

THE GUIDED LIGHT

LA CROSSE COUNTY'S DEMENTIA NEWSLETTER FOR
HOPE, SUPPORT, AND RESOURCES

"Research in Dementia Care"

Clinical trials are a type of research study that involves people. Most clinical trials test a new treatment for a health problem, like a new drug, diet, or medical device. Scientists continue to make great strides in identifying potential new ways to diagnose, treat, and even prevent Alzheimer's disease and related dementias. These medical advances would not be possible without the participation of a diverse range of study volunteers.

Research studies help us learn if a new treatment or approach to care is better, the same, or worse than what is currently happening. Others test ways to prevent disease or find it early. Before the Federal Government can approve a medicine or other treatment for people, it must be tested to make sure it is safe, and it works.



When you choose to participate in research, you become an important part of scientific discovery. Your contribution may also help your family, community, and future generations lead healthier lives.



Why Research is Important to Consider

There are many reasons why people choose to join a clinical trial. Some join because there is no other treatment for their health problem or because the treatments they tried did not work. Some people who are healthy may also join studies to help find ways to prevent a disease, such as one that may be common in their family.



You might choose to participate in Alzheimer's and related dementias research because you may want to:

- Help people, including family members, who may be at risk for developing Alzheimer's or a related dementia in the future
- Feel like you're playing a more active role in your health
- Learn more about dementia and your health, including symptoms and risk factors
- Find out about resources, such as educational materials and support
- Share your experience with researchers so more people can benefit

October 2024

Sign up for this newsletter : adrc@lacrossecounty.org

How to find a good fit for you and a study

Are you looking for something short-term or research that follows participants over a longer time? Do you want to be part of in-person research, or would you be more interested in taking online surveys? Many different types of clinical trials and studies are available, and there are likely options that would work for you. Researchers carefully screen all volunteers to ensure they are appropriate for particular studies. The screening may involve cognitive and physical tests, and you may be asked questions about your health, medications, and family history. Researchers also need to make certain that people are a good fit for safety reasons.

Here are some questions you may have about joining a clinical trial.

1. What is this study trying to find out? and What will I have to do?
2. What treatment or tests will I have? Will they hurt? Can I get the treatment after I finish the study? What are the possible risks, side effects, and benefits? What other options are available?
3. How could being in this study affect my daily life? and How long will the trial last?
4. Will there be any travel or other costs to consider while I am in the trial? What, if any, expenses covered, or stipends are available?
5. Where will the study take place? Will I have to stay in the hospital?
6. Will you tell me the results of the study? How will I be told?



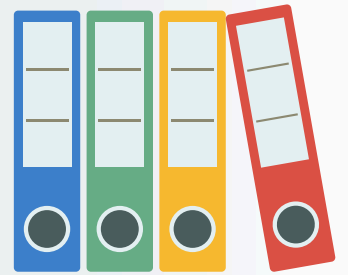
What new approaches are they researching?

When people think of research, they often think of a clinical trial that is testing a new drug. But there are many types of research that need participants. Here are some of the areas related to Alzheimer's and related dementias that researchers are exploring:

1. Medications. Some evaluate the safety and effectiveness of medications and therapies designed to help prevent disease or slow disease progression.
2. Non-medication strategies. These studies evaluate the safety and effectiveness of lifestyle and behavioral changes, like exercise, diet, or brain training, to help prevent disease, slow disease progression, or improve quality of life for people with dementia.
3. Diagnostic tools. New approaches, like blood test or a brain scan, are tested to see whether they can accurately diagnose Alzheimer's or a related dementia.
4. Medical devices. Tools and other equipment that can monitor and manage disease symptoms. Studies of medical devices determine whether they are safe and effective.
5. Treatments for changes in mood and personality. These studies test medication and non-medication strategies to treat common behavioral symptoms of Alzheimer's, including sleeplessness, wandering, agitation, anxiety, aggression, restlessness, etc.
6. Support for caregivers. Caring for someone with dementia can be challenging. Researchers are testing ways to reduce stress and increase overall well-being for caregivers and quality of life for people living with dementia.
7. Attitudes and knowledge. Some studies are designed to learn people's views about dementia, caregiving, or particular treatments, or to test educational tools to increase people's knowledge.



Research - Where to Find Studies



There are many ways to find a clinical trial that might be right for you.

You can:

- Ask your doctor to help you find trials in your area, including:
 - <https://www.adrc.wisc.edu/get-involved>
- Sign up for a registry or a matching service to connect you with trials in your area.
 - https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/trialmatch
- Search the National Institutes of Health website and Alzheimer's.gov
 - www.ClinicalTrials.gov.
 - <https://www.alzheimers.gov/clinical-trials>
- Local area agency on aging news articles and coalitions may also share opportunities



Benefits & Risks

You may wonder, "Why should I try something researchers are not sure will work?" That is a good question. Being part of a clinical trial may have risks and may also have benefits. It's important to consider what is best for you and your situation.

Benefits of a clinical trial

- You may get a new treatment for a disease before it is available to everyone.
- You may help others get a better treatment for their health problems in the future.
- You play a more active role in your own health care.
- You can help researchers find new ways to prevent, detect, and treat diseases.

Risks of a clinical trial

- The new treatment may cause side effects or may be uncomfortable.
- The new treatment may not work, or it may not be better than normal care.
- For randomized studies, you may NOT be part of the treatment group that gets the new treatment. Instead, you may be part of the control group, which means you get the normal treatment or no treatment (a placebo).
- The clinical trial could take time, or you may need to travel to the study site several times.

Representation Matters

It is important for clinical trials to have people of different ages, sexes, races, cultures, and health conditions. Having different groups of people take part helps doctors know if the treatment works for everyone. We encourage all people to check out opportunities because their input, their experiences, their responses matter for the advancement of understanding Alzheimer's and other related dementias!





UPCOMING CLASSES & EVENTS

October - November - December 2024

- **Autumn Memory Respite Camp** - **Wednesdays 10:30a-1:30p Oct. 1, 8, 15, 22.**
The Nature Place La Crosse. Free. Each day has in/outdoor activities, lunch, and socialization. Register: 608-780-0471 (all or as your calendar permits)
- **Boost Your Brain & Memory** - **Tuesdays Oct1-Nov 5, 2:00-3:30p** La Crosse YMCA
Education on variety of lifestyle factors that impact brain health. Learn Memory strategies. Register: 608-785-5700.
- **UWL-Neurocognitive Wellness Group** **"Purposeful Paws"** **Wednesdays Oct. 16-Nov. 20, 2:30-3:30pm** Health Science Center La Crosse Rm 2030 (Parking Passes Available). Connect with students, socialize and interact with therapy dog, Rossi. Register: Call Emily 608-785-8203.
- **STAR Center Brain & Body Fitness** **Tuesdays & Thursdays 2:30-3:30p Sept 10-Oct 24 & Nov. 5-Dec.19** Concordia Ballroom La Crosse. Register 608-797-6295
- **Savvy Caregiver Education** **Thursdays Oct 3 to Nov. 7, 10:30am-Noon** at Black River Beach Neighborhood Center. Register 608-785-5700
- **Caregiver Education - Financial Matters** **Tuesday Oct. 15, 1:00-2:30pm** West Salem Library. Register 608-785-5700
- **Healthy Living with MCI Education Series** - **Friday Dec. 13, 9:30-11:30am** at Black River Beach Neighborhood. Education from researchers and Lunch discussion following- Open to public. Those impacted by MCI encouraged to attend. Register: 608-785-5700
- **NEW! Day Respite Resource "A Time For Joy"** **Wednesdays 10a-2p** at Immanuel Lutheran Church, 1004 W. Broadway St. Viroqua. Register: 608-637-3983

Local Caregiver Grant "Caregiver Wishes"

For caregivers of a loved one living with Alzheimer's or other forms of dementia. EndAlz Fest Caregiver Wish Grants worth \$1,000.

More info. and To Apply:
<https://endalzfest.com/>



Wine, Women & Dementia

Thursday, November 14th
2pm-4:30pm

Rivoli Theater 117 N 4th St. La Crosse

An intimate look into the human side of dementia from the lens of the family caregiver. This documentary follows the journey of former dementia family caregiver Kitty Norton, as she embarks on a cross-country RV adventure with her friend, Beth Rigazio.

Followed up with influential discussion.
To register call the ADRC at 608-785-5700

FOR ALL LOCAL ONGOING dementia friendly programs, social activities, caregiver support or education, AND MORE...

**Stop by or Call Aging & Disability Resource Center
of La Crosse County 608-785-5700**