

COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER
of the Northwestern University Feinberg School of Medicine presents the

**FRONTOTEMPORAL DEMENTIA
AND
PRIMARY PROGRESSIVE APHASIA**

**CAREGIVER AND PROFESSIONAL
EDUCATION CONFERENCE**

MONDAY, AUGUST 10TH, 2009

NORTHWESTERN MEMORIAL HOSPITAL FEINBERG PAVILION
251 E. HURON STREET, 3RD FLOOR CHICAGO, IL 60611
WWW.BRAIN.NORTHWESTERN.EDU

FRONTOTEMPORAL DEMENTIA (FTD)

AND

PRIMARY PROGRESSIVE APHASIA (PPA)

CAREGIVER AND PROFESSIONAL EDUCATION CONFERENCE

AUGUST 10TH, 2009

AGENDA

- | | |
|----------|--|
| 8:00 AM | Registration and Breakfast |
| 9:00 AM | Welcome
<i>M.-Marsel Mesulam, MD</i> |
| 9:05 AM | Association for Frontotemporal Dementias
<i>Sharon Denny, MA</i> |
| 9:15 AM | Current FTD/PPA Research at the CNADC
<i>Sandra Weintraub, PhD</i> |
| 9:45 AM | The Road to Fearless Caregiving
<i>Tiffany Chow, MD</i> |
| 11:00 AM | Question and Answer Session |
| 12:15 PM | Lunch |
| 1:30 PM | <i>Caregivers:</i> Guided Support Sessions
<i>Professionals:</i> Person Centered Care for Persons with
FTD and PPA |
| 3:00 PM | Film on Frontotemporal Dementia: Preview
<i>Katie Moriarty</i> |
| 3:10 PM | The Stories of Our Lives
<i>Dan McAdams, PhD</i> |
| 4:00 PM | Adjourn |

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THANK YOU!

The Cognitive Neurology and Alzheimer's Disease Center of the Northwestern University School of Medicine thanks the Association for Frontotemporal Dementias for their generous support of this special event.

We also thank the Alzheimer's Association – Greater Illinois Chapter for generously providing social work continuing education credits.

Finally, we would like to thank our special caregivers, Mary Beth Riedner and Lorene Schlie for their part in this year's planning committee.

2009 Planning Committee Members:

CNADC Faculty and Staff

Joseph Boyle
Derin Cobia
Jim Monti
Darby Morhardt
Mary O'Hara
Emily Rogalski
Felecia Stokes
Sandra Weintraub
Christina Wieneke
Margaret Zonca

Mary Beth Riedner – Family Caregiver (PPA)
Lorene Schlie – Family Caregiver (FTD)
Nicole Batsch, Alzheimer's Association – Greater Illinois Chapter
Debra Crystal, NorthShore University HealthSystem
Sharon Denny, Association for Frontotemporal Dementias
Susan Dickinson, Association for Frontotemporal Dementias
Faith Langtiw, NorthShore University HealthSystem

PROGRAM HIGHLIGHTS

Keynote Speaker
Tiffany Chow, MD

Rotman Research Institute
Baycrest Brain Health Centre Ross Memory Clinic
University of Toronto

Dr. Tiffany Chow is a Clinician-Scientist at the Rotman Research Institute, staff Behavioural Neurologist at Baycrest's Brain Health Centre Ross Memory Clinic, and holds a dual appointment as Assistant Professor of Neurology and Geriatric Psychiatry with the University of Toronto. She earned her dual Bachelor's of the Arts and Sciences in German Studies and Biology, and a Master's degree in Marine Biology at Stanford before attending Rush Medical College in Chicago. She completed Neurology residency training at University of California San Diego, followed by a Fellowship in Dementia and Behavioral Neuroscience at University of California Los Angeles. She went on to join the faculty at the UCLA School of Medicine, then became Clinical Core Director at the University of Southern California Alzheimer's Research Center with a research program for frontotemporal dementia.

Dr. Chow serves patients with early onset dementias in her Baycrest clinic. Her research focuses on behavioural disturbances brought on by dementia, as well as their apparent opposite, apathy, and how these symptoms relate to brain chemistry as seen with functional neuroimaging. She has authored more than 25 peer-reviewed papers and 8 book chapters. At an international level, she chairs the Education Committee for the Medical Advisory Committee of the Association for Frontotemporal Dementias. Dr. Chow's commitment to caregiver issues in dementia motivates her active participation as a Board member of the Alzheimer's Society of Toronto. She also serves on the Board and as the Head of the Medical Advisory Committee for Dancing with Parkinson's, a non-profit organization based in Toronto.

Sandra Weintraub, PhD

Dr. Sandra Weintraub is Professor of Psychiatry and Neurology at Northwestern University Feinberg School of Medicine and the Director of Neuropsychology in the Cognitive Neurology and Alzheimer's Disease Center (CNADC). She has been the director of the Clinical Core of the Northwestern CNADC funded by the NIA since 1996. Dr. Weintraub has been awarded independent research grants from the National Institute on Aging and the Illinois Department of Public Health. She has authored over 130 articles and book chapters on the neuropsychology of dementia and aging, aphasia and hemispatial neglect and is currently working on a project to understand word retrieval and grammatical processing failures in patients with Primary Progressive Aphasia.

Dr. Weintraub is a native of Montreal, Canada and received her bachelor's degree from McGill University. She received her PhD in Psychology from Boston University in 1978. In 1977 she started the Clinical Neuropsychology program in Behavioral Neurology at the Beth Israel Hospital in Boston. She was Associate Professor of Neurology at Harvard Medical School until 1994 when she joined the faculty of Northwestern University where she is also the director of the graduate Clinical Neuropsychology track in the Division of Psychology at the Feinberg School of Medicine. She is board certified in Clinical Neuropsychology by the American Board of Professional Psychology and directs the outpatient clinical neuropsychology service at the Neurobehavior Service, Northwestern Medical Faculty Foundation, a multidisciplinary clinic dedicated to state-of-the-art diagnostic, treatment and research resources for patients and families.

Dr. Weintraub was one of the two Scientific Honorees recognized at the Rita Hayworth Gala of the National Alzheimer's Association in 1997 and has served twice as a member on the board of directors of the Greater Illinois Chapter of the Alzheimer's Association. She is frequently invited to consult on matters related to Alzheimer's disease epidemiology, diagnostic criteria and public health issues.

Dan McAdams, PhD

Dan P. McAdams is Professor of Psychology and Professor of Human Development and Social Policy at Northwestern University, Evanston, IL. Professor McAdams received his B.S. degree from Valparaiso University in 1976 and his Ph.D. in Psychology and Social Relations from Harvard University in 1979. Honored as a Charles Deering McCormick Professor of Teaching Excellence at Northwestern, Professor McAdams teaches courses in Personality Psychology, Adult Development and Aging, Theories of Personality and Development, and the Literatures of Identity and Generativity.

Author of over 150 articles and chapters and author or editor of 14 books, Professor McAdams works in the areas of personality and life-span developmental psychology. Most recently, Professor McAdams is the author of *The Redemptive Self: Stories Americans Live By* (Oxford University Press, 2006). *The Redemptive Self* charts a new psychology of American identity as expressed in cultural and historical American texts and images and in the life stories of caring and productive American adults in their midlife years. The book won the 2006 William James Award from the American Psychological Association for best general-interest book in psychology, across all subfields. It also earned the 2006 Theodore Sarbin Award from the American Psychological Association for its contribution to theoretical and philosophical psychology.

Professor McAdams is also the 1989 winner of the Henry A. Murray Award from the American Psychological Association, for his work on personality and the study of lives. With Ruthellen Josselson and Amia Lieblich, he is co-editor of the book series, *The Narrative Study of Lives* (APA Press). His work has been featured in many national publications and media outlets including the *New York Times*, *Wall Street Journal*, *USA Today*, *Newsweek*, *Psychology Today*, *Self* magazine, and *Good Morning America*.

PROGRAM HIGHLIGHTS

Afternoon Guided Support Sessions for Caregivers

Newly Diagnosed: What Now?

After a diagnosis is made, families face a tremendous unknown. We will discuss the feelings and realities that set in after a diagnosis is made, the decision to tell others, putting together a care team and the information necessary to begin legal and financial planning in the future.

Changes in Behavior

A common symptom of FTD and later in PPA is a change in personality and emotion. Behaviors can include apathy, loss of inhibition and empathy, ritualistic and compulsive behaviors, impaired judgment and loss of insight into personal conduct. These behaviors can be emotionally and physically exhausting to manage. We will explore the effect these behaviors have on family relationships. We will also discuss different types of meaningful activities that families can introduce to the person, as their needs change over time.

Communication Tools in PPA

As the disease progresses, many individuals with PPA lose the ability to speak and other areas of cognition are affected. By learning how to use alternative methods of communication, families can help a person remain engaged. In this session, we will share experiences and explore alternative forms of communication. We will also discuss non-verbal forms of communication and expression that can enhance a person's involvement in their relationships.

When Do I Start to Take Over?

This question is one that many family members face. It is not always obvious when a person needs more supervision or assistance, and it is easier said than done. We will share experiences as we discuss ways to introduce a change in care and ways to balance safety with allowing a person to feel in control. We will also explore how to help the person with FTD/PPA and the family adjust to changes in care or restrictions to their independence.

Thinking About the Future

This group will explore the options for a loved one's future care. We will review care options available to the person and family as the person's needs change. We will also discuss the importance of educating care staff about FTD/PPA if they are unfamiliar with the diagnosis. We will learn about end of life care options that promote comfort and dignity at end of life.

PROGRAM HIGHLIGHTS

Afternoon Guided Support Sessions for Caregivers

Group Facilitators

Derin Cobia, PhD is a postdoctoral fellow in the Department of Psychiatry and Behavioral sciences at the Northwestern University Feinberg School of Medicine. He earned his degree in clinical psychology, specializing in neuropsychology.

Debi Crystal, LCSW is the social worker and Coordinator of Community Education at the Alzheimer's and Memory Assessment Center at NorthShore University HealthSystem. She provides support to the Center's patients and their families. Debi is a licensed clinical social worker and has worked as a social worker with older adults both in the community and in facilities for over twenty years.

Sharon S. Denny, MA is the program director at the Association for Frontotemporal Dementias where she directs the caregiver support and education initiatives. She has a Masters degree in Clinical Psychology and more than twenty-five years experience with nonprofit organizations serving people with medical and psychiatric disabilities and their families.

Amy and Eileen Duhig are daughters of Marty, who was diagnosed with FTD in March 2005. They are both employed full time and go home to provide their mother respite on a weekly basis.

Rebecca Gavett, MA is a doctoral student in clinical neuropsychology at the CNADC. She received her BA from University of Rochester and her MA from University at Buffalo in behavioral neuroscience. Rebecca currently is researching predictors of successful aging.

Robert Hurley, MA is a doctoral candidate in Neuroscience at the CNADC. He has his BA from University of North Carolina at Greensboro and MA in experimental psychology from Wake Forest University.

Mary O'Hara, MA, LSW is a social worker and education and outreach specialist at Northwestern's Cognitive Neurology and Alzheimer's Disease Center (CNADC). In addition to helping to facilitate the CNADC's Quality of Life Enrichment programs, Mary also provides education and support to diagnosed persons and their families.

Diana Kerwin, MD is Assistant Professor of Medicine, Division of Geriatrics, Northwestern University Feinberg School of Medicine. She recently returned to Northwestern from the Medical College of Wisconsin, Milwaukee where she directed a Memory Disorders Clinic and was Assistant Professor of Medicine, Division of Geriatric. Dr. Kerwin will begin seeing patients and families in the CNADC's Neurobehavior and Memory Health Clinic in September 2009, in addition to conducting dementia research on the effects of body weight as a risk factor for dementia.

Caregiver Group Facilitators, continued

Daniel Kuhn, MSW is the Director of the Professional Training Institute for the Alzheimer's Association - Greater Illinois Chapter, based in Chicago. He completed a master's degree in social work at the University of Illinois in Chicago and is a licensed clinical social worker. He has authored or co-authored more than 50 publications on dementia care including his most recent book, *The Art of Dementia Care*. He is the 2009 recipient of the Mental Health and Aging Award by the American Society on Aging.

Julia Rao joined the CNADC in September 2008 as a graduate student in Northwestern's Clinical Neuropsychology program and works in the lab of Dr. Sandra Weintraub. She is a graduate of psychology from the University of Wisconsin-Madison and is now working on the project researching Primary Progressive Aphasia.

Mary Beth Riedner and her husband Steve have been married for 36 years. Steve was diagnosed with Primary Progressive Aphasia in the fall of 2006. They have three grown children and two adorable grand-daughters. Mary Beth retired a year ago from Roosevelt University where she served as University Librarian for nine years.

Emily Rogalski, PhD is an Assistant Research Professor at the CNADC. Dr. Rogalski is a neuroscientist whose research focuses on using structural neuroimaging as a tool to understand the consequences of aging and dementia.

Lorene Schlie is a mother and grandmother, married 41 years to Ron, who was diagnosed with FTD March 2006. She is employed full time and is Ron's advocate and caregiver. In March 2008, she started an FTD support group with eight people that has grown to fifteen plus caregivers and now includes other dementias.

Christina Wieneke joined the CNADC almost three years ago and is the project coordinator for the Language in PPA research study at the CNADC. She received her Bachelor's degree in Behavioral Neuroscience from Purdue University in 2006.

Sandra Weintraub, PhD is Professor of Psychiatry and Neurology at Northwestern University Feinberg School of Medicine and the Director of Neuropsychology in the CNADC. Her research focuses on the neuropsychology of dementia and aging.

PROGRAM HIGHLIGHTS

Afternoon Panel for Professionals “Person Centered Care for Persons with FTD and PPA”

Facilitator

Darby Morhardt, MSW, LCSW is Research Associate Professor and Director of Education for the Cognitive Neurology and Alzheimer’s Disease Center (CNADC) at Northwestern University Feinberg School of Medicine. Ms. Morhardt holds a master’s degree in social work from Jane Addams College of Social Work and has completed postgraduate work in family therapy at the University of Illinois at Chicago. She has 25 years of clinical experience with cognitively impaired individuals and their families. This work led to the development of support, education and social programs for persons in early stage dementia including the Northwestern University Buddy Program™, pairing first year medical students with persons with Alzheimer’s disease. In addition to studying the effectiveness of these programs, other areas of research are the experience and needs of persons and families with primary progressive aphasia (PPA) and frontotemporal dementia (FTD). Ms. Morhardt is also responsible for organizing the CNADC’s community education and outreach programs throughout Chicago and has worked to build Alzheimer’s awareness in limited English proficiency communities.

Panel Members

Joan and Theresa Brzezinski are the wife and daughter of Tom Brzezinski who was diagnosed with FTD at the age of 54. They cared for Tom for 5 years until his very recent death on July 27, 2009. While Tom was able to live at home for the first 3-4 years after diagnosis, Joan and Theresa eventually had to seek long term care when they were no longer able to manage Tom’s increasingly difficult symptoms and behavior. This afternoon, they will share the experience they had with long-term care service providers as they attempted to find the best care for Tom. They will describe what worked, and what didn’t, the effects on their lives, and what they believe all dementia care providers can learn from their experience.

Stuart Gaines, CPA, MBA, has spent the past 25 years helping organizations provide cost effective programming for persons with health challenges. He was one of the lead designers of the Illinois assisted living industry and authored the standards of dementia care incorporated into Illinois statutes. He has promoted home and community-based services and the use of Medicaid waivers to finance home care for the families of persons with dementia. Mr. Gaines is also recognized for his expertise in all facets of dementia programming and his ability to work with professional staff to provide person-centered care for those with a dementia. Mr. Gaines currently sits on the board of directors of the Alzheimer’s Association of Greater Illinois and is chair of the board of directors for the Alzheimer’s Association of Central and North Florida. He also is a board member of Seguin Services, an organization serving the disability community. He has also shaped the direction of long-term care in both Illinois and Wisconsin. In 1989, Mr. Gaines co-founded Wisconsin-based ElderHaus Concepts, Ltd. and grew the business to national prominence. ElderHaus employed a variety of innovative approaches to dementia care, allowing persons with dementia to remain in their communities. At the time of its sale in 1997, ElderHaus had grown to 29 dementia-specific facilities and was one of the largest providers of dementia services in the nation.

Professional Panel Members, continued

Bernice (Bernie) Marinelli, RN/BSN, brings 20 years of dementia and behavioral industry experience as an educator, clinician and administrator. Ms. Marinelli is the founder and CEO of Anam Care, Inc., a residential care organization, specializing in behavioral programming and late stage dementia care. Prior to founding Anam Care, she was hospice supervisor for OSF, Inc. and later the director of dementia services for Highview Corporation. In the mid-1990s, Ms. Marinelli created one of the first late-stage palliative care dementia programs in the state. She is chair of the Northern Illinois Palliative Care Consortium, a certified holistic Reiki practitioner and a frequent speaker at long-term care conferences. Ms. Marinelli has served the Rockford community in the field of “Community Health Nursing” and Hospice, developing Rockford’s first twenty-four hour on-call service to families in need of immediate care in the home. She has been certified in pain management and hospice care since 1988. Over the past fifteen years, Ms. Marinelli has been dedicated to developing community-based case management and home care services for the treatment of Alzheimer’s disease, FTD (frontal lobe dementia) and behavioral health programming.

Jane Stansell, RN, MSN is the Director of the Alzheimer’s Family Care Center in Chicago. Experience has convinced her that with a supportive environment, people with dementia can use 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. She has worked with other adult day service providers at the state and national level, as well as; regulatory bodies to promote care for appropriate to the needs and abilities of people with dementia.

Mary Weaver, RN is Nurse Coordinator for the House of Welcome Adult Day Services, North Shore Senior Center in Northfield, Illinois where she has worked for over 20 years. She received her diploma in nursing from St. Joseph Hospital School of Nursing and a certificate in gerontology in 2002. In her role at the House of Welcome, Ms. Weaver coordinates and provides nursing services, in addition to day-to-day program management. Her many duties include the planning and implementation of daily activities, communication with family caregivers on issues relating to participants’ needs. She also conducts the orientation, training and supervision of HOW staff, students and volunteers.

WHO WE ARE

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

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 dementia 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.

Research Areas:

- Human Cognitive Brain Mapping
- Experimental Treatments
- Chemistry of Memory
- Maintenance of Cognitive Functions in Aging
- Genetics
- Treatment and Prevention of Alzheimer's Disease
- Causes and Treatments of Primary Progressive Aphasia, Frontal Dementia and other Early Onset Dementia
- Nature of Cognitive and Behavioral Changes in Alzheimer's Disease

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<http://www.brain.northwestern.edu>

NEUROBEHAVIOR AND MEMORY HEALTH CLINIC NORTHWESTERN MEDICAL FACULTY FOUNDATION

Care for Patients and Families:

The Neurobehavior & Memory Health Clinic is designed to meet the needs of persons experiencing memory loss or other symptoms of dementia, and their families.

Services Include:

- Evaluation and follow-up care by behavioral neurologists who specialize in the diagnosis and treatment of dementia syndromes.
- Evaluation of memory and other thinking abilities with the use of specialized tests given by a clinical neuropsychologist.
- Management of medication for memory disorders.
- The opportunity to participate in clinical research and clinical drug trials.
- Psychiatric evaluation and treatment for mood and behavior disorders associated with neurological disease.
- Education and counseling for patients and families.
- Information and referral to other supported services.

A Dedicated Clinical Team

Behavioral Neurologists

M.-Marsel Mesulam, MD, Director
Darren R. Gitelman, MD
Jay Gottfried, MD, PhD
Jaime Grutzendler, MD
Chuang-Kuo Wu, MD, PhD
G. Peter Gliabus, MD

Geriatrician

Diana Kerwin, MD

Neuropsychiatrist

Deborah Reed, MD

Neuropsychologists

Beth Borosh, PhD
Nancy Johnson, PhD, ABPP-CN
Sandra Weintraub, PhD, ABPP-CN

Social Workers

Darby Morhardt, MSW, LCSW
Mary O'Hara, MA, LSW

Clinic Manager

Jill Verhagen

Patient Access Representative

Anthony Nowaske

675 North St. Clair Street, Galter 20-100, Chicago, IL 60611
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FRONTOTEMPORAL DEMENTIA (FTD) AND PRIMARY PROGRESSIVE APHASIA (PPA)

WHAT IS FTD AND PPA? FTD and PPA are types of dementia caused by “neurodegenerative” changes in the brain. Early symptoms of FTD include trouble regulating behavior, changes in personality and/or typical emotional responses, and reduced self-awareness. Early symptoms of PPA are mild difficulties speaking normally, thinking of common words, and/or understanding what others are saying.

WHAT DOES DEMENTIA MEAN? Dementia is a condition in which brain cells slowly and progressively die. This process is called “neurodegeneration.” It causes a decline in cognitive abilities to the point that an individual is no longer able to maintain independence in daily living activities. Dementia is caused by abnormal proteins in brain tissue for reasons that are not well known. The abnormalities settle in different brain regions, determining exactly what symptoms an individual will have.

HOW ARE FTD AND PPA DIFFERENT FROM ALZHEIMER’S DISEASE (AD)? AD is the most frequent kind of dementia. Short-term memory loss is the main symptom. In FTD, the main symptom is changes in behavior because the brain abnormality initially affects the frontal areas of the brain, which are involved in planning, organizing and successfully completing activities, and not the memory areas. Brain cell abnormalities in FTD are almost always of the Frontotemporal Lobar Degeneration (FTLD) type. In PPA, the main symptom is aphasia (loss of words) because brain abnormality initially affects the language areas in the brain. Brain cell abnormalities of PPA are similar to AD in only 30% of cases. In all other cases, FTLD is found.

FEATURES OF FTD: Changes in behavior and personality are progressive, creating difficulties with interpersonal interactions and self-awareness. Other noticeable symptoms may include:

- Reduced personal hygiene
- Distractibility
- Repetitive behavior
- Decreased frustration tolerance or impulsivity
- Changes in emotional expression and recognition

FEATURES OF PPA: Language impairment is progressive, creating difficulties with speech, writing, spelling and reading. Sometimes finding words is the only difficulty, other times grammar is impaired. Other noticeable symptoms may include:

- Slowed or halting speech
- Substitutions of words (“table” instead of “chair”) or words that are incomprehensible
- Difficulty understanding conversation despite normal hearing
- Inability to think of names, even though they can recognize you.

WHAT HAPPENS WITH TIME? FTD and PPA are progressive. In time, the disease spreads into other brain areas and the individual begins to develop other cognitive symptoms. In FTD, the most common cognitive change is difficulty with language while in PPA the most common change is personality change. Individuals with either disease can also develop memory loss, a decline in visual skills, trouble maintaining attention and difficulty making decisions.

HOW CAN YOU HELP PERSONS WITH FTD/PPA AND THEIR FAMILIES? Be aware that these individuals may not respond in the same way as they used to, which is a result of the disease and not because they are not interested in what you are saying. Give them more time to process the information and to express themselves. Talk in simplified sentences and break questions down to Yes/No questions. Encourage them to stay active both mentally and physically. Family caregivers need special attention as well. They may need to adjust to new responsibilities, which is difficult and tiring. Your compassion and support is what they need most!

Clinical Recommendations for Families and Individuals Diagnosed with Primary Progressive Aphasia and Frontotemporal Dementia

Jennifer Medina, BS, Sara Banks, BSc, and Sandra Weintraub, PhD

PPA is an atypical dementia that causes progressive breakdown of language, and such the needs of individuals with diagnosis are unique. FTD is a related disorder that causes a progressive breakdown in behavior. The two disorders often overlap, with PPA patients eventually showing behavioral change and FTD patients showing language symptoms. Here are some suggestions to help FTD and PPA patients and their families improve quality of life:

- 1. Avoiding Depression.** Depression is quite common in PPA, where the patient is usually unaware of their language problem. The family and physician should watch for signs of depression, which include tearfulness, changes in sleeping or eating patterns, irritability, and withdrawal. In some cases, a physician might choose to introduce an antidepressant to boost the patient so they may become more engaged and hopefully feel better.
- 2. Improving Communication.** Language problems can be extremely frustrating, so we recommend introducing alternate modes of communication as early as possible in the disease to help minimize frustration. Many families choose to work with a speech-language pathologist to tailor-make alternative communication strategies for their situation. This may include a communication notebook (pages devoted to family, emergency information, and everyday information such as groceries and prescription details) to help bolster independence and allow the patient to get their point across. We also recommend that all language-impaired patients carry a wallet card with a brief explanation of their condition and pertinent emergency information so they can communicate their situation quickly to anyone they interact with.
- 3. Avoiding Confrontation.** Especially in FTD, where patients may not appreciate that there is anything wrong with them, confrontational situations may emerge. In FTD, poor judgment is common, and inappropriate behaviors such as telling offensive jokes, approaching strangers, sexual disinhibition, and indiscriminant spending are common—leading to difficulty with other family members. If a confrontation emerges, remember not to argue or try to reason with the patient. Try to identify exactly what is causing the situation, and understand triggers or warning signs. Often, changes in volume, tone of voice, or body language can indicate that the patient is upset. Pick your battles, and only intervene in really disruptive cases. Try to keep a sense of humor. Keeping decision-making to a minimum decreases confusion and frustration. Validate feelings and make them feel safe. Finally, certain medications may be introduced to minimize some aberrant behaviors.
- 4. Maximizing Activity.** When an individual has language or behavioral problems, keeping them active can be a challenge, yet it is important to maximize brain health and improve mood. Adult day health and leisure programs provide socialization and structured daily activity. A hired companion who comes to the home may be able to provide some stimulation, help with language practice, or help to get the patient out of the house for some exercise. Nonverbal activities such as listening to music, art activities, spending time with a pet, or completing nonverbal puzzles may all be soothing.
- 5. Caregiver Health.** Finally, caregivers are extremely precious and need to be cared for. Dementia care giving can be very stressful, and it is important to stay healthy and fit. Make sure you take the time for yourself, recruiting friends, family, and professionals to provide respite. Identify activities that are relaxing and fun for you, and make time for them. Your mood is important too—many caregivers seek psychotherapy to help them cope. Support groups are available through Northwestern, the Alzheimer's Association, and the community, and many find such groups useful.

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CURRENT FTD/PPA RESEARCH AT NORTHWESTERN

FTD Memantine Study: Researchers are evaluating the use of memantine (Namenda®) in those with a diagnosis of frontotemporal dementia (FTD). Memantine is currently an FDA approved treatment for Alzheimer's disease. Evidence from studies of persons with Alzheimer's disease suggests memantine may reduce damage to brain cells and therefore may also be effective in people with FTD. This study is designed to evaluate the safety and tolerability of memantine in FTD and to evaluate whether memantine will slow the rate of decline in thinking and in problem behaviors in FTD.

Participation in the 26-week study will include 6 office visits two of which will include a blood draw and ECG. Study participants will be randomized to either a placebo group or a treatment group. At each office visit, there will be testing of memory and thinking skills, and at certain visits there will be a physical and neurological exam. For more info, contact Kristine Lipowski: k-lipowski@northwestern.edu or 312-503-2486, NU IRB # STU00014621

All eligible participants must:

- Have a diagnosis of FTD
- Have a reliable caregiver to assist with medication and study visits
- Be between the age of 40 to 80
- Not currently taking a prescription of memantine, donepezil (Aricept®), rivastigmine (Exelon®), or galantamine (Razadyne®)

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 and may not be claustrophobic. For more info, contact Christina Wieneke: 312-908-9681 or c-wieneke@northwestern.edu, NU IRB # 0352-028

Memory Disorders Research Core: The purpose of the research core is to better understand various dementia syndromes, including Alzheimer's disease, frontotemporal dementia, primary progressive aphasia, and other related disorders. This project supports many different research studies on aging and dementia as well as helping to understand 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 ½ hour in length. There is no cost for participation. For more info, contact Lauren Silinsky: 312-926-1851 or l-silinsky@northwestern.edu, NU IRB # 0352-007

Speaker Disclosures

Dr. Chow has received a grant from Lundbeck Canada for an investigator-initiated study.



The Road to Fearless Caregiving

Tiffany Chow, MD
Clinician-Scientist, Rotman Research Inst.
Asst. Prof, University of Toronto Neurology & Geriatric Psychiatry



Learning Objectives

Audience members will:

1. Understand the rationale behind creating FTD-specific interventions.
2. Appreciate the power of non-pharmacologic interventions that can be applied at home.
3. Be prepared to advocate for community resources early and often!



How our clinic approaches FTD caregivers

- How many patients do you have on this visit?
- Consequences of delay in diagnosis
- Importance of a reliable informant
 - Patient confidentiality vs. getting info from "outside" Circle of Care
 - Beware substance abuse confound



Cgr Issues 2

- Supervision for the patient
 - Financial Risks
 - Firearms
 - Driving privileges
- Difficulties at work
 - Long Term Disability vs Early Retirement
- Divorce



Divorce

- Spouses who don't realize they're caregivers to someone with a dementia
- Patients unaware of illness
- Spouses and patients protecting finances
- Proportion of divorcés >65 has risen ~60% since 1990



Divorce (cont.)

- Adult step-children and inheritance
- Power of Attorney designation



Family Values & FTD

- Children in the house
- Sex and intimacy
 - Promiscuity
 - STDs
 - Compulsions



Loss of emotional reactivity

- FTD subjects CAN react to stimuli (facially, verbally, and physiologically)
 - Even the ones with blunted affect
- ↓ Emotional *recognition*
- Hurdles for patients:
 - Ambiguous situations
 - No external higher level cogn processing
 - Self-monitoring and appraisal

Werner et al. *Neurology*, 2007



From a member of the LBDA

PHASE I	FREAKIN' OUT, Scared, Overwhelmed, Confused
PHASE II	Desperate Denial, False Hope, Spurts of Startling Events, Calm Before the Storm, Controlled FREAKIN' OUT
PHASE III	Roller Coaster, Unpredictable Days, Glimpses of Reality, Disaster Preparedness Drills, Uncontrollable Anger, Personality Changes, Back to FREAKIN' OUT, Overwhelming Stress, Unstable Health, Depression, Guilt
PHASE IV	Gets Easier, Managed Depression, Exhaustion, Numbness of the Brain, Shell Shocked, Realistic sense of future, Stress and Guilt--they travel as a pair by now, Hopelessness
PHASE V	Sad, Hollow, Personal Integrity or Despair--our choice on a daily basis, Managed Exhaustion, Sense of Personal Competence, Mixed feelings, Hoping it Ends Soon



"Have a heart that never hardens,
and a temper that never tires, and
a touch that never hurts."
- Charles Dickens



Quality of Life

for Patient:

- Pain-free
- Safe
- Meaningful activities
 - +/- meaningful social interactions
- Maximal autonomy

For Cgr: *Meaningful interaction with patient*

- Emotional connection
- "Doing for" ~feeding
- Good downtime together (rest)
- Everything that can be done IS being done



What Does a Master Caregiver Do?

- Emotional connection & quality together time
 - Adjust expectations, understand where conflict arises
- "Doing for" ~feeding
 - Learn safe practices from your consultants
- Everything that can be done IS being done
 - Advocate for your patient and others



"Am I the problem?"

- ✓ What exactly is s/he doing vs. my interpretation of it
- ✓ Are my expectations fair?
 - What have I lost?
 - What can I do about it?
- ✓ How am I doing?
 - Safe?
 - Loved?
 - Happy?
 - Healthy?

From D. Rewilak's guidelines, see www.rotman-baycrest.on.ca/Index.php?section=204



How Does a Caregiver Become Fearless?

- Adjust expectations, understand where conflict arises
- **Learn safe practices from your consultants**
- Advocate for your patient and others



Your Allies

- Speech and Language Pathology
 - Swallow
 - Communication
- Nursing/Psychology
- Occupational Therapy
- Physiotherapy
- Your doctor(!)



How Does a Caregiver Become Fearless?

- Adjust expectations, understand where conflict arises
- Learn safe practices from your consultants
- **Advocate for your patient and others**



Appropriate Management Begins with Differential Diagnosis

- Mood disorder, stress reaction
- Early onset AD
- AD, frontal variant/ "difficult personality"
- Parkinsonian syndromes
- MCI
- NPH
- Heroin inhalation
- CADASIL



Differs from Primary Psychiatric Disorders

- Less insight than in BAD, major depression, obsessive-compulsive disorder
 - 1° OCD understand that their behaviors are abnl
 - 1° mania: conviction, purpose, goal-direction and has mean onset 30 yrs
- Non-FTD Kleptomania is tic-like
 - Relief of tension, ego-dystonic, remorseful



Creating Resources de novo

- Caregiver support if you can't meet in person
- Day Program
- Lobbying



Can We Offer Day Program Participation?

Stretching the usual Limits of Care

- 2-person assistance for transferring or toileting
- Regular incontinence
- Med dosing outside of lunchtime
- Threat to self or others
- Require total assistance with eating
- Swallowing precautions
- Wanderers



Getting past the Barriers

Football guy here

- New alliances ⇒ ↓ staff anxieties
- Flexibility about participation
- Importance of family meetings
- Keep an open mind ⇒ We are poor predictors of course of illness!



Where to Contribute to FTD Advocacy

- Local research
 - Remote research www.clinicaltrials.gov
- Local Alzheimer's Association branch
- Association for Frontotemporal Dementias www.ftd-picks.org

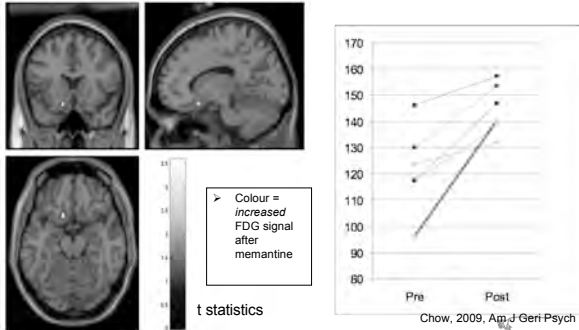


A Couple of Words on Prescription Meds for FTD

- Bear with us
- No disease modification proven yet(?)
- FTD patients "have not read the book"



SPM2: Single Condition and Covariates
Results at $p < .05$ (N=7)
Left Orbitofrontal Cortex



Take-Home Points

- Make some time to think about what's really going on here:
 - What are the most important issues for your quality of life together?
 - What is actually "the small stuff"?
- We are a community: make sure you are as connected as you can be
- Take advantage of all opportunities to learn more



NEWLY DIAGNOSED CHECK LIST

Created by L. Schlie and M. O'Hara

- Tell Someone.* Share this life-changing event with others who can support you.
- Educate yourself about the diagnosis. Become knowledgeable, but don't obsess over it.
- Acknowledge that your life will be very different and that the person cannot control their behavior.

Legal and Financial

- Meet with an Elder Law Attorney to discuss:
 - Durable Power of Attorney for Health Care and Property
 - Legal and financial planning
 - Social Security Disability
- If possible, begin discussions about future care wishes and options
- Find out about financial supports available through caregiver tax credits or prescription drug coverage

Support

- Join a support group or seek out individual counseling
- Find out about local programs and services for the person and your family
- Take time for yourself and ask others to help you commit to this promise

Safety

- Consider a Medical Alert Safe Return bracelet for you and the person with FTD/PPA.
- Be watchful of day-to-day activities (checkbook, paying bills, eating, going places alone, driving, hygiene) and regularly evaluate the safety of leaving the person alone.
- Be aware of their decision making or ideas
- Don't argue or try to change their behavior – distract instead

Quality of Life

- Take lots of pictures with family and friends
- Include the person in conversation
- Adapt to their behaviors and needs
- Help them continue to enjoy their favorite activities as long as they can
- Help them maintain their dignity
- Exercise together

Medical Care

- Be a partner with your doctor and medical team
- Begin a list of questions that you can ask the doctor at the next visit.
- Track changes in behavior so the neurologist can better understand the changes you are seeing
- Ask your doctor about getting involved in research
- Ask your doctor's office who you can call there when you need help urgently

CHANGES IN BEHAVIOR

Created by M.O'Hara, S. Weintraub, D. Morhardt, J. Rao and A. Duhig

Significant changes in behavior and personality are the main symptoms of FTDBv. 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, boisterous and disinhibited. Personality changes can also involve increased agitation, irritability, anger and even verbal or physical outbursts toward others (usually the caregiver). Not all patients will adopt one or another symptom. Symptoms don't occur in "stages" but rather existing symptoms will worsen and new symptoms may appear in an unpredictable manner. Remind yourself that these are not the behaviors of the person you love- *These behaviors are a result of an illness.*

BEHAVIOR	EXAMPLES	SUGGESTED INTERVENTIONS
<p>Apathy/Lack of Motivation</p> <ul style="list-style-type: none"> Lack of interest, drive and/or inability to initiate activity Often confused with depression 	<ul style="list-style-type: none"> A person can no longer take the steps to go on a bike ride on their own, but if guided to a stationary bike, they will engage in riding. A person can no longer follow the steps to make a bowl of cereal. However, if the objects involved are laid out for them, and they are cued appropriately, they can execute the numerous steps involved. 	<ul style="list-style-type: none"> Don't rely on the person to initiate activities on their own. While they might have 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.
<p>Perseveration</p> <ul style="list-style-type: none"> Repeating the same activity over and over when it no longer makes sense to do so 	<ul style="list-style-type: none"> Repeatedly do the laundry even if there is only one item to wash. Continuously talking about the same topic over and over. 	<ul style="list-style-type: none"> 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 them do it.
<p>Disinhibition</p> <ul style="list-style-type: none"> Acting impulsively without considering the social effects of inappropriate behavior Lack insight that the behavior can offend others/cause harm 	<ul style="list-style-type: none"> Making offensive comments to others or to strangers. Speaking about personal issues with strangers. Approaching other people's children as if they were acquainted, or hugging and kissing children. Shoplifting. 	<ul style="list-style-type: none"> Let friends and neighbors know about the diagnosis so they understand the behavior is not intentional. Go to places where person is known well. Distract by getting their immediate attention onto another activity. It's ok 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 FTD" card.

<p>Lack of Empathy/Emotional Changes</p> <ul style="list-style-type: none"> • Showing no emotions- seeming flat and disinterested • Showing exaggerated, jocular or improper emotions. • A lack of sympathy or compassion to others' distress 	<ul style="list-style-type: none"> • Seems to withdraw in familiar company. • Displays emotions that are inappropriate- e.g. laughing at a funeral. • Seems to “not care” about other’s distress. • Seems indifferent to spouse with a diagnosis of cancer. 	<ul style="list-style-type: none"> • Although it is very difficult, do not take this personally. • Find emotional support and companionship from other friends/family or support group. • Seek professional counseling. • Let others know about the diagnosis so they are not offended.
<p>Utilization Behavior</p> <ul style="list-style-type: none"> • Difficulty resisting impulses to operate or manipulate objects that are within reach • “Automatic” behavior, the kind of action we have all experienced when an elevator door opens and you automatically exit despite the fact that it is the wrong floor 	<ul style="list-style-type: none"> • Seems to be drawn to objects or actions in the immediate environment (e.g., picks up objects that are part of others’ activities, seems to imitate other others’ behaviors) even when those objects or actions are not purposeful or appropriate for the moment. • Picking up the phone when walking by it even if it is not ringing or there is no intention of making a call. 	<ul style="list-style-type: none"> • 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 that is automatic behavior. • Note that calling their name may not work to get their immediate attention.
<p>Hyperorality</p> <ul style="list-style-type: none"> • Compulsive eating • Craving carbohydrates or sweets and no ability to regulate intake or “feel full” 	<ul style="list-style-type: none"> • Taking food from someone else’s plate at a dinner table. • Gorging on food to the point of vomiting. • Eating anything in sight with no consideration to how much eaten. • Eating uncooked meat from the fridge. • Eating only a certain type of cookie. 	<ul style="list-style-type: none"> • Provide supervision while eating, setting out portions. • If necessary, lock up foods and keep raw foods out of sight. • Use distraction.
<p>Ritualistic/Compulsive Behaviors</p> <ul style="list-style-type: none"> • Acts that are completed over and over again, without purpose and unrelated to the circumstances in which they occur 	<ul style="list-style-type: none"> • Person needs to continuously walk on the same route for 2 hours every day at 2pm. • Continuous whistling, drumming fingers in certain patterns. • Rigidity and inflexibility, and insistence on having his or her own way, increasing difficulty adapting to new or changing circumstances. 	<ul style="list-style-type: none"> • If it is safe, accept the behavior and arrange for necessary supervision. • If unsafe (scratching at a sore until it bleeds), consult with a physician to consider medications that can minimize compulsive behaviors.

<p>Aggression</p> <ul style="list-style-type: none"> Because many individuals with FTD are not aware of their illness, they may become frustrated at limitations and constraints that they do not understand and consider to be unfair and punitive. As a result, the person may occasionally strike out at the caregiver or resist assistance. 	<ul style="list-style-type: none"> Shouting, name-calling or physical abuse (hitting, pushing). These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation. 	<ul style="list-style-type: none"> Stay out of the person’s way if they are combative. In extreme cases, call police but explain the person with FTD’s condition. Never point out the problem to the person, try to reason about their behavior, or argue about the “logical” solution.
<p>Reasoning</p> <ul style="list-style-type: none"> Not able 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 	<ul style="list-style-type: none"> Person cannot understand explanations about their own illness and is resistant to continued attempts to make things clear. May behave as if the caregiver is “bossy” or unreasonable or trying to control them. Cannot reason logically about the solutions to simple problems (e.g., how to respond in the event of a fire). 	<ul style="list-style-type: none"> Do not argue. No amount of reasoning will make the person able to grasp the ideas. Instead, distract. Tell them firmly 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.

General Communication Tips

- Always avoid confrontation. This can be done by not arguing or trying to point out the truth.
- Try not to take the person’s behavior personally. There is no intent to hurt but only the inability to have normal reactions and feelings.
- When it’s 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 frontotemporal dementia are better at understanding positive emotional expressions than negative ones. So if you are frowning or looking sad or angry, the person may not understand. Alternatively, the caregiver’s emotional facial expression can elicit the exact same expression in the patient even though the patient is not feeling that way but is showing imitative behavior. But a smile will elicit a more positive response.

Meaningful Activities

- Provide materials that are readily available and not dangerous. Jigsaw puzzles, drawing materials, 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 who can be hired to take the person out for a walk daily, but also to do other types of stimulating activities. Using such a label for getting the proper assistance the patient needs may be more acceptable to the patient than a “companion” or a “caretaker.”

When the individual with behavioral changes shows new symptoms, don’t assume that it is the disease. Because patients 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 this be a separate **medical problem** that is 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 dementia 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/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 18-month old child 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 judgment. Even though the patient may be able to play with the 18-month old 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 serotonergic 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.

Understanding Language Problems in PPA

created by Robert Hurley, MA

No two people with PPA are alike. Knowing the particular language problems that your friend or family member is experiencing can help you to communicate more effectively.

Production versus Comprehension

Almost all people with PPA will have problems in **producing** language, coming up with words and phrases, which may result in halting or choppy speech. Not all, however, will have trouble **comprehending** language. In other words, even though you may have trouble understanding them, they may or may not have trouble understanding you. You may have to change your speech patterns and communication methods in order for people with comprehension deficits to more easily understand you.

Problems with Single Words

Many people with PPA may have trouble coming up with or understanding individual words. Failure to produce single words, such as the names of objects, is known as “anomia”, and is very common in PPA. Others may no longer comprehend or recognize certain words anymore. In individuals with single-word problems, both the person with PPA and the caregiver may find a communication notebook (described in more detail later) to be particularly helpful. Using other words that he/she is still able to produce/understand may also help to work around single-word problems.

Problems with Sentences

Other people with PPA may understand individual words just fine, but have trouble when those words are put together into sentences. These are often referred to as grammatical or syntactic impairments, since these individuals have trouble with the relationships between words. In general, short and simple sentences are most easily understood. The simplest kind of sentence (known as a “canonical sentence”) has a noun followed by a verb, such as “the boy threw the ball”. In contrast, a non-canonical, or complex, sentence such as “the ball which was thrown by the boy” is much harder to understand. Use of simple sentences may help in communicating with people with sentence comprehension problems.

Augmentative and Alternative Communication, Communication Notebooks and PPA

created by Christina Wieneke

When conversing, there are two people: the *communicator* and the *communication partner*. If either of these individuals has a language disorder such as PPA, communication can become difficult. Alternative and Augmentative Communication (AAC) is a general term that encompasses the methods used to meet the communication needs of people with speech and language difficulties. There are three types of communication methods: natural, low-tech and high-tech.

Type of Communication Method	Examples
Natural	<ul style="list-style-type: none"> ◆ Gestures ◆ Miming ◆ Facial Expressions ◆ Body Language
Low-tech	<ul style="list-style-type: none"> ◆ Communication Notebook ◆ Communication Board ◆ Index Cards with Pre-written Phrases
High-tech	<ul style="list-style-type: none"> ◆ Computers ◆ Amplifiers ◆ Voice Output Communication Aids ◆ Synthetic Speech

People with PPA often have difficulty using high-tech communication methods. Learning how to use a high-tech device is similar to learning a new language; the learning process can be quite frustrating to a person with PPA. In this case, many people with PPA turn to low-tech or natural communication methods.

Because PPA progressively worsens to the point where verbal communication by any means is difficult, communication notebooks can become very handy. Although some individuals lose the ability to speak early in the illness, they may retain the ability to read and write for a longer period of time. The preservation of these visual components of language can be used to construct an intervention tool to help with everyday forms of communication.

A communication notebook is a set of photos, drawings, symbols or words that are used by an individual to enhance communication. Although available commercially, these notebooks are most effective when created by and tailored to the communicator’s individual needs. Also, a personal notebook can be created for very little cost while commercially available notebooks and notebook software can run from \$25 to hundreds of dollars.

The first step in creating a personalized communication notebook is to gather pictures of family, friends, activities, and events, and sort them into groups. Glue pictures onto separate pages of a notebook and write the name of the picture underneath. Also include common phrases used by the individual and words that can facilitate conversation. Special focus can be placed on things that are the most troubling for the communicator. Some example pages of a communication notebook are listed on the next page.


I have primary progressive aphasia.


This is caused by a condition in the 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. There is nothing wrong with my hearing, my memory, or my thinking abilities.


I use this book to help me communicate.

YES NO

 BANANA

 APPLE


 STRAWBERRY





vacation beach

Hawaii mountains

family retirement

 KNIFE


 FORK

 SPOON


I'm hungry. I'm full.


Can you help me put away the dishes?


What is for dinner?




I go to yoga on Mondays, Wednesdays and Fridays at 10am.

 LAWNMOWER

 RAKE

 DIRT

 GRASS

COMMON PHRASES

Hello. Goodbye.

Thank you. How are you?

I love you. Can you help?


Please listen. Please repeat.


Please write it down.


I have something to tell you.


Please speak slower.


I have a question.

 HAPPY

 SAD

 ANGRY

 SURPRISED

 I DON'T FEEL WELL

JANUARY	MONDAY
FEBRUARY	TUESDAY
MARCH	WEDNESDAY
APRIL	THURSDAY
MAY	FRIDAY
JUNE	SATURDAY
JULY	SUNDAY
AUGUST	
SEPTEMBER	
OCTOBER	
NOVEMBER	
DECEMBER	

1	2	3	4	5	6	7	8	9	
10	20	30	40	50	60	70	80	90	
100	200	300	400	500	600	700	800	900	1000

15 Tips for Communicating with Individuals with Primary Progressive Aphasia (PPA)

Adapted from www.brain.northwestern.edu

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

WHEN DO I START TO TAKE OVER?

Created by M. Riedner, D. Crystal, R. Gavett, and M.O'Hara

Introduction:

As a family member, the decision about when to initiate a change in care for a loved one is never easy and comes with a number of complex considerations. Families fear that “taking over” too soon will affect the person’s sense of worth, self-confidence and in some cases results in them losing something very meaningful to them. However, waiting too long to take over or make changes in care can result in unforeseen situations that can put the person’s and others’ safety at risk. So, when is the right time and how do we best approach these difficult changes?

Ethical Context:

Sometimes the decisions you make about care for a loved one with FTD/PPA might be clear. More often they are complicated decisions weighing competing needs with no perfect answer. Many people struggle with allowing their loved one to have some control over choices while keeping them safe at the same time. These are then ethical decisions and it is often useful to define these competing needs. Some issues where ethical considerations become important are when discussing driving, living alone, decision making/individual choice, and quality of life.

In making these decisions, one may consider not only the person’s needs, but also other family members’ needs and sometimes other larger societal needs. Especially for persons with children at home, it is extraordinarily difficult to balance the needs of the person with FTD/PPA with the needs of young or adolescent children. Every family is unique and through trial and error, finds a unique way to balance the person’s needs with those of the family. The needs may change with progression of disease and changes in the family (e.g. ages of children).

Driving is an issue that raises ethical issues within families. The person with FTD/PPA may want to maintain independence, the family may want the person to continue driving and maintain autonomy while also wanting everyone to be safe. There are also concerns about the larger community and how safe your loved one is driving on the streets.

While it may begin with the finances or driving, as the disease progresses, families find themselves making more of these types of decisions that result in taking away day-to-day responsibilities of the diagnosed person. When persons retain insight into their diagnosis, they are more aware of what they are no longer able to do and may accept changes more readily. Each loss is significant in any case and families often face uncertainty and may question the decision each time. What does become clearer is how to best introduce changes to the person and how to continue to maintain their dignity, sense of self-worth and independence, despite these losses.

Strategies that Help with Decision about Changes in Care:

Ask yourself the following questions and write down the answers:

- What are the goals for the person's care/quality of life?
- What are your goals for your own care/quality of life?
- What are your goals for your family?
- What are the person's needs? What are your needs?
- How do you feel about having to take on more responsibility?
- Are you emotionally and physically ready to take on more responsibility?
- Who in your support system might be able to help you with these responsibilities?
- What community support systems might be helpful to your family?

Problem solving:

Consider writing down a list of your concerns about your loved one, what are strategies that might resolve those concerns and the benefits and drawbacks to those strategies.

Consider using published checklists as a tool to evaluate safety issues like driving and staying home alone. A couple of these lists are referenced at the end of this hand out.

It will be more important to work together with your Primary Care Physician, Neurologist, and Neuropsychologist to help understand the decisional capacity of your loved one at different points in the disease process.

It may be important to consult with an elder law attorney to explore your loved one's legal rights as well as your own, as the disease progresses. For instance, this may be important when the person with FTD/PPA has no insight into disease process and insists on continuing to do tasks such as managing finances that he/she can no longer do.

Strategies on Ways to Introduce Change in Care to a Loved One:

Do your best to avoid arguments or elaborate explanations about why a change is necessary. Keeping the message short and simple will maximize chances it will be understood.

- Pay attention to *any and all* kinds of expression related to changes in care (sadness, frustration, low self confidence, anxiety, new behaviors) - validate this as the person's experience and do your best to empathize with and reassure them. If they can express their feelings about the loss, acknowledge how difficult this must be. Sometimes persons with FTD/PPA are not able to articulate their feelings about the change. Putting words to the feelings might help.
- Identify what has worked in the past when a change was introduced and retrace the steps involved in that approach. If this does not work, expect to use trial and error until you find the best new approach.
- If the person is resistant to the change that must happen, (especially for safety reasons), focus your energy on helping the person adjust to the change rather than reasoning with them about why the change had to happen.

For persons experiencing ongoing loss, we must do our best to replace what is lost with something else. For example:

- If a person has to stop driving, seek out alternative forms of transportation as options so they can still go to the places they enjoy.
- If it is determined that it is no longer safe for a person to watch young children alone, but it is something they love to do, consider having someone else with them.
- If it's no longer safe for a person to go to the shooting range, but this was always a hobby of theirs, help them engage in a new (modified) hobby that offers the same feelings of success and enjoyment.

Resources:

The Hartford, At the Crossroads: Family Conversation about Alzheimer's Disease, Dementia and Driving - includes a checklist – www.thehartford.com/alzheimers

Home Alone Checklist

www.aging-parents-and-elder-care.com/Pages/Elder_Care_Checklists.html

Alzheimer Care – Ethical Guidelines developed by Alzheimer Society of Canada

www.alzheimer.ca/english/care/articles-ethics.htm

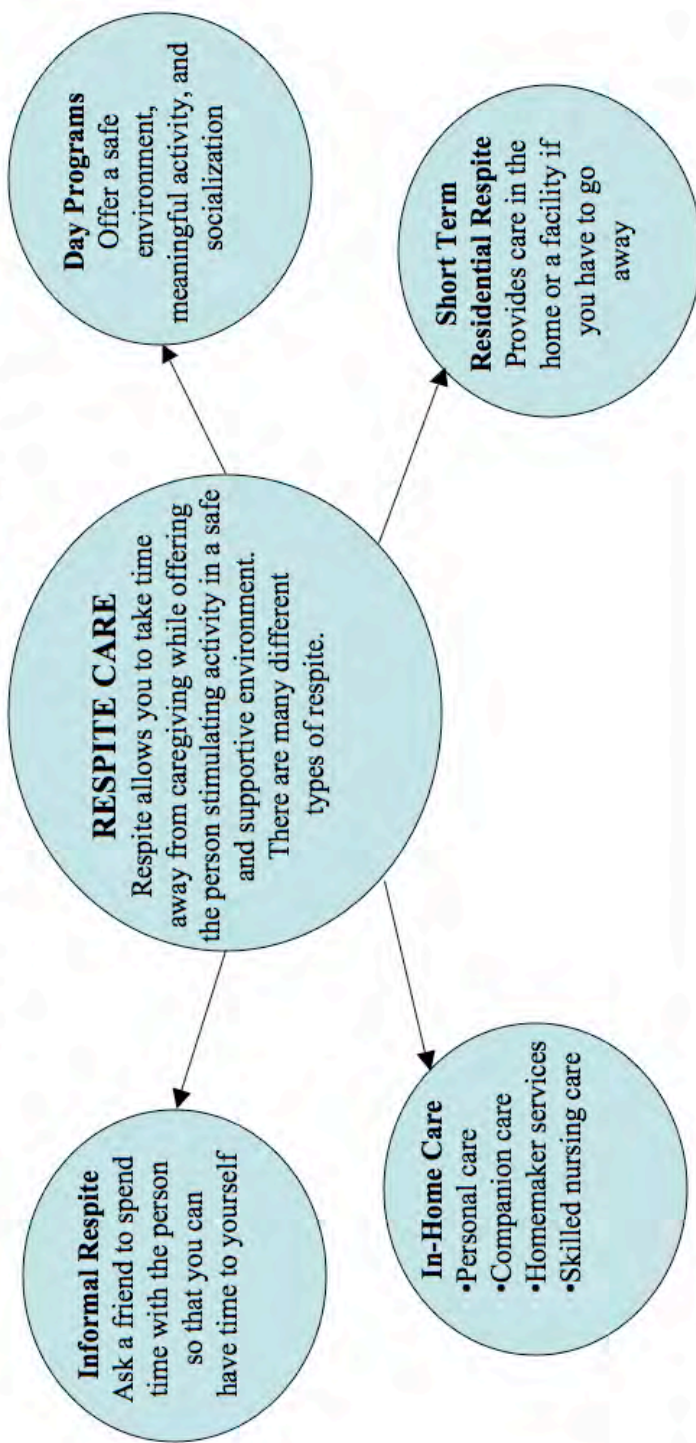
Legal and Financial Issues: A List of Resources (www.nia.nih.gov/Alzheimers/Publications/legal.htm).

The Institute on Aging, part of the U. S. National Institutes of Health, has developed a list of brochures, handbooks, tool kits, and other materials to help people with dementia, and their caregivers, with the decision making process.

Legal plans: Assisting the person with dementia in planning for the future

(www.alz.org/national/documents/brochure_legalplans.pdf) This 16 page brochure from the Alzheimer's Association includes basic information on legal capacity, legal documents (guardianship, living will, living trust, power of attorney, will), how to find a lawyer, preparing for your meeting, what to discuss with your lawyer, and terms your lawyer may use.

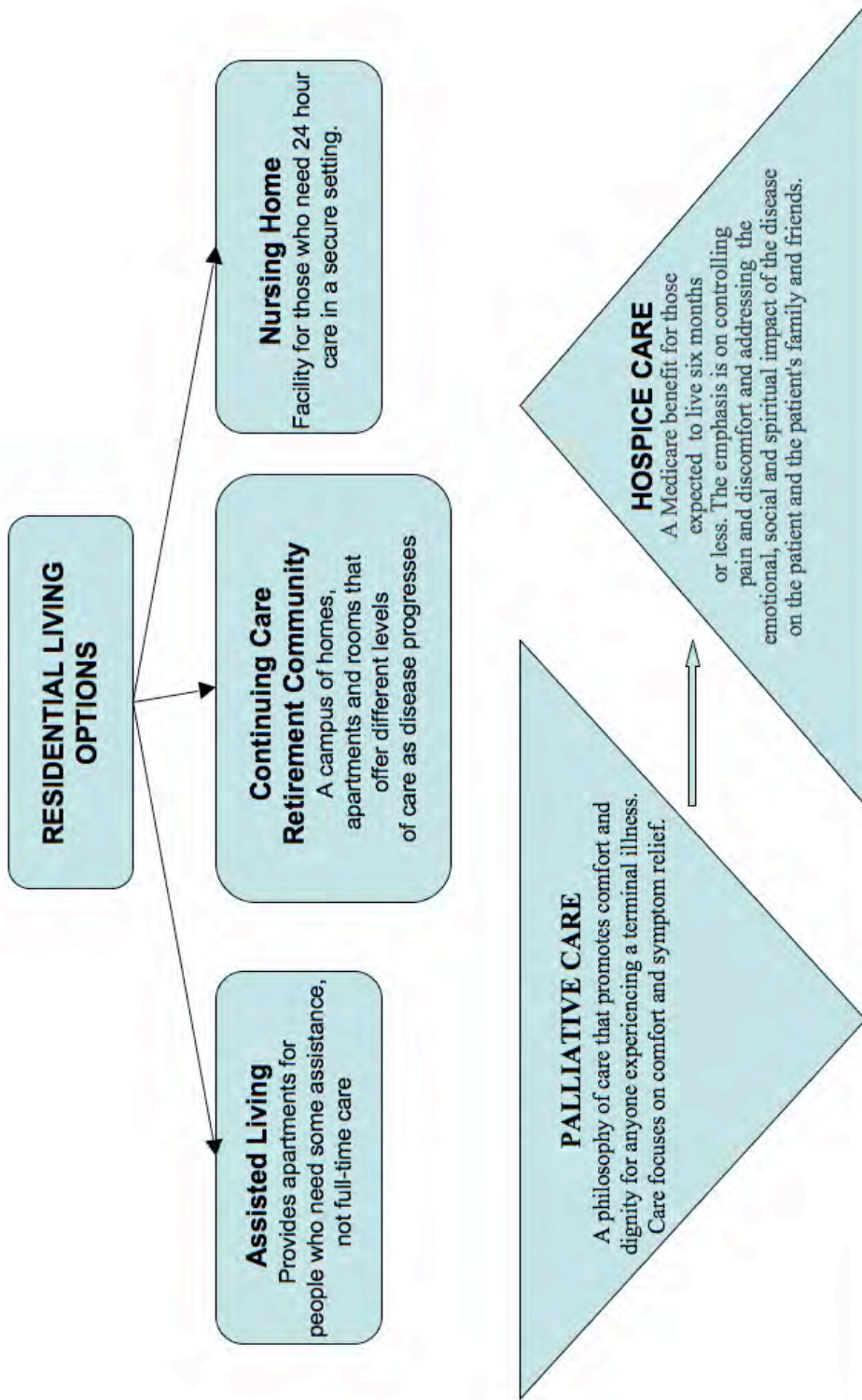
Thinking About the Future



RESPITE TIPS:

- Find what is best for the person **AND** for you
- Ask about scholarships available or volunteers who care provide companionship or informal respite
- Consider a combination of respite services that together provide necessary structure in the person's day or week
- Continuously re-evaluate what is working and what is not working
- Be prepared to educate care staff and friends/family.

Created by M. O'Hara and D. Kuhn



Who to Contact:

- The Alzheimer's Association 1.800.272.3900 or www.alz.org/illinois
- Association for Frontotemporal Dementias (AFTD) 866.507.7222 or www.ftd-picks.org
- Elder Care Locator 800.677.1116 or www.eldercare.gov
- Cognitive Neurology and Alzheimer's Disease Center (CNADC): 312.503.0604 or www.brain.northwestern.edu

Person Centered Care

created by Jane Stansell, RN, MSN

According to Kitwood's model of person centered care, the experience of a person with dementia is shaped by two kinds of change – changes in the brain and changes in patterns of relationships and interactions. The person's sense of personhood and well being can be supported or undermined by how those around the person interact with him or her. The goal of person centered care is to help the person maintain a relative sense of well-being despite the cognitive changes that are occurring.

Key Principles of Person Centered Care

- **Attend to the whole person** - help to attain a state physical, social, emotion well being
- **See each person as special/unique-** develop a meaningful relationship with each person
- **Give respect to the past** - take the person's whole history into account
- **Focus on the positives** – celebrate retained skills, not losses due to the disease process
- **Stay in communication** – use both verbal and non-verbal approaches
- **Nourish Attachments-** form a psychological safety net through personal attachments
- **Create community** - a supportive group promotes a sense of identity and self esteem
- **Maximize freedom and minimize control-** maintain safety without being controlling
- **Don't just give, receive as well-** people with dementia are not just "care receivers"
- **Maintain a moral world** – provide a milieu that contributes to feeling valued and known

It is necessary to emphasize at the outset, that this is an area of work that cannot rest simply on good intentions, general kindness and common sense. These things are important, of course, but they are not enough. Good care requires a sound knowledge base, to provide a clear understanding of what we re trying to do. It involves developing empathy, sensitivity and communication capability to the very highest level. It demands of us a moral commitment so that we recognize and value people whose mental powers are failing and treat them as an equal in their rights. In order to undertake this daunting task we will need to draw on our natural humanity, but also to develop attitudes and skills not commonly found in everyday life. That is why it is essential to provide people who are working in dementia care the proper preparation for their task.

Tom Kitwood, 1998

Professional Growth and Development Needed to Provide Person Centered Care

- Promote appropriate attitudes
- Develop skills required for carework
- Develop a sound knowledge base
- Subject our practice to reflection
- Lower defensive barriers
- Grow in practical morality

Tom Kitwood, 1998

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 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

**Cognitive Neurology and Alzheimer's Disease Center (CNADC)
Frontotemporal Dementia (FTD) & Primary Progressive Aphasia (PPA)
Caregiver Information and Resources**

CNADC

Cognitive Neurology & Alzheimer's Disease Center

www.brain.northwestern.edu
CNADC-Admin@northwestern.edu

Clinical Services

Northwestern Memorial Faculty Foundation
Neurobehavior and Memory Health Clinic
675 N. St. Clair, #20-100
Chicago, IL 60611
For appointments: 312-695-9627

Education

FTD and PPA Caregiver and Professional Education Conference
Contact: Mary O'Hara, 312-503-0604

Support Group

Northwestern FTD/PPA Family Support Group
3rd Monday of the Month, Feinberg Pavilion, 3rd Floor, Room B
Contact: Darby Morhardt, 312-908-9432

National Organizations

The Association for Frontotemporal Dementias (AFTD)

www.ftd-picks.org
866-507-7222 (Toll Free Helpline)

National Institute of Neurological Disorders and Stroke (NINDS)

www.ninds.nih.gov
800-352-9424

National Aphasia Association (NAA)

www.aphasia.org
800-922-4622

National Organization for Rare Disorders (NORD)

www.rarediseases.org
800-999-6673 (voicemail only)
203-744-0100

Legal and Financial Resources

Social Security (SSA)

www.ssa.gov
800-772-1213

If the person is working and needs to file for disability, it is best to speak to their employer as well as the local security office. As of October 2008, FTD (including PPA) is one of 50 "Compassionate Allowance" diseases that the SSA has marked for expedited approval.

Medicare

www.medicare.gov
800-MEDICARE

Medicare is a health insurance program for people over the age of 65 or under 65 with certain disability. Part A covers inpatient care without monthly premiums. Part B covers outpatient care with a monthly premium.

The National Academy of Elder Law Attorneys

www.naela.org
703-942-5711

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

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 Association of Professional Geriatric Care Managers

www.caremanager.org or 520-881-8008

Geriatric Care Managers help families care for older relatives. They act as a guide and an advocate and provide ongoing assessments, referrals and care to an older adult.

National Private Duty Home Care

www.privatedutyhomecare.org or 317-663-3637

The National Private Duty Association (NPDA) represents more than 1,200 care agencies throughout the US. Members of the NPDA meet specific standards for private duty homecare, staff education, ethics and best practices within the home care industry.

ARCH National Respite Network and Resource Center

www.archrespite.org

Families can search the database for local respite agencies/services.

Palliative Dementia Care Resources

www.pdcronline.org

Connects family caregivers with information and resources for palliative dementia care.

Support and Support Groups

FTD Support Forum

www.ftdsupportforum.com

An excellent online support forum set up by caregivers of people with various types of FTD, including PPA. While most posters are caregivers, there are special sections dedicated to individuals with PPA and FTD.

PPA Support Group Online

<http://health.groups.yahoo.com/group/PPA-support>

Pick's Disease Support Group Online

www.pdsg.org.uk

FTD Caregiver Support Center

www.ftdsupport.com

Includes a listing of support groups by country.

Support Groups, by State

www.ftd-picks.org/support-resources/us-regions

Share the Care

www.sharethecare.org

A unique site developed by caregivers that discusses how to organize a group to care for someone who is seriously ill.

Special Topics

Camp Building Bridges

<http://www.freewebs.com/campbuildingbridges08/>

417-933-2030

A summer camp for teens 12-16 that have a family member diagnosed with dementia.

Interactive Therapeutics

www.interactivetherapy.com

800-253-5111

Source of the Daily Communicator® and other communication materials.

Dementia and Driving

www.thehartford.com/alzheimers

The Genetic Alliance

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

A resource for information and support about genetic conditions.

Alzheimer's Resources

Although geared towards Alzheimer's Disease, many of the resources listed below are helpful for FTD and PPA as well.

Alzheimer's Association

www.alz.org
800-272-3900

Alzheimer's Disease Education and Referral Center (ADEAR)

www.nia.nih.gov/Alzheimers
800-438-4380

Books

What if It's Not Alzheimer's? A Caregiver's Guide to Dementia

Lisa Radin and Gary Radin, editors. Prometheus Books, 2003.
The first caregiver manual devoted exclusively to FTD.

Losing Lou-Ann

Erb, Clinton A. Brandon, VT: Holistic Education Press, 1996.
An inspiring account of a spouse caring for his wife with Pick's disease.

Pick's Disease and Pick Complex

Kertesz, Andrew and Munoz, David G. Chichester, U.K.: Wiley-Liss, 1998
A comprehensive reference that clarifies Pick's diagnosis compared to other forms of dementia.

The Banana Lady and Other Stories of Curious Behavior and Speech

Kertesz, Andrew. Trafford Publishing: 2006.
Nineteen lives are chronicled as told by caregivers, followed by tips for caregiving, a useful glossary of terms, plus FTD references.

An Evolution of Love: Life and Love with Frontotemporal Dementia

Marie Sykes & Michelle Stafford. Georgetown Publishing, LLC: 2007.
A memoir describing the life of Bob Sykes, Jr., a man who passed away from FTD at age 50.

When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver

McCurry, Susan M. Praeger Publishers: 2006.

The Executive Brain: Frontal Lobes and the Civilized Mind

Goldberg, Elkhonon. Oxford University Press: 2001.

The Dysphagia Cookbook: Great Tasting and Nutritious Recipes for People with Swallowing Difficulties.

Achilles, Elayne. Cumberland House Publishing: 2004.
A recipe book for individuals with dysphagia, a condition of swallowing difficulty that sometimes occurs in dementia.

Frontotemporal Dementia (FTD) & Primary Progressive Aphasia (PPA) Information and Resources for Professionals

Banks S., Rogalski E., Medina J., Skoglund A., Morhardt D. Organizing a series of education and support conferences for caregivers of individuals with frontotemporal dementia. *Alzheimer's Care Quarterly*. 2006; 7(4):243-250.

Weintraub S., Morhardt D. Treatment, education, and resources for non-Alzheimer's dementia: one size does not fit all. *Alzheimer's Care Quarterly*. 2005; 6(3):201-214.

Chow, T. A Dementia By Any Other Name: What If It's Not Alzheimer's Disease? *Alzheimer's Care Quarterly*. 2005; 6(3):215-224

Merrilees, J. A Model for Management of Behavioral Symptoms in Frontotemporal Lobar Degeneration. *Alzheimer Disease and Associated Disorders*. 2007; 21(4):S64-9

Grinberg, A. Lagunoff, J. Phillips, D. Stern, B. Goodman, M. Chow, T. Multidisciplinary Design and Implementation of a Day program Specialized for the Frontotemporal Dementias. *American Journal of Alzheimer's Disease & Other Dementias*. 2008; 22(6):499-506.

Cox, S. & Keady, J. (Eds.). *Younger people with dementia: Planning, practice and development*. Jessica Kingsley: London, 1999.

Miller, B. L., Cummings, J. L., (Eds.). *The Human Frontal Lobes: Functions and Disorders* Guilford Press: New York, 2007.

American Speech-Language-Hearing Association

Dementia: Benefits of Speech-Language Pathology Services

<http://www.asha.org/public/speech/disorders/DementiaSLPservices.htm>

An excellent site with links that details speech-language therapy guidelines for dementia.

Practice Guidelines of the ANCDs

<http://ancds.org/practice.shtml>

A site from the Academy of Neurological Communication Disorders & Sciences that provides guidelines for the management of communication disorders in neurologically impaired individuals.

Shnall, A. Supporting family caregivers of people with frontotemporal dementia. *Canadian Review of Alzheimer's Disease and Other Dementias* 2009; 12(2):14-16.

Grinberg, A. & Phillips, D. The impact of a community day program on the lives of patients with Frontotemporal dementia and their caregivers. *Canadian Review of Alzheimer's Disease and Other Dementias* 2009; 12(2):17-22.

Rajaram, R. D., Herrmann, N., Lanctôt, K. L. Behavioral and psychological symptoms of frontotemporal dementia: A review. *Canadian Review of Alzheimer's Disease and Other Dementias* 2009; 12(2):9-13.

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