

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>

LBD Specific Resources

Support Groups

MN E Metro LBD Caregiver Support Group - Maplewood, Minnesota

Paula Bieber - 651-641-0130

paula.bieber@gmail.com

Twin Cities Support Group for Persons with Lewy Body Dementia - Roseville, Minnesota

Paula Bieber - 651-641-0130

paula.bieber@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/>

Caregiver Briefs: <https://www.lbda.org/page/caregiving-briefs>

Booklet for Medical Professionals:

<https://www.lbda.org/sites/default/files/3737-lbda-physicians-book-22dec17.pdf>

Emergency Room Treatment of Psychosis:

https://www.lbda.org/sites/default/files/emergency_room_treatment_of_psychosis.pdf

Lewy Body Dementia Resource Center Helpline: 516-218-2026

<https://lewybodyresourcecenter.org/>

Lewy Body Dementia - Learning to Live with Lewy Body Dementia

www.lewybodydementia.ca

LBD Caring Spouses Support Group

<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=IwAR2l_Xuczr5k-wOt80ywl__ielVhKbH_fgIz1AJ4409blynNkcFyvE0YznE

LBDU Webinar Series: The Reality of LBD - Hallucinations & Delusions & How to Manage Them

https://www.youtube.com/watch?v=Xmw560hu1WE&fbclid=IwAR0a9Reyi6dNgZyZO-01FE6V4_zAci5fQd8gsZY4FCiC3F1W_7HAA6rfko

Dementia with Lewy Bodies and Managing Behavioral Changes

https://www.youtube.com/watch?v=Xmw560hu1WE&feature=youtu.be&t=1096&fbclid=IwAR1UJ3isjnsdX2vv25-6D5CnjjN-e1IFKty8kDCShBwL_y2NIFXmhWJQ-t0

Teepa Snow - Lewy Body Dementia

<https://www.youtube.com/watch?v=U6kz-mcNNzo>

Teepa Snow videos on dementia basics

<http://myalzheimersstory.com/2015/06/09/10-teepa-snow-videos-on-dementia-basics/?fbclid=IwAR3HxgPIZcgeS03PKWxfpsjLjdB0UIyOpsoUtg7agzBSGqch27-8aJkooE8>

Don Kent - A Patient's Perspective

https://www.youtube.com/watch?v=NqdRMzdxWlo&feature=youtu.be&fbclid=IwAR18ayM-aPaYZk4FWaZM8DQLO7vc0Zkjd_N_D0aCFZQudG09OCR9pH8Gy_M

Mike Belleville - (Person living with Lewy)

Dementia with Lewy Body often goes undiagnosed. Information about the DIAMOND study

<http://www.alzheimersweekly.com/2019/08/diamond-releases-lewy-body-diagnosis.html>

Tim Perkins - (Person living with Lewy) Apathy and LBD - Dementia Mentors

https://vimeo.com/363359890?fbclid=IwAR2FJADNRK8F7PTFmcqOIs4brmOQJzqJwqJbeY222S1y4IKrn_J7XK7qrns

Medical Clinics in Minnesota with LBD expertise

LBD Research Center of Excellence and RCOE Coordinating Campus - Mayo Clinic - Rochester, MN

<https://www.lbda.org/go/coordinating-center-mayo-clinic-campus-rochester-minnesota>

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

<https://www.healthpartners.com/care/find/practitioner-detail.html?practitionerId=79833>

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 Vessel, MD

<https://med.umn.edu/bio/neurology-faculty/keith-vessel>

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//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/>