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
800-447-6673
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
520-881-4005
An elder law attorney can assist you with legal and financial planning.

Care Services and Resources

Illinois Department of Rehabilitation (For persons under age 60)
http://www.dhs.state.il.us/ or (800) 843-6154
State agency serving individuals with disabilities under age 60 and their families. In-home services, respite and support are available to those who qualify.

Eldercare Locator (For persons over age 60)
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
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
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://groups.yahoo.com/group/PPA-support

Pick’s Disease Support Group Online  
www.pdsog.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/
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
The first caregiver manual devoted exclusively to FTD.

Losing Lou-Ann
An inspiring account of a spouse caring for his wife with Pick’s disease.

Pick’s Disease and Pick Complex
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
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
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

The Executive Brain: Frontal Lobes and the Civilized Mind

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


Chow, T. A Dementia By Any Other Name: What If It’s Not Alzheimer’s Disease? Alzheimer’s care Quarterly 6(3), 2005.


Younger People with Dementia: Planning, Practice & Development  
A book for professionals that describes the different type of care needed for younger individuals with dementia.

The Human Frontal Lobes: Functions and Disorders  
An informative book discussing the functioning of the frontal lobes.

The Frontal Lobes  

American Speech-Language-Hearing Association  
Dementia: Benefits of Speech-Language Pathology Services  
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.

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Primary progressive aphasia, or PPA, is a type of frontotemporal dementia that affects speech and language—thus, the word “aphasia” which refers to difficulty with expressive and/or receptive communication. Unlike Alzheimer’s disease, other cognitive functions tend to remain intact in early PPA. Symptoms of PPA. They offer several local support groups, as well as online information and phone support. Was this page helpful? Thanks for your feedback! Office of Rare Diseases Research. Primary Progressive Aphasia. http://rarediseases.info.nih.gov/GARD/Disease.aspx?PageID=4&diseaseID=8541. Northwestern University. Feinberg School of Medicine.