A guide of programs, events, support, and hope for persons living with memory loss or dementia, support partners, families, professionals, and those who care.
Engage, Educate, Empower is a health-promotion guide of the Mayo Clinic Alzheimer’s Disease Research Center featuring Mayo Clinic and community-based programs and resources focused on mild cognitive impairment, Alzheimer’s disease, Lewy body dementia, and frontotemporal degeneration.

Mayo Clinic Alzheimer’s Disease Research Center

The Alzheimer’s Disease Research Center at Mayo Clinic, which is jointly based at the Mayo Clinic campuses in Rochester, Minnesota and Jacksonville, Florida, engages in groundbreaking and state of the art research in Alzheimer’s disease, Lewy body dementia, frontotemporal degeneration, and other related dementia disorders. The Center also studies the entire spectrum of aging, including normal aging and mild cognitive impairment in cooperation with the Mayo Clinic Study of Aging.

The Center offers outreach that includes innovative patient-centered research, programs, and events designed to meet the needs of those affected by dementia. This includes those living with the disorder, as well as families, care partners, communities, and care and service professionals.

For more information call 504-284-1324 or go to www.mayo.edu/research.
Definitions

MILD COGNITIVE IMPAIRMENT (MCI)
Mild cognitive impairment (MCI) is the stage between the expected cognitive changes of normal aging and the more serious decline of dementia. It can involve problems with memory, language, thinking, and judgment that are greater than normal age-related changes. Mild cognitive impairment may increase your risk of later developing dementia caused by Alzheimer’s disease or other neurological conditions.

DEMENTIA
Dementia is a word to describe a group of symptoms affecting memory, thinking and social abilities severe enough to interfere with daily functioning. Though dementia generally involves memory loss, memory loss has different causes. Alzheimer’s disease is the most common cause of dementia in older adults, but there are a number of causes of dementia. Depending on the cause, some dementia symptoms can be reversed.

ALZHEIMER’S DISEASE (AD)
Alzheimer’s disease is the most common cause of dementia. In Alzheimer’s disease, the brain cells degenerate due to the accumulation of amyloid plaques and neurofibrillary tangles. The result is a steady decline in memory and mental function. The rate at which symptoms worsen varies from person to person.

LEWY BODY DEMENTIA (LBD)
Lewy body dementia, also known as dementia with Lewy bodies, is the second most common type of progressive dementia after Alzheimer’s disease. Protein deposits, called Lewy bodies, develop in nerve cells in the brain regions involved in thinking, memory, and movement. Some people with Lewy body dementia experience hallucinations and changes in alertness and attention. Other effects can include Parkinson’s disease-like symptoms such as rigid muscles, slow movement, and tremors.

FRONTOTEMPORAL DEGENERATION (FTD) SUBTYPES
Frontotemporal degeneration is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain. Some people with frontotemporal degeneration undergo changes in their personality and social skills and can be impulsive or emotionally indifferent, called behavioral variant FTD.

Another subtype called Primary Progressive Aphasia (PPA) affects the ability to use of language. People with PPA can have trouble expressing their thoughts and understanding or finding words.

Corticobasal syndrome (CBS) belongs to the category of FTD disorders and this disorder primarily affects movement. The condition may cause those affected to have poor coordination, stiffness, cognitive changes, and speech or language difficulty.

Progressive Supranuclear Palsy (PSP) also belongs to the category of FTD disorders and primarily affects movement including walking, balance and eye movements.
Virtual Offerings Added in 2021

This year we’ve added many virtual programs, groups or classes through Zoom or a similar online platform. We want you to have access to the information, education and support you need in a way that is safe, convenient and easily accessible. Joining a Zoom event is easy as long as you have a device with a camera, (although being on camera is optional) and built in speakers, a microphone and a good internet connection.

HERE’S HOW IT WORKS:

1  Find a class, program or group you want to join and then call or e-mail to register in advance.

2  After you register, you will receive an e-mail with a link to the session you registered for.

3  At the time of the event (or a few minutes before) click on the link. There are no codes to enter, and usually you won’t need an account to join a Zoom or online meeting but you may be asked to enter a first name and e-mail address.

HERE ARE SOME ADDITIONAL TIPS IF YOU ARE PARTICIPATING IN A PROGRAM WITH GROUP INTERACTION:

- When your microphone is not muted, avoid activities that could create additional background noise such as talking to others in your household, shuffling papers, eating, or having the TV on in a nearby location.

- Position your camera in a stable position and focused at eye level if possible; doing this helps to create a more direct sense of engagement with other participants. We do encourage all participants especially in the support groups to be on camera, as this helps normalize the meeting; people generally feel more relaxed in seeing each other.

- In general, all of the virtual classes, programs, and groups are very relaxed and always friendly.
The Mayo Clinic Conference on Brain Health and Dementia will take place on Friday October 29th, 2021. This event succeeds the Meeting of the Minds Dementia Conference hosted for over a decade by the Alzheimer’s Association and Mayo Clinic. This year’s event aims to offer a similar high quality experience with continued collaboration between Mayo Clinic, The Alzheimer’s Association, and now AARP!

The conference is targeted at persons living with dementia, care partners and families, healthcare and other professionals who serve older adults. Anyone interested in age-friendly community efforts and understanding ways to support friends and neighbors who may be experiencing memory loss, Alzheimer’s or a related dementia is encouraged to attend.

CEU and CME credits will be offered.

More information will be posted on the conference website as details, including the program agenda become available.

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<tr>
<th>DATE AND TIME</th>
<th>LOCATION OPTIONS</th>
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<tbody>
<tr>
<td>Friday, October 29, 2021</td>
<td>• Mayo Civic Center, Rochester MN</td>
<td>Conference Website</td>
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<tr>
<td>Times to be announced</td>
<td>• Various Minnesota host sites</td>
<td>ce.mayo.edu/brainhealth2021</td>
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<tr>
<td></td>
<td>• Virtual viewing at home</td>
<td>Contact: Jodi Melius</td>
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<tr>
<td></td>
<td></td>
<td>at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a></td>
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“This conference validated the struggles I had as a daughter to a dad with Lewy Body Dementia, while giving me added knowledge, support, and hope.”

— Former participant
**SPARK — A FILM ABOUT ROBIN AND SUSAN WILLIAMS**

In the few years prior to Robin Williams’ death, Robin and Susan Williams were on a quest; a hard fought battle to seek understanding and truth for the inexplicable changes Robin was experiencing. Tragically, Robin did not live to know his truth, but his wife Susan got their answer; it was called Lewy Body Dementia (LBD). Armed with this knowledge, Susan Schneider Williams has passionately and lovingly devoted her efforts to share their story and raise awareness about LBD through SPARK.

October is Lewy Body Dementia Awareness Month and you are invited to watch SPARK at a location near either the Mayo Clinic Rochester or Jacksonville campuses. Following the film there will be time for questions and discussion. Exact dates, times and locations will be determined in the months before the event.

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<th>DATE AND TIME</th>
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<tbody>
<tr>
<td>October 2021</td>
<td>• Rochester MN</td>
<td>Contact: Jodi Melius at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a> or call 507-284-1324</td>
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<tr>
<td>Exact date and time to be determined</td>
<td>• Jacksonville, FL</td>
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Dementia Program Guide
Engage, Educate, Empower
**LEWY BODY DEMENTIA KNOWLEDGE AND SUPPORT SUMMIT — INCLUDING ACCESS TO A PRE-SUMMIT LEWY BODY DEMENTIA (LBD) VIDEO COLLECTION**

Offered virtually (online)

The LBD Knowledge and Support Summit is a comprehensive learning and support event for those living with LBD and their families, as well as interested individuals and healthcare professionals. Two weeks before the Summit, registered participants receive access to a series of new short videos on important topics related to LBD from Mayo Clinic experts in Rochester MN and Jacksonville FL. The event culminates on May 3rd with a live 2-hour webinar that highlights key messages from the videos and includes plenty of time to address your questions. In addition, the webinar provides a unique opportunity to connect with others impacted by Lewy in small group conversations. The program is open to the public and is free.

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<th>DATE AND TIME</th>
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<tr>
<td>April 20-May 3: Access to video collection</td>
<td>Virtual (online)</td>
<td>Contact: Jodi Melius at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a> or call 507-284-1324</td>
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<tr>
<td>May 3: Live Webinar Event</td>
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<td>9:00 a.m. - 11:00 a.m. CST</td>
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**CARING FOR LEWY- AN EDUCATION AND SUPPORT PROGRAM FOR PERSONS CARING FOR A FAMILY MEMBER, PARTNER, OTHER RELATIVE OR FRIEND WITH LEWY BODY DEMENTIA (LBD)**

Offered virtually (online)

Caring for Lewy is a monthly education and support program uniquely designed for families and relatives who provide care and/or support to a person with LBD. The program offers a group setting where participants share experiences and feelings confidentially with others who are on a similar caregiving path with opportunities for reflection, problem-solving, and information exchange. Some of the meetings will include a presentation by Mayo Clinic experts from both Rochester MN and Jacksonville FL on topics related to LBD. Time for questions and discussion will follow. The program is open to the public and is free.

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<th>DATE AND TIME</th>
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<tr>
<td>2nd Thursday of each month</td>
<td>Virtual (online)</td>
<td>Contact: Jodi Melius at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a> or call 507-284-1324</td>
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<td>2:00 p.m. – 3:00 p.m. CST</td>
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<td>3:00 p.m. - 4:00 p.m. EST</td>
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CARING CONVERSATIONS: A SUPPORT GROUP FOR ALL DEMENTIA CAREGIVERS

Offered virtually (online)

Caring Conversations is a virtual support group intended for anyone who is providing support and care to a spouse, partner, or other relative or close friend living with Alzheimer’s disease, Lewy Body dementia, Frontotemporal degeneration, mild cognitive impairment or a related disorder.

Led by Mayo Clinic facilitators, the purpose of these meetings is for individuals to feel heard, understood and supported. The group offers a place to share experiences and feelings confidentially with others who are on a similar path with opportunities for reflection, problem-solving, and information gathering. Meetings are open to the public and are free.

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<tr>
<td>1st Thursday of each month</td>
<td>Virtual (online)</td>
<td>Contact: Jodi Melius at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a> or call 507-284-1324</td>
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MINDFULNESS-BASED DEMENTIA CARING (MBDC)

MBDC is an 8-week program specifically designed for family care partners of persons with dementia. Learn how the practice of mindfulness can help you cope with the challenges and stresses of dementia care. The program includes interactive mindful care practices, gentle yoga, lectures, group sharing and at home assignments. The program is free, open to the public and will be offered twice in 2021.

For all the details including program dates and times, please contact Angela Lunde at: lunde.angela@mayo.edu or call 507-284-1324.

“Every doctor who diagnoses a person with dementia should refer their care partner to this program.”

— Former participant

MEMORY LOSS: A GUIDE TO ‘WHAT NOW?’

Offered virtually (online or by phone)

Have you recently been told you have memory loss, mild cognitive impairment, or been diagnosed with Alzheimer’s disease, Lewy body disease or another dementia? If so, join us for this introductory class and learn about resources in our community and helpful places to get good information and support. Get your questions answered and leave feeling connected and less alone.

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<tr>
<td>2nd Wednesday of each month</td>
<td>Virtual (online or by phone)</td>
<td>Contact: Jodi Melius at <a href="mailto:melius.jodi@mayo.edu">melius.jodi@mayo.edu</a> or call 507-284-1324</td>
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<td>beginning in August 2021</td>
<td>2:00-3:15 p.m. CST</td>
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We value your input, if you have ideas or recommendations on the types of outreach, education and support programs you would like to see, please let us know.

You can send us an e-mail at: melius.jodi@mayo.edu

Or call us at: 507-284-1324

CAREGIVER FOCUSED RESEARCH
To inquire about research opportunities focused on the caregiving experience, feel free to contact us.

You can send us an e-mail at: melius.jodi@mayo.edu

Or call us at: 507-284-1324

NEW MAYO CLINIC BOOK ON ALZHEIMER’S DISEASE AND OTHER DEMENTIAS
In this new edition you’ll gain an understanding of dementia based on what researchers and other medical experts know about it today. You’ll also learn that dementia isn’t just about loss and decline. For many, a good quality of life can — and does — continue.


MAYO CLINIC ALZHEIMER’S DISEASE RESEARCH CENTER (ADRC) WEBSITE:
Visit the ADRC website for details and updates about all of the events listed in this booklet. In addition you will find information about our research, clinical trial information, publications and community outreach and support. The easiest way to find the Mayo Clinic ADRC website is by using your internet search box, and type in: Mayo Clinic Alzheimer’s Disease Research Center, or: www.mayo.edu/research/centers-programs/alzheimers-disease-research-center

Are you a person living with dementia or a care partner?

We’d like to hear from you.
Mayo Clinic’s HABIT Healthy Action to Benefit Independence & Thinking® is a comprehensive program specifically designed for individuals who have received the diagnosis of Mild Cognitive Impairment. The program proactively addresses cognitive changes and helps participants learn and incorporate new habits that can play a role in optimizing independence, improving overall health, and maintaining normal daily activities. During HABIT, participants and support partners:

- Engage in discussions of wellness
- Learn to incorporate a memory tracking and organization tool into their daily routine
- Participate in physical and cognitive exercise
- Receive emotional support and have opportunities to broaden their support network

**DATE AND TIME**
For more details including program dates, locations and times, please contact the HABIT team at habitprogram@mayo.edu or call 608-392-9371.

**LOCATION**
Offered at all 3 Mayo Clinic geographic regions:
- Midwest (La Crosse, WI)
- Florida (Jacksonville)
- Arizona (Scottsdale)
A mix of virtual and in-person options are planned for 2021.

**FOR UPDATED INFORMATION**
Email habitprogram@mayo.edu or call 608-392-9371.
Other Resources

AFTD THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION
AFTD’s mission is to improve the quality of life of people affected by FTD and to work every day to advance: Research, Awareness, Support, Education and Advocacy.

Contact
Helpline: 1-866-507-7222
Web: www.theaftd.org/

ALZCONNECTED®
Powered by the Alzheimer’s Association®, this is a free online community for everyone affected by Alzheimer’s or other dementia.

Visit
www.alzconnected.org

ALZHEIMER’S ASSOCIATION SUPPORT GROUPS
The Alzheimer’s Association offers in-person support groups throughout Minnesota and across all states. These groups are for individuals living with Alzheimer’s, caregivers, and others dealing with the disease. All support groups are facilitated by trained individuals.

Contact
1-800-272-3900

ALZHEIMER’S ASSOCIATION HELPLINE
The Alzheimer’s Association® 24/7 Helpline is available around the clock, 365 days a year. Through this free service, specialists and master’s-level clinicians offer confidential support and information to people living with the disease, caregivers, families and the public.

Contact
Helpline: 1-800-272-3900

CUREPSP
CurePSP is the leading source of information and support for patients and their families, other caregivers, researchers, and healthcare professionals on prime of life neurodegeneration including PSP, CBD, MSA, and related diseases.

Contact
1-800-457-4777
Email: info@curepsp.org

ELDERCARE LOCATOR
Offered by the U.S. Administration on Aging connects individuals to services for older adults and families in the communities in which they live.

Contact
1-800-677-1116
Web: eldercare.acl.gov

ELDER NETWORK
Elder Network offers non-medical care services including Senior Advocacy, Education & Support, Companion Services, Respite Care In-Home, Peer Support, Friendly Visitors, and Transportation in Southeast Minnesota; Olmsted, Wabasha and Winona.

Contact
507-285-5272
Email: info@elder-network.org

GIVING VOICE
Giving Voice inspires and equips organizations worldwide to bring together people with Alzheimer’s and their care partners to sing in choruses that foster joy, well-being, purpose and community understanding.

Contact
612-440-9660
Web: givingvoicechorus.org/
Other Resources, cont.

**LBDA LEWY BODY DEMENTIA ASSOCIATION**

The Lewy Body Dementia Association (LBDA) is dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. The Association’s purposes are charitable, educational, and scientific.

**Contact**

LBD Caregiver Link: 1-888-204-3054
National Office, Atlanta, Georgia: 404-418-7396
Web: www.lbda.org/

**OLMSTED COUNTY AGING & CARE COORDINATION SERVICES**

Home & Community Care programs designed to support elderly and disabled people in their efforts to remain living as independently in the community as possible.

**Contact**

507-328-6519

**RESOUNDING VOICES**

A community chorus in Rochester, MN, welcoming those experiencing Alzheimer’s disease or a related dementia and their support partners. Resounding Voices rehearses weekly and performs publicly.

**Contact**

507-218-8376

Web: www.resoundingvoices.org/

**SOUTHEAST MINNESOTA AREA AGENCY ON AGING (SEMAAA)**

Southeast Minnesota Area Agency on Aging is a private non-profit agency serving the eleven counties of SE MN. The Area Agency on Aging works with families, seniors, service providers, and public agencies to help support, coordinate or develop community services. Their mission is to promote the independence and dignity of older adults so they can age successfully and remain in their home for as long as possible. SEMAAA operates the Senior Linkage Line® a free service that links people to information and assistance.

**Contact**

Senior LinkAge Line®: 1-800-333-2433