



MBWC Lewy Body Dementia Caregiver Resource List

The UW Memory and Brain Wellness Center is a Lewy Body Dementia Association Research Center of Excellence

INFORMATION

Lewy Body Dementia Booklet: Information for Patients, Families, and Professionals by the Lewy Body Dementia Association (LBDA). Download: <https://www.lbda.org/wp-content/uploads/2021/03/lewy-body-dementia-booklet.pdf>

- Print copies of this publication can be ordered by calling toll-free 1-800-438-4380.

Caregiving Publications (LBDA)

- The Role of Palliative and Hospice Care in Lewy Body Dementias
- Caregiver Burden in Lewy Body Dementias
- Understanding Behavioral Changes in Dementia
- And more!

Link: www.lbda.org/caregiving-publications/

WEBSITES

NINDS Dementia With Lewy Bodies Information Page: www.ninds.nih.gov/Disorders/All-Disorders/Dementia-Lewy-Bodies-Information-Page

Mayo Clinic Dementia With Lewy Bodies: <https://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/symptoms-causes/syc-20352025>

ORGANIZATIONS & EVENTS

Lewy Body Dementia Association: 1.800.539.9767, www.lbda.org

American Parkinson Disease Association, Northwest Chapter, 206.695.2905, www.apdaparkinson.org/community/northwest

Northwest Parkinson's Foundation: 206.748.9481, nwpf.org

Alzheimer's Association, Washington State Chapter: 206.363.5500 www.alzwa.org

National Parkinson Foundation: 1.800.473.4636 www.parkinson.org

Michael J. Fox Foundation: www.michaeljfox.org

PERSONAL EXPERIENCES WITH LEWY BODY DEMENTIA

Lewy Body Stories (LBDA): https://www.lbda.org/lbda_story/

Personal Experiences with Lewy Body Dementia, an essay by Jean Rough for the UW Memory and Brain Wellness Center: <https://depts.washington.edu/mbwc/news/article/personal-experiences-with-lewy-body-dementia>

SUPPORT GROUPS

Lewy Body Dementia Caregiver Support Group (WA State)

- Time: 4th Wednesday of each month from 6:30-8:00pm PT
- Location: St. Benedict Parish - Pastoral Office - Ground Floor - St. Teresa Room.
- Contact: Rena Ferretti, volunteer support group facilitator with the Alzheimer's Association.
- Email: renamf@fulllifecare.org
- Phone: 206-473-2565 (call prior to attending)

Lewy Body Line: Those living with Lewy body dementia, care partners, and others can connect to the licensed professionals with LBDA Support Services through the LBDA Lewy Line or email. Link: www.lbda.org/lbda-lewy-line/

BOOKS

- A Caregivers Guide to Lewy Body Dementia by Helen Buell Whitworth & Jim Whitworth
- The 36 Hour Day by Nancy Mace and Peter Rabins
- Be Brave: A Wife's Journey Through Caregiving by Florrie Munat
- Activities for the Family Caregiver, Lewy Body Dementia by Scott Silknitter, Robert Brennan, & Linda Redhead
- Lewy Body Dementia: Causes, Tests and Treatment Options by Adam Wainwright, Erik Stevenson, & Deanna R. Miller
- Forget Memory: Creating Better Lives for People with Dementia by Anne Basting
- Who Says Men Don't Care? by James V. Gambone
- The Unexpected Caregiver by Kari Berit Sexuality and Dementia by Douglas Wornell
- Loving Someone Who Has Dementia by Pauline Boss
- VIDEO: "Lewy Body Dementia: It isn't Alzheimer's or Parkinson's Disease" with Teepa Snow (available on Youtube)

RESEARCH STUDIES AND CLINICAL TRIALS

The following research studies and clinical trials are actively recruiting people with dementia with Lewy bodies or Parkinson's disease dementia, and LBD caregivers. Find a study near you and contact the study coordinator to see if you may qualify. Link: <https://www.lbda.org/research/clinical-trials/>

UW ADRC' Clinical Trials and Studies: Go to the sections for 'Dementia with Lewy Bodies,' 'Parkinson's Disease Dementia,' or 'Caregiving Roles.' Link: <https://depts.washington.edu/mbwc/adrc/page/clinical-trials>