Community and Online Resources for Carepartners and Persons Living with Lewy Body Dementia

Available online at [https://www.cityofroseville.com/3139/Dementia-Caring-Coping-Presentations](https://www.cityofroseville.com/3139/Dementia-Caring-Coping-Presentations)

**LBD Specific Resources**

**Support Groups**

**MN E Metro LBD Caregiver Support Group - Maplewood, Minnesota**
Paula Biever - 651-641-0130
paula.biever@gmail.com

**Twin Cities Support Group for Persons with Lewy Body Dementia - Roseville, Minnesota**
Paula Biever - 651-641-0130
paula.biever@gmail.com

**Mayo Clinic Caring Conversations - Rochester, Minnesota**
Emily Farah Miller - 507-284-1324

**Websites**

**Lewy Body Dementia Association** Helpline: 800-539-9767
[https://www.lbda.org/](https://www.lbda.org/)

Caregiver Briefs: [https://www.lbda.org/page/caregiving-briefs](https://www.lbda.org/page/caregiving-briefs)
Booklet for Medical Professionals:
Emergency Room Treatment of Psychosis:

**Lewy Body Dementia Resource Center** Helpline: 516-218-2026
[https://lewybodyresourcecenter.org/](https://lewybodyresourcecenter.org/)

**Lewy Body Dementia - Learning to Live with Lewy Body Dementia**
[www.lewybodydementia.ca](http://www.lewybodydementia.ca)

**LBD Caring Spouses Support Group**
[https://groups.io/g/LBDCaringSpouses](https://groups.io/g/LBDCaringSpouses)

**Facebook pages for Carepartners:**

LBDA Care Partners Support Group
Lewy Body Dementia Carers
Lewy Body Support Group

**Facebook pages for both Carepartners and Persons with Lewy body dementia**

LBDA Living Together with Lewy
Facebook pages for Persons with Lewy body dementia:

LBDA Living with Lewy

Additional online resources for persons with dementia:

Dementia Action Alliance is an advocacy group for and by persons with dementia.
https://daanow.org/

Dementia Mentors matches people with similar dementias - phone consultation also available.
https://www.dementiamentors.org/

Videos about Lewy Body Dementia

2019 LBD Knowledge and Support Summit - Rochester Mayo Clinic
https://www mayo.edu/research/centers-programs/alzheimers-disease-research-center/videos/outreach-videos

Dr. Boeve - Rochester Mayo Clinic Researcher & Clinician
https://www youtube.com/watch?v=wCJPv0eXeQk&feature=share&fbclid=IwAR2I_Xuczr5k-wOt8oyl_ielVhKbh_fglz1AJ4409blynNkcFyvE0YznE

LBDU Webinar Series: The Reality of LBD - Hallucinations & Delusions & How to Manage Them
https://www youtube.com/watch?v=Xmw560hu1WE&fbclid=IwAR0a9Reyi6dNgZyZO-01FE6V4_zAcil5fQd8gsZY4FCiC3F1W_7HAA6risko

Dementia with Lewy Bodies and Managing Behavioral Changes
https://www youtube.com/watch?v=Xmw560hu1WE&feature=youtubbe&t=1096&fbclid=IwAR1UJ3isjnsdX2vv25-6D5Cnjln-e11FKty8kDCShBwL_y2NIFXmhWJQ-t0

Teepa Snow - Lewy Body Dementia
https://www youtube.com/watch?v=U6kz mcNnzo

Teepa Snow videos on dementia basics
http://myalzheimersstory.com/2015/06/09-teepa-snow-videos-on-dementia-basics/?fbclid=IwAR3HxgPIZgeS03PKWxfpsjLjdB0UlyOpsoUtg7aqzBSGqch27-8aJkooE8

Don Kent - A Patient’s Perspective
https://www youtube.com/watch?v=NqRMzdWlo&feature=youtubbe&fbclid=IwAR18ayM-aPaYZk4FWaZM8DQL07vc0Zkjd_N_D0aCFZQuqG09OCR9pH8Gy_M

Mike Belleville - (Person living with Lewy)
Dementia with Lewy Body often goes undiagnosed. Information about the DIAMOND study

Tim Perkins - (Person living with Lewy) Apathy and LBD - Dementia Mentors
https://vimeo.com/363359890?fbclid=IwAR2FJADNRK8F7PTFmcqOIs4brmOQJzqJwgJbeY222S1y4lKrNiJ7XK7grns
Medical Clinics in Minnesota with LBD expertise

LBD Research Center of Excellence and RCOE Coordinating Campus - Mayo Clinic - Rochester, MN
Mayo Clinic Department of Neurology, Rochester, Minnesota
507-538-1038
Neurology Department
Alzheimer's Disease Research Center
Dr. Bradley Boeve  https://www.mayo.edu/research/faculty/boeve-bradley-f-m-d/bio-00083427
Lewy Body Dementia Overview

Health Partners Neuroscience Center - St. Paul, MN
651-495-6300
https://www.healthpartners.com/find/centers/neuroscience/neurology
Dr. Michael Rosenbloom

N. Bud Grossman Center for Memory Research and Care - University of Minnesota - Mpls, MN
(952) 525-4500
https://www.memory.umn.edu/memory-clinic/
Dr. Keith Vossel, MD
https://med.umn.edu/bio/neurology-faculty/keith-vossel

Cognitive and Behavior Disorders Care - St. Paul, MN
651-326-2173
https://www.fairview.org/services/memory-loss-and-dementia
https://www.fairview.org/services/caregiver-assurance
Dr. Alvin Holm
https://www.fairview.org/providers/h/o/l/m/a/holmalvin-551610452

Books

Dementia with Lewy Bodies and Parkinson's Disease Dementia: Patient, Family, and Clinician Working Together for Better Outcomes
by J. Eric Ahlskog

Dancing with Elephants: Mindfulness Training For Those Living With Dementia, Chronic Illness or an Aging Brain
by Jarem Sawatsky

A Caregiver's Guide to Lewy Body Dementia
by Helen Buell Whitworth & James Whitworth

Loving Someone Who Has Dementia: How to Find Hope while Coping with Stress and Grief
by Pauline Boss

Living with Lewy Body Dementia: One Caregiver’s Personal, In-Depth Experience
by Judy Towne Jennings
Dementia Beyond Drugs: Changing the Culture of Care
by G. Allen Power

Daily Comforts for Caregivers
by Pat Samples - This is really a great little book. It is encouraging without being sappy, practical as well as being sympathetic.

Non-Lewy Body Dementia Specific Resources:

Statewide and County Agencies

Minnesota/North Dakota Alzheimer’s Association  800-272-3900 (Hotline)
https://www.alz.org/mnnd

Senior LinkAge Line  800-333-2433
http://www.mnaging.org/advisor/SLL.htm

Minnesota Care Planning Council
http://www.careminnesota.org/

Leading Age Minnesota
https://www.leadingagemn.org/

Dakota County caregiving resources  651-455-1560
https://dartsconnects.org/caregiving/

Hennepin County Services for Seniors  612-348-4111
https://www.hennepin.us/residents/human-services/services-for-seniors

Caregiving Resources

Alzheimer’s / Dementia Roseville Community Action Team
https://www.cityofroseville.com/dementiainfo

Amherst H. Wilder Foundation - St Paul, Minnesota  651-280-2500
https://www.wilder.org/what-we-offer/healthy-aging-caregiving-services

Family Means - Help for caregivers - Stillwater, Minnesota  651-439-4840
https://www.familymeans.org/help-for-caregivers/

Jewish Family Service of St. Paul - Aging and Disability Services  651-698-0767
https://jfssp.org/services/aging-disability-services

Lutheran Social Services - Older Adult Services  651-642-5990
https://www.lssmn.org/services/older-adults

Second Half with Lyngblomsten - Roseville, Minnesota  651-632-5331
https://www.lyngblomsten.org/community-services/caregiver-resources/