

## Resources Page for Webinar #4: Younger Onset Dementia

- 1) **“Overview”** (Darby Morhardt, MSW, LCSW, Research Associate Professor/Director-Education, Cognitive Neurology and Alzheimer’s Disease Center, Northwestern University Feinberg School of Medicine)

### *Defining Younger Onset Dementia*

- Report: Early Onset Dementia: A National Challenge, A Future Crisis. Alzheimer’s Association. June 2008: [http://www.alz.org/national/documents/report\\_earlyonset\\_full.pdf](http://www.alz.org/national/documents/report_earlyonset_full.pdf)
- IMPACT, 2013: <http://www.ppaconnection.org/>
- Rascovsky, K., Hodges, J.R., Knopman, D., Mendez, M.F., Kramer, J.H., Neuhaus, J., et al. (2011). Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain*, 134(9), 2456–77. doi: 10.1093/brain/awr179  
<http://www.ncbi.nlm.nih.gov/pubmed/21810890>

### *Caregiver Outcomes*

- Freyne A., Kidd N., Coen R., Lawlor B. Burden in carers of dementia patients: higher levels in carers of younger sufferers. *Int J Geriatr Psychiatry*. 1999;14:784–748.  
<http://www.ncbi.nlm.nih.gov/pubmed/10479751>
- Boutoleau-Brettonniere C, Vercelletto M, Volteau C, Renou P, Lamy E. Zarit Burden Inventory and Activities of Daily Living in the behavioral variant of frontotemporal dementia. *Dement Geriatr Cogn Disord*. 2008;25:272–277. doi: 10.1159/000117394  
<http://www.ncbi.nlm.nih.gov/pubmed/18285675>
- de Vugt, M. E., Riedijk, S. R., Aalten, P., Tibben, A., van Swieten, J. C., & Verhey, F. R. (2006). Impact of behavioural problems on spousal caregivers: A comparison between Alzheimer’s disease and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders*, 22, 35–41.  
<http://www.ncbi.nlm.nih.gov/pubmed/16679763>
- Svanberg et al. (2011) The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics*, 23, 256-371. DOI:  
<http://dx.doi.org/10.1017/S1041610210001353>  
<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8133255&fulltextType=RV&fileId=S1041610210001353>

### *Resources: Education, Care & Support*

- National Association of Elder Law Attorneys : <http://www.naela.org/>
- Long Term Care Services: Eldercare Locator & In-Home and Adult Day Services
  - <http://www.eldercare.gov/>
  - <http://www.homecareaoa.org/>
  - <http://www.nadsa.org/>
- ADEAR - Alzheimer Disease Education and Research Center - National Institute on Aging:  
<http://www.nia.nih.gov/alzheimers>
- Alzheimer’s Association: <http://www.alz.org>
- Association for Frontotemporal Degeneration (AFTD): <http://www.theaftd.org/>
- CurePSP: Foundation for PSP CBD and related Brain Diseases: <http://www.psp.org/>
- National Aphasia Association (NAA): <http://www.aphasia.org/>
- FTD/PPA Caregiver & Professional Education and Support Conference, November 4, 2013 in Chicago: <http://www.brain.northwestern.edu/>

- Northwestern CNADC 2012 conference booklet: [www.brain.northwestern.edu](http://www.brain.northwestern.edu)
  - Darby Morhardt, MSW, LCSW, Research Associate Professor, Director, Education Core: [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu)
  - Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine, 320 E. Superior St, Searle 11, Chicago, IL 60611, 312.926.1851: <http://www.brain.northwestern.edu/>
  - Northwestern Neurobehavior and Memory Health Clinic, 676 N. St. Clair, Suite 945, Chicago, IL 60611, 312.695.9267
- 2) **"Detection and Diagnosis"** (Sandra Weintraub, PhD, Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine)
- J.B. Chawluk; M.-M. Mesulam; H. Hurtig; M. Kushner; S. Weintraub; A. Saykin; N. Rubin; A. Alavi; M. Reivich (Profiled Authors: [Marek-Marsel Mesulam](#); [Sandra Weintraub](#)). Slowly progressive aphasia without generalized dementia: Studies with positron emission tomography. *Annals of Neurology*. 1986;19(1):68-74.: [http://www.scholars.northwestern.edu/pubDetail.asp?t=pm&id=22622021&u\\_id=1604](http://www.scholars.northwestern.edu/pubDetail.asp?t=pm&id=22622021&u_id=1604)
  - <http://www.nia.nih.gov/Alzheimers/Publications/FTLD/>
  - Sandra Weintraub, PhD, Professor of Psychiatry, Neurology, and Psychology, Clinical Core Leader, Cognitive Neurology and Alzheimer's Disease Center, Northwestern University Feinberg School of Medicine, 312-908-901: [sweintraub@northwestern.edu](mailto:sweintraub@northwestern.edu)
- 3) **"Specialized Resources"** (Sharon S. Denny, Program Director, The Association for Frontotemporal Degeneration - AFTD)
- Website The Association for Frontotemporal Degeneration: <http://www.theaftd.org/>
  - Frontotemporal Disorders: Information for Patients, Families, and Caregivers. Booklet by the National Institute on Aging: [http://www.flextherapistceus.com/material/frontotemporal\\_disorders\\_information\\_for\\_patients\\_families\\_and\\_caregivers.pdf](http://www.flextherapistceus.com/material/frontotemporal_disorders_information_for_patients_families_and_caregivers.pdf)
  - A guide for Managing a New Diagnosis – The Doctor Thinks It's FTD. What now?: [http://www.theaftd.org/wp-content/uploads/2009/03/AFTD-40-pg-booklet-NewDiag\\_Website.pdf](http://www.theaftd.org/wp-content/uploads/2009/03/AFTD-40-pg-booklet-NewDiag_Website.pdf)
  - What About the Kids? Booklet: <http://www.theaftd.org/wp-content/uploads/2009/03/What-About-the-Kids-web-version.pdf>
  - Understanding the Genetics of FTD: A Guide for Patients and Their Families: <http://www.theaftd.org/wp-content/uploads/2009/02/Final-FTD-Genetics-Brochure-with-Cover-8-2-2012.pdf>
  - Healthcare Professional Section of AFTD website: <http://www.theaftd.org/healthcare-professionals>
  - Journal of Gerontological Nursing: <http://www.healio.com/nursing/journals/jgn/> American
  - Journal of Alzheimer's Disease and Other Dementias: <http://aja.sagepub.com/> Partners in FTD
  - care: <http://www.theaftd.org/healthcare-professionals/partners-in-ftd-care-2>
  - AFTD Helpline: 866-507-7222
  - AFTD Email Contact: [info@theaftd.org](mailto:info@theaftd.org)