

RESOURCES

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.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/>

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 and primary progressive aphasia. *Alzheimer Care Quarterly*, 7(4), 2006.

Weintraub, S., Morhardt, D. Treatment, Education and Resources for Non-Alzheimer Dementia: One Size Does Not Fit All. *Alzheimer Care Quarterly* 6(3), 201-215, July/September 2005.

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

Merrilees, J. A Model for Management of Behavioral Symptoms in Frontotemporal Lobar Degeneration. *Alzheimer Disease Assoc. Disord.* Vol 21, No. 4, October- December 2007.

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 Dementia.* Vol 22, No. 6 December 2007/January 2008.

Younger People with Dementia: Planning, Practice & Development
Sylvia Cox & John Keady (Eds.) Jessica Kingsley Publishers: 1999.
A book for professionals that describes the different type of care needed for younger individuals with dementia.

The Human Frontal Lobes: Functions and Disorders
Bruce Miller & Jeffery L. Cummings. The Guilford Press: 1998.
An informative book discussing the functioning of the frontal lobes.

The Frontal Lobes
Jarl Risberg & Jordan Grafman. Cambridge University Press: 2006.

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://an cds.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.

FTD is much less common than Alzheimer's disease and vascular dementia. Figures vary, but it probably accounts for less than 5% of all dementia.[6] It is, however, the second or third most common type of dementia presenting in those under the age of 65. A Cambridge-based study estimated incidence in the 45- to 64-year-old age group as 3.5 per 100,000 person-years.[7](Incidence of Alzheimer's in the same group was 4.2.) It is probably, however, significantly under-diagnosed. Management is therefore directed at alleviating symptoms, providing support and information for those with FTD and their families, and keeping them safe. This will involve multi-disciplinary health and social care, which needs to be co-ordinated. Mesulam Center for Cognitive Neurology and Alzheimer Disease, Northwestern University Feinberg School of Medicine, Chicago, Illinois. AQ3. Aims Primary progressive aphasia (PPA) is a clinical syndrome characterized by selective language impairments associated with focal cortical atrophy favouring the language dominant hemisphere. PPA is associated with Alzheimer's disease (AD), frontotemporal lobar degeneration (FTLD), and significant accumulation of activated microglia. Activated microglia can initiate an inflammatory cascade that may contribute to neurodegeneration, but their quantitative distribution in cortical white matter and their relationship with cortical atrophy are unknown. Primary progressive aphasia (PPA) Primary progressive aphasia is characterized by changes in the ability to speak, write, read and understand language. Primary progressive aphasia is broken down into two main forms – the semantic variant and the nonfluent agrammatic variant. There is also a third form called the logopenic variant. Affected individuals have a slow, progressive loss of language skills. Aphasia, which is described as difficulties in understanding or expressing language, is the most common initial language deficit. Lillo P, Hodges JR. Frontotemporal dementia and motor neurone disease: overlapping clinic-pathological disorders. J Clin Neurosci. 2009;16:1131-1135. <http://www.ncbi.nlm.nih.gov/pubmed/19556136>.