and practice the use of strategies/tools in various communication situations before they are absolutely needed so that the diagnosed individual and family members feel comfortable using them. For example, create a communication notebook or become familiar with communication technology before it is needed.

The Role of the Supportive Communication Partner

- Should you fill in the word for the individual? This is up to the individual with PPA. Some prefer for those who know them well to jump in with the word. Others prefer to try to think of the word themselves. Establish a gesture that signals that the individual would like help.
- Be patient. Give the individual time to respond and speak more slowly when needed.
- Ask a question that requires a choice between two items/possibilities: "Do you want eggs or cereal?" or "Do you want to go for a walk or take a nap?" Try to avoid open-ended questions, like: "What do you feel like eating?" or "What do you want to do today?"
- Manage the environment (background noise, number of people present).
- Manage your feelings, language, thoughts, and expectations.
- Have realistic expectations based on the individual's communication strengths and areas of difficulty.
- Continue to reevaluate the individual's changing needs as time goes on.

IDENTIFYING COMMUNICATION STRATEGIES FOR PPA

Establish a Home Program for Daily Practice

- There is some evidence that the rehearsal of personally relevant words or phrases may result in the individual being able to retrieve or pronounce this core set of words for a longer time.
- Identify 30-50 words that the individual uses on a daily or weekly basis during communication exchanges.
 - ❖ May include important personal information, such as address, phone number, date of birth, age.
- Develop a notebook or index cards with the words and a description and/or picture of each word.
- Individual can quiz self on these words on a daily basis, improving retrieval and pronunciation.

METHOD	STRATEGIES FOR EFFECTIVE COMMUNICATION
<u>LISTENING</u>	<ul style="list-style-type: none"> • Listen for key pieces of information: who, what, where, when, why • Be aware of distracting background noise, and reduce it if possible
<u>SPEAKING</u>	<ul style="list-style-type: none"> • Cue the individual to talk around the word he/she is trying to say by encouraging, "Tell me about it..." (describe it's function, appearance, location or use synonym)
<u>WRITING</u>	<ul style="list-style-type: none"> • If the individual with PPA has difficulty pronouncing longer words, may benefit from writing out the word first and then using the written cues to say the word, along with tapping out the syllables • Communication partner can write out choices and the individual can choose an appropriate response • Write out conversational scripts to use during specific situations (see below)
<u>GESTURES</u>	<ul style="list-style-type: none"> • Gestures can be developed for core daily functions • Practice and have gestures in place, before you actually need them
<u>TOUCHING</u>	<ul style="list-style-type: none"> • So much of communication is nonverbal! Remember to use facial expressions and the sense of touch when communicating with an individual with PPA

Scripts

- An individual with PPA can often speak more easily when reading off of a script that has been practiced daily.
- A communication partner can work with the individual to make scripts for different situations, such as speaking over the telephone, telling stories or jokes, or giving a speech.
- Type out each script in a large font, highlight difficult words and repeat them several times before rehearsing the entire script. Put scripts in a binder and practice for 15-30 minutes each day.
- A computer script program is available for purchase here:
<http://ricaphasiascripts.digitalcontentcenter.com>

IDENTIFYING COMMUNICATION STRATEGIES FOR PPA

Alternative/Augmentative Communication Tools

- **Low Tech Devices**

Communication Wallet: Portable communication aide consisting of index cards on a key ring. Place personally relevant words and information on the cards by category so individual can easily refer to during conversations (e.g., people, locations, phone numbers, pictures)

- ❖ *Communication Notebook:*

- Commercially available ready-made books for general communication needs with some room to personalize (e.g. Alimed)
- Personalized Communication Book includes a collection of pictures of family, friends, activities, and commonly used phrases. Pictures are arranged by category. Use a 3-ring binder with plastic page protectors. Try using Google Images or your own digital pictures to find images that are meaningful to the individual.

- ❖ *Communication Board:* can either be dry-erase board or a board containing important images and words that individual uses frequently.

- **Use of Smart Phones/tablets**

- ❖ Pictures: Encourage the individual to take pictures throughout the day. Pictures can be easily referred to during conversation to help communicate message
- ❖ See list of helpful apps on AAC handout

- **High Tech Devices**

- ❖ See AAC handout for examples
- ❖ Remember: simpler is better!
- ❖ Consider devices or programs that allow the material to be customized

TO USE OR NOT TO USE?

High-Tech Augmentation and Alternative Communication Devices for Persons with Primary Progressive Aphasia (PPA)

High-tech augmentation and alternative communication (AAC) devices are technologies that assist persons with communication who have impaired language and speech functioning.

AAC options for persons living with PPA

There are many AAC options to consider. It is essential that the person with PPA and their family have a chance to try several different devices under the supervision of a speech and language pathologist (SLP) familiar with these technologies. SLPs should assist the family to determine which device, if any, will best help the individual with PPA communicate their needs in various social environments. Due to other non-language cognitive changes common with PPA, these devices are not always a good fit.

Not designed for persons living with PPA

At this time, no AAC device has been specifically designed to meet the needs and unique communication and cognitive changes of a person with PPA. Some AAC devices are intended to accommodate children and young adults with developmental or early cognitive language challenges. Others have been developed for persons with aphasia caused by a traumatic brain injury or stroke. The flow chart on the next page can help you decide if a high-tech AAC device is a good fit for a person with PPA.

Where do I learn more?

There is not a lot of information on specific applications and devices for people with PPA. Finding the right resource is essential. The best place to try a communication device is a local rehabilitation center or with the guidance of a SLP well-versed in aphasia and communication devices. However, not all health care providers are familiar with PPA and often the family needs to educate the provider on the challenges the person with PPA experiences.

Examples of AAC Products

Stand-alone AAC devices

GoTalk20 (\$200): This low-tech device allows the user to record their own voice for up to 100 short utterances. If the user has difficulty producing fluent speech on their own but has the ability to repeat, this device may be a good option. The user can repeat a phrase after the SLP and the speech is recorded and programmed into the device.

DynaVox V or DynaVox VMax (approx. \$8,000) and Lingraphica (\$7,500) are two examples of speech-generating devices. They offer comprehensive systems for communication, including the ability to formulate novel sentences and to select from pre-programmed messages.

AAC applications for the Apple iPhone, iPad, and iPod Touch

Proloquo2Go (\$150) (*for the iPhone and iPad*) Speech generating program. Does not have a voice recording option, so the voice is computerized. It is very comprehensive but complex.

Products by Small Talk (free version available) (*for the iPod Touch or iPhone*) This application allows users to save their favorite photos, phrases, and videos. It is ideal for use in everyday situations such as shopping, doctors appointments, phone conversations, or during emergencies. Free version can't be customized.

Pictello (\$20) Application that allows users to create photo albums by category with their own digital pictures. Users can create captions for each picture and record their own speech. Program will also read the caption for you. Inexpensive and easy to use.

TO USE OR NOT TO USE?

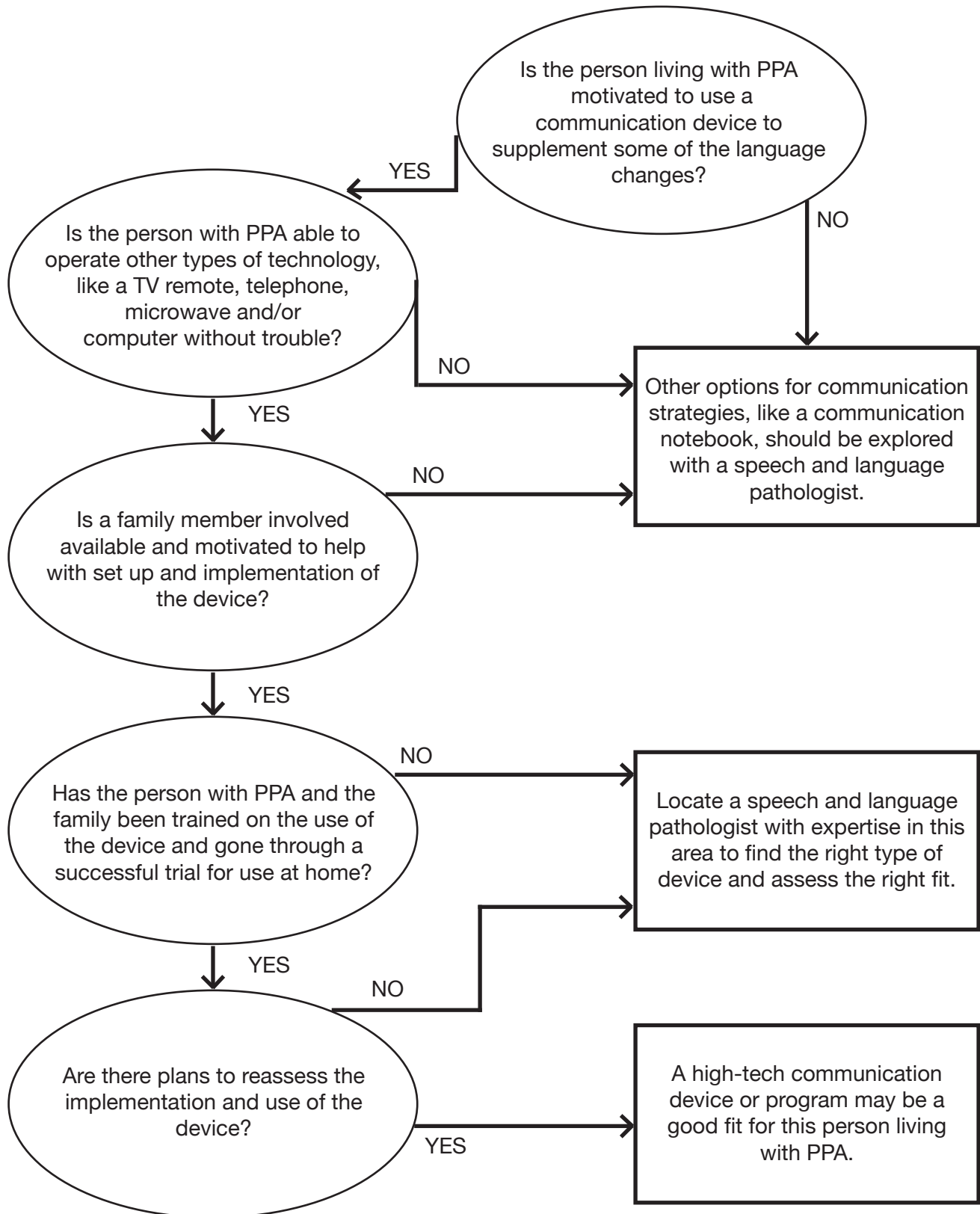
High-Tech Augmentation and Alternative Communication Devices for Persons with Primary Progressive Aphasia (PPA)

Scene & Heard (\$50) Interactive communication app that allows users to use their own pictures to create “scenes.” Users can record their own voice messages for each scene, to make requests or share stories. Easy to program and navigate.

Speech Recognition Software (Dragon, Personal Assistant, vBox): Dictate words or sentences into device and it will write out. For those individuals who have difficulty with spelling but speech is fairly intact. Can use for writing emails or “To Do” lists.

TO USE OR NOT TO USE? A PPA High-Tech Device Flow Chart

Follow this flow chart to help determine if a high-tech device is a good fit for your family.



DEPRESSION IN PPA: WHAT IS IT?

Primary progressive aphasia (PPA) is a rare form of dementia in which a person progressively loses their ability to use and understand language. The diagnosed person is often aware of their problem, however, due to the disease, their ability to verbally express their feelings is limited. Due to the various losses that diagnosed individuals face, people with PPA are at an increased risk of developing depression. Studies have shown that 1 in 3 people diagnosed with PPA experience depressed mood and a substantial number report at least some symptoms of depression to the point where it interferes with their quality of life.

What Should I Look For?

Below is a list of the most common signs and symptoms of depression in PPA:

- Loss of interest or reduced pleasure in previously enjoyed activities
- Social withdrawal
- Trouble concentrating
- Difficulty making decisions
- Trouble falling asleep or staying asleep
- Sleeping too much or too little
- Restlessness
- Fatigue or loss of energy
- Comments such as: “I’m a burden to my family” or “You won’t have to worry about me for much longer” or other comments suggesting hopelessness or “giving up”
- Thoughts of death/suicide
- Giving away possessions
- Feelings of guilt, worthlessness or hopelessness
- Irritability
- Episodes of crying
- Excessive emotional reactions and frequent mood changes
- Loss of appetite or changes in food preference
- Unexplained weight loss or gain
- Vague body, head or stomach aches with no clear medical reason

How Do I Know it is Depression?

It can be difficult to tell if your loved one is experiencing depression. Some of the symptoms of depression can overlap with symptoms of dementia. It is important to be evaluated by a specialist familiar with these syndromes.

TREATING DEPRESSION IN PPA

Depression in individuals diagnosed with PPA may arise due to preserved awareness of difficulties, especially in the early stages. Persons with PPA often withdraw from routine activities and social interaction with peers and family members due to the inability to perform everyday tasks that require language (i.e. reading the newspaper, watching television, answering the telephone and engaging in simple conversation). This gradual accumulation of losses may take an emotional toll on persons with PPA. Below are some treatment options for people with depression and PPA.

Meaningful Activity

Meaningful activity includes activities that offer feelings of success, joy, and purpose. When people with PPA lose their ability to participate in certain hobbies or activities, it is important to replace this loss with something engaging and meaningful.

Losses for person with PPA could include: retirement from work, loss of driving, changes in relationships, withdrawal from social activities, loss of confidence and self-identity.

Creating successful moments and adding meaningful activity can help prevent and combat depression. Doing this takes creativity. Success may be found in activities that the person has never done before, or regular activities that require modification.

Therapies

Creative arts therapies like music, dance and art therapy have been shown to promote relaxation, support concentration, enhance self-esteem and offer purpose for persons with cognitive impairment.

Counseling, also known as talk therapy, can assist the person with PPA to develop helpful strategies and attitudes to cope with loss, and identify ways to compensate for the changes in life brought on by the diagnosis.

Rehabilitation services include speech, occupational, and/or physical therapies. Some of these services may be available at a local rehabilitation center, or may be provided in the person's home. These services teach patients and family members techniques to maximize communication and independence despite the changes caused by the condition.

Medications

Medical treatments for depression include anti-depressant and/or anti-anxiety medication. Typically, these medications have tolerable side effects and are found to be effective. When prescribed medication to treat depression, it is important that the individual is monitored to ensure the medication is effective or to make necessary adjustments. Primary physicians and psychiatrists can assist families when making decisions related to medication options.

15 TIPS FOR COMMUNICATING WHEN SPEECH AND/OR WORD FINDING ABILITY IS CHANGING

1. Be a partner not a therapist
2. Ensure a “communication friendly” environment; quiet, calm, relaxed room, minimal background noise (turn off the TV/radio), good lighting. Practice good communication skills. Look at your partner. Speak directly and slowly.
3. Accept any form of communication as valid. Perfection is not the goal. Do not correct grammar or pronunciation if your partner gets the message across. Allow any method of communication (speech, gesture, communication notebook, writing, etc.)
4. In individuals with these word finding changes, a particular word/phrase may be easy one day but difficult the next. Avoid comments such as “you said it yesterday, so why can’t you say it today?”
5. Do not speak for the individual with the changes unless it is absolutely necessary or the person has asked that you step in to help. Do not interrupt. Only supply words or finish sentences if help is requested.
6. Never pretend that you understand when you do not. If you and your partner cannot get the message across, try again later. When you do not understand, repeat the phrase to confirm
7. When seeking clarification, avoid open ended questions or questions with multiple choices. Use yes/no questions. Instead of “What is the weather like outside?” or “Is it raining, cloudy or sunny?” say “Is it raining?”
8. Don’t shout. Avoid a rapid speech rate.
9. Do not assume that a person with these changes understands everything you are saying. Never talk about him/her in his/her presence without including them in the conversation.
10. Establish your partner’s attention by saying her name or touch her lightly before conversations.
11. You may have to repeat or rephrase what you say often. Write down key words if necessary.
12. In a group only one person should speak at a time.
13. Supplement your statements with facial expressions and gestures.
14. Keep your own communication simple, but adult. Don’t use “baby talk”.
15. Make sure you sit down at least once a day and have a pleasant conversation with your partner.

FTD AND PPA - TUNING INTO THE NEEDS OF CHILDREN AND TEENS

FTD and PPA are rare diseases with challenging symptoms that turn a family upside down. Maintaining open communication with your children will help them learn to cope and create a sense of well-being. Further, taking care of yourself by practicing positive behaviors to increase communication and decrease anxiety, may relieve your stress and set a good example for the kids.

You might worry that talking about FTD with your children might scare them. Kids are intuitive and can sense anxiety or tension within the home. Even preschoolers often sense the changes FTD brings. If they are not given factual information, they use their imagination to fill in knowledge gaps. However, if questions are answered in a supportive and honest environment, a lot of their fears and anxieties will be addressed. If they feel they will be listened to they will ask more questions as they arise.

Approach at an age-appropriate level

Children understand and process information differently as they develop. Consider the development of their thinking and feeling as a guide to how you approach them. If you have more than one child, you may want to address each one individually. No matter what your child's age, always be honest. Children need to know they can trust you.

Infants and Toddlers: Even the youngest children may perceive that adults are sad, angry, or anxious and need additional comfort, soothing and routine.

Preschoolers: Young children tend to engage in "magical thinking." They may know the basics about illness, but imagine that it can be reversed by wishing it were so. The child may also believe that the disease was caused by their being "bad," or if they are very good, the disease will go away. Communication ensures the child does not blame themselves for the disease or for their parent's behaviors.

Early Elementary School: Children from about 5-9 begin to understand things in terms of cause and effect. They see that FTD causes symptoms in their parent and how those changes affect other things in the family. They have more understanding of illness and that people die of some illnesses. They do not tend to verbally describe emotions, and process events and emotions through play.

Tips for Talking about FTD with Children and Teens

Communicate in a straightforward manner.

Communicate at a level that is appropriate to a child's age and development level.

Watch your child's reaction during the discussion.

Slow down or back up if your child becomes confused or looks upset.

Provide details if the child asks, but do not force children or teens to hear or manage information.

Always tell your children the truth.

Remember - it is always OK to say you don't know.

It is also OK to let children know you have feelings and that being scared, sad or mad is normal.

FTD AND PPA - TUNING INTO THE NEEDS OF CHILDREN AND TEENS

Middle School: Children at this level will likely be able to understand how the disease causes changes in their parent and why. They may be able to identify specific feelings, and are more likely to want and need to talk about what is going on. At this age, children are developing stronger peer relationships and may voice concerns about embarrassment or develop a desire to be secretive about the family.

High School: Teens will be able to understand the facts and identify concerns and emotions. Most teens will grasp the implications of an FTD diagnosis and may be concerned about what it will mean for them. They may turn to friends and family or they may withdraw. They typically respond more positively to an open dialogue, but shut down when the conversation feels like a lecture; they often talk more openly with their peers than with their parents.

Family structure and role changes

When a parent gets FTD, family life turns upside down. Kids might be confused at changes in the parenting partnership as the well parent becomes a solo parent. The kids will need to understand that the ill parent will be limited in what they can do for the children. In behavioral variant FTD, the parent may use poor judgment or act in immature and inappropriate ways. The FTD parent may not understand when play is unsafe or when play is too rough. Changes in the parent's behavior that are acutely embarrassing to pre-teens and teens may shape many decisions.

Children are able to help to a point, but may feel that they have too much responsibility around the home. You can explain that everyone simply has to pitch in more since the FTD parent no longer does some of the chores they used to do. Respect too, that children need to have regular involvement with peer activities for their overall growth and well-being. Mutual respect and shared problem-solving can foster coping and new strength in the family.

Dealing with kids' emotions

Even when given lots of support, many children who have a parent with FTD feel different from their peers. Children often feel very isolated and that others do not understand. As the main caregiver for the ill-parent you simply will not be as available to your children. They will miss the attention of their parent with FTD, too. Reach out to a trusted relative or friend as a mentor to nurture and support each child. Take a break with the kids from the FTD parent—anything from a brief outing to the park to a vacation to reinforce your relationship.

All kids need a way to work off anger and frustration in their lives, so physical activity from sports and time outside is probably more important than ever for your kids. Creative arts such as painting, music and dance allow for the expression of feelings not easily put into words.

Resources

The Association for Frontotemporal Degeneration (AFTD) – Listing of resources for families with children and teens.

<http://www.theaftd.org/support-resources/caregiving-challenges/children-and-teens>

When Dementia is in the House – website and companion booklet for parents and teens

<http://www.lifeandminds.ca/whendementiaisinthehouse/>

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UNDERSTANDING GENETICS IN FTD AND PPA

Genetic testing can be extremely complex. Not all tests are 100% diagnostic, and often there are ethical and social concerns that influence one's decision to have or not to have genetic testing.

Genetic Counselors

- Genetic counselors are health professionals with specialized degrees and experience in the areas of medical genetics and counseling.
- Genetic counselors work as members of the health care team to analyze inheritance patterns and risks of recurrence. They review available options with the family and provide supportive counseling, serve as patient advocates and refer individuals and families to community or state support services.
- Due to the implications of genetic testing, all families with questions about a condition's inheritability must meet with a genetic counselor.

Commercial/Clinical Genetic Testing Considerations

- Most commercial genetic testing labs require individuals to meet with a genetic counselor and often have a psychiatric evaluation to determine the motivation and appropriateness of the genetic testing.
- Most tests for conditions like frontotemporal temporal lobar degeneration (FTLD) are not covered by medical insurance and require out-of-pocket cost. Some tests can cost over \$ 2,000.
- Because there is no long-term treatment or cure for conditions like FTD & PPA, confirming a genetic link for a person who does not yet have symptoms can be extremely devastating. For this reason, genetic testing is very serious and all interested individuals need to speak with a genetic counselor.
- The first step to testing is to find a genetic counselor either by discussing genetic testing with your neurologist or online at the National Society of Genetic Counselors website: <http://www.nsgc.org>.

Research Genetic Testing

- Typically genetic testing for FTLD is performed as a part of a research study at a University or medical center.
- The research-based genetic testing is NOT a tool to diagnosis a person with a condition. Often the results of this testing are never shared with the research subject who was tested or with their family.
- The purpose of research genetic testing is to provide information to scientists to better understand the condition and advance knowledge and diagnostic and treatment options for future generations.

FTLD Genetics Basics

- Genes are sections of our DNA and the instructions that tell our cells how to function. We have two copies of each gene – one from our mother and one from our father. If these genes are changed (a “mutation”), the instructions are garbled and may lead to genetic disease.

Adapted from The Association for Frontotemporal Degeneration (AFTD). The Genetics of FTD: Should you worry?
<http://www.theaftd.org/frontotemporal-degeneration/genetics>

UNDERSTANDING GENETICS IN FTD AND PPA

- FTLD can be sporadic, familial, or hereditary.
 - ❖ In **sporadic** cases, the disease develops by chance. There is no increased risk for other family members to develop the condition.
 - ❖ Some people with FTD or PPA have a positive family history of FTD or related degenerative condition (e.g., Alzheimer's disease, Parkinson's disease, ALS, etc.). This indicates that there is a predisposition for neurological disease in the family. The word "**familial**" is used to describe the undetermined, but likely increased risk for relatives to develop one of these conditions.
 - ❖ In **hereditary** cases, there is a clear pattern of FTD-type diagnoses being passed from parent to child. Virtually every person with hereditary FTD/PPA has an affected parent. Also, each child and sibling of the person with hereditary FTD/PPA has a 50% chance of inheriting the disease.
- The most common genes associated with hereditary FTD/PPA are the GRN gene (makes a protein called progranulin), the MAPT gene (makes a protein called tau) and the newly discovered *C9orf72* mutation on chromosome 9, which is found in both FTD and ALS. Other genes are currently being investigated.

CARING FOR THOSE WITH BEHAVIORAL SYMPTOMS CAUSED BY FTD AND PPA IN HOME, ADULT DAY SERVICES AND LONG-TERM SETTINGS

As FTD and PPA progress, a person needs additional care, engagement and supervision. When this becomes more difficult for families to do alone, they often look to community resources to assist them in caring for their loved one. Because services are typically designed to care for those who are elderly and have Alzheimer's Disease (AD), it can be a challenge to find appropriate care for a younger person whose presenting symptoms greatly differ from AD.

Additional barriers to finding care include cost, discomfort in care settings due to age, and lack of staff education and understanding of FTD and PPA. As health care providers, we must address these barriers to care so that we can improve services for people with FTD and PPA and their families.

Caring for those in a community or long term care (LTC) setting requires that staff develop the skills and knowledge specific to the care for persons with FTD and PPA. These skills are not normally taught in typical AD training. In addition to understanding how to respond to common behaviors and provide support to families, staff must also feel supported and have a place to turn for guidance.

What is so different about caring for someone with FTD or PPA?

Understanding the disease, symptoms and progression is difficult

- ❖ Memory, awareness and other cognitive abilities often remain intact in the early stages.
 - Avoid making assumptions about abilities. A person may be able to do more (or less) than is expected. In some cases, neuropsychological testing can help identify a person's strengths and areas of decline.
 - Due to the lack of memory symptoms, adjusting to transitions in care can be more difficult for a person with FTD or PPA. Because memory often remains intact in the early stages, "therapeutic fibs" told to support a person through a transition in care may not always work.
 - Additionally, a person is often younger and physically stronger. Staff may be concerned about the person leaving the care setting more easily.
- ❖ Changes in behavior and personality are symptoms of FTD and not within the person's control.
 - The disease is causing these behaviors. Thinking about the behaviors as symptoms caused by the disease, rather than personality, will open more options for creative intervention.
 - When behaviors are misinterpreted as personality traits, we inappropriately label people as "difficult" or "resistant". We should think carefully about our own transference, and how these labels affect our ability, motivation and sense of responsibility to help the person.
 - Instead of labeling patients with these negative terms, we should think of these individuals as having unique care needs that require our most thoughtful efforts.
- ❖ Persons with PPA in the moderate to severe stages may have completely lost their ability to communicate verbally and may exhibit some challenging behavior related symptoms.
 - Consider how to use other methods of communication to connect with this person.

CARING FOR THOSE WITH BEHAVIORAL SYMPTOMS CAUSED BY FTD AND PPA IN HOME, ADULT DAY SERVICES AND LONG-TERM SETTINGS

What works today may not work tomorrow

- ❖ Progression is unpredictable.
 - Staff must continuously adapt to the person's changing needs. This can feel disruptive, exhausting and challenging to the structure of the care setting.
 - Remain as flexible as you can. Empower your staff to think creatively about ways to adapt to ongoing changes.
 - While this is not AD, consider successful strategies used with persons living with AD related behavioral symptoms

Responding to behaviors is sometimes counter-intuitive to our thinking

- ❖ People with FTD & PPA often respond best to calm and positive communication (verbal and non-verbal).
- ❖ It is normal to want to “stop” certain behaviors that are dangerous, disruptive or frustrating. Before you try to “stop” the behavior, consider:
 - Is the behavior safe?
 - If not, what needs to be done to keep the person and others safe?
 - If the behavior is safe, but you have difficulty redirecting the person, how can you incorporate the behavior into your setting? Can a person who continuously likes to stack and restack a bookshelf be allowed to do this without disrupting others?
 - Is the behavior affecting others? What can be done to minimize the impact on others?
 - *Example:* One adult day program was caring for a man, a former architect, with bvFTD whose compulsive behavior caused him to insist that the chairs in the activity room be organized a certain way. This bothered the other members. Before the program began and after the program was finished, staff invited him into the room to arrange the chairs. This allowed him to be satisfied with the arrangement of chairs and spared the other member's frustration about his compulsion. They also used the activity of rearranging chairs whenever they needed to redirect him.
 - Behaviors are a form of communication.
 - Instead of thinking of a behavior as “making care difficult”, consider that the behavior is “difficult” because we are unable to meet the person's needs.
 - First, attempt to understand what the person needs. Assess what is causing the behavior? When is it happening? From this information we will be more informed to know what the person is trying to tell us through this behavior.
- ❖ Do not assume everything is related to FTD or PPA.
 - Consider how an infection, reaction to medications, etc can also contribute to new behaviors.
 - Avoid hospitalization, if possible. Consult with psychiatric staff or other medical and mental health resources.
- ❖ If safety remains a concern, acknowledge the limits of you and your staff.

Understanding the symptoms does not mean we know the person. Both are equally important.

- ❖ Get to know the person. Respect their past. Use this information to guide interventions in the present.

CARING FOR THOSE WITH BEHAVIORAL SYMPTOMS CAUSED BY FTD AND PPA IN HOME, ADULT DAY SERVICES AND LONG-TERM SETTINGS

Needs of people with FTD & PPA often do not fit easily into the care structures available

- ❖ People with FTD & PPA often need more staff attention.
 - Participation in group activities is difficult because of FTD's effect on social engagement.
 - Providing individual attention is challenging, but can be done. Use information from family to identify low-key 1:1 activities. Engage their help during key times as possible.
 - *Example:* a resident may watch the same show over and over. For other residents this might be discouraged, but could be adaptive for someone with FTD.
- ❖ The behaviors can upset or bother other members/residents/clients you are serving.
 - *Example:* If a person is eating food off other's plates, have them sit in-between staff at meals.
 - *Example:* If a person is continuously clapping and the behavior is upsetting others, is there another group that he can attend with people who would not be as bothered? Or is there an activity that everyone could do that involves clapping?
- ❖ Rules, regulations and the realities of our established care systems sometimes conflict with the unique needs of persons with FTD & PPA.
 - High turnover of staff, limited resources for training, low pay of direct care workers, and financial bottom line all contribute to possible conflicts with care. While it seems we cannot change these problems right away, we can look for advocacy opportunities to ensure better resources for those living with FTD & PPA.
 - Consider how administrators can amend policies or advocate for changes to provide better care.

Reflections on care

- ❖ You are doing very important work caring for mothers, fathers, daughters and sons. This is a disease that robs a person of themselves and families of someone they love. You are witness to an ultimate loss to which we all have an emotional reaction. It is common to feel sad, devastated and afraid. Take care of yourself and your staff.
- ❖ We are learning together and from each other. Do not be embarrassed to ask for help. Discussing difficult situations or providing staff with examples of successful interventions, can promote understanding of how to respond and give them permission to think creatively. If regular in-service trainings are not possible, consider what other ways you can you educate your staff.
- ❖ Continue to look for moments of strength and ability amidst loss and decline.
- ❖ Partner with the family, they are often experts, but become exhausted by round the clock care. They need access to appropriate services and deeply appreciate your efforts to help.
- ❖ Join partners in care

INFORMATION AND RESOURCES

Northwestern Cognitive Neurology and Alzheimer's Disease Center

Neurobehavior and Memory Health Clinic

676 N. St. Clair, #945, Chicago, IL 60611

For appointments: 312-695-9627

For research: 312-926-1851

www.brain.northwestern.edu

Disease Information and Education

The Association for Frontotemporal Degeneration (AFTD)

www.theaftd.org or 866.507.7222 (Toll Free Helpline)

National Aphasia Association (NAA)

www.aphasia.org or 800.922.4622

Cure PSP: Foundation for PSP CBD and related disorders

www.PSP.org or 800-457-4777

The International PPA Connection, IMPACT

www.ppaconnection.org

Legal and Financial Resources

The National Academy of Elder Law Attorneys

www.naela.org or 520-881-4005

An elder law attorney can assist you with legal and financial planning.

Social Security (SSA)

www.ssa.gov or 800-772-1213

If the person is diagnosed under age 65, they may be eligible for disability. PPA and bvFTD are on the list of "Compassionate Allowance" that the SSA has marked for expedited approval.

Medicare

www.medicare.gov or 800-MEDICARE

Medicare is a health insurance program for people over the age of 65 or under 65 with disability.

Medicaid

<http://www.medicaid.gov/>

Medicaid provides health care to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law.

National Clearing House for Long-Term Care Information

<http://www.longtermcare.gov/>

Information and resources to help plan for future long-term care (LTC) needs.

Financial Planning Association

www.fpanet.org or 800-322-4237

INFORMATION AND RESOURCES

Finding Care Services and Resources

Eldercare Locator

www.eldercare.gov or 800-677-1116

The Eldercare Locator contains information about local agencies that offer transportation, day programs, support groups, respite providers, in-home care, case management and caregiving services.

Homecare Association of America

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

Find agencies that provide home care aides, companion care, homemaker services and may provide nursing services in the client's home or place of residence.

National Association of Professional Geriatric Care Managers

www.caremanager.org

Care Managers act as a guide, an advocate and provide ongoing assessments, referrals and care.

National Hospice and Palliative Care Organization

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

Lotsa Helping Hands

www.lotsahelpinghands.com

Safety

MedicAlert® + Alzheimer's Association Safe Return®

www.alz.org/SafeReturn or 1.888.572.8566

A 24-hour nationwide emergency response service for individuals with dementia.

This Caring Home

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

Provides tips and tool to enhance home safety in each room of the home.

Dementia and Driving

www.thehartford.com/alzheimers/

Support

Northwestern Support Groups- Contact Mary O'Hara at 312.503.0604

- bvFTD/PPA Family Support Group- 3rd Monday of the Month, 6pm

AFTD Telephone Support Group

For more information about one of the phone support groups contact info@theaftd.org.

Online Support

- The FTD Support Forum: <http://www.ftdsupportforum.com/>
- PPA Support: <http://health.groups.yahoo.com/group/PPA-support/>

IMPPACT List of PPA Groups

www.ppaconnection.org

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Memory loss...

shouldn't take away purpose and passion in life



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Bridging the Gap for Patients with Dementia and Cognitive Disorders



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- Dementia patients commonly develop dysphagia (swallowing problems), malnutrition, pneumonia and immobility issues.
- Aspiration pneumonia and dysphagia are the most common causes of death in late stage Alzheimer's disease.
- Dementia and cognitive declines impact the patient's ability to communicate wants and needs, as well as the caregiver's ability to communicate with the patient.

Our Speech-Language Pathology Program utilizes a skilled multi-disciplinary team including nurses, occupational therapists, physical therapy and social workers to help patients live as independently as possible. Our team will:

- Evaluate and treat communication disorders, swallowing and cognition deficits
- Provide rehabilitative and compensatory interventions for memory and cognition, communication, and swallowing
- Develop individualized feeding, eating and swallowing techniques for safe nutritional intake
- Neuromuscular Electrical Stimulation (NMES) for the treatment of dysphagia
- Address Activities of Daily Living (ADL)
- Identify risk of decreased mobility, falls, and wound development
- Medication intervention and monitoring
- Educate and train the patient and family/caregivers on interventions

Contact us today to learn more or refer a patient to our Speech-Language Pathology Program.

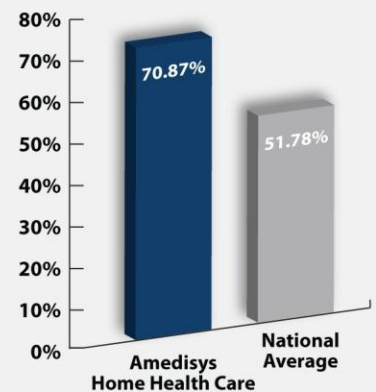


Please contact a specialist at:

312.280.5498

www.amedisys.com/SLP

AMEDISYS SCORES 19% ABOVE NATIONAL AVERAGE ON TREATMENT GOALS MET AT HOME



Source: 2011 National Outcomes Measurement System, American Speech-Language & Hearing Association (ASHA)

Remote control? Or telephone?



For a person with frontotemporal degeneration (FTD) or related dementias, this could be mistaken for a telephone. It seems harmless enough until it's an emergency situation, and they try to dial 911.

Don't wait for a crisis to make the decision for you. Talk to Arden Courts. We have the expertise and experience to maximize the quality of life your loved one deserves to give you the peace of mind you deserve.

And, remember, no longer being able to care for a loved one doesn't mean you no longer care. If you'd like more information, please visit us at www.arden-courts.com. We know. We understand. We can help.SM

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847.534.8815

Hazel Crest
708.799.7099

South Holland
708.895.1600

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Northbrook
847.795.9000

Glen Ellyn
630.469.5500

Palos Heights
708.361.8070





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Our residents wake up every day with a fresh start to a full schedule that Harbor House offers, leaving the residents feeling successful and accomplished at every opportunity.

Harbor House Memory Care is comprised of three ranch style homes that house sixteen individuals in each home. The intimate setting allows residents to feel at home with the support of caring staff, planned activities and medical oversight.

Each home caters to various levels of the disease and each resident is able to feel secure and comfortable in their environment.

Families can feel secure that their loved one is not only receiving exceptional care but also that they are truly happy in their surroundings.

We invite you to tour

Harbor House Memory Care

to experience the difference yourself!

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Wheeling, IL 60090
(847) 465-1100

info@harborhousemc.com

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Respite care is available for your loved one during the meeting.

For more information about our services or support group,
please call (773) 769-5500 or visit us at www.cmsschicago.org



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For adult children, this may be the second set of eyes they need – and the peace of mind they crave – when they know they can't be with their aging parent as frequently as they would like.

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The Sprau Advocate Group, LLC. – www.sprauag.com - 847-721-5083 – ksprau@sprauag.com



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She forgot to eat again.”
“What if she wanders off?
That would be horrible.”
“We need to keep her safe at home.
We need more help.”***

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