

Frontotemporal Dementia Resource List



FTD General Information & Resources

- The Association for Frontotemporal Degeneration: www.theaftd.org
FTD Helpline: 1-866-507-7222 or email info@theaftd.org
Regional Coordinator volunteer, Joanne Linerud: jlinerud@theaftd.org
\$500 Comstock grants for quality of life, caregiver respite.
- Alzheimer's Association: www.alz.org
24hr Helpline: 1-800-272-3900
Caregiver support groups and early stage memory loss support groups for any neurodegenerative condition (not just Alzheimer's).
Connections Care Consultants provide home visits in King and Snohomish Counties.
- FTD Factsheets: www.ftdtalk.org/factsheets
- UCSF FTD Info: <https://memory.ucsf.edu/frontotemporal-dementia>
- Penn FTD Center: <https://ftd.med.upenn.edu/living-with-ftd-related-disorders>
- FTD Caregiver Support/Info Center: www.ftdsupport.com/#
- FTD Advocacy Resources Network: www.ftdarn.org
- FTD Awareness Cards: www.theaftd.org/living-with-ftd/resources/awareness-cards

Local and Online Support Groups

- Local FTD caregiver support groups: Seattle area, sponsored by the Alzheimer's Association, contact facilitator Karin Miller, MSW, 206-384-0096. South Puget Sound area, contact facilitator Steve Zamberlin, 206-380-2854.
- Online support for persons with FTD: ZOOM-based group, info@theaftd.org; Private Facebook group, email SherylWhitman.FTD@gmail.com.
- Online support for persons with FTD and caregivers: www.ftdsupportforum.com, www.facebook.com/groups/ftdinfoandsupport, The AFTD Facebook Group
- Online FTD spouse groups:
https://groups.yahoo.com/neo/groups/FTD_Spouse_Caregiver_Support/info
www.facebook.com/groups/TheFTDspouse/

How to Find Other Programs in Your Area (Activities, Support or Education)

- Alzheimer's Association 24-hour Helpline: 1-800-272-3900
- Area Agencies on Aging: www.agingwashington.org/area-agencies-on-aging
- Momentia Seattle: www.momentiaSeattle.org – Dementia-friendly programs in King, Snohomish, and Pierce counties. Also growing in Bellingham, Olympia areas.
- Try local senior centers, parks and recreation departments, faith communities.

Safety

- Dementia Action Collaborative "Safety Info Kit" addresses wandering, driving, exploitation, home safety, falls prevention, and emergency preparedness. Included under "Resources," here: www.dshs.wa.gov/altsa/dementia-action-collaborative
- Medical Alert IDs: MedicAlert Foundation provides free medical IDs for people who are low income and/or on Medicaid. www.medicalert.org/donate/sponsored-membership

Legal and Financial Planning

- AFTD resources: www.theaftd.org/living-with-ftd/legal-financial-planning
- Alzheimer's Association resources: www.alz.org/help-support/caregiving/financial-legal-planning

Driving and Transportation

- The Hartford Group (free publication on driving and dementia) www.thehartford.com/resources/mature-market-excellence/dementia-driving
- Certified Driving Rehabilitation Specialist Evaluation Options
 - NW Driver Rehabilitation Program 425-373-1315
 - CHC Services 425-275-5858
 - UW Medicine 206-598-4830
 - VA Medical Center: Ask for a referral from VA provider
- GoGoGrandparent: www.GoGoGrandparent.com Enhanced care hailing program.
- Regional Reduced Fair Permit: www.soundtransit.org/sites/default/files/orca_rfp_app.pdf

Children and Teens

- AFTD Kids/Teens Center: www.theaftd.org/living-with-ftd/kids-and-teens
- AFTD Young Adults Facebook Group: Email youngadults@theaftd.org to join

Local Adult Day Health / Adult Day Care Programs

- Full Life Care (Seattle, Kent, Everett): www.fulllifecare.org
- Legacy House (Seattle): www.legacyhouse.org
- Northshore Senior Center (Bothell): www.northshoreseniorcenter.org
- Old Friends Club (Kirkland, Sammamish, Carnation): www.olderfriendsclub.org
- Elderwise (Seattle): www.elderwise.org

Books, Guides & Videos

- *What If It's Not Alzheimer's?* by Gary and Lisa Radin. A family's guide to managing daily care, adapting to changes, and finding resources in the days and weeks after a diagnosis of FTD.
- *What the Hell Happened to My Brain?: Living Beyond Dementia*, by Kate Swaffer. The author describes how FTD has affected her life as she discusses her own journey of self-discovery and empowerment.
- *Losing Clive to Younger Onset Dementia: One Family's Story*, by Helen Beaumont. A memoir suggesting ways for families to cope with younger-onset dementia.
- *Younger Onset Dementia: A Practical Guide*. www.ftdrg.org/wp-content/uploads/yod-practical.pdf
- *Living with Memory Loss: A Basic Guide*. A publication of the UW Memory and Brain Wellness Center including a section on living with FTD: www.depts.washington.edu/mbwc/resources/living-with-memory-loss
- *Dementia Road Map: A Guide for Family and Care Partners*. A publication of the WA State Dementia Action Collaborative. Free PDF available online; Google the title.
- *It Is What It Is*. A short documentary about the family experience of FTD: www.youtube.com/watch?v=Ue3y60AsMCE