

COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER

of the Northwestern University Feinberg School of Medicine presents the

**FRONTOTEMPORAL DEGENERATION
and PRIMARY PROGRESSIVE APHASIA
FAMILY CAREGIVER AND PROFESSIONAL
EDUCATION AND SUPPORT CONFERENCE
SATURDAY, MARCH 24, 2012**

THE CNADC WOULD LIKE TO THANK THE
GLEN & WENDY MILLER FAMILY FOUNDATION
FOR THEIR GENEROUS SUPPORT OF THIS EVENT

NORTHWESTERN UNIVERSITY • THORNE AUDITORIUM • RUBLOFF BUILDING
375 EAST CHICAGO AVENUE • CHICAGO, IL 60611

WWW.BRAIN.NORTHWESTERN.EDU

FRONTOTEMPORAL DEGENERATION *and* PRIMARY PROGRESSIVE APHASIA

FAMILY CAREGIVER AND PROFESSIONAL EDUCATION AND SUPPORT CONFERENCE

SATURDAY, MARCH 24TH, 2012

AGENDA

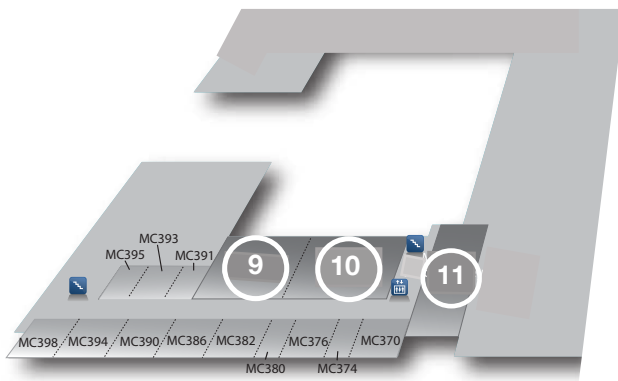
- | | |
|----------------|--|
| 7:30-8:45 AM | Registration and Vendor Fair |
| 8:45-9:00 AM | Welcome
<i>Thorne Auditorium</i>
M.-Marsel Mesulam, MD; director, CNADC
Darby Morhardt, MSW, LCSW; education director, CNADC |
| 9:00-9:30 AM | Overview of bvFTD and PPA
<i>Thorne Auditorium</i>
Diana Kerwin, MD; assistant professor of geriatrics, Northwestern University |
| 9:30-10:15 AM | Keynote Address: “Challenges of Family Caregiving: Behaviors, Language, and Communication”
<i>Thorne Auditorium</i>
Geri Hall, PhD, ARNP, GCNS, FAAN; clinical nurse specialist,
Banner Alzheimer’s Institute, Phoenix |
| 10:15-10:30 AM | Break and Vendor Fair |
| 10:30 AM-noon | Question-and-Answer Session
<i>Thorne Auditorium</i>
Dr. Kerwin, Dr. Hall, a PPA caregiver, and a bvFTD caregiver |
| noon-1:15 PM | Lunch (provided) and Vendor Fair |
| 1:30-2:45 PM | Breakout Session 1
<i>Please see page 3 for breakout session locations</i> |
| 3:00-4:15 PM | Breakout Session 2
<i>Please see page 3 for breakout session locations</i> |
| 4:30-5:00 PM | Closing Plenary: “Stress and Caregiving: Mindfulness as a Coping Tool”
<i>Thorne Auditorium</i>
Jennifer Medina, PhD; instructor in psychiatry and behavioral sciences,
Northwestern University Department of Psychiatry |

TABLE OF CONTENTS

<u>Page</u>	<u>Content</u>
3	Map of Conference
4	Map of Vendor Fair
8	Program Highlights
17	About the CNADC
21	“Stress and Caregiving: Mindfulness as a Coping Tool” Presentation Slides, Jennifer Medina, PhD
27	Educational Handouts
81	FTD and PPA Emergency Cut-Out Cards
89	Notes

MAP OF CONFERENCE

Breakout Sessions		
Map #	Session Topic	Room Name
1	Caring for Persons with bvFTD and PPA in Home Care and Adult Day Services	Thorne Auditorium
1	Caring for Persons with bvFTD and PPA in a Long-Term-Care Setting	Thorne Auditorium
2	Understanding Genetics in bvFTD and PPA	RB140
3	Responding to Behavior and Personality Changes in bvFTD and PPA	RB150
4	Newly Diagnosed: Now What?	RB180
5	Reviewing Care Options for Advanced-Stage bvFTD and PPA	RB175
6	Support Group for Families with Children and Teens	MC175 (<i>Getz Courtroom</i>)
7	Support Group for Navigating Family Conflict	MC185 (<i>Sidley Hall</i>)
8	Identifying Communication Strategies	MC195 (<i>Strawn Hall</i>)
9	Exploring Creative Arts Therapies	MC381 (<i>Cutting Hall</i>)
10	When Is It Time? Identifying Options and Making Transitions for Care	MC375 (<i>Smith Hall</i>)
11	Support Group for Family Caregivers	MC371 (<i>MacChesney Hall</i>)



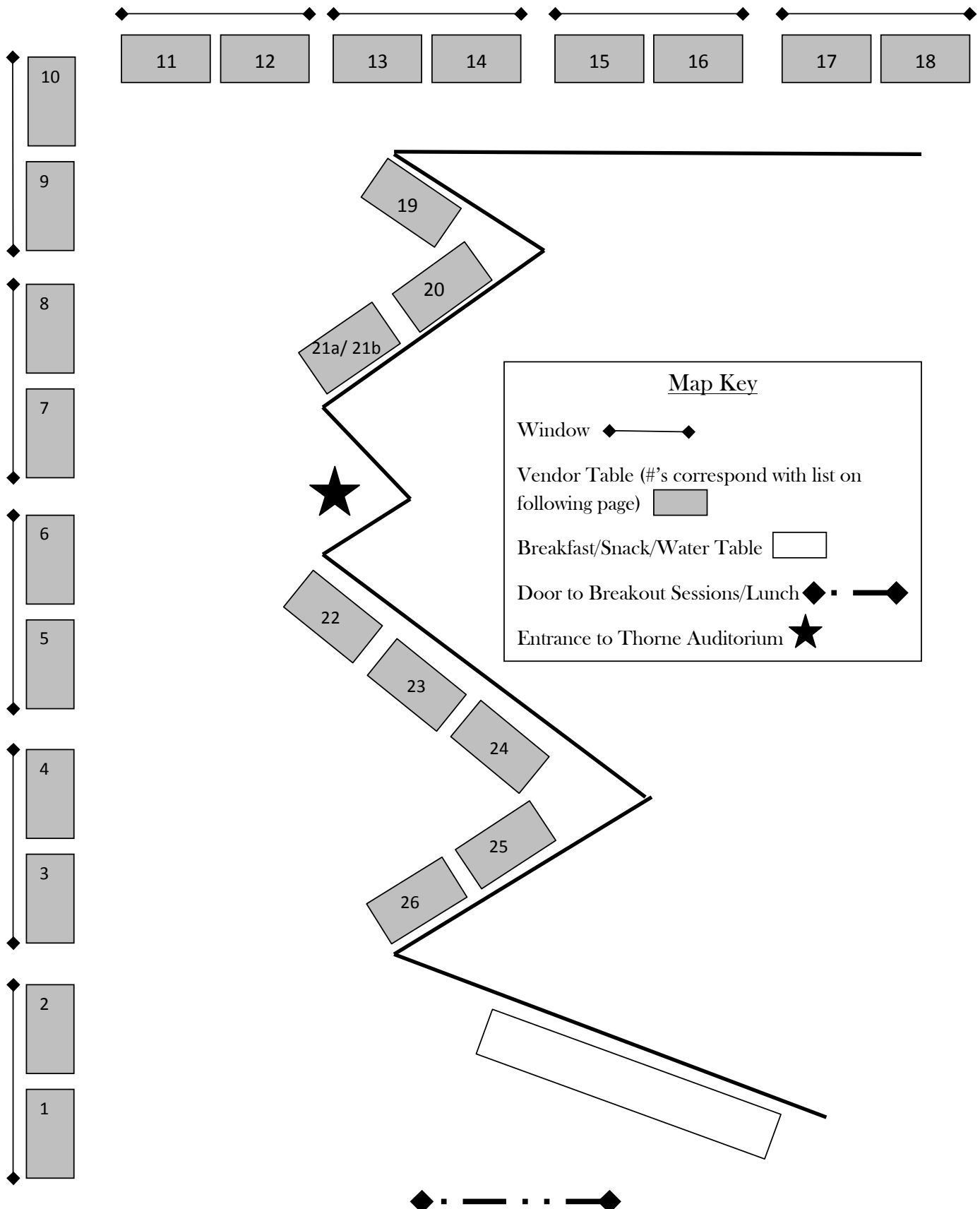
**Third Floor Plan
#9-11**

The Keynote Address and Closing Plenary will take place in Thorne Auditorium (#1)



**First Floor Plan
#1-8**

MAP OF VENDOR FAIR



LIST OF VENDOR AND SPONSOR TABLES BY NUMBER

The numbers of each vendor/sponsor correspond to the Map of Vendor Fair on page 4.

1. Senior Bridge*
2. Chicagoland Methodist Senior Services*
3. Amedisys Home Health*
4. Harbor House*
5. Sunrise Assisted Living*
6. Care Choice Home Health, Inc.*
7. Senior Helpers of Chicago*
8. Arden Courts*
9. Dutton & Casey, PC
10. Mather LifeWays
11. Home Instead Senior Care
12. CJE SeniorLife
13. Right at Home
14. Midwest Palliative and Hospice Care Center
15. The Wealshire
16. Brightstar
17. The Abington of Glenview
18. A-Abiding Care
19. All Trust Home Care
20. Horizon Hospice
- 21a. Poster presentation Serving 'Generation Alzheimer's' Libraries enriching the lives of people with dementia by Mary Beth Riedner
- 21b. The Health Care Passport by Melissa Kahn
22. Private Home Care Services*
23. National Aphasia Association (NAA)*
24. Association of Frontotemporal Degeneration (AFTD)*
25. Run4Papa- Jason Boschan PPA research fundraising
26. Cognitive Neurology and Alzheimer's Disease Center (CNADC)

* Sponsors of the 2012 FTD/PPA Family and Professional Educational Conference

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.



THANK YOU!

We appreciate the support of our sponsors.

Silver sponsors

Amedisys, Inc.
Harbor House Memory Care

Bronze sponsors

Arden Courts
Care Choice Home Health, Inc.
Chicagoland Methodist Senior Services
Private Home Care Services
SeniorBridge
Senior Helpers of Chicago
Sunrise Assisted Living

Thank you to patients and family members who are living with
bvFTD and PPA who provided support for this conference,
including Pati Bradstreet and Marc Toles.

2012 Planning Committee Members:

CNADC Faculty and Staff

Stefanie Bonnell
Jennifer Medina
Darby Morhardt
Mary O'Hara
Mary Popelar
Jaimie Robinson
Emily Rogalski
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

Keynote Speaker
Geri Hall, PhD, ARNP, GCNS, FAAN

Clinical Nurse Specialist
Banner Alzheimer's Institute
Phoenix, Arizona

Geri R. Hall, PhD, ARNP, GCNS, FAAN has been specializing in the care of people with Alzheimer's disease and related dementias since 1978. She developed, wrote, and tested the first theoretical model, the Progressively Lowered Stress Threshold, for planning and evaluating care of people with Alzheimer's disease.

Dr. Hall facilitated the Washington University, St. Louis online "Alzheimer List" for 16 years. She has been an Adjunct Professor at the Arizona State University College of Nursing since 2011. Currently working at the Banner Alzheimer's Institute in Phoenix, she continues to see and counsel only the most complex cases. This complexity results in many of her cases being focused on care of people and families with FTD. She co-facilitates a live FTD support group and an online extension of the group.

Dr. Hall is a well-known speaker nationally and internationally and has served on state and federal expert panels on issues related to dementia.

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

Marsel Mesulam was born in Istanbul in 1945. He received the degrees of Bachelor of Arts in 1968 and Medical Doctor in 1972, both from Harvard University. He was appointed Professor of Neurology at Harvard Medical School where he founded and led the Behavioral Neurology Unit of Boston's Beth Israel Hospital. In 1994 he was appointed the Dunbar Professor of Neurology and Psychiatry and the Director of the multidisciplinary 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 and the Lishman Award from the International Neuropsychiatry Association and the Bengt Winblad Life Achievement Award from the Alzheimer's 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 300 research papers and edited a popular textbook of Behavioral and Cognitive Neurology. He is 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.

PROGRAM HIGHLIGHTS

Diana R. Kerwin, MD

Dr. Diana Kerwin is an Assistant Professor in the Department of Medicine, Division of Geriatrics and Cognitive Neurology and Alzheimer's Disease Center of Northwestern University. Dr. Kerwin's area of research and clinical interest is in the identification of risk markers and prevention of cognitive decline and dementia. Her clinical practice focuses on the care, evaluation and management of memory loss and cognitive decline in persons over age 60, and she is currently the site investigator for the ADCS ADNI-GO study, and therapeutic trials for frontal temporal lobe dementia.

Dr. Kerwin serves as a reviewer for the *Journal of General Internal Medicine*, *Journal of Palliative Medicine* and abstract reviewer for the *American Geriatric Society*. She has been active in the community and served as President of the Board of the Southeastern Wisconsin Chapter of the Alzheimer's Association, Scientific Advisory Board to the Alzheimer's Association and on the Board of the Extendicare Foundation. She was the Clinic Director of the Geriatric Memory Disorders Clinic and Latino Dementia Center at the United Community Center in Milwaukee, WI and was recognized with awards from the United Community Center "Friends of the Hispanic Community" in 2008, the "Young Investigator Award" in 2003 by the Alzheimer's Association and the "Dr. Judith Stitt Faculty Scholar Award" in 2004 by the Wisconsin Women's Health Foundation. Dr. Kerwin was awarded the 2006 *T. Franklin Williams Research Scholar*, a competitive national award for her research investigating the effects of body weight and vascular risk factors in the development of cognitive decline and dementia. She has lectured extensively on cognitive aging, caregiving and Alzheimer disease both regionally and nationally and is the academic partner on several community initiatives to improve care of elderly with dementia in underserved areas. Her research on the relationship of obesity and memory function in women was recently featured in Time Magazine, Boston Globe, ABC News, CBS Radio, BBC and she appeared on a Chicago morning news program to discuss the results of her findings.

Jennifer Medina, PhD

Dr. Jennifer Medina 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.

As a clinical neuropsychologist in the Neurobehavior and Memory Clinic of the Cognitive Neurology and Alzheimer's Disease Center, Dr. Medina specializes in the assessment of cognition and behavior in adults, particularly the evaluation of cognitive disorders related to aging and dementia. Her current clinical and research interests include the co-morbidity of mood disorder and neurological conditions. Dr. Medina has published papers related to education and support for patients and families coping with dementia, as well as in the area of depression in individuals diagnosed with Primary Progressive Aphasia.

PROGRAM HIGHLIGHTS

Breakout Sessions

Caring for Persons with bvFTD and PPA in Home Care and Adult Day Services

Geri Hall, PhD, ARNP, GCNS, FAAN, clinical nurse specialist, Banner Alzheimer's Institute

Sheila McMackin, MSW, LCSW, president, Wellspring Personal Care

Sandra Meyer, RN, registered nurse, Amedisys Home Health Services

Mary O'Hara, AM, LCSW, assistant director of education, CNADC

Jane Stansell, RN, MSN, director, Alzheimer's Family Care Center, Rush University

Individuals with bvFTD and PPA and their families face many challenges and barriers to care when turning to the community for resources and support. Service providers are often unfamiliar with bvFTD and PPA or how to help. In this session, presenters will address the unique needs of persons with bvFTD and PPA, and helpful approaches for home care and adult day service staff. This session is designed for professionals, but family caregivers are welcome.

Caring for Persons with bvFTD and PPA in a Long-Term-Care Setting

Sharon Denny, MA, program director, Association for Frontotemporal Degeneration

Geri Hall, PhD, ARNP, GCNS, FAAN, clinical nurse specialist, Banner Alzheimer's Institute

Hedy Ciocci, BSN, RN, LSNH, registered nurse, SelfHelp Home

Colleen Kamin, LNHA, CDP, nursing home administrator, Harbor House

Darby Morhardt, MSW, LCSW, education director, CNADC

Courtney Bouker, LNHA, marketing director, Arden Courts of Northbrook

As bvFTD and PPA progresses, more care is needed and some family members are faced with the decision to move their loved one to an assisted living or skilled care facility. Many of these long-term-care settings are not equipped to care for an individual with behavioral symptoms typical of bvFTD and PPA. Patients and families are frequently turned away, transferred from one facility to another, and endure frequent psychiatric hospitalizations. In this session, attendees will discuss the challenges they face in caring for someone with bvFTD and PPA in long-term-care and the most helpful approaches and strategies. This session is designed for professionals, but family caregivers are welcome.

Exploring Creative Arts Therapies

Deb Del Signore, MAAT, ATR-BC, manager of special programs, Lieberman Center for Health and Rehabilitation

Rebecca Froman, MA, MT-BC, music therapist, Lieberman Center for Health and Rehabilitation

Erica Hornthal, MA, LCPC, BC-DMT, movement-oriented therapist, North Shore Dance Therapy

Creative arts as a supportive intervention have shown to improve the quality of life of the patient and family. These interventions include: movement, dance, art, music, drama, improv, horticultural therapy and many more. In this presentation you will learn about some creative arts options, the benefits, and ways to connect your family or clients to these interventions.

Identifying Communication Strategies

Becky Khayum, MS, CCC-SLP, CEO and president, MemoryCare Corporation

This educational presentation will review communication challenges in bvFTD and PPA, the benefits of speech therapy, and alternative forms of communication. Attendees will learn tips and strategies for supporting language abilities, and resources available to maximize communication among family members.

PROGRAM HIGHLIGHTS

Breakout Sessions

Newly Diagnosed: Now What?

Sandra Weintraub, PhD, director, Clinical Core, CNADC

Janna Dutton, JD, elder law attorney, Dutton & Casey

After receiving a diagnosis, family members can be overwhelmed with the important considerations and decisions for both the present and future. This educational session will focus on the first steps one should take after a diagnosis, including the basics of legal and financial planning and safety and communication issues, in addition to education, resources and support.

Responding to Behavior and Personality Changes in bvFTD and PPA

Michelle Sanfilippo, MPAS, PA-C, physician assistant, Alexian Brothers Neuroscience Institute

Tory Eitz, RN, clinical coordinator, Alzheimer's Family Care Center

It is common for persons living with bvFTD and PPA to experience changes in personality and behavior that can be difficult for families to understand and know how to best respond. This educational session will review non-pharmacological interventions as well as medications to address changes in mood, behavior and improve quality of life. Attendees of this session will learn about methods of intervention for common behavioral changes in bvFTD and PPA.

Reviewing Care Options for Advanced-Stage bvFTD and PPA

Pamela Palmentera, MSW, LCSW, bereavement coordinator, Northwestern Memorial Hospital

Joshua Hauser, MD, geriatrician, Northwestern Buehler Center on Aging

The advanced stages of bvFTD and PPA present families with emotionally difficult decisions. Each family member has unique needs for information and support. This educational session will review late stage symptoms, in addition to common questions and concerns about the end of life. Attendees of this session will learn how to speak with their health care team, how to access and evaluate care options, and how to maximize family support.

Support Group for Families with Children and Teens

Sharon Denny, MA, program director, Association for Frontotemporal Degeneration

Darby Morhardt, MSW, LCSW, education director, CNADC

This professionally facilitated and confidential support group will offer a safe environment for young families to discuss the impact of the diagnosis. Attendees will have an opportunity to share their experience, hear others' strategies for coping with difficult situations, and benefit from support offered by others.

Support Group for Family Caregivers

Jennifer Medina, PhD, instructor in psychiatry and behavioral sciences, CNADC

This professionally facilitated and confidential support group will offer a safe environment for family caregivers to share with others who understand the experience of having a loved one diagnosed with bvFTD or PPA. Support groups can offer a greater understanding of a shared experience, provide an opportunity for empathy, and help develop a sense of identity for participants through mutual support and validation from other group members. Attendees will share their personal experience in order to receive support, learn new ways to cope with challenges, and share strategies and knowledge with others in a similar situation.

PROGRAM HIGHLIGHTS

Breakout Sessions

Support Group for Navigating Family Conflict

Marcia Spira, PhD, director, Institute on Aging and Intergenerational Study and Practice, Loyola University Chicago School of Social Work

Dealing with family dynamics when a loved one has dementia can be difficult, complex, and emotional. This is made more challenging in the context of long standing family conflict. Whether the difficult dynamics were present prior to the diagnosis, or began after, 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.

Understanding Genetics in bvFTD and PPA

*Lisa Kinsley, MS, CGC, genetic counselor, Northwestern
HyungSub Shim, MD, neurology fellow, CNADC*

This educational session, led by a genetic counselor, will discuss the genetics of bvFTD and PPA, including what we know and what we hope to uncover in the future through research. The decision to get genetic testing for a disease without treatment is not one that should be taken lightly. Attendees will learn about genetic risk factors, the steps involved in genetic counseling and testing, and implications for family members.

When Is It Time? Identifying Options and Making Transitions for Care

*Jaimie Robinson, MSW, LCSW, resource navigator, CNADC
Signe Gleeson, MS, RNC, CCM, nurse care manager, ElderCare Solutions*

The decision to initiate a change in care is never easy for the diagnosed individual nor the family. “Taking over” too soon may affect the person’s self-worth and sense of confidence; however, waiting too long can put the safety of the person and others at risk. This educational session will review the difficult decisions involved in transitions, possible approaches to necessary change and support available to both the diagnosed individual, as well as family. Attendees of this session will learn how to recognize when more care is needed, what care options are available, and how to adjust to the care transition.

PROGRAM HIGHLIGHTS

Speaker Biographies

Courtney Bouker, LNHA is a licensed nursing home administrator and Marketing Director at Arden Courts of Northbrook. She is on the Board of the Illinois Pioneer Coalition, a Board dedicated to person-centered care and culture change and heads up the education committee. She has a bachelor's degree in marketing with a secondary degree in gerontology from Kansas State University.

Pati Bradstreet is a wife, mother of 5, and grandmother of 11. She is a retired librarian and currently her husband John's caregiver. John was diagnosed with PPA in August of 2006 but had symptoms for a year prior. This is her 2nd year to attend the conference at Northwestern.

Hedy Ciocci, BSN, RN, LSNH has been the Administrator of The Selfhelp Home for the past 7 years and is responsible for the day-to-day operations of this community. Ms. Ciocci's background in Adult Day Services for The Council for Jewish Elderly and her expertise in Dementia Care, as a Dementia Specialist, allows her to be knowledgeable in the many individual challenges that present in these illnesses. She has also worked with Northwestern's CNADC in their Educational Core on a specialized program for persons with early stage, early age dementia know as "The Culture Bus."

Deborah Del Signore, MAAT, ATR-BC has been with CJE SeniorLife since 1999 as a practicing art therapist serving the residents of the LTC community, Lieberman Center. She currently holds the position of Manager of Special Programs, which encompasses creative arts therapy, life enrichment and memory care. She also teaches art therapy graduate students at the School of the Art Institute of Chicago. Deborah is extremely interested in how ongoing self-expression can improve the lives of healthy and frail older adults challenged by psychological, cognitive and physical changes and how the arts can impact community building within traditionally institutionalized settings.

Sharon Denny, MA is the Program Director at the Association for Frontotemporal Degeneration (AFTD). She leads AFTD's Task Force on Families with Children which will produce an educational booklet this year. Mrs. Denny convened a committee of nurse practitioners, social workers, health educators and family caregivers to increase education of professionals working long-term care and adult day program settings. The first results of their work were introduced in September 2011 under the name *Partners in FTD Care*. Mrs. Denny has a Master's degree in Clinical Psychology and more than twenty-five years' experience in program development with nonprofit organizations that serve people with medical and psychiatric disabilities.

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.

Tory Eitz, RN has worked in dementia care for the past 13 years. In her current position as Clinical Coordinator at the Alzheimer's Family Care Center, she has had the opportunity to work with multiple types of dementia and gained a wealth of knowledge about dementia, the specific type of dementia's impact on functioning, and the therapeutic approaches that best promote well-being in her clients. Tory has also been a "dementia expert panelist" on a web chat for caregivers of people with Alzheimer's Disease, hosted by the Chicago Tribune.

PROGRAM HIGHLIGHTS

Speaker Biographies

Rebecca Froman, MA, MT-BC is a board certified music therapist specializing in clinical practice with individuals with dementia both through her private practice as well as with CJE SeniorLife in the greater Chicago area. At the University of Iowa, she earned her Masters degree in music therapy and completed her neurologic music therapy training at the Center for Biomedical Music Research. Rebecca currently serves as a clinical training director of both music therapy and dance/movement therapy and counseling students.

Signe Gleeson RNC, CCM, MS has been caring for older adults throughout her nursing career. Her extensive background in geriatrics and, more specifically, geriatric psychiatry, provides her with first hand knowledge of and expertise in addressing the needs of families who are struggling to make the best care decisions for older relatives. The creator of ElderCare Solutions, Ms. Gleeson is a board certified gerontological nurse, a certified care manager and a registered guardian.

Joshua Hauser, MD is Assistant Professor of Medicine and Palliative Care at Northwestern's Feinberg School of Medicine, Fellowship Director in Palliative Care, and Director of The Education on Palliative and End of Life Care (EPEC) Project. At Northwestern, he currently chairs the Professional Development Committee, one of four committees responsible for curriculum renewal. Dr. Hauser has been former member and chair of an NIH study section on research ethics, co-chair of the American Society of Bioethics and Humanities program committee and chairman of its palliative care affinity and current chair of the American Academy of Hospice and Palliative Medicine ethics committee.

Erica Hornthal, MA, LCPC, BC-DMT received her MA in Dance/Movement Therapy & Counseling from Columbia College Chicago. In her private practice, Erica focuses on maintaining the integrity and dignity of each client regardless of the progression of their dementia through holistic body-based interventions. Along with the client, Erica works intensively with families and caregivers to educate them on how to maintain healthy communication and relationships with their loved ones.

Colleen Kamin, LNHA, CDP is the Regional Director of Operations at Harbor House of Wheeling. She has twenty years experience as a licensed nursing home administrator and has had the opportunity to be involved in the development in specialty units, including dementia programs, ventilator units, and dialysis units, within a variety of facilities. Colleen has been involved with the Illinois Pioneer Coalition, which promotes change and resident centered care within the industry.

Becky Khayum, MA, CCC-SLP 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. Becky has developed a passion for educating professionals and caregivers on strategies that facilitate communication and memory for individuals with dementia.

Lisa Kinsley, MS, CGC is a board-certified genetic counselor practicing in the Chicago area since 2009. She now works for Northwestern University as a research genetic counselor in Dr. Teepu Siddique's Neuromuscular Research Laboratory, and as a clinical genetic counselor for MDA and ALS clinics and other patients from a variety of neurologic specialties. She is also an adjunct faculty member with Northwestern's Genetic Counseling Graduate Program.

PROGRAM HIGHLIGHTS

Speaker Biographies

Sheila McMackin, MSW, LCSW established Wellspring Personal Care after recognizing the urgent need for a quality private duty home care agency through her work as a care manager and advocate for the elderly and the disabled. After more than a decade as President of Wellspring, she launched a national movement to unite private duty home care providers in an effort to promote standards and ethical practices for the industry. The National Association for Private Duty Home Care was established in the fall of 2002, and Sheila serves as its first Board President.

Sandra Meyer, RN is a board-certified psychiatric and mental health nurse with thirty-five years experience in the health care field in a variety of settings. She is currently the Regional Behavioral Health Program Manager at Amedisys Home Health Services. Sandra is responsible for developing, planning, implementing, coordinating, evaluating and promoting a comprehensive psychiatric care program. She also oversees the Empowered for Life Program in all agencies in Illinois, Wisconsin, and Indiana.

Darby Morhardt, MSW, LCSW is Research Associate Professor, Director of Education and Social Worker for the CNADC at Northwestern. She has 25 years clinical experience with persons with dementia and their families. Her research interests focus on the evaluation of quality of life enrichment programs for patients and families.

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.

Pamela Palmentera, MSW, LCSW has worked at Northwestern Memorial Hospital since 2006, where she develops, plans, organizes, leads and implements the bereavement program of NMH Hospice. Prior to coming to NMH, she worked for eleven years in child welfare at Catholic Charities and worked as Program Director at a shelter for homeless women in the Uptown neighborhood of Chicago. Pamela received both her BSW and MSW degrees at the University of Illinois-Chicago, Jane Addams College of Social Work.

Jaimie Robinson, MSW, LCSW is the Resource Navigator at the Neurobehavior and Memory Clinic of the Cognitive Neurology and Alzheimer's Disease Center. In addition to providing patients and families with symptom specific ideas, interventions and resources, she provides education and support for patients and families living with a young onset form of dementia. Jaimie received her Master's in Social Work from Loyola University School of Social Work and is a Licensed Clinical Social Worker in the state of Illinois. Currently, Jaimie is a member of the Board of Directors for the Chicago Society of Social Work Leadership in Health Care.

Michelle SanFilippo, MPAS, PA-C is a board-certified physician assistant in neurology working with Dr. Concetta M. Forchetti at the Alexian Brothers Neurosciences Institute. She has worked in the field of dementia care for 13 years and with Dr. Forchetti for the last 8 years. In her role at Alexian, Michelle assists in the diagnosis and management of patients with dementia and specializes in behavioral management and family education, provides community education and co-facilitates support groups. Recently, she has become involved in the development of the memory center and movement disorder center at Alexian Neurosciences Institute.

PROGRAM HIGHLIGHTS

Speaker Biographies

HyungSub Shim, MD is a behavioral neurology fellow at the Cognitive Neurology and Alzheimer's Disease Center of Northwestern University. His undergraduate degree from Lawrence University is in Neuroscience and Linguistics. He earned his medical degree at the Medical College of Wisconsin, and did his neurology residency at the University of Iowa. He continues to pursue his interests in language and the brain in the clinic as well as with research.

Marcia Spira, PhD, LCSW is a professor of social work in the School of Social Work at Loyola University. 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.

Jane Stansell, RN, MSN is the Director of the Alzheimer's Family Care Center in Chicago. Her nursing, administrative and direct care experience has convinced her that people with dementia need programs that utilize their retained skills and abilities throughout the illness to maintain a sense of well-being. She has been a strong advocate for change in the way care is provided to include both emotional and functional support to compensate for losses associated with the illness.

Marc Toles and his wife Gretchen met on a hayride in the seventh grade. They didn't start dating until a year after high school, and were married a year after that in 1979. They raised three daughters who have given them 5 grandchildren. Gretchen was diagnosed with bvFTD in August 2007. As her illness progressed, Gretchen continued to enjoy her hobby of photography. She is now able to speak just a few words and needs someone with her at all times. Marc continues to care for her at home.

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.

Christina Wieneke is a research project manager at the Northwestern University Cognitive Neurology and Alzheimer's Disease Center (CNADC). At the CNADC, she manages all components of the longitudinal, NIH-funded Language in Primary Progressive Aphasia research program. She received a BA from Purdue University in behavioral neuroscience.

ABOUT THE CNADC

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

Patient Care

Neurobehavior and Memory Clinic
Northwestern Medical Faculty Foundation
676 North St. Clair Street, Suite 945
Chicago, IL 60611
312-695-9627

Research and Education

Alzheimer's Disease Center
320 E. Superior Street, Searle 11
Chicago, IL 60611
312-926-1851
www.brain.northwestern.edu

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 newly renovated 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 services 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.

CURRENT bvFTD/PPA RESEARCH AT NORTHWESTERN CNADC

Language in Primary Progressive Aphasia

The purpose of the study is to gain a better understanding of the 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.

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, safe for an MRI, and may not be claustrophobic. 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 project 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, contact Mallory Swift: 312-926-1851 or memoryresearch@northwestern.edu.

Other Research Directions

- Research programs for people with and without dementia
- Clinically testing new drug therapies for Alzheimer's disease (AD) and Behavioral-Variant Frontotemporal Degeneration (bvFTD)
- Studying the effect of sleep deficits on memory and cognitive function
- Measuring the impact of stress on AD's and dementia's progression
- Causes and treatments of PPA, bvFTD, and other younger onset dementias
- Identifying brain factors associated with "SuperAging"
- Treatment and prevention of dementia diseases
- Nature of cognitive and behavioral changes in dementia
- Identification and treatment of Mild Cognitive Impairment (MCI)

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 memoryresearch@northwestern.edu

RUN4PAPA

An Average Person Doing Extraordinary Things



From left: As part of his training regime for the Great Wall of China Marathon, Jason raced up 94 flights of stairs for Hustle Up The Hancock. Jason with his grandfather, Dr. Louis Heyman. The Great Wall of China Marathon is extremely exclusive; only 1,748 people ran in 2011. Jason created a video to bring awareness to the cause and PPA.

Jason Boschan has partnered with the CNADC to raise funds in support of primary progressive aphasia (PPA) research. Jason's grandfather, Dr. Louis "Papa" Heyman, a pediatrician for 50+ years, was diagnosed with PPA, a dementia that makes a person progressively lose the ability to communicate and comprehend language, in 2009.

Jason is running the Great Wall of China Marathon in May 2012 to honor his grandfather and everyone battling the disease. The marathon is very exclusive and includes steep inclines that total over 5,000 steps. It is the equivalent of running up and down the Hancock Building & Willis Tower, and then taking a round trip between the Chicago and Evanston campuses of Northwestern University.

Jason has trained and run races in 9 states to prepare for the Great Wall of China Marathon. This campaign has helped bring awareness to PPA research and there have been over 360 individuals who have donated to the cause.

**Please support this important journey by visiting www.run4papa.com.
Help Jason reach his goal of raising \$50,000 for PPA research at the CNADC!**

Stress and Caregiving: Mindfulness as a coping tool

Jennifer Medina, Ph.D.

Clinical Psychologist
Neuropsychologist, Neurobehavior and Memory Clinic
Northwestern University Cognitive Neurology and Alzheimer's Disease Center



Copyright 2012. Please do not distribute or replicate without permission.

Outline

- Define stress
- Physiological Stress Response
- Coping with Stress/Stress Management
- Mindfulness and Meditation
- Caregivers and Mindfulness
- Mindful Experience Exercise

.....inspired action.

Stress

Stress can be positive or negative.

It is a process by which we appraise and cope with environmental challenges and threats that affect our well being.

Positive Stress

When short-lived or taken as a challenge, stressors may have positive effects.

Negative stress

A circumstance (real or perceived) that threatens a person's well-being. When we feel severe negative stress, our ability to cope with a situation is impaired.

The Stress Response System

The brain sends an alarm signal when a stressful event occurs.

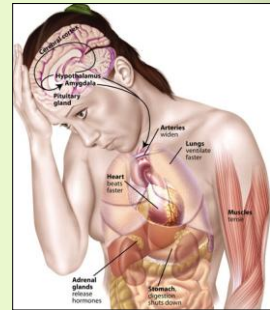
Heart rate increases: pumps blood with greater speed, carrying oxygen and nutrients to cells and clearing away waste products more quickly.

Breathing becomes rapid and shallow.

Lipids (fats) are released into the bloodstream

Liver releases stored **sugar** into the blood to meet the increased energy needs

Blood flow is restricted to the **digestive system** as it increases to the brain and major muscles.



The Stress Response System

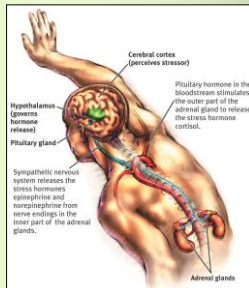
Pupils Dilate to let in more light, all of the senses heightened.

Muscles tense for movement or protective actions.

Hands and feet get cold as blood is pumped to our most needed muscles such as arms and legs which would help us fight or run away from the danger we face.

Body Perspires – the cooling system as increased metabolism generates more heat.

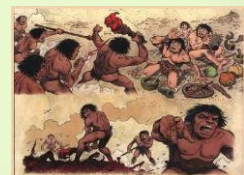
Skin pales with the constriction of small blood vessels in the skin, blood is redirected to the muscles.



Stress can be adaptive and functional

In a fearful or stress-causing situation (pos. and neg.), the physiological responses serves a purpose.

Evolutionary perspective:



Stress can be adaptive and functional

In a fearful or stress-causing situation (pos. and neg.), the physiological responses serves a purpose.

Modern day perspective:



Stress can be maladaptive



Prolonged (chronic) stress increases our risk of illness and health problems. Resources are depleted and we are unable to cope with minor things.



Being a caregiver has the potential to cause chronic levels of stress.

Stress of everyday life

- Too much to do, not enough time
- Work/employment
- Family/relationships
- Health & Safety
- Finances
- Laundry, groceries, chores
- Traffic
- Cell phones, tablets, computers
- Focus on productivity



Stress of dementia caregiving

- Increased demand on time
- Can require constant attention
- Employment difficulty
- Increase in health problems
- Less time for self care
- Increased in family conflict
- Increased depression
- Increased mortality

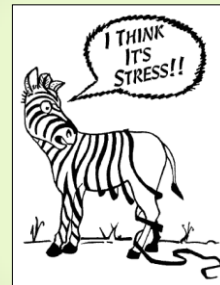
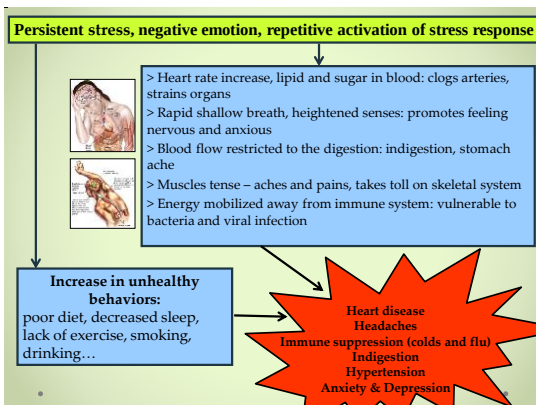
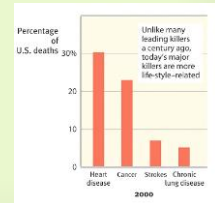
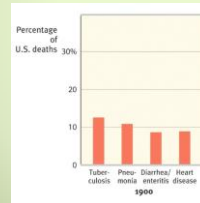
Ory, et al, 1999; Schulz, 1995; NEJM, 2006

Stress and Health

Poor coping leads to unhealthy behavior: insufficient exercise, poor diet, smoking, drugs & alcohol

Prolonged stress combined with unhealthy behaviors may increase our risk for one of today's four leading diseases.

Half of the deaths in the US are due to people's behaviors – unhealthy ways of coping with stress. (Center for Disease Control)



Promoting Health

We often only think of health when we are sick or unhealthy.

However, promoting health begins by preventing illness and enhancing well-being, which is a constant endeavor.

Managing Stress

- Aerobic **exercise** can elevate mood and well-being by improving energy level, increasing self-confidence, and lowering tension, depression, and anxiety.
- Healthy lifestyle: balanced **diet**, no smoking, alcohol in moderation, good sleep all promote well-being
- Relaxation and **meditation** reduce tension and anxiety and give people a chance to bring their physiological response to a healthier range
- The idea is to train the body to avoid the physiological reaction when it is not adaptive.

Meditation...

What is it?

- "to think, contemplate, devise, ponder"
- A practice of mental discipline
- An inwardly oriented, personal practice
- Cultivates or invokes an internal state (e.g., relaxation)
- Many different styles, modalities, views
- Suggested as a way of living and not just an isolated exercise

Meditation is NOT: Having a quiet mind, a silent mind, or not thinking. It is a practice of having awareness.

How is it used?

- Reduces depression and anxiety and improves perceived self-efficacy (Waelde, et al. 2004)
- Significant reduction in anxiety, specifically when practiced long term.
- Used with a number of medical populations
- Avoids relapse of depressive symptoms
- ❖ Mindfulness intervention (7-90 min sessions) reduces dementia caregiver stress (Oken et al. 2010)

What is Mindfulness?

Uses **meditation** to cultivate a friendly, non-judging, present moment awareness.

Each moment holds within it an opportunity to work towards greater self-understanding and peacefulness.

Being awake and fully aware.

Paying attention on purpose.

Helps to maintain openness and accept difficult experiences especially when feeling clouded by fear and worry

Mindful presence promotes *being* instead of *doing*

2 qualities of mindfulness:

- **Kindness:** friendliness, openheartedness, a feeling of welcoming while understanding your experiences
- **Compassion:** feelings of empathy and concern for pain or suffering. The practice of compassion carries a willingness to remain present and in contact with the painful situation, in the hope of bringing some measure of relief.

Mindful approach

Everything happens in the **present moment**.

- The past is a memory that is occurring in the present moment
- The future is something being imagined in the present moment

We really only have control of what is happening in the present moment!

Every moment is a chance to be your best self, in that very moment. Practicing mindfulness gives you the opportunity to embrace that.

How does mindfulness work?

Meditation practices help cultivate mindfulness by helping you become aware, becoming present to each moment in it's fullness.

As you become aware of your experiences you begin to see them as 'conditions of the present moment' instead of your 'enemy' or 'problem'

You turn toward the experience rather than resist it or be fearful of it.

7 essential attitudes of mindfulness:

Nonjudging: take the position of an unbiased, nonreactive, non critical witness to your experience without judgment

Patience: bear difficulty with calmness and self control, have faith and courage in yourself

Beginner's mind: be open to the experience in each moment as if meeting it for the first time

Trust: of yourself and your feelings. You and you alone are the best person to know what is going on with you

Non-striving: being instead of doing, allow what is happening to happen without yearning for something more or something different

Acceptance: the willingness to see things exactly as they are in the present moment rather than as you think they are or should be

Letting Go: non-attachment, non-clinging to ideas or views about yourself, others, and situations

Common experiences of caregivers:

- Fear
- Worry
- Powerlessness
- Uncertainty
- Lack of control
- Frustration
- Grief
- Constant need to plan for the future



How can mindfulness help with caregiving?

- Achieve a positive approach to interacting with a loved one (rather than fear based or critical) by existing in the moment and attending to the feelings at hand in a nonjudgmental manner
- Embrace the reality of the present moment, pleasant or unpleasant
- Appreciating the ebbs and flows rather than ignore or turn away from them will allow you to welcome new experiences rather than dread them

How can mindfulness help with caregiving?

- Create a more compassionate and kinder approach to coping with the stresses of caregiving
- Be better able to stop judging events and occurrences over which one has no control
- Training the body to have a more adaptive physiological response when things are frustrating or difficult
- Achieve a balanced and centered state of mind when things get hectic

How can mindfulness help with caregiving?

Caregivers can focus on **present moment awareness** to stop judgment of past behavior, extend forgiveness to themselves for real or perceived failings and recognize that they, and everyone else, are doing the best they can.

"Acceptance does not mean "liking" or "approving" or even "condoning." Acceptance simply means coming to a serenity with what IS.

No one likes having a loved one with a dementing disease, but to constantly fight and deny is to keep ourselves from being compassionate and effective caregivers."

How can mindfulness help with caregiving?

- Mindfulness can be helpful to the diagnosed individual, whose world often only exists in the present moment. A caregiver who understands this mindset has a powerful perspective.
- Mindful approach focuses on *being* instead of *doing*. In a situation that calls for a lot of *doing*, practicing *being* can be helpful for both partners.



The "Cope" Chest

Wake from sleep +3 credits
 Construction, slow commute -1 = 2 credits left
 Left your wallet at home -1 = 1 credit left
 Neighbor can't pick up your loved one -1 = 0 credits left

You have a conversation with your loved one about tomorrow's doctor appointment, and 5 minutes later they ask you questions that YOU JUST ANSWERED.

But you have no credits left.....



The "Cope" Chest (revised)

Wake from sleep +3 credits
 5 minute mindfulness meditation +1 = 4 credits
 Construction, slow commute -1 = 3 credits left
 Left your wallet at home -1 = 2 credit left
 Neighbor can't pick up your loved one -1 = 1 credit left
 5 minute mindfulness meditation +1 = 2 credits left

You have a conversation with your loved one about tomorrow's doctor appointment, and 5 minutes later they ask you questions that YOU JUST ANSWERED...



You take a deep breath, smile, and repeat yourself, without judgment of the situation, accepting the circumstance for what it is, and acknowledging yourself and your loved one for doing the best you can.

Sherril Bover

caregiver coach and educator, co-author and co-presenter of The Alzheimer's Dialogues, Conversations About Caregiving

"Caring for a loved one with dementia can strengthen or weaken us. It can be an opportunity for growth or a destructive passage. It is our own choice: mindfulness in caregiving leads us to assess our attitudes and beliefs, to grow in forgiveness and compassion.

Mindfulness can mean that when we reach the end of our caregiving journey, we emerge as whole people, with mind, body and spirit forged anew by challenges met and surpassed. For me, though, **the overarching result of mindful caregiving is that we will know, beyond any doubt, that we have done the very best we could for our loved one with dementia and that is what makes all the difference.**"

Examples of mindful exercises

- Mindful breathing
- Mindful eating
- Mindful body scan
- Mindful walking
- Loving-kindness exercises



Breathe...Relax

Mindful breathing can help reverse the stress response and retrain the body to be less reactive to stressful situations when it would be maladaptive (e.g., traffic, work, being asked repetitive questions over and over, etc).



Key points of mindfulness for caregivers

- Present moment awareness
- Kindness and compassion
- 7 essential components: Nonjudging, Patience, Beginner's Mind, Trust, Non-striving, Acceptance, Letting Go
- A mindful caregiver develops the strength to look at reality with kindness and acceptance without using up energy wishing things were different.
- They live with a belief in their own strength and grace.
- They enjoy knowing that they are doing the very best for their loved ones and for themselves.

Suggestions for starting a mindfulness/meditation practice



Start with 5 minutes per day (you will want more!)

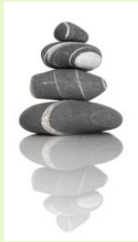
Find a community (local or online)

- Mindful practices are easier to sustain with a supportive community
- A community can be as small as two people. Partner with a fellow caregiver. Find a spiritual buddy.

Find a way to practice that works best for you, fits with your day and your lifestyle

"The best way for caregivers to start and end the day is by practicing mindfulness by finding a quiet place, sitting in a relaxed posture, and closing the eyes to focus on breathing. A twice-a-day routine such as this can combat caregiver stress, and can also help caregivers incorporate mindfulness into the daily routine." ~ Marguerite Manteau-Rao, LCSW

Mindful breathing exercise



Copyright 2012.

Please do not distribute or replicate these slides or the information contained in this presentation without permission.

EDUCATIONAL HANDOUTS

Table of Contents

Page	Content
28	Helpful Definitions and Acronyms
30	Frequently Asked Questions about Primary Progressive Aphasia (PPA): Diagnosis, Causes, Genetics, and Treatment
36	Frequently Asked Questions about Behavioral-Variant Frontotemporal Degeneration (bvFTD)
39	Frequently Asked Questions about Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD)
42	The bvFTD/PPA Medical Care Team
44	Continuum of Care: Caring for Those with Behavioral Symptoms Caused by bvFTD or PPA in Home, Adult Day Services and Long-Term Care Settings
47	Hospitalization for Persons with bvFTD and PPA
48	Common Goals of Creative Arts Therapies with bvFTD and PPA
52	Identifying Communication Strategies for PPA
55	To Use or Not To Use? High-Tech Augmentation and Alternative Communication Devices for Persons with PPA and bvFTD
57	Newly Diagnosed Checklist for bvFTD and PPA
59	Responding to Changes in Behavior
63	Depression in PPA: What Is It?
64	Treating Depression in PPA
65	Late Stage Care in bvFTD and PPA
67	Legal and Financial Planning for the Future
69	bvFTD and PPA - Tuning Into the Needs of Children and Teens
71	Understanding Genetics in bvFTD and PPA
73	When Is It Time? Making Care Transitions
75	Available Care Services
77	Rules of PPA by the Early-Stage PPA Support Group
78	Mindfulness Information and Resources
79	Information and Resources

HELPFUL DEFINITIONS AND ACRONYMS

Activities of Daily Living (ADL) - Includes bathing, dressing, toileting, transfers, continence and feeding.

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 Disease (AD) or Dementia of the Alzheimer Type (DAT) is a form of brain degeneration where memory is the primary symptom; however the disease progressively affects other cognitive abilities including, language, behavior/personality, visuospatial, motor abilities, and ability to carry out daily activities (ADLs). This is the most common form of dementia in persons over age 65.

Agnosia – Loss of the ability to recognize objects.

Agrammatic PPA (PPA-G) – A subtype of PPA usually presenting with word-order, syntax, and grammar 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 or concern of activities, others, or self.

Aphasia – Loss of language.

Apraxia of Speech – The difficulty performing purposeful movements of the mouth in order to produce speech. Also known as oral-motor apraxia or verbal dyspraxia.

Atrophy – Degeneration of an organ or body part. AD, PPA, and bvFTD are each associated with atrophy in specific areas of the brain.

bvFTD – Behavioral-variant frontotemporal dementia (bvFTD). bvFTD is a condition characterized by gradual changes in behavior, personality, reasoning, and problem solving. Most people with bvFTD are in their 50s and 60s at onset but it can affect adults at any age.

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 syndrome, made by the doctor’s impression based on initial and presenting symptoms.

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

Communication Notebook – An alternative and augmentative communication device that contains pictures and words of common objects and situations that an individual with language difficulty can use to aid communication.

Dementia – A generic term to describe a progressive decline in cognition or behavior over time.

HELPFUL DEFINITIONS AND ACRONYMS

Depression – A behavioral condition characterized by sadness and emotional withdrawal.

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 – The 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 Lobar Degeneration (FTLD) – A pathological diagnosis that refers to the specific types of changes seen in the brain in most cases 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).

Magnetic Resonance Imaging or Image (MRI) – A type of scan using powerful magnets to visualize deep structures of the body or brain.

Behavioral Neurology – A subspecialty of neurology that studies the neurological basis of 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 to determine the underlying cause for the clinical symptoms. In PPA, this can only be done at autopsy.

Pick's Disease – A pathological diagnosis that is a type of frontotemporal lobar degeneration. Some clinicians may still refer to the clinical diagnosis of bvFTD as Pick's Disease.

Primary Progressive Aphasia (PPA) – A clinical syndrome defined by the progressive loss of language over at least a two-year period. Sometimes referred to as “temporal-variant” or “language-variant FTD”.

Progressive Supranuclear Palsy (PSP) – A type of frontotemporal lobar degeneration (FTLD). PSP is 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.

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 that controls language, auditory processing and memory.

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):

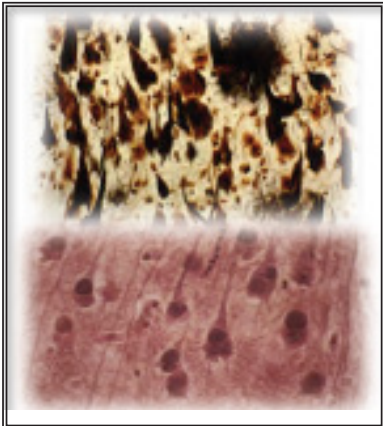
A problem with *word-finding*

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 BEHAVIORAL-VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

What is Behavioral-Variant Frontotemporal Degeneration (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 can affect adults at any age.

What are some features of bvFTD?

- Impairments in social skills and inappropriate or bizarre social behavior
- Lack of awareness (insight) about changes
- 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 but cannot be attributed to clear-cut causes such as head trauma, stroke, or cancer.
- Specifically in bvFTD, cells in the frontal lobe (the area of the brain which controls behavior, judgment, personality and emotion) begin to die.

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, behavioral-variant frontotemporal degeneration is one of the most common dementia diagnoses of people under the age of 65.
- 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.

FREQUENTLY ASKED QUESTIONS ABOUT BEHAVIORAL-VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

How does bvFTD progress?

- The progression of bvFTD is variable and can unfold over many years.
- 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 proteins that can accumulate in malfunctioning brain cells in bvFTD: tau, TDP-43 and FUS. Pathologists are still working to understand the full implications of these different chemical accumulations.
- 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 dementia 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), or Aricept (donepezil), are not effective in bvFTD. Studies are currently underway on another Alzheimer Disease medication, Namenda (memantine), to understand if it can help the symptoms of bvFTD. We do not yet know the results of these studies.
- 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.

FREQUENTLY ASKED QUESTIONS ABOUT BEHAVIORAL-VARIANT FRONTOTEMPORAL DEGENERATION (bvFTD)

- 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.

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 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, resulting in a wide-eyed appearance. They may also develop difficulty swallowing. Unlike Parkinson 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 the cortex, which is the outer part of the brain, and the basal ganglia, which are deep within the brain. Like Parkinson 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. 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 bvFTD 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 bvFTD/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 first symptoms include behavior, attention, concentration, or language, they may be diagnosed with bvFTD 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 bvFTD, 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 Disease medication, such as carbidopa-levodopa, but in general, these medications are less effective in PSP or CBD than in Parkinson 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.

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. In families with this gene, affected people may develop PSP, CBD, bvFTD, or PPA. Different family members may develop different diseases, and develop them at different ages. There is a genetic test

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

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 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 FTLD MEDICAL CARE TEAM

Assembling a care team is important when someone in the family has a diagnosis of Frontotemporal Lobar Degeneration (FTLD). Together, your team can help you navigate the various questions, concerns and uncertainties that can affect the well-being and quality of life for the person and the family. Below is a list of possible Medical Care Team members. Keep in mind not all of the professionals listed below may be available in your area, covered by your health insurance, or familiar with FTLD.

Primary Care Team: This team can consist of a medical doctor, nurse practitioner, and 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. This team will still be in charge of your overall care even if you see a specialist for a particular condition.

Neurologist: This clinician is trained to identify and treat illnesses related to the nervous system and is typically the first to diagnosis FTLD. A behavioral neurologist is specially trained in neurological disorders that affect cognition. Behavioral neurologists are most often found in university health care settings.

Neuropsychologist: 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. These tests help the neurologist either make a diagnosis or understand more specifically what may be causing the symptoms.

Psychiatrist: This clinician specializes in evaluating behaviors and moods of individuals. A psychiatrist may prescribe medications to modify challenging behaviors and moods specific to the diagnosis that are otherwise unmanageable. A special type of psychiatrist, called a neuropsychiatrist or geriatric psychiatrist, is specially trained in treating psychiatric problems in neurological disorders.

Social Worker: This clinician can help you and your family by providing counseling and support, helpful information about your particular diagnosis, in addition to local resources. Some local resources include home care agencies, long-term care options, adult day centers, support groups, specialized programs, meaningful activities & financial/disability resources.

Palliative Care Team: 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. 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.

Additional Clinical Therapies

Speech-Language Pathologist (SLP): This clinician works with those experiencing changes in language. They evaluate different aspects of language in detail and make recommendations and offer strategies to improve communication. SLPs can also help evaluate and treat swallowing disorders.

THE FTL D MEDICAL CARE TEAM

Occupational Therapist: This clinician works with individuals and their family members to improve or maintain the person's daily functioning and reduce the burden on the family caregiver by developing ways to modify or adapt activities of everyday life. This is particularly helpful for movement or motor changes.

Physical Therapist: A physical therapist works with individuals to maximize quality of life through building physical strength, improving balance, preventing falls, conducting home safety assessments, and implementing physical exercise techniques tailored to each individual.

Behavioral Health: This clinician is typically a psychiatric nurse who addresses changes in mood or behavior in the home. This nurse works with the person's psychiatrist and/or primary care physician, to ensure the emotional needs of the patient are being managed effectively.

CONTINUUM OF CARE:

Caring for Those with Behavioral Symptoms Caused by bvFTD or PPA in Home, Adult Day Services and Long-Term Care Settings

As Behavioral-Variant Frontotemporal Degeneration (bvFTD) and Primary Progressive Aphasia (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 bvFTD and PPA. As health care providers, we must address these barriers to care so that we can improve services to people with bvFTD 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 bvFTD 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 bvFTD 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. However, there are limitations to this testing for persons with bvFTD.
 - Due to the lack of memory symptoms, adjusting to transitions in care can be more difficult for a person with bvFTD 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 bvFTD 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 allow for more creative interventions.
 - 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.

CONTINUUM OF CARE:

Caring for Those with Behavioral Symptoms Caused by bvFTD or PPA in Home, Adult Day Services and Long-Term Care 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 bvFTD & PPA often respond best to calm and positive communication (verbal and nonverbal).
- ❖ 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?
 - If safety remains a concern, acknowledge the limits of you and your staff.
 - 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 bvFTD/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.

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.

CONTINUUM OF CARE:

Caring for Those with Behavioral Symptoms Caused by bvFTD or PPA in Home, Adult Day Services and Long-Term Care Settings

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

- ❖ People with bvFTD & PPA often need more staff attention.
 - Participation in group activities is difficult because of bvFTD's effect on social engagement.
 - Providing individual attention is challenging, but can be done. Use information from family to identify low-key one-on-one 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 bvFTD.
- ❖ 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 bvFTD & 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 bvFTD & PPA.
 - Consider how administrators can amend policies or advocate for changes to provide better care.

Reflections on care for professional care staff

- ❖ 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 educate your staff.
- ❖ Continue to look for moments of strength and ability amidst loss and decline.
- ❖ Partner with 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.

HOSPITALIZATION FOR PERSONS WITH bvFTD AND PPA

Hospitalizations can be extremely disorienting for people with cognitive impairment. Often, it is an acute change in behavior you may be unable to identify and the person is unable to describe that may lead to hospitalization. This can include an infection, reaction to medications, or other illness or pain. If concerned about sudden changes in behavior or symptoms, contact your doctor. While it may be possible to avoid hospitalization in some cases, unfortunately, there are times when a person must be hospitalized for their own safety and wellbeing.

Reason for Hospitalization	What to Expect	Be an Advocate
Behaviors • <i>verbal and/or physical aggression;</i> • <i>danger to self/others;</i> • <i>paranoid delusions or hallucinations</i> Infection • <i>Urinary tract infection</i> Other Medical Condition • <i>Pain due to physical injury or other discomfort</i>	Upon Admission: • <i>Medication review</i> • <i>Medical work up</i> • <i>Blood work</i> Patient may experience: • <i>Increased disorientation</i> • <i>Decline in cognitive abilities</i> • <i>Confusion resulting in refusal of medical care</i> • <i>Altered state due to changes in medications</i> Possibilities upon discharge: • <i>Patient may be discharged home with additional care</i> • <i>Patient may be discharged to a facility for short-term rehabilitation therapy</i> • <i>Patient may be discharged to a long-term care setting</i>	• Notify person's neurologist and psychiatrist of the hospitalization. Ask if they are available to speak with hospital staff, if needed. • Request the hospital assign a specialist familiar with your loved one's case. • If helpful, place a sign above the bed stating the person has cognitive impairment (so staff on each shift are aware) • Have a copy of the POA with you • Request to speak with a social worker to begin discharge planning. • Take care of yourself. Take breaks. Call upon family and friends to stay at the hospital with your loved when you are unable to do so.

Sources:

Douglass-Dunbar, M; Gardner, P. Support for carers of people with dementia during hospital admission. *Nursing Older People*, (2007), Vol. 19 Issue 8, p27-30, 4p

Hall, Geri R., MA, RN, CS, *This Hospital Patient Has Alzheimer's*, *American Journal of Nursing* (1991), pp. 45-50.

COMMON GOALS FOR CREATIVE ARTS THERAPIES WITH bvFTD AND PPA

Cognitive Domains Affected by bvFTD	Creative Art Therapy Goals
Psychosocial	- Engage in meaningful activities to enhance motivation - Channel agitation and aggression into healthy modes of expression - Support the highest level of quality of life - Explore alternate behaviors for social inappropriateness, disinhibition, and impulse control problems
Emotional	- Provide opportunities for safe and dignified expressions of thoughts and emotions - Improve mood stability
Communicative	- Provide outlet for self-expression - Develop alternative approaches to communication
Cognitive	- Provide appropriate outlet for perseverative and compulsive behaviors - Practice flexibility in reasoning and decision making skills - Increase tolerance for changing circumstances
Cognitive Domains Affected by PPA	Creative Art Therapy Goals
Psychosocial	- Support the highest level of quality of life - Improve self-confidence in social interactions - Decrease isolation and withdrawal - Stress management - Lower feelings of loneliness by establishing a sense of universality - Support with reaction to initial diagnosis
Emotional	- Decrease depression and anxiety - Build coping skills - Provide opportunities for safe and dignified expressions of thoughts and emotions
Communicative	- Develop alternate approaches to communication - Provide outlet for self-expression - Improve expressive and receptive language skills - Incorporate and create alternative and augmentative communication tools for everyday use
Cognitive	- Provide tools for facilitating word retrieval - Strengthen neurological pathways utilized in communication tasks

Erica Hornthal, LCPC, BC-DMT, Rebecca J. Froman, MA, MT-BC & Deborah Del Signore, M.A.A.T., ATR-BC

COMMON GOALS FOR CREATIVE ARTS THERAPIES WITH bvFTD AND PPA

"Movement never lies. It is a barometer telling the state of the soul's weather to all who can read it."
Martha Graham

"I see dance being used as communication between body and soul, to express what is too deep to find for words."
Ruth St. Denis

DANCE/MOVEMENT THERAPY

What is dance/movement therapy?

- Dance/Movement therapy, as defined by the American Dance Therapy Association, is the psychotherapeutic use of movement to further the emotional, cognitive, physical, and social integration of the individual.
- Dance/movement therapy supports that mind, body, and spirit are connected and that individuals should be treated in such a way that supports integration of these three entities.

What are the benefits of dance/movement therapy?

- Promotes self expression, creativity, and self awareness
- Facilitates insight into habits and behaviors on a body level
- Facilitates communication when verbal skills are compromised or hard to access
- Provides opportunities for restoration, maintenance or improvement of memory, mood, and social interaction

What do dance/movement therapists do?

- Use body movement, as the core component of dance, to provide the means of assessment and the mode of intervention for dance/movement therapy.
- Assess through both psychological and movement parameters to determine needs and goals.
- Use interventions and dance/movement therapy techniques to facilitate therapeutic processes.
- In a dance/movement therapy session, music and props are often incorporated to encourage extension of movement, self expression and socialization.
- Many movement styles and approaches can be used to attain interaction and authentic expression including, but not limited to, creative drama, exercise, relaxation techniques, massage, social dancing, and interactive psychosocial games.

Who are dance/movement therapists?

- Dance/movement therapists have completed graduate degrees at collegiate programs approved by the American Dance Therapy Association.
- Course work includes biological, social, psychological, and behavioral sciences, research methodology, movement assessment and observation, history, theory, and techniques of dance/movement therapy.
- The National Board of Certified Counselors (NBCC) has recognized dance/movement therapy as a specialty of counseling since 1998.

For more information:

- Contact the American Dance Therapy Association at www.adta.org or (410) 997-4040 or the IL Chapter of the American Dance Therapy Association at: <http://www.facebook.com/people/Adta-Illinois-Chapter/1824751080>.

Erica Hornthal, MA, LCPC, BC-DMT
Dance Therapist

COMMON GOALS FOR CREATIVE ARTS THERAPIES WITH bvFTD AND PPA

"Music can lift us out of depression or move us to tears---it is a remedy, a tonic, orange juice for the ear. But for many of my neurological patients, music is even more- it can provide access, even when no medication can, to movement, to speech, to life. For them, music is not a luxury, but a necessity."

Dr. Oliver Sacks, neurologist and author

MUSIC THERAPY

What Is Music Therapy?

- Individualized clinical music intervention addressing needs and goals relating to psychological, physiological, cognitive, communicative, behavioral, social, and emotional functioning.
- Music is used as a tool in therapy treatment with a board certified music therapy professional.
- The use of evidence-based, dignified, and creative music interventions to promote adaptive and constructive skills, behaviors, thoughts, feelings, and strategies to enhance the quality of life, health, and well-being of the client.

What Music Therapy Is Not:

- For those only with musical skill or talent.
- Solely for the sake of activity, entertainment, education, performance, or product.
- One type of music used for all individuals with the same diagnosis or therapy goals.

What Do Music Therapists Do?

- Assess both non-music and musical responses to develop treatment based on national standards of clinical practice.
- Combine creative processes, physiological knowledge, therapeutic approaches, and personal strengths to benefit the client.
- Work with clinical populations of all ages in many settings with expertise in specializations.

Why Music Therapy For People With bvFTD and PPA?

- Music therapy can provide a normalizing experience for adults and their loved ones because it is a natural, familiar, engaging, motivating, and non-invasive medium that can incorporate preferences meaningful to the clients, their families, and care team members.
- Sessions provide individual and group opportunities for intervention using alternative means of communication, self-expression, interaction, and thinking.
- Music is especially beneficial for those with neurological impairments such as bvFTD and PPA due to the way music is processed in the brain and qualities inherent in music.

Who Are Music Therapists?

- Music therapists have completed baccalaureate degrees or higher in music therapy at collegiate programs approved by the American Music Therapy Association.
- Course work: biological, social, psychological, and behavioral sciences, research methodology, multicultural and ethical competency, musicianship, and music therapy principles.
- National credentials are earned upon completion of certification exam and are maintained.

To Learn More Or Find A Music Therapist:

- American Music Therapy Association: (301) 589-3300 or www.musictherapy.org
- Certification Board for Music Therapists: (800) 765-CBMT or www.cbmt.org

Rebecca J. Froman, MA, MT-BC | Music Therapist-Board Certified

COMMON GOALS FOR CREATIVE ARTS THERAPIES WITH bvFTD AND PPA

ART THERAPY

Art therapy is a master's level mental health profession where the creative process of art making is utilized to support people of all ages through psychological, emotional, cognitive and/or physical change. The goal is to achieve higher levels of well-being. It is not an art lesson or a recreational activity per se, but it can be pleasurable. Previous experience in making art is not necessary to benefit from art therapy.

Fundamentally, it is based on the belief that the creative process of self-expression innately:

- Informs people about conflict and problems
- Connects people with others
- Positively impacts behaviors
- Lowers stress
- Improves confidence and ability to cope with situations
- Assists with developing enhanced self-awareness

How does Art Therapy work?

- With an art therapist, diagnosed persons can reflect on their art product and/or art making process and discover an increased awareness of self and others and how to cope with symptoms, stress and traumatic experiences.
- Art therapy uses visual art (drawing, painting, sculpture, and other forms) and the creative process in conjunction with counseling and psychotherapy techniques.
- Art therapy can also be administered in ways to support social activism in communities.

Why choose Art Therapy for bvFTD and PPA?

- Many people living with dementia may not benefit from talk therapy because their use of and ability to process language becomes increasingly impaired.
- Art therapy can be tailored to safely support undesirable behaviors, (e.g. perseveration, expressions of anger and aggression) and be adapted to meet the needs of an individual (e.g. opportunities to feel and be in control of self and a situation, explore alternate ways of communication, serve as an outlet for frustrations).
- Since art therapy is a mental health profession it also lends itself to supporting the entire care-relationship, the person with the diagnosis and their loved ones. It affords a unique opportunity to bring all parties involved together to improve communication and cope in general.

Who are Art Therapists?

- Art therapists are found in community and clinical settings.
- They are trained, registered professionals in the application of: a variety of art mediums for treatment, assessment and evaluation purposes; psychotherapy and counseling for individuals, groups and families.
- They have a thorough understanding of human and creative development; multicultural issues; research methods; ethics and standards of practice.
- American Art Therapy Association: www.arttherapy.org

Deborah Del Signore, M.A.A.T., ATR-BC | Art Therapist

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 therapist can help you learn these new strategies and tools.

On a Daily Basis

- Remember that the goal is communication, not perfection.
- Do not speak for the individual. Establish a cue to use that implies help is needed.
- Speak slowly, and allow enough time for the individual to respond to questions.
- If a response is incomplete or unclear, ask for clarification; repeat what you heard. Do not pretend to understand if you do not.
- Help the person avoid stress. It makes communication challenges more difficult.
- Continue to participate in social activities (gatherings with friends/family) as much as possible.
- Be aware of signs of depression. Because individuals with PPA are often aware of changes, they may experience depression, anxiety, frustration, and loneliness.
- There will be good days and bad days. Do your best to provide additional support on the more difficult days.

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 the communication notebook or become familiar with communication technology before it is needed.

IDENTIFYING COMMUNICATION STRATEGIES FOR PPA

The Role of the Supportive Communication Partner

- Try not to interrupt and supply a word unless your help is requested.
- Ask a question, which 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.

METHOD	STRATEGIES FOR EFFECTIVE COMMUNICATION
<u>LISTENING</u>	• 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>	• Cue the speaker to talk around the word he/she is trying to say by encouraging, “Tell me about it...” • Describe its purpose or function • General category (fruit, clothing, sport) • Physical description (size, shape, color) • Location • Synonym or antonym for the word
<u>WRITING</u>	• Can be used when reading and writing are relatively well preserved • 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 • Communication partner can write out choices and the individual can choose an appropriate response • Write out conversational scripts to use during specific situations (see description below)
<u>GESTURES</u>	• Gestures can be developed for core daily functions • Practice and have gestures in place, before you actually need them
<u>TOUCHING</u>	• So much of communication is nonverbal! Remember to use facial expressions and the sense of touch when communicating with an individual with PPA • Firm handshake, pat on the back, holding hands, giving a hug, sitting close

IDENTIFYING COMMUNICATION STRATEGIES FOR 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 30 minutes each day.
- A computer script program is available for purchase here:
<http://ricaphasiascripts.digitalcontentcenter.com>

Alternative/Augmentative Communication Tools: Low Tech Devices

- Communication Notebooks: Commercially available are 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 in different sections of the books and words and descriptive phrases are attached to each picture. Use a 3-ring binder with plastic page protectors. Pages can easily be added. Try using Google Images to search for pictures that are meaningful to the individual.
- Communication Board (e.g. dry erase board)
- Index cards with pre-written statements (“I would like a drink of water”) or pictures (glass of water image).

TO USE OR NOT TO USE?

High-tech Augmentation and Alternative Communication Devices for Persons with PPA and bvFTD

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/bvFTD

There are many AAC options to consider. It is essential that the person with PPA/bvFTD and the 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/bvFTD communicate their needs in various social environments. Due to other non-language cognitive changes common with PPA/bvFTD, these devices are not always a good fit.

Not designed for persons living with PPA/bvFTD

At this time, no AAC device has been specifically designed to meet the needs and unique communication and cognitive changes of a person with the diagnosis of PPA/bvFTD. 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 the diagnosis.

Where do I learn more?

There is not a lot of information on specific applications and devices for people with PPA/bvFTD. 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/bvFTD and often the family needs to educate the provider on the challenges the person with the diagnosis experiences.

Examples of AAC Products

Stand-alone AAC devices

GoTalk20 (\$200): This 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

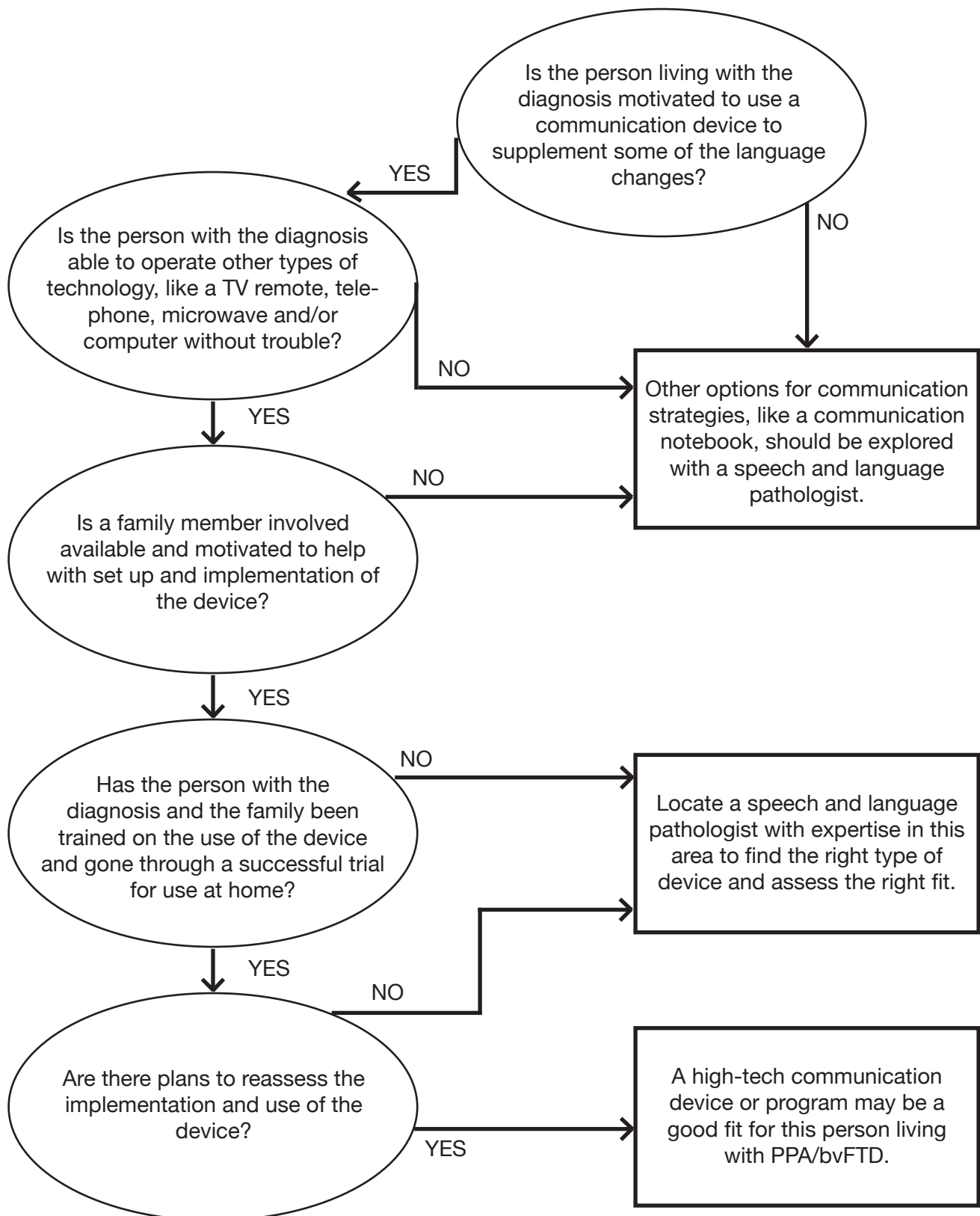
Proloquo2Go (\$150) (for the iPhone and iPad): This speech-generating device provides symbols and default vocabulary for over 7000 items. The program does not have a voice recording option, so the voice is computerized. It is very comprehensive but complex.

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. They are designed to work in tandem with the Lingraphica device. Users can create their own selection of icons, phrases, and videos on Lingraphica, and SmallTalk transfers them to the iPhone or iPod touch.

TO USE OR NOT TO USE?

A PPA/bvFTD High-Tech Device Flow Chart

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



NEWLY DIAGNOSED CHECKLIST FOR bvFTD AND PPA

SUPPORT

- ☐ Tell someone. Consider *how* and *when* to tell family and friends.
- ☐ Educate yourself about the diagnosis.
- ☐ Join a support group that meets your needs.
- ☐ Find out about local agencies and services for the diagnosed person and your family.
- ☐ Take time for yourself and ask others to help you commit to this promise.
- ☐ Find a social worker that can be an advocate for you.
- ☐ Look for and join a research study.

LEGAL AND FINANCIAL

- ☐ Evaluate options regarding continuing employment to retain health insurance.
- ☐ Start discussions early! If eligible for VA Benefits or Long-Term Care, inquire about these benefits early in the disease course.
- ☐ Apply for Social Security Disability Insurance. PPA and bvFTD are on the “Compassionate Allowances” list.
- ☐ Meet with an elder law attorney for financial planning.
- ☐ Begin to discuss future care wishes and options with the diagnosed person and doctors.
- ☐ Investigate options to pay for long-term care.
- ☐ Organize documents: Power of Attorney, wills, insurance paperwork, etc.
- ☐ Continuously review plans over time.

QUALITY OF LIFE

- ☐ Adapt to the person’s behaviors and needs. Use tools to help with day-to-day activities (e.g., ready-made grocery list, prepared card with favorite restaurant order, calendars, etc.).
- ☐ Help the diagnosed person continue to enjoy their favorite activities for as long as possible. Simplify if necessary.
- ☐ Encourage diagnosed person to exercise and stay active.
- ☐ Help them maintain their independence and dignity.
- ☐ Keep a daily routine.

SAFETY

- ☐ Be watchful of day-to-day activities (checkbook, paying bills, going places alone, driving). Regularly evaluate the abilities of the person.
- ☐ Be aware of the person’s decision-making and judgment.
- ☐ Don’t argue or try to change their behavior.
- ☐ Have the person carry an “I have PPA/bvFTD card.”
- ☐ Consult with an occupational or physical therapist if the person is experiencing changes in motor ability.

NEWLY DIAGNOSED CHECKLIST FOR bvFTD AND PPA

COMMUNICATION

- ☐ Continue to include the person in conversations but prepare for the conversations to take more time than before.
- ☐ Speak clearly and slowly to the person.
- ☐ Give simple instructions and use simple sentences. Don't bombard the person with too much information at once.
- ☐ Minimize noise and number of people in a conversation at a time. Speak face-to-face.
- ☐ Wait for the person to finish verbalizing their thought. Don't interrupt unless you have permission.
- ☐ Don't pretend to understand when you don't.

MEDICAL CARE

- ☐ Find a neurologist who understands PPA and bvFTD.
 - ☐ Be a partner with the doctor and medical team.
 - ☐ Make a list of questions that you can ask the doctor at the next visit.
 - ☐ Take notes when at the appointments.
 - ☐ Track changes in behavior and communication.
- ☐ Find a speech and language pathologist and start to learn ways to communicate in addition to speech (gestures, pictures, communication devices), etc.
- ☐ Find a psychiatrist, if appropriate, preferably one who understands bvFTD and PPA.
- ☐ Find a social worker.

COPING

- ☐ Be prepared to take on increased responsibilities that the other person used to handle.
- ☐ Seek individual counseling to deal with personal grief, depression or anger.
- ☐ Don't be afraid to ask others for help.

RESOURCES/WEBSITES

- www.brain.northwestern.edu - Northwestern University Cognitive Neurology and Alzheimer's Disease Center
- www.aphasia.org - National Aphasia Association
- www.theaftd.org - Association for Frontotemporal Degeneration
- www.ppaconnection.org - IMPPACT, The International PPA Connection
- www.caregiver.org - Family Caregiver Alliance
- www.naela.org - National Academy of Elder Law Attorneys
- www.fpanet.org - Financial Planning Association
- www.ssa.gov/disability - Social Security Administration Disability Programs
- www.cms.gov - Centers for Medicare and Medicaid Services

RESPONDING TO CHANGES IN BEHAVIOR

Significant changes in behavior and personality are the main symptoms of behavioral-variant fronto-temporal degeneration (bvFTD). This means that a generally active, involved person could become apathetic and disinterested. The opposite may also occur. A usually quiet individual may become more outgoing and disinhibited. Personality changes can also involve increased agitation, irritability, anger and even verbal or physical outbursts toward others (usually the primary caregiver). Not all people with bvFTD will develop 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
<u>APATHY/LACK OF MOTIVATION</u> Lack of interest, drive and/or inability to initiate activity. Often confused with depression. <i>Examples:</i> - Unable to take the steps to go 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.	- 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?" - If they resist, do not force the activity
<u>PERSEVERATION</u> Repeating the same activity over and over when it no longer makes sense to do so. <i>Examples:</i> - Repeatedly doing the laundry even if there is only one item to wash. - Continuously talking about the same topic over and over.	- Distract by getting their attention focused on something else. - Do not feel you need to explain why. - If the activity is not dangerous or costly, let it continue.
<u>DISINHIBITION</u> Acting impulsively without considering the social effects of inappropriate behavior, or lacking insight that the behavior can offend others or cause harm. <i>Examples:</i> - 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	- 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 "The person I am with has bvFTD" card.
<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. <i>Examples:</i> - 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	- 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. - Let others know about the diagnosis so they are not offended.

RESPONDING TO CHANGES IN BEHAVIOR

<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. <i>Examples:</i> • Picks up objects that are part of others’ activities • Imitate 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.	• 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.
<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. <i>Examples:</i> • 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 cookie	• Provide supervision, set out portions. • 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, benefits, risks or any medication (1) Grow, Sandi, RN. Discussion: Problem solving template for FTD: Hyperoral behaviors. AFTD Committee on LTC Education. December 12, 2011
<u>RITUALISTIC/COMPULSIVE BEHAVIORS</u> Acts that are completed over and over again, without purpose and unrelated to the circumstances in which they occur <i>Examples:</i> • 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.	• 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.
<u>AGGRESSION</u> Because many individuals with bvFTD 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. <i>Examples:</i> • Shouting or name-calling • Physical abuse (hitting, pushing)	• Stay out of the person’s way if they are combative. • In cases when you feel unsafe, call police but explain the person with bvFTD’s condition. • Never point out the problem to the person, try to reason about their behavior, or argue about the “logical” solution.

RESPONDING TO CHANGES IN BEHAVIOR

REASONING 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. <i>Examples:</i> • 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).	• 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.
SEXUAL DISINHIBITION⁽²⁾ 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. <i>Examples:</i> • 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	• 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 bvFTD" 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. (2) Discussion by Hall, Geri R. PhD; Bird, Thomas D. MD; Nichols, K. Frontotemporal Dementia: Issues of Sexuality. November 23, 2009

General Communication Tips

- Always avoid confrontation. Do not argue or try to point out the truth.
- Do not take the person's behavior personally. They are not intending to hurt you. They are no longer able to have normal reactions and feelings.
- When it is helpful for the person, keep decision making to a minimum. Don't put the person in a situation that stresses failing reasoning capacity.
- Approach the person with a calm, reassuring tone. Smile. Individuals with bvFTD are better at understanding positive emotional expressions than negative ones. If you are frowning or looking sad or angry, the person may not understand. Alternatively, the caregiver's emotional facial expression can elicit the same expression in the person through imitation (even though he/she is not feeling that way).

Meaningful Activities

- Provide materials that are readily available and not dangerous. (jigsaw puzzles, coins to be sorted, laundry to be folded)
- The person should be provided with physical activities within their capacity. They may require support, such as a "trainer," an individual hired to take the person out for a daily walk and other types of stimulating activities. Using such a label for the needed assistance may be more acceptable to the person than a "companion" or a "caretaker."

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.

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

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.

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.

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.

LATE STAGE CARE IN bvFTD AND PPA

“When we are dead, and people weep for us and grieve,
Let it be because we touched their lives with beauty and simplicity.
Let it not be said that life was good to us, but rather we were good to life!”
Jacob P. Rubin

LATE STAGE SYMPTOMS

Just as the progression of each person with Behavioral-Variant Frontotemporal Dementia (bvFTD) 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

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 can be provided where the person lives (in the home, hospital, or a long term care facility).
- It attends to the emotional, spiritual, psychological, and physical needs of the patient and recognizes the important role family and friends play as caregivers.
- Hospice offers a range of compassionate care for both the patient and family:
 - 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
- Speak to the physician managing the persons condition or visit National Hospice and Palliative Care Organization www.nhpco.org to connect to local agencies.

LATE STAGE CARE IN bvFTD AND PPA

- 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.
- It is never too early to learn about hospice and investigate hospice agencies as part of planning for care.
- The advanced stages of bvFTD 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 FTLD^(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 bvFTD, 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 FTLD and the benefits of hospice to the entire family.
- Persons with FTLD 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.

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 Behavioral-Variant Frontotemporal Dementia (bvFTD) 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 to 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 bvFTD/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	Joint Federal and State Government
<i>Pays for</i>	A percentage of out-patient health and mental health, hospital care, home health, some 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. For days 20-100, a co-pay is required.	Pays long-term care, home-health, community-based services, and skilled nursing if providers accept Medicaid as payment.
<i>Requirements</i>	Must have contributed to Medicare system and meet eligibility criteria to qualify.	Must meet income and asset limits to be eligible (differs by state).

Important Documents Checklist

This checklist is a tool to guide the family in completing the necessary legal documents important for each person living with bvFTD or PPA.

	Date Completed	Notes
<i>Power of Attorney for Health Care</i>		
<i>Power of Attorney for Property</i>		
<i>Will</i>		
<i>Living Will</i>		
<i>Do Not Resuscitate (DNR), if applicable</i>		

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

bvFTD 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 wellbeing. 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 bvFTD and PPA with your children might scare them. Kids are intuitive and can sense anxiety or tension within the home. Even preschoolers often sense the changes bvFTD and PPA bring. 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 bvFTD and PPA cause 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 bvFTD and PPA 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.

bvFTD 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 a bvFTD or PPA 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 bvFTD or PPA, 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 bvFTD, 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 bvFTD or PPA 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 bvFTD or PPA 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 bvFTD or PPA, 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 bvFTD or PPA 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/>

©2012. Adapted from a forthcoming publication of the AFTD Task Force on Families with Children, *What About the Kids? Frontotemporal Degeneration: A Booklet for Parents with Young Children and Teens*

UNDERSTANDING GENETICS IN bvFTD 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 bvFTD & 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 bvFTD AND PPA

- FTLT 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 bvFTD or PPA have a positive family history of bvFTD 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 bvFTD-type diagnoses being passed from parent to child. Virtually every person with hereditary bvFTD/PPA has an affected parent. Also, each child and sibling of the person with hereditary bvFTD/PPA has a 50% chance of inheriting the disease.
- The most common genes associated with hereditary bvFTD/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 bvFTD and ALS. Other genes are currently being investigated.

WHEN IS IT TIME? MAKING CARE TRANSITIONS

Throughout the course of Behavioral-Variant Frontotemporal Degeneration (bvFTD) and Primary Progressive Aphasia (PPA), diagnosed individuals and their family members are in a state of constant transition. Transitions occur in roles and relationships in all aspects of life, evidenced by ongoing adjustments in one's lifestyle and the need to adapt and cope with emotional, financial, and lifestyle changes in addition to facing decisions regarding care needs.

A care transition is the point between one level of care to the next. Care transitions are made based on (1) the level of functioning of the individual with the disease, (2) care needs within the current environment, and (3) care-giver needs and overall health. While care transitions can be difficult adjustments, they can improve quality of life for individuals living with a diagnosis and their families.

Three Care Transition Tools

1. **Taking Care: You Can Do It, But You Can't Do It Alone** Asking others to assist is key to healthy and successful caregiving. This brief inventory is meant to help gain awareness of your ability, perceptions and feelings around setting limits and accepting support from others.

Taking Care: You Can Do It, But You Can't Do It Alone		
Yes	No	I have created a list of individuals who have offered help.
Yes	No	I have asked those individuals for specific help.
Yes	No	I hesitate asking for help for fear of being a burden.
Yes	No	I shouldn't have to ask for help. People should see what I need and offer help.
Yes	No	I rarely set limits because I feel guilty saying "no" or "I can't."
Yes	No	I'm afraid of letting people down or disappointing them.
Yes	No	I'm afraid of expressing feelings of anger or frustration.

2. **"Creating a Community of Care"** represents the people who can be part of care - family, friends, neighbors, acquaintances or professionals. Being open to and specific about the role others can play, (however large or small), makes care more manageable and offers others an opportunity to contribute. Review the list below and begin to consider what help is needed, how often and who is available to assist you.

Creating a Community of Care		
What help is needed	How often is it needed	Who can provide it
Household maintenance		
Financial management		
Medical appointments		
Activity/Exercise		
Care of children in the home		
Companionship		
Safety supervision		
Meal preparation		
Dressing and grooming assistance		
Bathing		

WHEN IS IT TIME? MAKING CARE TRANSITIONS

3. Continuum of Care for bvFTD & PPA

This chart was developed as a guide to help determine care needs, next steps in care, and how to respond to changes in needs and safety of a person living with bvFTD & PPA. At any stage in the disease, it is important for the caregiver to continuously evaluate the person's level of functioning. Because the disease progression is different for each person, we are unable to predict when changes will occur. Despite this uncertainty, it is never too early to begin planning for the next level of care.

Continuum of Care for bvFTD & PPA		
	Indicators for Additional Care	Care Options
Mild Impairment	- Unable to initiate activities without assistance. - Unable to take medications properly. - Unable to perform job, hobbies, or regular household tasks without assistance. - Cannot manage finances; odd or excessive purchases and financial errors. - Has had accidents while driving, changes in ability to understand/obey traffic signs and laws. - Examples of poor judgment. - Making poor decisions that jeopardize individual safety at home and in public. - Caregiver feels that the person's care needs exceed abilities. - Caregiver feels increasingly stressed.	- Family or friend begins to assist/supervise activities as necessary. - Additional care in the form of volunteer, paid personal assistant, companion, "personal trainer", homemaker, driver, financial accountant, or nurse to assist with medication. - Adult Day Services to assist with supervision, social engagement and meaningful activity.
Moderate Impairment	- Unable to prepare food safely independently. Problems judging what is appropriate to eat. - 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. - Unsafe alone in public or alone at home. - Cannot communicate needs to others, especially in a crisis. - Caregiver feels that the person's needs exceed his/her abilities. - Caregiver is feeling increasingly stressed.	- Family/caregiver assists with more activities as person has more trouble functioning. - Increase supervision to ensure safety. - Home care aide or companion to assist with basic (define) needs. - Assisted Living Community to help support basic (define) and functional (define) needs. - Skilled Nursing Community with secure dementia unit to provide 24/7 supervision, appropriate activity, and support for basic and functional needs.
Severe Impairment	- Physically dependent, difficulty walking without falling. - Less interested in eating, is losing weight. - Trouble swallowing. - Incontinent. - Unable to communicate, understand others, express self. - Behavior changes are affecting the person's and family's safety. - Caregiver feels that the person's needs exceeds his/her abilities. - Caregiver is feeling increasingly stressed.	24 hour caregiving with family or paid in-home care. - Skilled Nursing Community with secure dementia unit to provide 24/7 supervision, appropriate activity and safety, as well as meeting all basic and functional needs. - Hospice team to evaluate condition, provide palliative care and support patient & family.

Throughout the illness families experience ongoing loss and grief. There are resources available through local medical communities, including palliative and hospice teams, to provide ongoing support to the family.

AVAILABLE CARE SERVICES

Service	Description of care	How is it paid for?
Adult Day Program http://www.eldercare.gov/ www.alz.org (search by local chapter)	Care for individuals during the day. Provide meals, supervision, stimulating and structured activity and social engagement. Some offer assistance with personal and medical care.	Private Pay Some Long Term Care Insurance Department on Aging Sliding Scale Fee Financial Assistance Some Veteran's Benefits
In-Home Health Care www.medicare.gov/homehealth-compare	(Includes physical, speech, & occupational therapies, skilled nursing, & behavioral health). Temporary/short-term and provided in the home. One must be "homebound" to be eligible for in-home care.	Private Insurance Medicare
Care Management www.caremanager.org	Care managers provide assistance managing, organizing and overseeing care. Facilitate transitions in care and are especially helpful for long distance caregivers and families in conflict.	Private Pay Some Long Term Care Insurance
Private Duty Home Care www.private-duty-homecare.org	Private Duty Home Care staff provide/arrange services, from companion services to skilled nursing care.	Private Pay Some Long Term Care Insurance Some Disability Services Some Veteran's Benefits
Assisted Living Facility/Group Homes http://longtermcare.gov/ http://www.seniorhousingfinder.org/	Provides assistance with basic activities of daily living (ADLs) such as bathing, grooming, dressing, and other activities of daily living. Most offer structured social activity and some provide medication assistance. Assisted living does not offer complex medical services.	Some Long Term Care Insurance Private Pay Some Veteran's Benefits
Nursing Home www.medicare.gov/nhcompare/ http://longtermcare.gov/ http://www.seniorhousingfinder.org/	24-hour skilled nursing and personal care and supervision. Some provide security to prevent wandering. For those able to participate, structured activities are provided.	Some Long Term Care Insurance Some Veteran's Benefits Private Pay Medicare (limited benefits)
Hospice and Palliative Care http://www.nhpco.org/	Care that promotes dignity and comfort at the end of life. Provides therapies and support for diagnosed individual and family.	Private Insurance Medicare Hospice Benefit Medicaid Hospice Benefit

Services and definitions can vary by state. The descriptions and websites listed are not exhaustive. Contact your local providers for specific referrals. Speak with your insurance company about benefits.

AVAILABLE CARE SERVICES

When evaluating care services, it is important to inquire about the following:

- Tell me what you and your staff know about FTD and/or PPA.
- How will you help the person adjust to the change in care/the new environment?
- My loved one experiences symptoms of (example). How have you managed these behaviors/symptoms before?
- At what point will you no longer be able to provide care?
- How can you help the person transition to the next level of care?

RULES OF PPA

BY THE EARLY-STAGE PPA SUPPORT GROUP

1. It's okay to just listen.
2. Don't be afraid to ask for help.
3. Difficulties with speaking, writing and reading do not begin at the same time. Some challenges are easier to deal with than others.
4. There are good days and bad days, don't be afraid of the bad days.
5. It's not the worst thing that is going to happen. It won't get better but there are people out there with other problems.
6. Speech therapy is good practice.
7. Write out notes for what you're going to say and practice it.
8. Tell other people (e.g., friends and family) about your condition.
9. Carry an "I have PPA card" - it's good for emergencies and to quickly explain your difficulty with language to people. Also keep a phone card with emergency numbers.
10. See a good neurologist who is knowledgeable about PPA.

MINDFULNESS INFORMATION AND RESOURCES

General

- *Mindfulness-Based Stress Reduction (MBSR)* is a structured program that teaches individuals the principles of mindfulness and how to apply them to deal more effectively with stress. The MBSR program was originally developed at the University of Massachusetts Medical Center by Jon Kabat-Zinn, Ph.D. He and his staff have gone on to train practitioners who have established independent MBSR programs throughout the United States and the world. Some practitioners use the MBSR techniques in a strict sense and others incorporate mindfulness based practices less formally into their work with individuals. The University of Massachusetts has a search engine that includes a directory of national and international practitioners:
<http://w3.umassmed.edu/MBSR/public/searchmember.aspx>
- Mindfulness based meditation practices, formal or informal, can be found at many other types of community centers, yoga studios, and other organizations that promote this type of philosophy and practice.
- Internet as a resource: Google search “mindfulness training Chicago” (or your local city/area). Lots of good resources pop up for Chicago and the surrounding area. You can also find guided meditations online (often free), on YouTube, or for purchase (e.g., Amazon).

Books and Guided Meditations (Audio)

Full Catastrophe Living by Jon Kabat-Zinn

Mindfulness for Beginners (audio cd) by Jon Kabat-Zinn

Guided Mindfulness Meditation (audio cd) by Jon Kabat-Zinn

Calming Your Anxious Mind by Jeffrey Brantley, M.D.

The Miracle of Mindfulness by Thich Nhat Hanh

For Caregivers

- In her new book, **“Leaves Falling Gently: Living Fully with Serious and Life-Limiting Illness Through Mindfulness, Compassion and Connectedness”** Susan Bauer-Wu, PhD, RN, FAAN, associate professor of nursing at Emory’s Nell Hodgson Woodruff School of Nursing, offers practical guidance on using mindfulness meditation for coping with physical pain and life changes or when faced with serious conditions such as cancer, Alzheimer’s disease or caregiver stress.
http://www.youtube.com/watch?v=Nv-vktP-e_s
- **Mind Deep:** A Mindfulness Practice Blog (can choose the dementia related posts)
<http://minddeep.blogspot.com/>
- **Marguerite Manteau-Rao** runs a mindfulness-based training program for care partners of persons with dementia in Palo Alto, CA. The Presence Care Project: *Less Stress, Greater Well-being for Dementia Care Partners* includes helpful articles, resources, and podcasts.
<http://www.presencecareproject.com/>

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 800-866.507.7222 (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, IMPPACT

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 and is no longer able to work due to the disease, 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. Part A covers inpatient care without monthly premiums. Part B covers outpatient care with a monthly premium.

Medicaid

1-800-843-6154

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.

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 day programs, support groups, respite providers, in-home care, case management and care giving services.

National Private Duty Association

<http://www.privatedutyhomecare.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

Geriatric Care act as a guide and an advocate and provide ongoing assessments, referrals and care to an older adult.

National Hospice and Palliative Care Organization

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

Safety

Dementia and Driving

www.thehartford.com/alzheimers/

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 who wander or have a medical emergency.

Support

Camp Building Bridges

417-880-7910 or email: tandamobley@centurylink.net

A summer camp for teens (12-16) who have a family members with any form of dementia.

Northwestern Support Groups- Contact Mary O'Hara at 312.503.0604

- bvFTD/PPA Family Support Group- *3rd Monday of the Month, 6pm*
- Early Stage PPA Patient Support Group- *Ongoing sessions.*

Northwestern bvFTD and PPA Family Contact List

Contact c-wieneke@northwestern.edu

Online Support

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

Cut out the cards below to keep in your wallet for emergency situations.



The person I am with has Frontotemporal Degeneration.

This is caused by a condition in the brain that impairs behavior and judgment.

Sometimes they may say things or act in a way that seems strange or inappropriate. They are unaware that they are acting in this fashion.

How you can help: Please be patient. Do not laugh if they speak or act inappropriately. Speak simply and directly.

Northwestern CNADC: www.brain.northwestern.edu

In Case of Emergency

Name: _____

Address: _____

Phone: _____

Please Contact:

Name: _____

Phone: _____

Relationship: _____

I have Primary Progressive Aphasia.

This is caused by a condition in my brain that makes it difficult for me to say the words I mean to say.

Sometimes I may also have difficulty understanding what others are saying to me.

I am not under the influence of alcohol or drugs. There is nothing wrong with my hearing, memory or thinking abilities.

How you can help: Give me time to communicate. Speak simply and directly to me. Do not shout; it does not help. Ask yes/no questions.

Northwestern CNADC: www.brain.northwestern.edu

In Case of Emergency

Name: _____

Address: _____

Phone: _____

Please Contact:

Name: _____

Phone: _____

Relationship: _____

Advocate Health Care has many services available that are designed to assist with the challenges of Alzheimer's disease.

Advocate Memory Assessment Centers

These centers offer a comprehensive evaluation and functional assessment to aid in the diagnosis and treatment of Alzheimer's disease and other types of dementia.

- Chicago – Hyde Park 773.493.8212
- Chicago – Ravenswood 773.561.7500
- Downers Grove 630.275.6171
- Oak Lawn 708.684.4393
- Orland Park 708.873.4500
- Park Ridge 847.318.2500

Advocate Adult Day Services

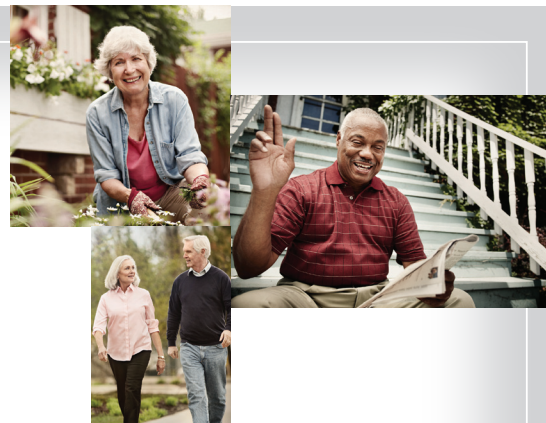
These centers are interactive, safe and secure community-based programs for participants requiring supervised care during the day.

- Des Plaines 847.824.5079
- Libertyville 847.990.5817

Advocate EXPRESSIONS

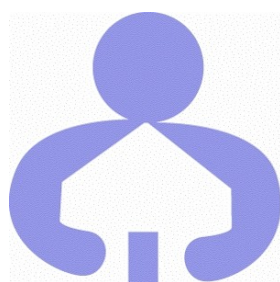
EXPRESSIONS is a program for people diagnosed with the earliest stages of Alzheimer's disease and related dementia. Activities are designed to foster engagement with others who are experiencing the realities of living with memory loss.

- Des Plaines 847.824.5143



Advocate Health Care

Inspiring medicine. Changing lives.



Care Choice Home Health, Inc.

Home Health Care You can rely on.

Services:

- Skilled Nursing
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Home Health Aide
- Medical Social Work
- Medical Supplies
- Nutritional Counseling

Areas of Expertise:

- Parkinson's Disease Management
- Stroke, Brain and Spinal Injury Rehab
- Orthopedic Rehab
- End Stage Renal Disease
- Heart Failure Management

Tel. 847.329.0648 Fax. 847.329.0360

www.carechoicelhomehealth.com



Professional Advice. Professional Care.

Caring for a cognitively impaired loved one is overwhelming.

SeniorBridge provides care in the home for people with dementia and other chronic health conditions. And isn't home where you and your loved ones want to be?

Let our professional Care Managers help you with long term care decisions.

Benefits of SeniorBridge:

- Reduced hospitalizations
- Better overall physical health
- Improved quality of life
- Less family stress



"Call Today For A Free Consultation"

500 N. Michigan Avenue, Suite 1540 Chicago, IL 60611

Phone: (312) 329-9060

Toll-free: (800) 801-0420



Amedisys is a leading home health and hospice care company focused on bringing home the continuum of care. We deliver personalized home health and hospice care to thousands of patients and their families, in the comfort of their own homes.

- **Skilled Nursing**
- **Chronic Care Programs**
- **Physical Therapy**
- **Speech-Language Pathology**
- **Occupational Therapy**
- **Medical Social Work**
- **Home Health Aid**
- **Behavioral Health**

Amedisys of Chicago Care Center (312) 280-5498

Amedisys care centers serve our patients and their families in 45 states, D.C., and Puerto Rico.

To find a care center near you visit www.amedisys.com



760 McHenry Road
Wheeling, IL. 60090

HARBOR HOUSE OF WHEELING

MEMORY CARE COMMUNITY

THE Harbor House Mission of nourishing the spirit and embracing life is evident in all that we do. By providing a peaceful and supportive environment for those requiring special care we can make a difference.

Harbor House has developed its own unique programs to meet the needs of those suffering from Dementia disorders.

Our purpose built community allows for the celebration of those activities that promote a sense of accomplishment and dignity.

Specially trained staff provides 24 hour care and provide this with compassion and knowledge.

A full activity schedule provides each resident with meaningful days and honors past life roles.

Dementia specific physicians provide care within the facility allowing family members to become just that, their family.

A secure environment with spacious grounds allows our residents a feeling of freedom yet provides for their safety.

We are happy to share more information about our unique facility.

Please visit us at www.harborhousemc.com or call 847-465-110 to schedule a personal tour.

Live Independently. Let our Experience Help



Live-In, Daily, or Hourly Service Available

*Our caregivers assist with daily living, allowing seniors
to remain independent and active at home*

Contact us today for a free in-home assessment

708.869.8100

19 W. Hillgrove Avenue

La Grange, IL

Info@PrivateHomeCareServices.com



Remote control? Or telephone?

Memory Care is all we do.

For a person with Alzheimer's or related dementias, this could be mistaken for a telephone. Seems harmless enough. Until it's an emergency situation, and they try to dial 911. When you're caring for a loved one with memory loss, it's difficult – if not impossible – to keep a watchful eye on them 24/7. And even though it's obvious that you can't do it alone, feelings of guilt won't allow you to make the decision to get help.

Don't wait for a crisis to make the decision for you. Talk to Arden Courts. We understand what you're going through because memory care is all we do. In fact, Arden Courts was created exclusively for persons living with Alzheimer's disease and related dementias. 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, or to schedule a personalized tour, please visit us at www.arden-courts.com. We know. We understand. We can help.

Arden Courts of Elk Grove Village 847.534.8815	Arden Courts of Hazel Crest 708.799.7099	Arden Courts of South Holland 708.895.1600
Arden Courts of Geneva 630.262.3900	Arden Courts of Northbrook 847.795.9000	
Arden Courts of Glen Ellyn 630.469.5500	Arden Courts of Palos Heights 708.361.8070	

©2012 K.E. Matthews, LLC

Arden Courts 
Memory Care Community

Dementia Care at CHICAGOLAND METHODIST SENIOR SERVICES is designed to fit the needs of the individual regardless of the stage of the disease or their level of ability.

We offer in home services, residential communities, and respite options.

- **WESLEY PLACE:** *specialized memory support in a skilled nursing setting*
- **THE HARTWELL:** *memory support assisted living*
- **METHODIST SENIOR HOME CARE:** *in-home services by caregivers specifically trained to care for those with dementia*

All are welcome to our free support and resource group.

1st Wednesday of each month, beginning at 5:00pm
THE HARTWELL, 5520 N Paulina St. Chicago, IL 60640

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



**CHICAGOLAND METHODIST
SENIOR SERVICES**

The Most Extensive Senior Services Network On Chicago's North Side

**For more information about our services or support group,
please call 773-596-2296 or visit us at www.cmsschicago.org**

The care you need,
when you need it most.



Senior Helpers stands ready to serve your family's needs with personalized, in-home care and expertly trained, professional caregivers. The first step to quality care is simple. Call today to learn more about your complimentary in-home care initial consultation.

(312) 867-7110
www.seniorhelpers.com



**SENIOR
Helpers**

Care and comfort at a moment's notice.

Bonded and insured. Senior Helpers locations are independently owned and operated. ©2011 SH Franchising, LLC.



*Call today to schedule your
personal tour!*

Our Dementia care begins with what's been forgotten.

Each senior has a history that makes them a unique individual. At Sunrise, our approach to Alzheimer's care begins with understanding the stories and details of a senior's life.

Knowing our residents better means we can help them attain what we call "pleasant days" by finding activities they can enjoy and be successful at. We do this in specially designed surroundings that are both safe and nurturing, where who they are is never forgotten.

Sunrise of Wilmette is the premier community on the North Shore specializing in memory care for seniors in all stages of memory loss. Visit or call today for more information about how we care for seniors with memory impairment.

SUNRISE
ASSISTED LIVING



Sunrise of Wilmette

847-256-1600

615 Ridge Rd, Wilmette, IL 60091

Memory Care

For more information and a FREE online newsletter, visit www.sunriseseniorliving.com

©2012 Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine

Please do not reproduce, transmit or distribute any portion(s) of this work without written permission.

NOTES

[illegible]